



**Royal Commission**  
into Violence, Abuse, Neglect and Exploitation  
of People with Disability

# Public Hearing Report

**Public hearing 4**  
Health care and  
services for people  
with cognitive disability

Sydney  
18 – 28 February 2020

## **Report of Public hearing 4: Health Care and Services for People with Cognitive Disability**

**Novotel, Olympic Park, Sydney**

**18-28 February 2020**

### **Commissioners**

The Honourable Ronald Sackville AO QC

The Honourable Roslyn Atkinson AO

Ms Barbara Bennett PSM

Professor Rhonda Galbally AC

### **Content warnings**

This report contains information that may be distressing to readers.

It includes accounts of violence against, and abuse, neglect and exploitation of, people with disability and references to suicide and self-harming behaviour.

In some firsthand accounts of violence, abuse, neglect and exploitation, people have told us of abusive or offensive language they have experienced or witnessed. As a result, some direct quotes in the report contain language that may be offensive to some people.

First Nations readers should be aware that some information in this report has been provided by or refers to First Nations people who have passed away.

If you need support to deal with difficult feelings after reading this report, there are free services available to help you.

Blue Knot Foundation offers specialist counselling support and a referral service for anyone affected by the Disability Royal Commission.

For support please call their national hotline on **1800 421 468** (they are open every day).

In addition to the Blue Knot Foundation, the Australian Government provides support to assist people to engage with the Royal Commission. This support includes:

- free legal advisory services provided by National Legal Aid and the National Aboriginal and Torres Strait Islander Legal Services through the Your Story Disability Legal Service
- advocacy support services provided under the National Disability Advocacy Program.

Further information about these supports, including how to access them, is available on our website: [disability.royalcommission.gov.au/counselling-and-support](https://disability.royalcommission.gov.au/counselling-and-support)

# Contents

<b>Part 1: Introduction .....</b>	<b>5</b>
Scope and purpose of Public hearing 4.....	5
Preparation of this report .....	6
Terminology .....	7
<b>Part 2: Outline of evidence .....</b>	<b>8</b>
Direct experience witnesses .....	9
Witnesses from advocacy groups.....	28
Medical expert witnesses.....	37
Government agency witnesses .....	45
<b>Part 3: Key themes emerging from Public hearing 4 .....</b>	<b>53</b>
Australian health system.....	54
Quality health care .....	55
Attitudes, assumptions and culture.....	59
Communication and information sharing .....	66
Health system challenges.....	75
Lifetime health care .....	87
Integration of the health and disability service sectors.....	105
Reduction of distress and trauma .....	109
Training and education of health professionals .....	115
Collection of data and research .....	124
Initiatives to improve health care .....	128
<b>Part 4: Neglect .....</b>	<b>137</b>
<b>Part 5: Future inquiries and directions.....</b>	<b>140</b>
Quality health care .....	140
Attitudes, assumptions and culture.....	141
Communication and information sharing .....	142
Health system challenges.....	144
Lifetime health care .....	145
Integration of health and disability services.....	148
Reduction of distress and trauma .....	148
Training and education of health professionals .....	149
Collection of data and research .....	150

Initiatives to improve health care .....	151
<b>Part 6: Appendices.....</b>	<b>153</b>
Appendix A – Parties granted leave to appear .....	153
Appendix B – Links to exhibits and transcripts .....	154
Appendix C – List of Acronyms.....	155

## Part 1: Introduction

1. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (**Royal Commission**) was established in April 2019, under Letters Patent. The Letters Patent appoint the Commissioners who are to conduct the inquiry and specify the terms of reference for the Royal Commission. The Commonwealth Government and each State Government in Australia issued Letters Patent for this Royal Commission in substantially the same terms.
2. The Royal Commission's fourth public hearing was held from 18 to 28 February 2020, in the Novotel hotel at Sydney Olympic Park (**Public hearing 4**). The following Commissioners participated in the hearing:
  - the Hon Ronald Sackville AO QC (Chair)
  - the Hon Roslyn Atkinson AO
  - Ms Barbara Bennett PSM
  - Professor Rhonda Galbally AC
3. Counsel Assisting the Royal Commission at the hearing were Ms Kate Eastman SC, Ms Georgina Wright and Ms Simone Fraser and, instructed by the Office of the Solicitor Assisting the Royal Commission. A number of parties were granted leave to appear at the hearing. Those parties and their legal representative are listed in **Appendix A**.
4. During Public hearing 4, Counsel Assisting the Royal Commission presented evidence from 38 witnesses. The witnesses included people with cognitive disability, parents, siblings, carers and support persons of people with cognitive disability, advocates, experts, medical professionals and representatives of government departments and agencies. In addition, over 500 exhibits were tendered and accepted into evidence.
5. Links to those exhibits, as well as to the transcripts of Public hearing 4 and the Royal Commission's Terms of Reference are provided in **Appendix B**.
6. This Report uses a number of acronyms. A List of Acronyms is set out in **Appendix C**.

### Scope and purpose of Public hearing 4

7. Public hearing 4 was the first hearing of the Royal Commission to inquire into and examine health issues for people with disability.
8. The purpose of the hearing was to examine the health care and services provided to people with cognitive disability in Australia and to investigate whether this group of people is subject to systemic neglect by the health system. The hearing also

examined why people with intellectual disability have a higher mortality rate compared to the general population, with death rates reported to be two to four times higher and life expectancy two decades shorter.<sup>1</sup>

9. The evidence presented at the hearing included firsthand accounts from people with cognitive disability and their families as to their experiences with and within the health system. Their evidence, as well as evidence from experts, health professionals and others, provided an opportunity for the Royal Commission to consider the extent to which the human rights of people with cognitive disability in Australia are protected in an area fundamental to their wellbeing.
10. The evidence dealt with the experiences of people with cognitive disability in a number of different states. Similarly, the expert evidence described the health care challenges faced by people with cognitive disability around Australia. However, the principal focus was on the New South Wales (**NSW**) health system. The evidence did not concentrate exclusively on the deficiencies in the health system but included an examination of initiatives, both at state and Commonwealth level, designed to improve health care and services for people with intellectual disability and autism.

## Preparation of this Report

11. At the end of Public hearing 4, the Chair of the Royal Commission directed Counsel Assisting to:

*prepare a document setting out a brief outline of the evidence during the hearing, a number of the key themes that have emerged from the evidence, and some of the possible recommendations that the Royal Commission may wish to make or further lines of inquiry that may be pursued.*<sup>2</sup>
12. The Chair further directed that this document should be made available, on a confidential basis, to the parties who had leave to appear at the hearing, to the witnesses who gave evidence, and to any institutions or entities that had received a procedural fairness letter from the Office of Solicitor Assisting the Royal Commission.
13. On 17 April 2020, the Office of the Solicitor Assisting sent a document prepared by Counsel Assisting, which was titled “Submissions of Counsel Assisting following Public Hearing 4” to those witnesses, institutions and entities specified by the Chair (**Counsel Assisting’s Submissions**). Counsel Assisting’s Submissions were and continue to be subject to a Direction Not to Publish dated 16 April 2020 (**Direction**).

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<sup>1</sup> Exhibit 4-171, EXP.0015.0002.0490 at 0490.

<sup>2</sup> Transcript, Commissioner Sackville, Public Hearing 4, 28 February 2020, P-884.

14. The recipients of the Counsel Assisting's Submissions were invited to respond to them in writing, also on a confidential basis. Substantive responses were received from Professor Julian Trollor, Mr Jim Simpson, and on behalf of the Commonwealth of Australia and the State of NSW (collectively, **Responses**). Other witnesses and entities either provided no substantive response or indicated that they were satisfied with the content of the Counsel Assisting's Submissions.
15. This document is the Report of the four Commissioners who participated in Public hearing 4. It has been prepared taking into account Counsel Assisting's Submissions and the Responses referred to in [14] above. As with Counsel Assisting's Submissions, this Report does not attempt to provide a comprehensive account of the evidence given at the hearing. Nor does it make factual findings in relation to the experiences of individual witnesses or members of their families. It identifies the key themes that emerged from consideration of the totality of the evidence and makes findings in the nature of general observations based on the totality of the evidence.
16. The Royal Commission will need to undertake further investigations and gather more evidence before making final recommendations on issues explored at Public hearing 4. However this Report identifies issues arising out of the hearing that will be the subject of further inquiry by the Royal Commission and, in due course, recommendations in the Royal Commission's Final Report.

## Terminology

17. The term "cognitive disability" is often used as an umbrella term to indicate a disability that results in actual or perceived differences in cognition. These include differences in concentration, processing, remembering or communicating information, as well as differences in learning, awareness or decision-making. Much of the evidence during Public hearing 4 concerned people with intellectual disability and people with autism. Both groups of people fall within the category of people with cognitive disability.
18. Given that Public hearing 4 concentrated on health care for people with cognitive disability it is not surprising that witnesses frequently used medical terminology and classifications. For example, some witnesses used the term "developmental disability". Professor Trollor described intellectual disability as a form of developmental disability and stated that intellectual disability can be classified as mild, moderate, severe or profound. He told the Royal Commission that intellectual disability is a life-long condition, but that the resulting impairments must have been present during the person's developmental period in order to meet diagnostic criteria for intellectual disability. According to Professor Trollor approximately 1.8 per cent of the Australian population has an intellectual disability.<sup>3</sup>

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<sup>3</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020, at [19]–[21].

19. Professor Trollor described autism spectrum disorder as a developmental disorder, or developmental difference, characterised by impairments in social communication and restricted or repetitive behaviours, interests or activities. He observed that autism spectrum disorder occurs on a continuum, meaning that the impacts on daily functioning can range from mild to profound.<sup>4</sup> Some people with intellectual disability also have autism.<sup>5</sup>

## Part 2: Outline of evidence

20. This section sets out a brief description of evidence given by witnesses at Public hearing 4. As has been noted, it does not provide a comprehensive account of the evidence. Almost all witnesses touched on topics not covered in the summaries of their evidence. The absence of a specific reference in this Report to particular evidence does not diminish its significance to the work of the Royal Commission.
21. For ease of presentation the witnesses have been divided into four broad categories:
- direct experience witnesses;
  - witnesses from advocacy groups;
  - medical expert witnesses; and
  - government witnesses.
22. Too much significance should not be attached to these categories. Some witnesses could easily be placed in more than one category and others do not necessarily fit squarely within any single category. Nor should the categorisation adopted in this Report be taken as a reflection on the standing of any of the witnesses, or on the nature or importance of their evidence. The description given of the positions held by the witnesses was current at the time of Public hearing 4.
23. During and after Public hearing 4, the Royal Commission received submissions or evidence from health services or government agencies in response to the evidence provided by certain witnesses. That material has also been taken into consideration in the preparation of this Report and is referred to where relevant.

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<sup>4</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020, at [22]; Transcript, Julian Trollor, Public Hearing 4, 20 February 2020, P-176.

<sup>5</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020, at [25]; Transcript, Julian Trollor, Public Hearing 4, 20 February 2020, P-178.

## Direct experience witnesses

### Kylie Scott

24. Kylie Scott is a disability consumer representative for the Sydney Local Health District (**LHD**) and the NSW representative for the Down Syndrome Australia Advisory Network. She has her own public speaking and art business. Ms Scott prepared a written statement and gave oral evidence to the Royal Commission on 18 February 2020. Her evidence also included a video recording of a presentation she had previously given.<sup>6</sup>
25. Ms Scott, who has Down syndrome, told the Royal Commission about the approaches that work well for her in a health care context. For example, she discussed doctors making use of her 'My Health Matters' folder (a resources tool created by the Council for Intellectual Disability (**CID**)) and her practice of writing everything that she would like to discuss with her doctor down before she attends an appointment.<sup>7</sup> She also suggested approaches that doctors should implement when treating patients with intellectual disability such as asking short questions, speaking clearly and explaining things patiently in plain English to support patients in making their own decisions.<sup>8</sup> Ms Scott said that when she makes decisions about her health care, she often places her trust in doctors.<sup>9</sup> For more complicated decisions, she requires extra time to think or talk to someone else such as her mother.<sup>10</sup>
26. Ms Scott stated that doctors should be aware of a number of important matters for people with intellectual disability. She identified regular ear, nose and throat tests, mental health assessments, sleep apnoea checks, good record-keeping and, for people with Down syndrome, familiarity with current research into epilepsy and Alzheimer's disease.<sup>11</sup>

### Ruth Oslington

27. Ruth Oslington gave oral evidence to the Royal Commission on 18 February 2020. Her evidence also included a video recording of a presentation that she had previously given about mental health.<sup>12</sup> Ms Oslington described some of the

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<sup>6</sup> Exhibit 4-1.1, NSW.9999.0002.0001; Exhibit 4-460, IND.0024.0001.0001.

<sup>7</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [17]; Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-20–21.

<sup>8</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [24]; Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-21.

<sup>9</sup> Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-21–22.

<sup>10</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [30].

<sup>11</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [33]; Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-22.

<sup>12</sup> Exhibit 4-3, IND.0017.0001.0001; Exhibit 4-461, IND.0024.0001.0001.

formidable challenges that she has faced as a person with disability when seeking health care and treatment, particularly when she has experienced mental illness.

28. Ms Oslington told the Royal Commission that, for her, establishing trust with medical professionals is very important, as is being listened to by them.<sup>13</sup> She also emphasised the need for doctors to take sufficient time to communicate with her, her family, her support workers, and other medical professionals.<sup>14</sup> She stated that everybody deserves good mental health care and recommended improvements to the public mental health system.<sup>15</sup>

### Rebecca Kelly

29. Dr Rebecca Kelly gave written and oral evidence to the Royal Commission about the experiences she and her eight year old son, Ryan, have had navigating the health systems in Tasmania and Victoria. Dr Kelly told the Royal Commission that Ryan lives with Down syndrome and is very medically complex.<sup>16</sup> She said that Ryan is a “wonderful, kind, happy and very cheeky human being”.<sup>17</sup>
30. Dr Kelly spoke about the specialist medical care that Ryan has required throughout his life, including many surgeries and other intrusive medical procedures.<sup>18</sup> She particularly discussed Ryan’s conductive hearing loss since birth and their experiences seeking treatment for the condition. She described feeling like there was a ‘revolving door of specialist clinics, with a different doctor at each appointment, none of whom knew Ryan’s history and who each provided different and usually contradictory advice’.<sup>19</sup>
31. Dr Kelly explained that, in the many years she and Ryan spent navigating the health system, Ryan’s care had been good when it involved consistent care co-ordinated by a single experienced specialist who ‘treats Ryan as a child, rather than “Ryan with Down Syndrome”’. This ensures that Ryan is seen as the equal of other children receiving treatment and as a person with potential, with the same rights to the full range of available treatment as any child.<sup>20</sup>
32. Dr Kelly spoke about her recent attempts to arrange surgery to address Ryan’s hearing loss, after it was recommended by an ear, nose and throat specialist at a

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<sup>13</sup> Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-35–36.

<sup>14</sup> Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-35–36.

<sup>15</sup> Exhibit 4-3, IND.0017.0001.0001 at [04:45]–[04:53], [06:21]–[06:28]; Exhibit 4-461, IND.0017.0002.0001; Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-36.

<sup>16</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [14].

<sup>17</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [11].

<sup>18</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [14]–[16], [24].

<sup>19</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [31].

<sup>20</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [17].

major tertiary hospital in Melbourne in late March 2019.<sup>21</sup> She said that she spent months writing emails, making phone calls and requesting information to obtain a date for this surgery. She also wrote a detailed letter of complaint to the hospital about her attempts to obtain a surgical date, and gave evidence that she spent months chasing a response.<sup>22</sup> At the time of giving oral evidence to the Royal Commission on 18 February 2020, Dr Kelly said that she had finally secured a date for Ryan's surgery, 12 months after it was initially recommended.<sup>23</sup>

33. A key issue raised by Dr Kelly in her evidence was the central role of a parent in facilitating communication among various health carers for a child with intellectual disability and complex health care needs.<sup>24</sup> Other issues emphasised by Dr Kelly included the importance of appropriate triaging of children with intellectual disability;<sup>25</sup> the need for accurate record keeping and information sharing;<sup>26</sup> greater respect for the role of parents, carers and patients as a conduit of knowledge;<sup>27</sup> cross-border issues arising for people accessing tertiary care in a different state from where they live;<sup>28</sup> ableism among medical professionals;<sup>29</sup> and the effects of trauma associated with numerous medical procedures on children with intellectual disability.<sup>30</sup>
34. In response to Dr Kelly's evidence about a complaint made to the Victorian Health Complaints Commission, the Royal Commission received a letter containing a statement from the Health Complaints Commissioner. That statement has been taken into consideration in the preparation of this Report.<sup>31</sup>

### **Rachel Browne**

35. In her written statement and in oral evidence, Rachel Browne described her son, Finlay, who passed away at the age of 16 on 10 December 2016. She told the Royal Commission how Finlay was the "middle cog" in their family of five and was happiest when the family was together.<sup>32</sup> Finlay lived with Down syndrome and

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<sup>21</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [59]–[61].

<sup>22</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [116]–[123].

<sup>23</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-42 [6]–[14].

<sup>24</sup> Exhibit 4-4, 'Statement of Rebecca Anne Kelly', 9 February 2020 at [186]–[187]; Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-45 [26] to 47 [10].

<sup>25</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [176]–[178].

<sup>26</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [180], [182]–[185].

<sup>27</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [186]–[190].

<sup>28</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [200]–[204].

<sup>29</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [205]–[212].

<sup>30</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [156]–[168].

<sup>31</sup> Exhibit 4-456, HCV.9999.0001.0001.

<sup>32</sup> Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [11].

autism, but Ms Browne stated that this did not define him and that he thrived in his early years of life.<sup>33</sup>

36. Ms Browne discussed a number of interactions that Finlay had with health care services in NSW. She emphasised the importance of basic, inexpensive adjustments that could make simple medical procedures less difficult for people with intellectual disability, such as taking of blood for testing.<sup>34</sup> She also highlighted the difficulties faced by people with intellectual disability who live in non-metropolitan areas and who need to travel long distances to see medical specialists.<sup>35</sup>
37. Ms Browne told the Royal Commission that she felt like she had to fight constantly to ensure that Finlay received proper medical care and treatment.<sup>36</sup> This was particularly the case when Finlay presented at an emergency department in September 2016 with a bowel obstruction.<sup>37</sup> Among other things, Ms Browne stated that she felt that she was not listened to sufficiently by medical staff and she felt there was a distinct lack of urgency in transferring Finlay to a hospital in Sydney once the seriousness of his condition was ascertained.<sup>38</sup> Ms Browne also expressed the view that Finlay was treated as a “second-class citizen” in the health system<sup>39</sup> and that he was subject to an internal bias which ultimately led to his death.<sup>40</sup>
38. Ms Browne described the impact of Finlay’s death on her family and set out her subsequent efforts to understand what happened to him and achieve accountability.<sup>41</sup> She was also distressed that among the causes of death listed on Finlay’s death certificate was ‘Trisomy 21’ (the extra chromosome which causes Down syndrome).<sup>42</sup> Ms Browne said this was inappropriate because Finlay did not die from Down syndrome. She proposed that there should be a system for recording the causes of death for people with intellectual disability that allows for a better understanding of the reasons for preventable deaths recurring.<sup>43</sup>

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<sup>33</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [17], [54].

<sup>34</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [35]–[45].

<sup>35</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [48]–[50]; Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-77, P-81, P-82.

<sup>36</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [64].

<sup>37</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-100.

<sup>38</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-103.

<sup>39</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [64].

<sup>40</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [137].

<sup>41</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [121]–[142].

<sup>42</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [144]; Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-109.

<sup>43</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [145].

## Toni Mitchell

39. Toni Mitchell gave oral evidence to the Royal Commission on 19 February 2020, supplementing her written statement. She described the many health challenges and barriers to health care that she has experienced with her son Joshua (Joshy) Mitchell over the 20 years of his life.<sup>44</sup> In particular, Ms Mitchell told the Royal Commission about Joshy's complex health needs and how she has had to fight throughout his life to ensure that he has received appropriate care and treatment from health professionals and in several hospitals in Queensland.<sup>45</sup> She believes that Joshy has never been given the care and treatment that he is entitled to and that he endured years of agony because medical practitioners did not take his health problems seriously.<sup>46</sup>
40. Ms Mitchell described numerous occasions from when Joshy was a newborn to more recently, when he required hospital and specialist care. She told the Royal Commission that Joshy has had no continuity of care<sup>47</sup> and it has therefore been up to her to provide medical support, case management and co-ordination as well as to be a forceful advocate for him.<sup>48</sup> She noted particularly that she had been responsible for obtaining referrals to specialists;<sup>49</sup> keeping accurate records of his medical history and various treatments;<sup>50</sup> and insisting that tests, treatment and procedures be carried out.<sup>51</sup> She said that she constantly feels that she is not listened to and that her knowledge is not respected even though she has developed considerable expertise in her son's medical issues and care needs.<sup>52</sup>
41. Ms Mitchell emphasised the need for greater training of health professionals with respect to people with disability and the importance of involving people with disability, their parents and carers in that training.<sup>53</sup> She drew a connection

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<sup>44</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [8].

<sup>45</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [120]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-113 [24]–[25].

<sup>46</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [11], [82], [120]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-117, P-130, P-145.

<sup>47</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [74]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-127.

<sup>48</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [79], [83], [98]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-127–128, P-138, P-140–141, P-146.

<sup>49</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020, [55]–[57], [105], [107]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-127, P-130, P-140.

<sup>50</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-138–139; P-146.

<sup>51</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [34], [38], [61]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-129.

<sup>52</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [107]–[108], [112]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-139.

<sup>53</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-143–145; Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [118]–[119], [122].

between these matters and the fundamental changes needed in attitudes towards people with disability to ensure that they are respected as valued members of society, rather than seen as somehow “wrong” and a burden to society.<sup>54</sup>

### **Christine Regan and Erin Sheehy**

42. Christine Regan provided a witness statement to the Royal Commission and gave oral evidence on 21 February 2020 about her daughter, Erin Sheehy. Ms Sheehy is 42 years of age and is Ms Regan’s eldest child.<sup>55</sup> Ms Sheehy joined Ms Regan for much of her oral evidence. Ms Regan made it clear that she had Ms Sheehy’s permission to share her story.<sup>56</sup>
43. Ms Regan recounted some of the experiences that Ms Sheehy has had as a person with Down syndrome in the health care system. Ms Regan spoke of her daughter’s independent nature, her passion for music and her love of reading and writing.<sup>57</sup> She said that Ms Sheehy has lived a very active and full life.<sup>58</sup>
44. Ms Regan told the Royal Commission that when Erin was born in the 1970s, the nurses tried to convince her and her husband to send Erin away to a place ‘where she can be cared for’.<sup>59</sup> She said that there was no support provided to her when she was told that Erin had Down syndrome, nor when Erin suffered a heart attack shortly after birth.<sup>60</sup>
45. Ms Regan explained that when Erin was a child, she had to learn to ask the right questions of doctors to be as informed as possible. Ms Regan said that it has been a constant struggle to get health services for her daughter.<sup>61</sup> She also stated that the quality of health care provided to Erin over her life has been variable. Ms Regan attributes this to doctors making social decisions for her daughter, rather than medical ones.<sup>62</sup> She described how doctors would often make assumptions about Ms Sheehy and her quality of life simply because she had Down syndrome. For example, it was assumed that she was completely dependent and had to be shepherded everywhere that she went.<sup>63</sup> Ms Regan also noted that it was common

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<sup>54</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-145–146.

<sup>55</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [6].

<sup>56</sup> Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-282.

<sup>57</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [9]–[12].

<sup>58</sup> Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-256.

<sup>59</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [23]; Transcript, Christine Regan, Public Hearing 4, 21 February, P-258.

<sup>60</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [20].

<sup>61</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [26], [91].

<sup>62</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [91].

<sup>63</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [32].

for doctors not to speak directly to Ms Sheehy when she attended hospitals or medical centres.<sup>64</sup>

46. Ms Sheehy had a major stroke at the age of 25.<sup>65</sup> Ms Regan told the Royal Commission that after three days in hospital, a young doctor said that they were ready to discharge her as her pain was under control.<sup>66</sup> Ms Regan said that when she queried what treatment was available for Ms Sheehy's recovery from the stroke, the doctor told her there was a nine-month 'stroke protocol' but did not offer it to Ms Sheehy. Ms Regan said that when she asked why not, the doctor said words to the effect of 'she has Down syndrome, how hard are you gonna try?'<sup>67</sup> Ms Regan explained that this comment still causes her enormous distress.<sup>68</sup>
47. At Ms Regan's insistence, Ms Sheehy was eventually signed up for the stroke protocol.<sup>69</sup> Ms Regan felt that she had been flagged by hospital staff as a 'nuisance' and that Ms Sheehy was not considered to be a priority, particularly when it came to treatment such as physiotherapy.<sup>70</sup> After Ms Sheehy was discharged from hospital, Ms Regan and her partner devised their own methods to ensure Ms Sheehy's recovery from the stroke, including the use of music therapy.<sup>71</sup> Despite the success of the music therapy, Ms Regan stated that Ms Sheehy is not the same person she was before the stroke.<sup>72</sup>
48. Ms Regan also described a much more positive experience in hospital that Ms Sheehy had 10 years after the stroke when medical staff spoke directly to her even though Ms Sheehy was unable to speak at that time. The staff also gave Ms Sheehy complete control over decisions related to her body.<sup>73</sup>

### Lorraine Clark

49. In her written statement and oral evidence to the Royal Commission on 21 February 2020, Lorraine Clark described her daughter, Gabrielle Clark,<sup>74</sup> who is

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<sup>64</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [33]; Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-263–264.

<sup>65</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [35]–[42].

<sup>66</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [44].

<sup>67</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [46].

<sup>68</sup> Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-268.

<sup>69</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [47]–[48].

<sup>70</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [51].

<sup>71</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [63]–[69]; Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-272–275.

<sup>72</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [82]–[84].

<sup>73</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [79]–[80]; Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-276.

<sup>74</sup> As Lorraine Clark and her daughter, Gabrielle Clark, both of whom are adults, share the same surname, we have used both their given and surnames to distinguish between them.

44 years old and has Down syndrome. Lorraine Clark has experience working with other people with intellectual disability in various roles, including as past president of Down Syndrome NSW and as a Special Olympics volunteer over many years.<sup>75</sup>

50. In January 2019, Gabrielle Clark became a resident at an aged care facility. Lorraine Clark described her daughter's life prior to January 2019. She said that Gabrielle Clark was 'extremely fit', participated in Little Athletics and had joined the local surf club.<sup>76</sup> Later, Gabrielle Clark was an advocate for people with Down syndrome, a competitive swimmer and an ambassador for the Special Olympics<sup>77</sup> and Australia Day.<sup>78</sup> Lorraine Clark stated that Gabrielle Clark was a determined and compassionate young woman.<sup>79</sup>
51. When Gabrielle was 13, she was diagnosed with Hashimoto's disease, a thyroid condition.<sup>80</sup> Despite this, Lorraine Clark described Gabrielle's health in her teenage years as 'probably the best it's ever been'.<sup>81</sup> Lorraine Clark outlined the decline of Gabrielle Clark's health from 2013, when she collapsed and was admitted to hospital.<sup>82</sup> Over the next few years Gabrielle Clark suffered several seizures and 'drops'. Gabrielle Clark experienced admissions to hospital and medication changes, which Lorraine Clark said significantly affected her personality and mood.<sup>83</sup>
52. In January 2019, Gabrielle Clark had another seizure and was admitted to hospital.<sup>84</sup> Lorraine Clark told the Royal Commission that during this admission Gabrielle Clark had a catheter procedure administered by a male nurse, which she found very distressing.<sup>85</sup> Lorraine Clark stated she believes this procedure was not adequately explained to her daughter.<sup>86</sup>

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<sup>75</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [7]–[8].

<sup>76</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-287–290.

<sup>77</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [5].

<sup>78</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-292.

<sup>79</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [5].

<sup>80</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-290.

<sup>81</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-291.

<sup>82</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-293–294.

<sup>83</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-294, P-297–300.

<sup>84</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-300–302.

<sup>85</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [64]–[67]; Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-303–305.

<sup>86</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-305–306.

53. Later, Gabrielle Clark stopped walking,<sup>87</sup> did not respond to physiotherapy,<sup>88</sup> and now resides in an aged care facility, where she is the youngest resident by 35 years.<sup>89</sup>
54. In 2019, Gabrielle Clark was diagnosed with rapidly advancing Alzheimer's,<sup>90</sup> a diagnosis which Lorraine Clark says she has questioned.<sup>91</sup> Lorraine Clark suggested that medical professionals should be aware of potential misdiagnoses of Alzheimer's in people with Down syndrome. She stated that in her experience doctors find it too easy to diagnose Alzheimer's and dementia when they do not really know what is going on.<sup>92</sup> She also expressed the view that younger people should not live in aged care facilities but rather live in places that are better suited to their needs.<sup>93</sup>

### Kim Creevey

55. Kim Creevey provided a written statement and oral evidence to the Royal Commission on 21 February 2020, concerning the experience of her son Harrison (Harri) Creevey who died in October 2015, at the age of 18.<sup>94</sup> Harri had an acquired brain injury as the result of a severe case of Murray Valley encephalitis when he was three years old. This meant he used a wheelchair and was non-verbal.<sup>95</sup> Ms Creevey described him as a quietly determined, fun-loving boy, with a wicked sense of humour.<sup>96</sup>
56. Ms Creevey told the Royal Commission that she believes that Harri was subjected to unconscious bias on several occasions when he was in hospital as a boy, which compromised his medical care.<sup>97</sup> She provided detail about the events leading up to Harri's death following his admission to a hospital in Queensland with suspected pneumonia.<sup>98</sup> She said that she and her husband strongly believe that Harri's care

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<sup>87</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [84].

<sup>88</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [74].

<sup>89</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [85]; Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-308–309.

<sup>90</sup> Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-306; Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [71].

<sup>91</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [77]; Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-308.

<sup>92</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [98]–[101].

<sup>93</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [107]–[109].

<sup>94</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [4], [17].

<sup>95</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [7]–[8].

<sup>96</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [6]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-316.

<sup>97</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [10].

<sup>98</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [17]–[45]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-321–327.

at this time was influenced by his disability, and that they observed this in a number of ways.<sup>99</sup>

57. Among other things, Ms Creevey suggested that health professionals need better training and education about unconscious bias and the impacts that it can have.<sup>100</sup> She also suggested that there should be an independent advocate to assist people with disability and their families in navigating the hospital system and advocating for their rights when necessary.<sup>101</sup>

### **Tara Elliffe**

58. Tara Elliffe works part time at the NSW Ombudsman and is on several advisory boards and committees including the advisory board of Down Syndrome NSW.<sup>102</sup> Ms Elliffe also presents at workshops to people with both high and low support needs. Ms Elliffe, who has Down syndrome, prepared a written statement for the Royal Commission and gave oral evidence on 21 February 2020.
59. Ms Elliffe told the Royal Commission about her general practitioner (**GP**), stating ‘it has been a good thing for me to have the same doctor for a long time’ and that she trusts her.<sup>103</sup> She said that she prepares to go to the GP, by writing down any questions and bringing them with her, along with her scripts.<sup>104</sup> This GP speaks directly to Ms Elliffe<sup>105</sup> and if the GP says she needs to take medication or have a particular procedure, she explains everything to Ms Elliffe first.<sup>106</sup>
60. Ms Elliffe described one experience that she had in 2018, when she was in a lot of pain and ended up in hospital. After blood tests, X-rays, and scans at the hospital, she said she ‘felt like a yo-yo’, and that her ‘head was exploding from all the noise and different people’.<sup>107</sup> After telling her mother that her shoulder hurt, another

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<sup>99</sup> Exhibit 4-13, ‘Statement of Kim Letitia Creevey’, 7 February 2020 at [20]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-322–327.

<sup>100</sup> Exhibit 4-13, ‘Statement of Kim Letitia Creevey’, 7 February 2020 at [51]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-330.

<sup>101</sup> Exhibit 4-13, ‘Statement of Kim Letitia Creevey’, 7 February 2020 at [53]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-330–331.

<sup>102</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [5].

<sup>103</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [23]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-338.

<sup>104</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [25].

<sup>105</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [22]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-338 [23]–[24].

<sup>106</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [29]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-341 [2]–[5].

<sup>107</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [39]–[40]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-343 [16] – P-344 [2].

ultrasound was requested, and Ms Elliffe underwent an operation. She stated that she 'needed mum or dad to be there to help me get painkillers and to feel safe'.<sup>108</sup>

61. Ms Elliffe told the Royal Commission a number of things she thinks doctors and hospitals can do better. These include listening carefully to people with disability, asking simple questions, using pictures and Easy Read, and talking to people with disability and not their parents.<sup>109</sup> Ms Elliffe suggested doctors and nurses should have disability training, including training presented by people with disability. It would also be beneficial for people with disability to have a tour of a hospital when they are well so they know what to expect if they need to go to hospital in an emergency one day.<sup>110</sup>

### **Sabrina Monaghan**

62. Sabrina Monaghan is a registered nurse and has a son who is referred to in her evidence as AAL.<sup>111</sup> AAL was born in 2000 and was diagnosed with moderate to severe autism at the age of three.<sup>112</sup> Ms Monaghan described her son as 'just like any other teenager', who likes music, riding his bike, and being cuddled by his mother.<sup>113</sup> Ms Monaghan provided a written statement, and gave oral evidence to the Royal Commission on 24 February 2020. She explained her experience in navigating the health system with AAL and, in particular, seeking dental care for AAL.
63. Ms Monaghan told the Royal Commission that when AAL was 12 years old, he attended a dental clinic at the local community health centre which had an allocated special needs dentist.<sup>114</sup> AAL attended this clinic every six months or yearly for check-ups, but Ms Monaghan said that on each occasion the consultation lasted about 10 minutes, AAL refused to sit in the dental chair and Ms Monaghan had to hold AAL's mouth open so the dentist could look at AAL's front teeth with a torch. The dentist did not examine AAL's back molars and no

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<sup>108</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [47]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-344 [14]–[15].

<sup>109</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [50]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-344 [25]–[28].

<sup>110</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [51]–[52]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-345 [28]–[33].

<sup>111</sup> The identity of AAL is the subject of a non-publication direction made by the Royal Commission. He was identified through the use of pseudonyms in Public hearing 4. This pseudonym will also be used throughout this Report.

<sup>112</sup> Transcript, Sabrina Monaghan, Public Hearing 4, 24 February 2020, P-357 [4]–[26].

<sup>113</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [14], [16].

<sup>114</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [35].

alternative procedures were offered to enable a proper examination of AAL's teeth to take place.<sup>115</sup>

64. Ms Monaghan stated that there were no measures taken or adjustments provided at the clinic to accommodate people with disability.<sup>116</sup> She suggested a number of adjustments for people with autism such as social stories to explain oral examinations, dimmer lighting, reduced background noise, noise-cancelling headphones to block out sound and more time for consultations to assist the person to transition into a new environment.<sup>117</sup>
65. Ms Monaghan also told the Royal Commission about AAL's experiences generally with health care. She described a number of instances where she had tried to coordinate an approach with hospital staff to minimise trauma for AAL from invasive medical procedures, such as by giving him medication before the procedure.<sup>118</sup> On some occasions she did not receive a response to her suggestions, which consequently led to AAL being restrained and experiencing other major traumatic events.<sup>119</sup>
66. Ms Monaghan said that she is 'consumed with anger at the injustice and everything that has happened to AAL and that he has not had timely access to dental and health care needs'.<sup>120</sup> In her view the whole system had let AAL down, leading her to feel that AAL is not safe and that she 'need[s] to live forever'.<sup>121</sup>
67. Ms Monaghan made a number of suggestions for change including:
- better training for medical, dental and nursing staff in dealing with people with disability;
  - improved strategies in hospitals;<sup>122</sup>
  - measures to accommodate specific sensory, environmental, behavioural and communication needs;<sup>123</sup> and
  - incorporation in the National Safety and Quality Health Standards of clearer standards to improve access to health care for people with disability.<sup>124</sup>

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<sup>115</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [41]–[43], [46].

<sup>116</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [37]–[38].

<sup>117</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [162].

<sup>118</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [73], [81]–[82], [90]–[92].

<sup>119</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [75], [83], [93].

<sup>120</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [138].

<sup>121</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [141].

<sup>122</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [146].

<sup>123</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [153].

<sup>124</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [167]–[168].

## Narelle Reynolds

68. Narelle Reynolds is a First Nations Wiradjuri woman.<sup>125</sup> She prepared a written statement for the Royal Commission and gave oral evidence on 24 February 2020. She addressed the barriers she has experienced in seeking health care and services for her sons, Luke and Justin who have an intellectual disability caused by a genetic condition called Fragile X syndrome.<sup>126</sup> Ms Reynolds has worked as an enrolled nurse and has coordinated health services for First Nations families over many years.<sup>127</sup> Her evidence included her views on what it is like for her to navigate the health care system in NSW as a First Nations person and advocate for her sons.<sup>128</sup> She said that ‘being Aboriginal on top of being a mother of children with intellectual disability is a double whammy’.<sup>129</sup>
69. Ms Reynolds described the difficulty of securing an appropriate assessment and diagnosis for her sons. Justin was initially diagnosed with autism<sup>130</sup> and was not offered genetic testing for Fragile X until he was at primary school.<sup>131</sup> Ms Reynolds also told the Royal Commission about the stigma of a Fragile X diagnosis in First Nations families.<sup>132</sup>
70. Ms Reynolds stated that both Luke and Justin experience significant fear and anxiety in medical settings. She emphasised that preparation before attending the doctor or hospital is vital.<sup>133</sup> She outlined a number of ‘extreme incidents’ that occurred before some doctors would listen to what Luke or Justin needed.<sup>134</sup>
71. Ms Reynolds also described an absence of culturally inclusive practices in health care and services.<sup>135</sup> She told the Royal Commission that she is aware of ‘a lot of Aboriginal people with disability who do not remain connected with, or continue to seek services from, NDIS.’<sup>136</sup> Ms Reynolds considers this is due to the fact that

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<sup>125</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [3]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-414 [26]–[27].

<sup>126</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [4].

<sup>127</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [10]–[11].

<sup>128</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [4].

<sup>129</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [61].

<sup>130</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [24]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-423 [17]–[19].

<sup>131</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [25]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-424 [6]–[21].

<sup>132</sup> Transcript, Narelle Reynolds Public Hearing 4, 24 February 2020, P-425 [10] – P-427 [15].

<sup>133</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-438 [9]–[11]; Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [32], [51].

<sup>134</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [33]–[35].

<sup>135</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-443 [7]–[13], P-448 [39] – P-449 [8].

<sup>136</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [68].

there are no Aboriginal liaison officers who could connect service providers and clients.<sup>137</sup>

### Jaqueline Mills

72. Jaqueline Mills gave oral evidence on 25 February 2020, outlining her experiences and opinions as both a mother and as an advocate for people with disability. Ms Mills, who is the Managing Director of Microboards Australia,<sup>138</sup> spoke about the microboard model, her advocacy work, and some of the barriers to health care experienced by her son, who has Angelman syndrome.<sup>139</sup>
73. Ms Mills described a ‘microboard’ as a group of people who incorporate as a not-for-profit association to support a person with disability in a supported decision-making structure.<sup>140</sup> She said that microboards are designed to outlive parents, and uphold quality of life, safeguards and human rights for vulnerable people.<sup>141</sup> Ms Mills also described her previous work as Chair of the Positive Behaviour Framework guiding committee in Western Australia;<sup>142</sup> her development of a new postgraduate certificate in Special Education: Complex Communication Needs;<sup>143</sup> and the outcomes of a Microboards Australia project, published in early 2020, which explored barriers to health services for people with complex needs.<sup>144</sup>
74. Ms Mills’ evidence included some of her observations on the experiences of other people with intellectual disability who she has engaged with during her advocacy work. She emphasised the importance of Augmentative and Assisted Communication devices for people with disability who experience challenging behaviour<sup>145</sup> and the differing ways in which acute pain and illness may be expressed,<sup>146</sup> which may lead to diagnostic overshadowing or missed diagnoses. Ms Mills described diagnostic overshadowing as occurring when a person’s

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<sup>137</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [68]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-448 [9–24].

<sup>138</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [7].

<sup>139</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [3].

<sup>140</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-474 [8–33].

<sup>141</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [8].

<sup>142</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [12]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-482 [20] – P-483 [19].

<sup>143</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [13]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-483 [25] – P-484 [23].

<sup>144</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [17]; Exhibit 4-196, IND.0018.0001.0001.

<sup>145</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [134]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-500 [5] – P-501 [8]; P-503 [16]–[33].

<sup>146</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-501 [12] – P-502 [8].

disability is used as an explanation for pain or illness that they have.<sup>147</sup> Diagnostic overshadowing is discussed in further detail at paragraph 213 of this Report.

75. In her written statement and her oral evidence Ms Mills also made a number of detailed suggestions for improvement to health care and services. She proposed that medical professionals should always err on the side of caution, especially when people have complex communication needs;<sup>148</sup> health practitioners should receive better education about the use of restraints, especially for the purpose of delivering important treatment;<sup>149</sup> primary health care should be provided routinely to people with disability;<sup>150</sup> and robust medication appropriate checks should be put in place for vulnerable people in hospital settings.<sup>151</sup> Ms Mills also proposed that people with complex needs should have someone with them at all times in a medical setting, who knows them well or is a properly trained communication partner or medical advocate.<sup>152</sup>
76. It should be noted that the Royal Commission received a letter from St John's Ambulance WA in response to aspects of Ms Mills' evidence that concern her experiences accessing ambulance services for her son, which has been considered in the preparation of this Report.<sup>153</sup>

### **Karen Barnett and Tracey Nash**

77. In their individual witness statements and joint oral evidence on 26 February 2020, Karen Barnett and Tracey Nash told the Royal Commission about Grant Barnett, who died on 9 April 2015. Ms Barnett was Mr Barnett's sister and Ms Nash was his full-time support worker in the final six months of his life. Mr Barnett had a genetic condition that is known to cause intellectual disability, developmental delays, and physical differences in males.<sup>154</sup> Ms Barnett told the Royal Commission that Mr Barnett was a 'quick-witted, mischievous, deep-thinking and sensitive man,'<sup>155</sup> and

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<sup>147</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [43].

<sup>148</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [143]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-488 [4] – P-489 [6]; P-504 [13]–[21].

<sup>149</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [144]–[145]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-504 [22]–[42].

<sup>150</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [161]–[163]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-506 [18]–[35].

<sup>151</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020, at [146]–[151]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-505 [1]–[31].

<sup>152</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [160]; Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-506 [1]–[17].

<sup>153</sup> Exhibit 4-457, SJW.9999.0001.0001.

<sup>154</sup> Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [13].

<sup>155</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [11].

that he loved machinery, especially aeroplanes, and to travel.<sup>156</sup> She spoke of her parents' 'utter commitment and devotion' to looking after their son for more than 40 years prior to their own ill health.<sup>157</sup>

78. Ms Barnett's and Ms Nash's evidence set out some of the experiences that they had with Mr Barnett's health care in the last months of his life, primarily in hospital.<sup>158</sup> In particular, they felt that hospital staff did not listen sufficiently to Mr Barnett's father, despite the fact that he knew Mr Barnett's health needs and behaviour well.<sup>159</sup> Ms Barnett said that she was 'quite shocked' by some of the care Mr Barnett received in the hospital in late 2014,<sup>160</sup> and both she and Ms Nash spoke of the medical staff's lack of direct engagement with Mr Barnett.<sup>161</sup>
79. Ms Nash said that in March 2015 Mr Barnett was admitted to hospital for the final time, for a routine procedure.<sup>162</sup> Following this procedure, Mr Barnett required surgery to repair his stomach and subsequently developed pneumonia and was transferred to the Intensive Care Unit.<sup>163</sup> He was eventually discharged under palliative care and died at home.<sup>164</sup> Both Ms Barnett and Ms Nash described the terrible impact of Mr Barnett's death and the events leading up to it on the Barnett family.<sup>165</sup>
80. The Royal Commission received material from the State of Queensland in response to various aspects of Ms Barnett's and Ms Nash's evidence, namely the following: correspondence from the Queensland Central Coroner in relation to his response to the correspondence received from Ms Nash and enclosing an autopsy report and the Coroner's findings; and material from Queensland Health including

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<sup>156</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [11]–[12]; Transcript, Karen Barnett, Public Hearing 4, 26 February 2020, P-648 [24]–[28].

<sup>157</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [17].

<sup>158</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [25]–[49]; Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [23]–[91].

<sup>159</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [27]; Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [38].

<sup>160</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [29].

<sup>161</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [29]; Transcript, Tracey Nash, Public Hearing 4, 26 February 2020, P-654 [10]–[27].

<sup>162</sup> Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [58].

<sup>163</sup> Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [69]–[77].

<sup>164</sup> Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [83]–[88].

<sup>165</sup> Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [95]–[97]; Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [63]–[67].

the Clinical Case Review.<sup>166</sup> These matters were taken into account when Ms Barnett and Ms Nash gave their evidence.<sup>167</sup>

81. The State of Queensland also provided material in response to factual matters contained in the evidence of Ms Barnett and Ms Nash.<sup>168</sup> All of these documents have been considered in the preparation of this Report.

## AAJ

82. Dr AAJ<sup>169</sup> is a doctor specialising in palliative care who works at a hospital in NSW.<sup>170</sup> She provided a written statement and gave oral evidence to the Royal Commission on 26 February 2020, setting out some of her experiences and observations concerning medical care for people with intellectual disability and autism. She stated that over 20 years she has developed an interest in the management of patients with intellectual disability and is often consulted by palliative care specialist colleagues about patients with intellectual disability.<sup>171</sup>
83. Dr AAJ gave detailed evidence about several cases she is aware of where people with intellectual disability were referred by doctors for palliative care rather than being provided with other available medical treatment.<sup>172</sup> She described most hospitals as busy and operating like a conveyor belt, which does not work for people with intellectual disability.<sup>173</sup> She also expressed concerns about the quality of primary health care in Australia for people with intellectual disability, noting that

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<sup>166</sup> Exhibit 4-35, QLD.9999.0024.0001; Exhibit 4-36, QLD.9999.0024.0002; Exhibit 4-37, QLD.9999.0024.0007; Exhibit 4-38, 9999.0022.1307; Exhibit 4-39, QLD.9999.0024.0009; Exhibit 4-40, QLD.9999.0022.1302.

<sup>167</sup> Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-655 [14]–[16]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-663 [15]–[17]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-664 [16]–[19]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-665 [9]–[17]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-666 [4]–[8], [10]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-668 [12], [16]–[17], [19], [22], [24]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-670 [24]–[27]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-673 [29]–[31], [33]–[34]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-674 [9]–[11]; Transcript, Kate Eastman SC, Public Hearing 4, 26 February 2020, P-677 [4]–[8].

<sup>168</sup> Exhibit 4-458, 'Statement of Dr Susan Page Mitchell', 12 March 2020; Exhibit 4-458.1, QLD.9999.0022.0436; Exhibit 4-463, QLD.9999.0051.0001.

<sup>169</sup> The identity of AAJ is the subject of a non-publication direction made by the Royal Commission. She was identified through the use of a pseudonym in Public hearing 4. This pseudonym will be used throughout this Report.

<sup>170</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [7].

<sup>171</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [10].

<sup>172</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [19]–[48].

<sup>173</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-609 [16]–[22].

this could be remedied by increasing the time available for appointments with GPs or providing home visits.<sup>174</sup>

84. Dr AAJ also expressed the view, based on both professional and personal experience, that there are virtually no services to support acutely unwell people with severe autism in Australian hospitals.<sup>175</sup>
85. Dr AAJ emphasised the importance of education and mandatory training for health professionals with respect to the needs of people with intellectual disability.<sup>176</sup> She also noted the need to change attitudes among health professionals towards people with intellectual disability and counter assumptions about their quality of life.<sup>177</sup>

### Jayne Lehmann

86. Jayne Lehmann is a Diabetes Nurse Specialist and director of a diabetes care and education business. In her written and oral evidence she described her experiences in accessing health care and services for her daughter, Sarah Lehmann, who passed away on 30 December 2019.<sup>178</sup> Jayne Lehmann<sup>179</sup> described her daughter as having a ‘strong personality and cheeky sense of humour’ and said she ‘enjoyed observing her world and what was happening around her’.<sup>180</sup>
87. Sarah Lehmann had an intellectual disability and was diagnosed with Dravet syndrome, which Jayne Lehmann said caused prolonged seizures that could be difficult to manage even with medication.<sup>181</sup> Sarah Lehmann also had verbal dyspraxia and echolalia which significantly impacted her capacity to communicate verbally.<sup>182</sup> Despite these communication challenges, Sarah Lehmann had excellent receptive language and could understand most things.<sup>183</sup>
88. Jayne Lehmann said that the health care and services delivered to Sarah Lehmann were, at times, hindered by health professionals who were not willing to

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<sup>174</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-606; Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [15]–[16].

<sup>175</sup> Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [52].

<sup>176</sup> Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [65]–[68].

<sup>177</sup> Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [65]–[67]; Transcript, AAJ, Public Hearing 4, 26 February 2020, P-617–618.

<sup>178</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [14].

<sup>179</sup> We have used the given names as well as the surnames of Jayne Lehmann and Sarah Lehmann throughout this Report to distinguish between them.

<sup>180</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [25].

<sup>181</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [20].

<sup>182</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [27].

<sup>183</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [32]; Transcript, Jayne Lehmann, Public Hearing 4, 26 February 2020, P-630 [7]–[36].

listen or value the information she and other family members could provide.<sup>184</sup> She referred to a particular incident when Sarah Lehmann presented to an emergency department in 2019 following a series of seizures, and emphasised the importance of information sharing between health professionals, family, people with intellectual disability and support staff to ensure quality health care.<sup>185</sup>

89. Jayne Lehmann said that health professionals who took the time to talk to Sarah Lehmann and get to know her, ‘made a huge difference’.<sup>186</sup> According to Jayne Lehmann, quality health care for Sarah Lehmann was delivered with respect and an open mind, and when Sarah Lehmann was the centre of everything.<sup>187</sup> It involved health professionals who were adaptive and non-judgmental;<sup>188</sup> accountable;<sup>189</sup> able to think outside the square;<sup>190</sup> and who involved the family but did not leave them with total responsibility.<sup>191</sup> Jayne Lehmann also discussed the use of resources such as low literacy tools and hospital passports as effective tools to minimise the barriers to communication for people with intellectual disability.<sup>192</sup>

### Jo Abi

90. Giuseppina Porte (known as Jo Abi) prepared a written statement and gave oral evidence to the Royal Commission on 28 February 2020. She spoke about experiences she has had accessing and receiving health care for her sons, Philip and Giovanni, who live with autism, as well as mental health care for Philip, who has been diagnosed with severe depression.
91. Ms Abi described her younger son, Giovanni, as a ‘brilliant, amazing little boy’ who likes gaming.<sup>193</sup> She outlined the difficulties she encountered in seeking an autism assessment for Giovanni, who she strongly suspected had autism from an early age,<sup>194</sup> stating that her concerns were frequently dismissed by doctors and teachers.<sup>195</sup> After Giovanni was diagnosed at the age of seven,<sup>196</sup> Ms Abi stated

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<sup>184</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [68].

<sup>185</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [77]–[92].

<sup>186</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [75]–[76].

<sup>187</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [38].

<sup>188</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [38].

<sup>189</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [40].

<sup>190</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [41].

<sup>191</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [43].

<sup>192</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [42]; Transcript, Jayne Lehmann, Public Hearing 4, 26 February 2020, P-634–635.

<sup>193</sup> Exhibit 4-7, ‘Statement of Giuseppina Cinzia Porte (Jo Abi)’, 26 February 2020 at [8].

<sup>194</sup> Exhibit 4-7, ‘Statement of Giuseppina Cinzia Porte (Jo Abi)’, 26 February 2020 at [11]; Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-818.

<sup>195</sup> Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-818.

<sup>196</sup> Exhibit 4-7, ‘Statement of Giuseppina Cinzia Porte (Jo Abi)’, 26 February 2020 at [27].

there was a lack of coordination of services and options for treatment from Giovanni's GP, paediatrician, and psychologist.<sup>197</sup> She also spoke about how she frequently had to explain to health professionals how best to communicate with Giovanni.<sup>198</sup>

92. Ms Abi told the Royal Commission that her older son, Philip, is an artist who likes cosmology and is 'miles ahead of any educational institution he's been to so far.'<sup>199</sup> She gave evidence about her experience seeking mental health services for Philip, who has attempted to take his own life on a number of occasions since he became a teenager.<sup>200</sup> Ms Abi said she was shocked when a psychiatrist suggested to her in 2018 that Philip may also have autism,<sup>201</sup> and recounted how one psychologist told her that psychological treatment was not working well for Philip because, prior to being diagnosed with autism, it was like there was a 'big brick wall in front of him.'<sup>202</sup>
93. Ms Abi said that online groups of people with autism and their parents have taught her more than any health professional with respect to care and treatment for her sons.<sup>203</sup> She also expressed the view that there are insufficient good health practitioners who are both affordable and available to meet the health needs of her children.<sup>204</sup>

### **Evelyn Scott OAM and Margot Elliffe**

94. Evelyn Scott OAM<sup>205</sup> and Margot Elliffe<sup>206</sup> prepared individual written statements and gave oral evidence to the Royal Commission together on 28 February 2020. Evelyn Scott's daughter, Kylie Scott, and Margot Elliffe's daughter, Tara Elliffe, also gave evidence at Public hearing 4. Evelyn Scott is a volunteer and advocate.

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<sup>197</sup> Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-822–823; Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [47]–[50].

<sup>198</sup> Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-823–824; Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [40]–[46].

<sup>199</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [7].

<sup>200</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [53]–[70], [80]; Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-829–831.

<sup>201</sup> Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-825–826; Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [71].

<sup>202</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [72].

<sup>203</sup> Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-842; Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [115].

<sup>204</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [116].

<sup>205</sup> As Kylie Scott and her mother, Evelyn Scott, share the same surname, we have used both their given and surnames to distinguish between them.

<sup>206</sup> As Tara Elliffe and her mother, Margot Elliffe, share the same surname, we have used both their given and surnames to distinguish between them.

Margot Elliffe is currently the Vice President of Down Syndrome NSW, a registered nurse, midwife, and child and family health nurse.

95. Evelyn Scott and Margot Elliffe told the Royal Commission about the reactions of health professionals after their daughters were born. Evelyn Scott spoke about the negative attitudes to her daughter's disability expressed to her by some health professionals.<sup>207</sup> Margot Elliffe spoke about her first visit to a medical centre after Tara was born, where a doctor asked why she chose to have Tara, and told Margot Elliffe she should have terminated the pregnancy.<sup>208</sup> Both Evelyn Scott and Margot Elliffe also gave evidence about prenatal testing and the insufficient information made available to families at the time of testing.<sup>209</sup>
96. Evelyn Scott outlined a number of her daughter Kylie's health needs and how these have been addressed by a patchwork of early intervention, private appointments, and National Disability Insurance Scheme (**NDIS**) planning.<sup>210</sup> Evelyn Scott also detailed the difficulties of accessing quality mental health care and support for Kylie Scott,<sup>211</sup> and stated that public speaking, contributing to the community, and independent living have been invaluable in the absence of appropriate mental health care and support.<sup>212</sup>
97. Margot Elliffe said that a community nurse assisted her to manage Tara's health care until she was five, stating this nurse relieved the burden of negotiating health care services for Tara.<sup>213</sup> Margot Elliffe also stated that Tara Elliffe's current GP has a particular interest in disability health care, is very good and has implemented a Care Plan for Tara Elliffe.<sup>214</sup> With respect to the particular hospital admission described by Tara Elliffe in her evidence, Margot Elliffe stated that there was a lack of consistency of care;<sup>215</sup> a failure to properly examine Tara Elliffe;<sup>216</sup> a lack of understanding of her pain levels or offers of pain relief;<sup>217</sup> and that procedures

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<sup>207</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-848, P-851-852; Exhibit 4-33, 'Statement of Evelyn Scott OAM', 11 February 2020 at [5].

<sup>208</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [12]; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-849.

<sup>209</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-850-851; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-849-850.

<sup>210</sup> Exhibit 4-33, 'Statement of Evelyn Scott OAM', 11 February 2020 at [21]-[36].

<sup>211</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-854-856, P-865.

<sup>212</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-865.

<sup>213</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [7]-[10]; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-852-853.

<sup>214</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [13]-[16]; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-856-857.

<sup>215</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [27].

<sup>216</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [28]; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-860.

<sup>217</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [27], [39]; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-861.

were not explained to Tara Elliffe.<sup>218</sup> Margot Elliffe stated she has not seen person-centred care implemented in hospital settings.<sup>219</sup>

98. Both Evelyn Scott and Margot Elliffe made a number of suggestions for health services to improve the health care of people with intellectual disability<sup>220</sup> and shared their views on the importance of decision-making training for their daughters.<sup>221</sup>

## Witnesses from advocacy groups

### Justine O'Neill and Jack Kelly

99. Justine O'Neill is the Chief Executive Officer of CID, a Sydney-based advocacy organisation. She provided a written statement and gave oral evidence to the Royal Commission on supported decision making, which she described as the idea that everybody needs support from time to time to help with decision making.<sup>222</sup> She said that people with intellectual disability may need such support more often and, without it, people with intellectual disability might lose their decision making rights, or be placed in a position of vulnerability and disadvantage.<sup>223</sup>
100. Ms O'Neill said that in a health setting, support for decision making can be encouraged by improving practices around accessibility and communication; listening and talking with the person with intellectual disability; recognising the role of supporters and valuing the information they can share; encouraging the use of communication tools; and taking time to identify a person's decision making ability before putting in supports and tools to build that ability.<sup>224</sup>
101. Jack Kelly, a person with disability who also works at CID, gave oral evidence in a question and answer format led by Ms O'Neill on 18 February 2020, about how he likes to make decisions.<sup>225</sup> Mr Kelly told the Royal Commission that he likes to gather relevant information and think about the pros and cons of the decision with enough time and notice.<sup>226</sup> He said he likes to talk to family, friends and support

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<sup>218</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [38].

<sup>219</sup> Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-864 [29]–[33].

<sup>220</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [45]; Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-865.

<sup>221</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-857–858; Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-858.

<sup>222</sup> Exhibit 4-2, 'Statement of Justine O'Neill', 11 February 2020 at [20].

<sup>223</sup> Exhibit 4-2, 'Statement of Justine O'Neill', 11 February 2020 at [21]–[22].

<sup>224</sup> Exhibit 4-2, 'Statement of Justine O'Neill', 11 February 2020 at [37]–[38].

<sup>225</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-26–29.

<sup>226</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-26 [28]–[32] and P-27 [1], [12]–[14].

workers as a sounding board, but that it is his choice as to whether or not to do so.<sup>227</sup>

102. Mr Kelly said that it is important for people with intellectual disability to be involved in decision making because ‘I feel like we all should be treated as an equal and not as a dis-equal’, and that it is important to see the person first and not the intellectual disability at the forefront.<sup>228</sup> He told the Royal Commission that if people are not involved, they are not getting choice and control, and are left ‘disheartened’ and ‘frustrated’ because another person is making that decision for them.<sup>229</sup>

### Dr Richard Zylan and Nathan Despott

103. Dr Richard Zylan and Nathan Despott gave oral evidence together on 24 February 2020 and spoke to the joint submission provided by the Disability and Oral Health Collaboration, Your Dental Health project team and the Australasian Academy of Paediatric Dentistry, dated 13 February 2020 (**Joint Submission**).<sup>230</sup> Their evidence was further supplemented by a response to questions taken on notice during Public hearing 4, received on 29 February 2020.<sup>231</sup> Dr Zylan has worked as a private dentist since 1994 and is a member of various associations and societies for intellectual disability and dentistry.<sup>232</sup> Mr Despott is the Manager, Policy and Projects, for Inclusion Melbourne, a support organisation for people with intellectual disability, and has experience as a disability support worker.<sup>233</sup>
104. Dr Zylan and Mr Despott gave evidence about the significant difficulties experienced by people with intellectual disability in accessing oral health care<sup>234</sup> and some of the modifications that can be made by dentists to address these difficulties.<sup>235</sup> They also gave evidence about the lack of data relating to the oral health needs and treatment of people with intellectual disability as another barrier to evaluating interventions.<sup>236</sup> They suggested possible changes to government funding that would, in their view, assist in addressing some of these shortcomings.<sup>237</sup>

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<sup>227</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-27 [3]–[7].

<sup>228</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-28 [26]–[29].

<sup>229</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-29 [1]–[3].

<sup>230</sup> Exhibit 4-16, SUB.100.00532.0001.

<sup>231</sup> Exhibit 4-452, EXP.0022.0003.0001.

<sup>232</sup> Exhibit 4-16.1, EXP.0021.0001.0001.

<sup>233</sup> Exhibit 4-16.2, EXP.0022.0001.0001.

<sup>234</sup> Exhibit 4-16, SUB.100.00532.0001 at 0002 at [1.b].

<sup>235</sup> Exhibit 4-16, SUB.100.00532.0001 at 0003–0004 at [1.d].

<sup>236</sup> Exhibit 4-16, SUB.100.00532.0001 at 0002–0003 at [1.c].

<sup>237</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-394, P-401, P-403 [17] – P-404 [4].

105. Dr Zylan and Mr Despott spoke of the need for dentists to spend more time with patients with intellectual disability,<sup>238</sup> and about the role of support workers in providing dental hygiene, identifying dental complaints and supporting a person with intellectual disability to attend the dentist.<sup>239</sup> They acknowledged that there is a general lack of knowledge and skill among support workers to undertake these roles, and that compulsory training in relation to dental health may assist in this regard.<sup>240</sup>
106. Dr Zylan and Mr Despott told the Royal Commission that there are 17 special needs dentists (**SNDs**) in Australia and that there are long wait times for appointments with SNDs.<sup>241</sup> They stated that if general dentists were better equipped to deal with patients with intellectual disability the need to refer to SNDs could be reduced.<sup>242</sup> They said there needs to be disability specific education and training provided to undergraduate dental students, along with the possible inclusion of disability training in the existing dental continuing professional development program.<sup>243</sup>
107. Dr Zylan and Mr Despott also emphasised the importance of clear communication between patients, carers, support persons or families and dentists, as well as between dentists and GPs.<sup>244</sup>

### Dr Scott Avery

108. Dr Scott Avery is an Aboriginal person descending from the Worimi people of NSW and is affiliated with the First Peoples Disability Network (**FPDN**), a community organisation established by, for, and on behalf of Aboriginal and Torres Strait Islander people with disability and their families. He was a community based researcher embedded in FPDN from 2014 to 2020.<sup>245</sup> Dr Avery provided a detailed written statement to the Royal Commission and gave oral evidence on 24 February 2020.

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<sup>238</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-401–402.

<sup>239</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-399–400.

<sup>240</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-400.

<sup>241</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-406; Exhibit 4-16, SUB.100.00532.0001 at 0008 at [3].

<sup>242</sup> Exhibit 4-16, SUB.100.00532.0001 at 0012–0013 at [5.j].

<sup>243</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-397, P-401, P-407–408.

<sup>244</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-409–410; Exhibit 4-16, SUB.100.00532.0001 at 0010–0011 at [5.g].

<sup>245</sup> Exhibit 4-18, 'Statement of Dr Scott Avery', 14 February 2020 at [5]–[7].

109. Dr Avery told the Royal Commission about his research in relation to access to health care and services for Aboriginal and Torres Strait Islander people with disability. In particular, he spoke about a research program he led, which resulted in the publication of a research monograph entitled *Culture is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability* in July 2018.<sup>246</sup>
110. Dr Avery discussed the methodology he developed for his research, which he said focused on gathering testimonial evidence through community engagement. This was an ‘open-ended exercise’ that did not specifically focus on health issues, but instead asked the single question, ‘What is your story?’<sup>247</sup> He said that his research also involved building a statistical profile of Aboriginal and Torres Strait Islander people with disability by ‘pool[ing] together various pieces of [existing] data’ on social, health and wellbeing outcomes compared to other groups.<sup>248</sup> Dr Avery stated that this statistical profile provided context to the testimonial evidence and ‘they validated each other’.<sup>249</sup>
111. Dr Avery gave evidence about the concept of ‘intersectionality’, which he explained to mean the ‘notion of being double-disadvantaged’ for people who are members of two or more marginalised groups.<sup>250</sup> He provided an example from the testimonial evidence he has collected to illustrate how ableism and racism can intersect to compound the discrimination faced by people who have a disability and are Aboriginal or Torres Strait Islander.<sup>251</sup> He said that this example is indicative of the way in which Aboriginal or Torres Strait Islander people with disability are ‘disempowered by those two things coming together’.<sup>252</sup> He added that, in his experience, ‘some of the stories that you will hear are disability stories, and if you add the Aboriginal component, it’s just like turning the volume switch right up’.<sup>253</sup>
112. Dr Avery told the Royal Commission about other key issues that emerged from the testimonial evidence he collected, such as difficulties in obtaining disability

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<sup>246</sup> Exhibit 4-184, EXP.0020.0001.0001; Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-453; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [7].

<sup>247</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-456.

<sup>248</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-456–457; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [29].

<sup>249</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-456 [41]–[42].

<sup>250</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-458–459; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [33].

<sup>251</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [35].

<sup>252</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-459.

<sup>253</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-459 [23]–[24].

diagnosis;<sup>254</sup> presumptions about lack of capacity;<sup>255</sup> diagnostic overshadowing;<sup>256</sup> and disproportionate rationing of health care resources.<sup>257</sup>

113. Dr Avery emphasised the need for a ‘sophisticated approach’ to address the health needs of Aboriginal and Torres Strait Islander people with disability, ‘in which all parts of a health care system come together collaboratively in accepting joint and several responsibility for attaining improvements in their health outcomes’.<sup>258</sup> Among his suggestions, Dr Avery mentioned the need for accountability;<sup>259</sup> to acknowledge Aboriginal methodology;<sup>260</sup> and the contribution of the disability community and their knowledge.<sup>261</sup>

### **James (Jim) Simpson**

114. Jim Simpson has many years of experience in legal and advocacy roles, with a focus on disability rights. He is currently the Senior Advocate at CID, and has been associated with CID since the 1980s.<sup>262</sup> In his written statement and oral evidence given on 25 February 2020, he said that since 2001 he has led CID’s advocacy concerning the health inequalities experienced by people with intellectual disability.<sup>263</sup>
115. In his written statement, Mr Simpson described some of the barriers to good health and health care for people with intellectual disability.<sup>264</sup> He also referred to the substantial research base demonstrating the health inequalities experienced by people with intellectual disability, noting that this research base has grown considerably since 2001.<sup>265</sup> He told the Royal Commission that ‘the most fundamental issue is one of values and attitudes’, stating that there has been a

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<sup>254</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-460; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [38]–[45].

<sup>255</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-461; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [46]–[49].

<sup>256</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-462; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [50]–[52].

<sup>257</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-463; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [53]–[55].

<sup>258</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [66].

<sup>259</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-466; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [69].

<sup>260</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-457–458.

<sup>261</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-467; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [72]–[74].

<sup>262</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [6].

<sup>263</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [9]; Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-509.

<sup>264</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [11].

<sup>265</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [12]–[13].

pervading view that people with intellectual disability are ‘lesser people with lesser rights.’<sup>266</sup>

116. Mr Simpson stated that from early on it was apparent that two basic strands of reform of the health system were required: changes to the mainstream health system so that it could respond appropriately to people with intellectual disability; and the creation of a network of specialised intellectual disability health services to back-up the mainstream.<sup>267</sup> He observed that, at the same time, reform is needed in the disability service system, so that people with intellectual disability are supported to lead healthy lifestyles, to access health services and to implement the advice of health services.<sup>268</sup>
117. Mr Simpson gave detailed evidence concerning previous, current and planned government strategies and initiatives that CID hoped would assist in improving the health of and health care provided to people with intellectual disability in Australia.<sup>269</sup> He emphasised the gap between some of these strategies and initiatives and their effective implementation.<sup>270</sup> He stated that through persistent advocacy,<sup>271</sup> some progress has been made in NSW, including through the development of a Service Framework to Improve Health Care of People with Intellectual Disability (**Service Framework**).<sup>272</sup> Mr Simpson said that CID has seen major gains in access to specialised health services when needed by people with intellectual disability in NSW, but that more funding is required.<sup>273</sup> He also noted the publication in 2017 of *The Essentials*, a guide for public health services to enhance their capability in working with people with intellectual disability, as a useful initiative but stated that he was not aware of any robust action to implement *The Essentials* across LHDs in NSW.<sup>274</sup> When asked what such robust action might be, he suggested a direction from the Ministry of Health with measurable steps to be taken by LHDs in accordance with *The Essentials*.<sup>275</sup> In his view, the failure to see such action to date was due to a lack of institutional priority given to its implementation.<sup>276</sup>

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<sup>266</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-513 [1]–[7].

<sup>267</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [15]; Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-517–519.

<sup>268</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [17].

<sup>269</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [20]–[103].

<sup>270</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-521–522.

<sup>271</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [29].

<sup>272</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-523–526.

<sup>273</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [42]–[43].

<sup>274</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [44]–[45].

<sup>275</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-529 [20]–[25].

<sup>276</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-531 [23]–[28].

118. Mr Simpson told the Royal Commission that CID's initial advocacy at a national level was for the creation in the Medicare Benefits Schedule (**MBS**) of annual health assessment items for people with intellectual disability.<sup>277</sup> This was successful in 2006.<sup>278</sup> However, no substantial implementation strategy was created by the federal government and the initial take-up rate was very low. However, in 2010 the intellectual disability items were consolidated with other annual health assessment items, making the gathering of data about take-up since then difficult.<sup>279</sup>
119. Mr Simpson also described some of CID's advocacy work in relation to improving mental health services for people with intellectual disability. A National Roundtable on this subject was held in 2013, resulting in a communiqué setting out eight key elements of an effective system of mental health care for people with intellectual disability.<sup>280</sup> Mr Simpson stated that CID continued to advocate for the implementation of reforms around these key elements, and in particular for national mental health plans and strategies to include a substantial focus on people with intellectual disability.<sup>281</sup>
120. Mr Simpson also described CID's 'Our Health Counts' campaign, which was conducted in 2019.<sup>282</sup> This culminated in a National Roundtable organised by the federal Minister for Health in August 2019, and a draft National Roadmap of action to improve health care for people with intellectual disability (**Draft Roadmap**) which should, pending the follow-up Roundtable that was scheduled for April 2020, become part of the proposed national Primary Health Care 10 Year Plan' (**10 Year Plan**).<sup>283</sup> Mr Simpson expressed the view that the Draft Roadmap could, with the right political imperative, be implemented 'in a measured, responsible way' within a shorter timeframe of five years.<sup>284</sup>
121. Mr Simpson also gave evidence that CID has been concerned that the roles of disability support services in ensuring good health of people with disability, including people with intellectual disability, may be diminished in the NDIS environment.<sup>285</sup> He noted the reporting previously done by the NSW Ombudsman on the deaths of people with disability in supported accommodation, which

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<sup>277</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [52].

<sup>278</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [57].

<sup>279</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [58]–[59]; Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-534–535.

<sup>280</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [75]–[76]; Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-537–538.

<sup>281</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [88].

<sup>282</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [91]–[103].

<sup>283</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [100].

<sup>284</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-541 [4]–[8].

<sup>285</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [108].

discussed problems in both the disability service system and the health system.<sup>286</sup> He stated that CID was concerned about the future of the review role formerly exercised by the NSW Ombudsman. In his opinion, these reviews provided ‘invaluable intelligence on the causes of death and broader gaps in good health practice in the health and disability support systems’.<sup>287</sup> He expressed concern that this important role is not entirely captured by the functions of the NDIS Quality and Safeguards Commission (**NDIS Commission**).<sup>288</sup>

### Robert Strike AM

122. Robert Strike AM is a co-founder of Self Advocacy Sydney and board member of CID. He is a person with intellectual disability and gave oral evidence to the Royal Commission on 28 February 2020 in a question and answer format led by Ms O’Neill. In particular, Mr Strike discussed how people with intellectual disability can speak up for themselves and advocate on their own behalf.<sup>289</sup>
123. Mr Strike spoke about communication between people with intellectual disability and health professionals. He emphasised the importance of listening and explaining things to people with intellectual disability,<sup>290</sup> saying that ‘being treated as a person, first and foremost’ is important.<sup>291</sup>
124. Mr Strike told the Royal Commission that people with intellectual disability should be able to ask questions,<sup>292</sup> obtain information they need,<sup>293</sup> and feel included, which can be achieved by making sure they understand what is being said to them.<sup>294</sup> He said that Easy Read and explaining Easy Read documents helps people with intellectual disability understand written information and the message of the document.<sup>295</sup>

### Medical expert witnesses

#### Professor Stephen Leeder

125. Professor Stephen Leeder is an Emeritus Professor of Public Health and Community Medicine at the University of Sydney. He is also a physician and epidemiologist and is currently based at Westmead Hospital. Professor Leeder has

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<sup>286</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [111]–[113].

<sup>287</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [122].

<sup>288</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [122]–[123]; Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-541–542.

<sup>289</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-868 [14]–[16].

<sup>290</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-873 [18] – P-875 [11].

<sup>291</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-875 [21]–[23].

<sup>292</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-875 [24]–[29].

<sup>293</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-876 [3]–[4].

<sup>294</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-876 [22]–[25].

<sup>295</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-877 [11]–[26].

served in academic and advisory roles in health care, prevention, public health, medical journalism, health policy, clinical epidemiology and medical education since 1975.<sup>296</sup> Professor Leeder prepared a brief expert statement for the Royal Commission on the Australian health system, and gave oral evidence on 20 February 2020.

126. Professor Leeder described the Australian health care system as ‘connected’ in many respects by the manner in which it is financed. He expressed the view that there are opportunities for greater integration of care between what happens in the community and what happens in hospital, which requires resolving some tensions in financing.<sup>297</sup> He also described some of the challenges that the health system faces. He stated that these include, responding to Australia’s changing demographic profile;<sup>298</sup> reporting mechanisms;<sup>299</sup> funding;<sup>300</sup> lack of co-ordinated care;<sup>301</sup> supply and distribution of the health work force;<sup>302</sup> workforce planning;<sup>303</sup> and equity of access and quality of health care provided to marginalised groups such as First Nations people and people with disability.<sup>304</sup>

### **Professor Julian Trollor**

127. Professor Julian Trollor is a specialist neuropsychiatrist with a focus on cognitive disability. He is the Chair in Intellectual Disability Mental Health and Head of the Department of Developmental Disability Neuropsychiatry at the University of NSW.<sup>305</sup> He was described by another witness as the current national leader in research in relation to the health inequalities and needs of people with intellectual disability.<sup>306</sup> Professor Trollor prepared a detailed and thoughtful expert statement for the Royal Commission and gave oral evidence on 20 February 2020.
128. Professor Trollor told the Royal Commission that the ‘current health care landscape in Australia is one of lack of preparedness for the needs of people with developmental disabilities.’<sup>307</sup> In his view the lack of preparedness is manifest at every level of the health system and has led to decreases in the life span of people

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<sup>296</sup> Exhibit 4-8.1, EXP.0018.0001.0001.

<sup>297</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-158.

<sup>298</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [27]; Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-161.

<sup>299</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [24]–[26].

<sup>300</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [28]–[33].

<sup>301</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-160 [24]–[34].

<sup>302</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [34].

<sup>303</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [35]–[36].

<sup>304</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [37]–[43].

<sup>305</sup> Exhibit 4-8.1, EXP.0015.0001.0001.

<sup>306</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-517 [17]–[18].

<sup>307</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [15]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-169 [11]–[25].

with disability. Professor Trollor also stated that ‘such systemic lack of preparedness is a major contributor to the stark mental and physical health disadvantage experienced by people with developmental disability compared to the rest of the Australian population.’<sup>308</sup>

129. Professor Trollor set out some of the particular health care needs of people with intellectual disability and people with autism. He noted the overrepresentation in these groups of mental and physical health co-morbidities, including sensory abnormalities, epilepsy, problematic feeding behaviours, respiratory and gastrointestinal diseases, mobility restrictions, frailty and premature ageing.<sup>309</sup>
130. Professor Trollor also observed that communication differences and adaptive functioning difficulties can pose particular challenges for the provision of health care to people with intellectual disability and people with autism.<sup>310</sup> In addition, diagnostic overshadowing can result in misdiagnoses.<sup>311</sup> He stated that the available evidence suggests that there is a failure in health care systems to meet the needs of people with intellectual disability and autistic people, in areas such as preventative health care.<sup>312</sup> These deficiencies result in delayed or missed diagnoses a lack of active management;<sup>313</sup> non-evidence based prescribing practices;<sup>314</sup> poorer health trajectories and over-representation of potentially avoidable morbidities and hospitalisations;<sup>315</sup> poor end of life care;<sup>316</sup> and high rates of premature mortality.<sup>317</sup>
131. Professor Trollor told the Royal Commission that significant changes to health care delivery are required in order to respond to the combination of psychiatric and physical health co-morbidities, difficulties with adaptive functioning, and contextual stressors experienced by people with intellectual disability and autism. These include ensuring innovation in health service models; a workforce with sufficient knowledge and training to tailor practice to patients’ complex needs and communication requirements; accessible health care information; and better cross-

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<sup>308</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [16]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-175 [26] – P-176 [7].

<sup>309</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [31]–[95].

<sup>310</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [96]–[111].

<sup>311</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [109]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-194 at [33] – P-195 at [28].

<sup>312</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [131]–[144].

<sup>313</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [145]–[152].

<sup>314</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [153]–[159].

<sup>315</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [160]–[169].

<sup>316</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [170]–[174].

<sup>317</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [175]–[206].

sector collaboration and well defined pathways to coordinate effective health care at the intersection of disability, mental and physical health domains.<sup>318</sup>

132. Professor Trollor outlined the research done recently by his team which has identified, among other things, that potentially avoidable deaths of people with intellectual disability represented 38 per cent of all deaths that occurred in a six and a half year period in NSW, a figure more than double that of the general population.<sup>319</sup> He also drew attention to research which found that the median age of death in NSW for an adult cohort with intellectual disability is 27 years lower than that of the general population (54 years compared with 81 years).<sup>320</sup> Extrapolating from this data, Professor Trollor estimated that, annually, about 400 Australians with intellectual disability, who are aged 20 and above, suffer a potentially avoidable death.<sup>321</sup>
133. Professor Trollor stated that there is currently a limited capacity for researchers to understand health outcomes for people with intellectual disability and people with autism because 'data systems are not connected and do not identify people with these conditions accurately.'<sup>322</sup> He described existing gaps in tracking and publishing mortality data, including through the National Australian Coronial Information System,<sup>323</sup> varying state regimes<sup>324</sup> and the new reportable deaths function of the NDIS Commission.<sup>325</sup>
134. Professor Trollor recommended mandatory training for the health workforce on the needs of people with intellectual disability and people with autism, including enhanced training for specific medical speciality groups and career pathways in sub-specialties.<sup>326</sup> In addition, Professor Trollor highlighted the importance of professionals working in the disability system acquiring basic competencies in disability health care.<sup>327</sup>

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<sup>318</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [128]–[129]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-196 [23]–[37].

<sup>319</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [179]–[197]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-183 [1]–[7], P-201.

<sup>320</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [179].

<sup>321</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-201 [23] – P-202 [2].

<sup>322</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-170 [23]–[25].

<sup>323</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [198]–[199], [299]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-207–208.

<sup>324</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [200]–[206].

<sup>325</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [293]–[298]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-199–201.

<sup>326</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [234]–[254].

<sup>327</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [287].

135. Professor Trollor's evidence also touched on the 'very high rates of mental ill health in people with intellectual disability.'<sup>328</sup> In relation to people with autism, he cited the results of a 2015 study in the United States, which found a five-fold risk of suicide attempts in autistic adults compared with a non-autistic control group.<sup>329</sup> He stated that in Australia the needs of people on the autism spectrum experiencing suicidal ideation 'are really not particularly well met.' He gave as an example the National Suicide Prevention Strategy which does not mention the needs of this group.<sup>330</sup>
136. Professor Trollor expressed the view that a co-design approach to develop and implement a national population health strategy to meet the unmet health needs of people with intellectual disability and autistic people is required.<sup>331</sup> He acknowledged the work that is underway in relation to the development of a National Roadmap to improve the health of Australians with intellectual disability<sup>332</sup> but said that there is a 'gulf between what needs to be done and what is currently on the plan to be done.'<sup>333</sup> In addition, he noted that the specific needs of people with intellectual disability and people on the autism spectrum are 'rarely incorporated in national, state or territory health and mental health policy documents, including in overarching health and mental health plans.'<sup>334</sup>
137. Professor Trollor concluded his statement as follows:

*People with intellectual disability and autistic people experience a mismatch between their health care needs and the health care services they currently receive. Gaps are systemic and pervasive in nature and span inadequate engagement in preventative health care services, missed diagnosis and poor end-of-life care and disease and risk management, and non-evidence based prescribing practices. Poor health trajectories and increased mortality among Australians with intellectual disability and autistic Australians, particularly from causes that are potentially avoidable or amenable to intervention emphasise core failures within our current health care system to meet the needs of these vulnerable populations. Urgent action on these issues is required in order that Australia meet its obligations under the UNCRPD.*<sup>335</sup>

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<sup>328</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-185 [4]–[6].

<sup>329</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [43]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-186 [17]–[21].

<sup>330</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-187 [4]–[14].

<sup>331</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [214]–[216].

<sup>332</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [217]–[218].

<sup>333</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-212 [40] – P-213 [2].

<sup>334</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [273].

<sup>335</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [301].

## Dr Jacqueline Small

138. Dr Jacqueline Small provided an expert witness statement to the Royal Commission and gave oral evidence on 20 February 2020. Dr Small is a developmental paediatrician with over 32 years of clinical experience.<sup>336</sup> Among other things, she is the President of the Australian Association of Developmental Disability Medicine and she gave her evidence to the Royal Commission in that capacity.<sup>337</sup> Dr Small also works as a consultant developmental paediatrician and team leader at the Disability Specialist Unit in the Sydney LHD.<sup>338</sup> In addition, she is the Clinical Lead for a new Specialised Team for Intellectual Disability, Sydney, within the Sydney LHD, which at the time of Public hearing 4 was in the establishment phase.<sup>339</sup>
139. In her written statement, Dr Small used the acronym IDD to indicate people with intellectual and developmental disability.<sup>340</sup> She described people with IDD as a minority group suffering significant health inequities, which she said were 'stark and persistent'.<sup>341</sup> She told the Royal Commission that people within this group have 2.5 times the number of health conditions of the general population and often have complex health needs.<sup>342</sup> However, in her opinion, people with IDD face significant barriers to accessing health care from the health system itself.<sup>343</sup> She stated that the absence of systemic implementation of collaborative and integrated care and other initiatives to improve the health of people with IDD, reflects systemic neglect by the health system of people with IDD.<sup>344</sup>
140. Among the factors contributing to this systemic neglect, Dr Small identified: deficiencies in training for health professionals in relation to the health care and treatment of people with IDD;<sup>345</sup> diagnostic overshadowing;<sup>346</sup> perceptions about the quality of life and value to society of people with IDD;<sup>347</sup> communication difficulties;<sup>348</sup> and lack of integration of health care for adults with IDD.<sup>349</sup> Dr Small

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<sup>336</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [3].

<sup>337</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-222 [25]–[27].

<sup>338</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [4].

<sup>339</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-224 [12]–[15].

<sup>340</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [9].

<sup>341</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-231 [10]; Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [24].

<sup>342</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [25]–[26].

<sup>343</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [27].

<sup>344</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [30]–[31].

<sup>345</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [33]–[34].

<sup>346</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [35]–[38].

<sup>347</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [36]–[37].

<sup>348</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [39]–[44].

<sup>349</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [48]–[51].

stated that the shortage of specialists and other health professionals with training in IDD has been widely recognised as an issue in Australia and internationally.<sup>350</sup>

141. Dr Small also told the Royal Commission about the delivery of paediatric care to people with IDD in NSW, and stated that she is not aware of any established comprehensive and evidence-based paediatric strategic health care plan in NSW or nationally for children and adolescents with IDD.<sup>351</sup> She said that the period of transition from paediatric to adult health care is often a challenging time and, in her opinion, it is likely that the majority of young people with IDD are not supported by a planned process of transition and may experience substantial service gaps and disruptions.<sup>352</sup> She described some of the differences between paediatric and adult health care for people with IDD, noting that paediatricians are specifically trained in development and are better placed to understand the functional implications of IDD.<sup>353</sup>
142. Dr Small also emphasised the importance of collaboration across disability and health services, and expressed the view that this is not currently occurring.<sup>354</sup> Dr Small noted some of the new initiatives that are being put in place in NSW as well as at the national level.<sup>355</sup> She particularly referred to the Roundtable on the Health of People with Intellectual Disability and the associated Draft Roadmap. Dr Small noted that there was support at the Roundtable for the funding of enhanced resources for the primary health care of people with IDD and for the development of a national roadmap. She characterised this as 'a very promising national initiative' but pointed out that the Draft Roadmap had not been finalised and funding had not been released.<sup>356</sup> Dr Small opined that these initiatives and others outlined in the National Disability Strategy require significant investment of funds if they are to be effectively delivered.<sup>357</sup> She expressed the view that greater strategic planning is required, particularly to address the gaps that have been left by withdrawal of state inter-agency funding models.<sup>358</sup>

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<sup>350</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [79].

<sup>351</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [67]; Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-243 [22]–[27].

<sup>352</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 12 February 2020, P-244 [11]–[18]; Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [71].

<sup>353</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [75]–[76].

<sup>354</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [80]–[81].

<sup>355</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [85], [90] and [100]–[109].

<sup>356</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [106]–[108].

<sup>357</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-231 [34]–[39].

<sup>358</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [90]–[91].

## Professor Nicholas Lennox

143. Professor Nicholas Lennox is a researcher, advocate and former GP with expertise on the health of adults with intellectual and developmental disability. In addition to having 35 years of practising medical experience, Professor Lennox established the Developmental Disability Unit at the University of Melbourne in 1992 and later established a similar unit at the University of Queensland, which became the Queensland Centre for Intellectual and Developmental Disability.<sup>359</sup>
144. Professor Lennox provided an expert statement to the Royal Commission discussing the barriers to high quality health care faced by people with intellectual disability in Australia. He also set out his opinion on how health care and services could be improved for people with intellectual disability, proposing a number of reforms and models of care based on his own research and experience along with that of others. He gave oral evidence to the Royal Commission on 25 February 2020.
145. Professor Lennox noted that the health issues experienced by adults with intellectual disability in Australia remain largely unchanged since he commenced practising and researching in this area in 1992.<sup>360</sup> He stated that system-wide and planned responses, with an injection of additional resources over the long term, are required to be directed towards the deficits in health care and disability support provided to adults with intellectual disability.<sup>361</sup>
146. Among the key barriers to quality health care for people with intellectual disability, Professor Lennox identified: widespread negative attitudes about and devaluing of people with intellectual disability;<sup>362</sup> communication challenges;<sup>363</sup> difficulties with access to health services;<sup>364</sup> and inadequacy in the integration of health services for people with intellectual disability.<sup>365</sup> With respect to the integration of health services, Professor Lennox mentioned some recent positive changes in NSW and particularly with the development of the Draft Roadmap for improving health services for people with intellectual disability.<sup>366</sup> However, he expressed the view

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<sup>359</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [4]–[8].

<sup>360</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [13].

<sup>361</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [20].

<sup>362</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [21]–[23].

<sup>363</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [24]–[31].

<sup>364</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [32].

<sup>365</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [33]–[40].

<sup>366</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0176–0178; Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [38]–[40].

that the Draft Roadmap does not respond urgently enough to address the deficits in health and health care and the systematic shortcomings of the health system for people with intellectual disability.<sup>367</sup>

147. Professor Lennox told the Royal Commission about his involvement in developing a Comprehensive Health Assessment Program (**CHAP**) tool in 1997.<sup>368</sup> In his view, the use of the CHAP tool can minimise the barriers to primary health care for people with intellectual disability by prompting health care and screening.<sup>369</sup> While a review of this tool resulted in the addition of a specific Medicare item number to fund GPs to provide health assessments to people with intellectual disability, Professor Lennox stated that there is evidence to suggest that there has been poor implementation of health assessments for people with intellectual disability in Australia.<sup>370</sup> Professor Lennox detailed the steps required to maximise the implementation of health assessments, and suggested amendment to the Draft Roadmap to facilitate these strategies.<sup>371</sup>
148. Professor Lennox also emphasised the importance of education and ongoing training for health professionals, as well as disability support workers about meeting the health care needs of people with intellectual disability.<sup>372</sup> He suggested that following the Netherlands' model of having 'intellectual disability physicians' with specialist training could potentially improve health care delivery for people with intellectual disability.<sup>373</sup>

## Government agency witnesses

### Kathryn McKenzie and Lyn Porter

149. Kathryn McKenzie is the Director of Operations at the NSW Ageing and Disability Commission (**ADC**).<sup>374</sup> The ADC has oversight of, and coordinates, the Official

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<sup>367</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [40]; Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-557 [14]–[26].

<sup>368</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [7].

<sup>369</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [7], [41]–[44]; Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-558–559.

<sup>370</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [45].

<sup>371</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [46]–[47].

<sup>372</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [58]–[69].

<sup>373</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [71], [75]; Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-563 [26] – P-564 [30].

<sup>374</sup> Transcript, Kathryn McKenzie, Public Hearing 4, 26 February 2020, P-576 [23]–[25].

Community Visitor (**OCV**) Scheme in NSW.<sup>375</sup> Lyn Porter is an OCV, having been first appointed to that role in 2001.<sup>376</sup>

150. Ms McKenzie and Ms Porter gave evidence together on 26 February 2020 about issues concerning the health care of people with cognitive disability observed by OCVs when visiting disability accommodation services and assisted boarding houses (also known as 'visitable services'). Ms McKenzie spoke to two documents provided by the ADC to the Royal Commission: a summary of the OCV Scheme,<sup>377</sup> and a response to the Royal Commission's Issues Paper in relation to health issues affecting persons with intellectual disability.<sup>378</sup>
151. Ms Porter gave evidence that OCVs have power under relevant legislation to enter a visitable service unannounced, and identify and raise any issues affecting residents.<sup>379</sup> She said that OCVs speak to residents and staff members, check documentation (written or electronic) and prepare a report raising any issues of concern to the service provider, who provides a response within a particular timeframe.<sup>380</sup>
152. Ms McKenzie said that unresolved complaints may be escalated to the NDIS Commission through the ADC, but expressed concern that the action taken or the outcome of a complaint may not be communicated to the ADC because of privacy concerns.<sup>381</sup> After Public hearing 4, the Royal Commission received material from the NDIS Commission in response to this evidence which stated that a meeting was held on 12 March 2020 between the ADC and the NDIS Commission, where it was agreed that this concern would be reviewed.<sup>382</sup>
153. Ms McKenzie discussed a number of concerns raised by OCVs about a range of health issues they have observed, including concerns about access to timely and appropriate health services;<sup>383</sup> adequacy of support provided by health staff during

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<sup>375</sup> Exhibit 4-26.1, ISS.001.00038 at 0002.

<sup>376</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-577–578.

<sup>377</sup> Exhibit 4-26, ADC.9999.0001.0001.

<sup>378</sup> Exhibit 4-26.1, ISS.001.00038.

<sup>379</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-579 [1]–[3], [9]–[10]; *Ageing and Disability Commissioner Act 2019* (NSW).

<sup>380</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-579 [3]–[7].

<sup>381</sup> Transcript, Kathryn McKenzie, Public Hearing 4, 26 February 2020, P-586 [14] – P-587 [6].

<sup>382</sup> Exhibit 4-455, 'Supplementary Statement of Graeme Head AO', 13 March 2020 at [19]–[23]; Exhibit 4-455.1, CTD.7200.0001.0347.

<sup>383</sup> Exhibit 4-26.1, ISS.001.00038 at 0003–0004.

hospitalisation;<sup>384</sup> transfer of care from hospital to home;<sup>385</sup> and the coordination of care between health and disability services for residents.<sup>386</sup>

154. Ms McKenzie spoke about the important role disability support staff have as ‘gatekeepers’ for residents’ access to GP and other health services.<sup>387</sup> Ms Porter described various examples where she said disability support staff had not taken a proactive role, leading to the health needs of some residents not being addressed.<sup>388</sup> This included an instance where one GP was selected for all residents for the convenience of staff,<sup>389</sup> and occasions where residents did not receive appropriate treatment because of poor documentation by staff simply ticking a box or marking a health plan as ‘not applicable’ without any follow up, or failing to explore alternative forms of examination and treatment for residents.<sup>390</sup> Ms Porter said:

*Time and time again I see out of date plans, out of date assessments, recommendations not being implemented. So people are falling between the cracks because nobody’s connecting the dots.*<sup>391</sup>

155. Both Ms McKenzie and Ms Porter emphasised the importance of a good culture from leadership down, placing an emphasis on individual health needs and an effective monitoring system.<sup>392</sup> Ms Porter also spoke of the importance of exploring alternative options and increased planning to prepare residents with intellectual disability for health appointments.<sup>393</sup> The ADC submission also noted the importance of having in place better arrangements with health services such as local hospitals to improve discharge planning and communication.<sup>394</sup>

### NSW Health (Dr Nigel Lyons)

156. Dr Nigel Lyons is the Deputy Secretary, Health System Strategy and Planning, for the NSW Ministry of Health, and his evidence was given on its behalf.<sup>395</sup> Dr Lyons provided two written statements in response to questions given in advance by the Royal Commission, and oral evidence on 27 February 2020. In addition, on 13

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<sup>384</sup> Exhibit 4-26.1, ISS.001.00038 at 0004–0005.

<sup>385</sup> Exhibit 4-26.1, ISS.001.00038 at 0005–0006.

<sup>386</sup> Exhibit 4-26.1, ISS.001.00038 at 0007.

<sup>387</sup> Exhibit 4-26.1, ISS.001.00038 at 0003.

<sup>388</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-582 [13]–[16].

<sup>389</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-583 [18] – P-584 [1].

<sup>390</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-588 [5] – 590 [5].

<sup>391</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-582 [12–14].

<sup>392</sup> Transcript, Kathryn McKenzie and Lyn Porter, Public Hearing 4, 26 February 2020, P-592–593.

<sup>393</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-590 [15]–[40].

<sup>394</sup> Exhibit 4-26.1, ISS.001.00038 at 0005–0007.

<sup>395</sup> Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [4], [6].

March 2020, NSW Health provided written responses to questions taken on notice by Dr Lyons during the hearing.<sup>396</sup>

157. In his statements, Dr Lyons used the term ‘NSW Health’ to refer to both the NSW Ministry of Health and the NSW public health system as a whole.<sup>397</sup> He provided an overview of the structure of NSW Health and described the role of the 15 LHDs in delivering hospital and community and mental health services as well as the role of the Ministry of Health as systems manager.<sup>398</sup> He also set out the NSW Health policies applying on a state-wide basis which he said have particular relevance to people with disability.<sup>399</sup> He outlined the mechanisms available to the Ministry of Health for ensuring that policies are understood and implemented by LHDs (and other health organisations in the public health system in NSW).<sup>400</sup> He was questioned about the practical implementation and accessibility of some of these policies and frameworks in relation to people with cognitive disability, and acknowledged that NSW Health could do better in some areas in addressing the needs of people with cognitive disability in its policies.<sup>401</sup>
158. In discussing the processes for ensuring implementation of the various NSW Health policies, Dr Lyons said that there needs to be a greater ability to identify people with cognitive disability within the services provided by NSW Health and ensure that they are receiving appropriate health care.<sup>402</sup> He told the Royal Commission that data is not captured on a system-wide basis, so as to enable patients with cognitive disability to be easily identified.<sup>403</sup> He said that this lack of data presents a challenge in assessing the care provided to people with cognitive disability and for planning and developing specific policies with respect to this cohort of patients.<sup>404</sup> He noted that the health system needs to have a greater ability to identify people with cognitive disability in datasets and to connect the data systems used in disability care with those in health care. He also said that the

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<sup>396</sup> Exhibit 4-453, NSW.9999.0004.0003.

<sup>397</sup> Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [9].

<sup>398</sup> Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [9]–[41]; Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-698 [26] – P-699 [23].

<sup>399</sup> Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [44]; Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-707–710.

<sup>400</sup> Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [42]–[43]; Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-699 [24] – P-702 at [25].

<sup>401</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-711–712, P-722–744.

Dr Lyons provided the Royal Commission with further information about accessibility and practical implementation of NSW Health policies for people with disability, including examples of resources available in Easy Read. See Exhibit 4-453, NSW.9999.0004.0001; Exhibit 4-453.9, NSW.9999.0004.0511.

<sup>402</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-703–704.

<sup>403</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-737 [33] – P-738 [6].

<sup>404</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-738–740.

Ministry of Health has been advocating at both state and national level in this area.<sup>405</sup>

159. Dr Lyons stated that the NSW Agency for Clinical Innovation (**ACI**) is one of five 'pillar organisations' in NSW Health established to work 'with clinicians, consumers and managers to design and promote better healthcare for NSW.'<sup>406</sup> He said that within ACI there are over 30 networks, including the Intellectual Disability Network, which has developed tools and resources that can be used by LHDs and health services in providing care to patients with cognitive disability.<sup>407</sup> When asked about one of these resources, referred to as *The Essentials* framework, Dr Lyons responded that it is not a mandatory NSW health policy, but has informed a range of initiatives taken by LHDs to improve care to patients with intellectual disability.<sup>408</sup>
160. Dr Lyons also told the Royal Commission about the Specialised Intellectual Disability Health Teams and Intellectual Disability Health positions being established in LHDs to improve the multidisciplinary approach to the care of patients with intellectual disability who have complex and chronic health problems in NSW.<sup>409</sup> In addition, he described the Intellectual Disability/Mental Health Specialist Hubs which will provide state-wide tertiary level services for adult, child and adolescent patients with intellectual disability who have co-morbid mental illness.<sup>410</sup> He said that these are significant recent initiatives in NSW, which will be subject to evaluation,<sup>411</sup> and acknowledged that there remains work to be done to further improve the health care and services provided to people with cognitive disability.<sup>412</sup> He also described efforts to improve the interface between NSW Health services and disability services provided under the NDIS.<sup>413</sup>

### **Commonwealth Department of Health (Tania Rishniw, Dr Andrew Singer and Simon Cotterell)**

161. Three witnesses gave written statements and oral evidence to the Royal Commission on behalf of the Commonwealth Department of Health

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<sup>405</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-739 [25]–[27].

<sup>406</sup> Exhibit 4-27, 'First Statement of Dr Nigel Lyons', 13 February 2020 at [37a].

<sup>407</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-704–706, P-742, P-744–745.

<sup>408</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-744 [9]–[31]; Exhibit 4-453, NSW.9999.0004.0003.

<sup>409</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [13]–[29], [107]–[109]; Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-747–749.

<sup>410</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [30]–[96], [110]–[114].

<sup>411</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [28], [39].

<sup>412</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-733 [34] – P-734 [8].

<sup>413</sup> Exhibit 4-28 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [115]–[163].

(**Commonwealth Health**): Tania Rishniw (Acting Deputy Secretary, Health Systems Policy and Primary Care);<sup>414</sup> Dr Andrew Singer (Principal Medical Adviser to the Chief Medical Officer);<sup>415</sup> and Simon Cotterell (First Assistant Secretary, Primary Care Division).<sup>416</sup> Their oral evidence was given as a panel on 27 February 2020.

162. In their written statements, the witnesses provided responses to questions provided in advance of the hearing by the Royal Commission on topics such as the nature and structure of the Australian health system, the operation of the MBS, the Primary Health Networks (**PHNs**) and the National Health Reform Agreement (**NHRA**).<sup>417</sup>
163. Mr Cotterell described PHNs as independent, not-for-profit companies contracted by Commonwealth Health to undertake functions including analysis of population health needs and commissioning of services to fill gaps.<sup>418</sup> He acknowledged that the health needs of people with intellectual disability are not specifically identified among the seven priority areas to guide the commissioning work of PHNs.<sup>419</sup>
164. Among other things, Ms Rishniw stated that a new NHRA, which is the governing mechanism for the payment of public hospital funding contributions between the Commonwealth and the states and territories, is being negotiated for the period 1 July 2020 to 30 June 2025. She said that included in the proposed agreement for the new NHRA there is a commitment from all parties to improve the approach to issues that arise at the interface between the health system and other social service systems, including disability services.<sup>420</sup>
165. Mr Cotterell described the Commonwealth Health 10 Year Plan, which he said should be completed by September 2020.<sup>421</sup> Much of Mr Cotterell's evidence focused on the Roundtable convened by Commonwealth Health in August 2019 concerning the health of people with intellectual disability, and the resulting Draft Roadmap, which was intended to be subject to further discussions in 2020.<sup>422</sup> He

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<sup>414</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020.

<sup>415</sup> Exhibit 4-30, 'Statement of Dr Andrew Singer', 5 February 2020.

<sup>416</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020.

<sup>417</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [11]–[28]; Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [29]–[45].

<sup>418</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [30]–[31].

<sup>419</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [43]–[44].

<sup>420</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [26]–[27].

<sup>421</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [11]–[12]; Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-757 [25] – P-758 [9].

<sup>422</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [13]–[28]; Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-757–782; Exhibit 4-130, EXP.0016.0001.1106.

said that while the Draft Roadmap is connected to the 10 Year Plan, it is not restricted to primary health care.<sup>423</sup> He also acknowledged the narrow focus of the Draft Roadmap on improving the health system to meet the needs of people with intellectual disability, noting that a similar initiative for people with autism would need to be considered separately by the Minister for Health, and to be appropriately resourced.<sup>424</sup>

166. While previously no decision had been taken by Commonwealth Health in relation to funding for various elements of the Draft Roadmap, during the hearing the Minister for Health made an announcement that \$6.5 million had been allocated over four years to fund one of these elements, namely the Primary Care Enhancement Program (**PCEP**).<sup>425</sup> Mr Cotterell said that this program comprises the development of national resources to build the capacity of PHNs to support health professionals in caring for people with intellectual disability, and of 'innovative and inclusive models and pathways of care to improve integration among health care services and the NDIS at regional level.'<sup>426</sup>
167. Dr Singer's witness statement focused on some aspects of the education and training provided to health professionals in Australia.<sup>427</sup> In the course of his oral evidence, Dr Singer distinguished the four 'phases' of medical education and training.<sup>428</sup> He said that in the earlier phases there might be a focus on education concerning working with people with intellectual disability in a respectful and compassionate way;<sup>429</sup> while the vocational training and continuing professional development training stages might include the development of special skills in working with patients with intellectual disability.<sup>430</sup> Mr Cotterell stated that Commonwealth Health is currently engaging in discussions with the deans of Australian medical and nursing schools, the Australian Medical Council and the Council of Presidents of Medical Colleges, about enhancing medical education and training with respect to health care and treatment for people with intellectual disability, as part of the National Roadmap.<sup>431</sup>

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<sup>423</sup> Transcript, Tania Rishniw, Public Hearing 4, 27 February 2020, P-758 [28]–[29].

<sup>424</sup> Transcript, Tania Rishniw, Public Hearing 4, 27 February 2020, P-761 [21] – P-762 [12].

<sup>425</sup> Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-763 [11]–[32].

<sup>426</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [23]–[24].

<sup>427</sup> Exhibit 4-30, 'Statement of Dr Andrew Singer', 5 February 2020 at [9]–[19].

<sup>428</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [5].

<sup>429</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [20]–[24].

<sup>430</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [27]–[29].

<sup>431</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [19]–[22]. Mr Cotterell provided the Royal Commission with copies of the correspondence from the Minister for Health and the relevant organisations opening these discussions, which were tendered into evidence as

## NDIS Quality and Safeguards Commissioner (Graeme Head AO)

168. The National Disability Insurance Scheme Quality and Safeguards Commissioner (**NDIS Commissioner**) is Mr Graeme Head AO. He was appointed in December 2017 and took up office on 1 July 2018.<sup>432</sup> Mr Head provided two written statements to the Royal Commission for the purposes of the hearing, including a supplementary statement after the closing of the hearing,<sup>433</sup> and gave oral evidence on 27 February 2020.
169. The statements provided by Mr Head were lengthy and addressed a number of issues, including: the role and jurisdiction of the NDIS Commission in the regulation of NDIS providers;<sup>434</sup> the NDIS Code of Conduct and the NDIS Practice Standards;<sup>435</sup> and the NDIS Quality and Safeguarding Framework and NDIS Commission Compliance and Enforcement Policy.<sup>436</sup> In addition, Mr Head provided evidence in relation to the NDIS Commission's functions including in relation to registration;<sup>437</sup> reportable incidents;<sup>438</sup> complaints;<sup>439</sup> and behaviour support.<sup>440</sup>
170. Mr Head described the role of the NDIS Commission in undertaking data collection.<sup>441</sup> In his oral evidence he also discussed the recently published NDIS Commission Activity Report for the period 1 July to 31 December 2019, which he said provides a snapshot of the levels of activity in relation to the various functions of his office.<sup>442</sup> He discussed the data collected by the NDIS Commission in relation to the deaths of people with disability, primarily through its reportable incidents function.<sup>443</sup> He also described two recent research projects

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Exhibit 4-237, CTD.0001.1000.0029; Exhibit 4-238, CTD.0001.1000.0031; Exhibit 4-239, CTD.0001.1000.0033; Exhibit 4-240, CTD.0001.1000.0035.

<sup>432</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [7].

<sup>433</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020; Exhibit 4-455, 'Supplementary Statement of Graeme Head AO', 13 March 2020.

<sup>434</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [10]–[15].

<sup>435</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [15]–[17], [161]–[169], [175]–[180], [191]–[195], [287]–[307].

<sup>436</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [18]–[44].

<sup>437</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [55]–[64].

<sup>438</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [65]–[80], [196]–[206].

<sup>439</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [81]–[88], [170]–[174], [207]–[218]; Transcript, Graeme Head AO, Public Hearing 4, 27 February 2020, P-793 [23] – P-794 [22].

<sup>440</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [89]–[94], [152]–[156], [187]–[190], [308]–[311].

<sup>441</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [95]–[104].

<sup>442</sup> Transcript, Graeme Head AO, Public Hearing 4, 27 February 2020, P-792–800; Exhibit 4-227, DRC.1000.0002.9658.

<sup>443</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [222]–[233].

commissioned by the NDIS Commission in relation to causes of and contributors to deaths of people with disability and mortality trends.<sup>444</sup> He noted the key findings and recommendations of one of these projects, which was undertaken by Professor Trollor and another researcher.<sup>445</sup> He then set out some of the work being done or anticipated to be done by the NDIS Commission to publish and respond to those findings and recommendations.<sup>446</sup>

171. Mr Head acknowledged the limitations of the NDIS Commission reportable incidents function in relation to gathering comprehensive data about the causes of and contributors to deaths of people with disability, particularly where a death occurs and there is no causal relationship with the provision of NDIS support.<sup>447</sup> He told the Royal Commission that ‘at some time in the future the NDIS Commissioner might decide to undertake a comprehensive national inquiry into deaths’ and that this would depend on a range of factors including an assessment of relative priorities and risks across the NDIS Commission functions and whether he considered there were ‘significant gaps in knowledge’ which the NDIS Commission would be best placed to fill.<sup>448</sup>

## Part 3: Key themes emerging from Public hearing 4

172. The key themes identified in this Part of the Report emerged from the evidence of numerous witnesses at Public hearing 4. The themes do not necessarily reflect the entirety of the evidence given at the hearing. However they show the importance attached by witnesses to the barriers encountered by people with cognitive disability in obtaining quality health care and to the need for far-reaching changes to remove those barriers. It is important to appreciate that just as the categories of witnesses are not mutually exclusive, the key themes overlap and intersect.
173. In brief, the key themes emerging from the evidence at Public hearing 4 are as follow:
- Quality health care
  - Attitudes, assumptions and culture
  - Communication and information sharing

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<sup>444</sup> Exhibit 4-32, ‘Statement of Graeme Head AO’, 11 February 2020 at [234]–[250].

<sup>445</sup> Exhibit 4-32, ‘Statement of Graeme Head AO’, 11 February 2020 at [251]–[267]; Exhibit 4-59, CTD.7200.0001.0060; Exhibit 4-60, CTD.7200.0001.0037; Exhibit 4-61, CTD.7200.0001.0046.

<sup>446</sup> Exhibit 4-32, ‘Statement of Graeme Head AO’, 11 February 2020 at [268]–[336].

<sup>447</sup> Exhibit 4-32, ‘Statement of Graeme Head AO’, 11 February 2020 at [340]–[341]; Transcript, Graeme Head AO, Public Hearing 4, 27 February 2020, P-806 [33] – P-808 [8].

<sup>448</sup> Exhibit 4-32, ‘Statement of Graeme Head AO’, 11 February 2020 at [345].

- Health system challenges
- Lifetime health care
- Integration of health and disability services
- Reduction of distress and trauma
- Training and education of health professionals
- Collection of data and research
- Initiatives to improve health care

174. Before discussing these key themes, we provide a brief outline of the Australian health system. The key themes are then considered in the context of that system.

### Australian health system

175. The Royal Commission heard evidence from representatives of Commonwealth Health and NSW Health outlining the health system in Australia and in NSW, respectively.<sup>449</sup> Professor Leeder also provided the Royal Commission with an overview of the health landscape and structure in Australia including government responsibilities.<sup>450</sup>
176. In Australia, the health system is described in terms of primary, secondary and tertiary care.<sup>451</sup> Financial and managerial responsibility of this system is shared by the Commonwealth and the state and territory governments.<sup>452</sup>
177. Primary care relates to treatment of patients who are not admitted to hospital and is described to be the first contact a person has with the health system for assessment of any health problems.<sup>453</sup> Secondary and tertiary care is provided by hospitals and private medical specialists.<sup>454</sup>

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<sup>449</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020; Exhibit 4-27, 'First Statement of Dr Nigel Lyons', 13 February 2020.

<sup>450</sup> Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020.

<sup>451</sup> Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020, at [14]; Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [21].

<sup>452</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [11]; Exhibit 4-8, 'Statement of Professor Stephen Leeder, 12 February 2020 at [10].

<sup>453</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [21]; Exhibit 4-8, 'Statement of Professor Stephen Leeder, 12 February 2020 at [15]; Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-155 [30] – P-156 [2].

<sup>454</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [25]; Exhibit 4-8, 'Statement of Professor Stephen Leeder, 12 February 2020 at [17].

178. In NSW, the public health system comprises: LHDs, which provide hospital and health services to communities within geographical areas of the state;<sup>455</sup> Statutory Health Corporations, which provide state-wide services that are defined based on functions;<sup>456</sup> and Affiliated Health Organisations, being not-for-profit religious, charitable or other non-government organisations that provide health services.<sup>457</sup> The Ministry of Health manages the public health system in NSW.<sup>458</sup>
179. For dental care, there are two pathways of access in Australia: the public or private system.<sup>459</sup> In the public system, the Commonwealth and the state and territory governments share responsibility for dental services, with the Commonwealth contributing funds for public services delivered by the states and territories.<sup>460</sup>
180. Dr Zylan said that the public system is different in each state, with their own priorities and funding mechanisms and how they go about providing treatment.<sup>461</sup> He said that dental treatment is offered generally at clinical health settings, or at dental hospitals,<sup>462</sup> some of which may be co-located in general hospitals.<sup>463</sup>

## Quality health care

*Person-centred care means that the individual ... is the centre of the care and everything is explained to her, everything is about what would benefit her. It's great policy. I don't know that it's practised.*<sup>464</sup> (Margot Elliffe)

181. Article 25 of the *Convention on the Rights of Persons with Disabilities (CRPD)* provides that people with disability have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Among other things, this means that health professionals must provide care of the same quality to people with disability as to others, including on the basis of free and informed consent.
182. During the course of the hearing, the Royal Commission heard about the various health care experiences of a number of people with cognitive disability. The Royal Commission also received into evidence a substantial body of independent and peer reviewed research conducted by experts in the field. That evidence suggests that the standards set out in the CRPD have often not been met and that there

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<sup>455</sup> Exhibit 4-27, 'First Statement of Dr Nigel Lyons', 13 February 2020 at [13], [25].

<sup>456</sup> Exhibit 4-27, 'First Statement of Dr Nigel Lyons', 13 February 2020 at [13], [31].

<sup>457</sup> Exhibit 4-27, 'First Statement of Dr Nigel Lyons', 13 February 2020 at [13], [38].

<sup>458</sup> Exhibit 4-27, 'First Statement of Dr Nigel Lyons', 13 February 2020 at [19].

<sup>459</sup> Exhibit 4-224, EXP.0022.0002.0106 at 0117.

<sup>460</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-780 [3]–[11].

<sup>461</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-396 [9]–[11].

<sup>462</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-396 [16]–[17].

<sup>463</sup> Exhibit 4-452, EXP.0022.0003.0001 at 0001.

<sup>464</sup> Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-864 [30]–[33].

continue to be systemic problems in the provision of health care and services to people with cognitive disability in Australia.

183. At the same time, witnesses with cognitive disability and their families described positive experiences in the health system. This evidence is significant for two reasons. The first is that the evidence does not support a finding that the Australian health system invariably neglects or fails to respond to the complex physical, psychological and communication requirements of people with cognitive disability. There are many health professionals who are well aware of the challenges that have to be met to provide high quality care to people with cognitive disability and are prepared to take the measures necessary to address these challenges. Some institutions have also introduced programs designed to provide better health care and outcomes for people with disability. Nothing said in this Report should be understood as detracting from these observations.
184. The second reason why this evidence is significant is that some witnesses contrasted their positive experiences with earlier negative experiences that had led to trauma and adverse health outcomes, sometimes preventable and very serious. The contrast brings into sharp focus the profound importance of health professionals and institutions not only understanding the barriers to high quality care for people with cognitive disability but adapting their training, procedures and practices to break down the barriers.

### **Person-centred care**

185. Witnesses who gave evidence from direct experience, as well as experts and advocates, told the Royal Commission that a 'person-centred approach' is fundamental to quality care. For example, Ms Monaghan said that, for her son, good health care is 'person-centred and individualised.'<sup>465</sup> Mr Simpson explained that the person-centred approach recognises an individual's needs and preferences as the foundations for their care and treatment.<sup>466</sup>
186. Dr Lyons stated that 'person-centred care' is a term used quite extensively in NSW Health and that it means contextualising health care to each individual's circumstances.<sup>467</sup> The NDIS Commissioner, Mr Head, also used the term throughout his witness statement, in describing standards and mechanisms applied or enforced by his office.<sup>468</sup>
187. A number of policies and directives state that a person-centred approach should be followed in a health care context. Its implementation in practice for people with

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<sup>465</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [17].

<sup>466</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-529 [1]–[6].

<sup>467</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-723 [25]–[31].

<sup>468</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [39], [91]–[92], [162], [290], [304].

cognitive disability in particular requires flexibility and adjustments to standard procedures. The importance of simple adjustments to minimise distress and trauma for people with cognitive disability interacting with the health system is discussed later.<sup>469</sup>

188. During his oral evidence, Dr Lyons agreed that taking a person-centred approach to a patient with intellectual disability might involve health professionals adapting methods of communication, taking extra steps to explain things simply and involving support people in the process.<sup>470</sup> Margot Elliffe said that if her daughter has to go to hospital, person-centred care would mean that people would stop and listen to her, and take their time to help her.<sup>471</sup>

### **Relationships based on trust and confidence**

189. The Royal Commission heard that a relationship of trust, confidence and respect between a person with cognitive disability and the medical practitioners who provide them with care and treatment is very important. Margot and Tara Elliffe both described Tara's GP in a very positive way. Tara Elliffe said that she trusts her.<sup>472</sup> Margot Elliffe said that the GP is 'special', and that she takes time, listens, and talks directly with Tara.<sup>473</sup> Kylie Scott said 'For me, it's about trust',<sup>474</sup> and:

*If I go to the doctor for a check-up or for a basic procedure, like if I have to take medication or have a blood test, I can understand. I can say, 'Yes' or 'No'. But I also have to trust the doctor to do what's right.*<sup>475</sup>

190. Ms Oslington also said that trust is important to her because it means she can be confident that she has choice over her life, and that doctors are there to help her. She also emphasised the importance of doctors taking time to talk to her and to her family and support workers, so that they can fully understand her problems.<sup>476</sup>

### **Collaborative planning**

191. The Royal Commission also heard that quality health care involves considering not just the present health issue, but also the future. Ms Mitchell said that one paediatrician who her son had was great, and 'looked at the bigger picture for Joshy'.<sup>477</sup> Ms Monaghan told the Royal Commission that her son's neurologist provided an example of quality care because 'he has a vision for where [her son]

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<sup>469</sup> At [386]-[396].

<sup>470</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-725-726.

<sup>471</sup> Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-864-865.

<sup>472</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [23].

<sup>473</sup> Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-856 [19-35].

<sup>474</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [28].

<sup>475</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [29].

<sup>476</sup> Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-35 [27] – P-36 [2].

<sup>477</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [115].

will be in a year, and the year after that'.<sup>478</sup> In this way, quality care is also dependent on recognising a person with disability as a person of value capable of leading a 'rich and varied life',<sup>479</sup> discussed further below.

192. Collaborative care planning between a person with cognitive disability, their support persons and medical practitioners also allows for the person to exercise greater choice and control over their care and treatment. Jayne Lehmann described how quality care for her daughter included health professionals being able to 'think outside the square' and being willing to be 'active partners' with her family and support persons.<sup>480</sup> Ms Mills told the Royal Commission that all aspects of treatment, including use of restraints if necessary, could be based on the prior consent of the patient if provision is made for 'robust planning'.<sup>481</sup>

### **Tools for supported decision making**

193. As discussed further below, good communication is crucial to quality care. Good communication requires people with cognitive disability to be supported to make informed decisions about their care and treatment. Ms Monaghan emphasised that medical practitioners need to speak directly to the patient rather than their parent, carer or support person and that they should never assume that a person lacks the capacity to consent or cannot understand what is being said.<sup>482</sup> Kylie Scott said that it helps her make decisions when doctors speak to her clearly and ask short questions in plain English.<sup>483</sup>
194. A number of witnesses, including Mr Strike and Ms Oslington, told the Royal Commission that allowing people enough time to process information and understand complicated problems is very important.<sup>484</sup> They said that medical practitioners should take the time to explain things to their patients, and talk them through procedures. Ms Abi spoke about the difference that it made to her son Giovanni's treatment when staff performing a procedure told him "...this is what we're going to do, and why."<sup>485</sup> In some cases, direct verbal communication is not possible and it is necessary to find alternative ways to communicate with a patient

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<sup>478</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [24].

<sup>479</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-242 [17-36].

<sup>480</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [39-43].

<sup>481</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-504 [28]-[34].

<sup>482</sup> Transcript, Sabrina Monaghan, Public Hearing 4, 24 February 2020, P-363 [18]-[21].

<sup>483</sup> Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-21 [10]-[14].

<sup>484</sup> Transcript, Robert Strike AM, Public Hearing 4, 28 February 2020, P-874 [3]-[6]; Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-35 [31] – P-36 [2].

<sup>485</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [41].

such as using a communication board;<sup>486</sup> obtaining assistance from an advocate, carer or support person;<sup>487</sup> or utilising accessible resources like Easy Read.<sup>488</sup>

195. Mr Kelly and Ms O'Neill from CID gave evidence about the importance of supported decision-making. Ms O'Neill observed that without support a person with intellectual disability might lose their decision-making rights informally or formally.<sup>489</sup> Mr Kelly stated that when he has a decision to make he likes to gather information first and uses that information to think about the pros and cons of the decision.<sup>490</sup> He also likes to talk about decisions with friends, family and support workers 'as a sounding board'.<sup>491</sup> He emphasised, however, that he has learned to trust in his own choices and that 'it's just important that you make the right decisions for you'.<sup>492</sup> Mr Kelly also stated that being involved in decision-making is important as an aspect of being treated equally to other people, and that it gives choice and control.<sup>493</sup>
196. As discussed above, Ms Mills gave detailed evidence about the 'microboards model' of supported decision-making, saying that, over time, microboards support people to make more significant decisions and to have a greater say in their lives.<sup>494</sup>

## Attitudes, assumptions and culture

*And [my son] understands what people are saying and he has his own home and he does the things that he wants to do in the course of the day, but he's spoken about in front of him as though he isn't actually a person that has a life like any other person ... his self-esteem is battered every time that that happens, every time he's treated as someone that obviously doesn't have any choice in his life, obviously wouldn't ever have a girlfriend or friends, or any of the other things that people enjoy.<sup>495</sup> (Jaqueline Mills)*

*I think the most fundamental issue is one of values and attitudes, that there has been a perception ... that these are other people out of sight, out of mind,*

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<sup>486</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-503 [11]–[33].

<sup>487</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [26].

<sup>488</sup> Transcript, Robert Strike AM, Public Hearing 4, 28 February 2020, P-877 [13]–[26].

<sup>489</sup> Exhibit 4-2, 'Statement of Justine O'Neill', 11 February 2020 at [21].

<sup>490</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-26 [28] – P-27 [1].

<sup>491</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-27 [2]–[7].

<sup>492</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-28 [17]–[23].

<sup>493</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-28 [24] – P-29 [3].

<sup>494</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-474–477.

<sup>495</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-507 [4]–[11].

*segregated away from society, a view that people with intellectual disability are, you know, lesser people with lesser rights.*<sup>496</sup> (Jim Simpson)

197. During Public hearing 4, the Royal Commission heard descriptions of the significant achievements and independence of people with cognitive disability including Kylie Scott, Ms Oslington, Tara Elliffe, Ms Sheehy, Mr Strike and Gabrielle Clark. Some witnesses described the value of people with cognitive disability to their local communities, such as Karen Barnett's brother Mr Barnett.<sup>497</sup> Other witnesses spoke about the considerable potential of their children with cognitive disability. For example, Ms Abi highlighted the tremendous contributions to society that her sons Giovanni and Philip could make in the future, if given the right support and opportunities.<sup>498</sup> All of the witnesses who had children or siblings with cognitive disability described them as much loved, integral members of their families.
198. Despite the richness and variety of the lives of people with cognitive disability, a number of witnesses told the Royal Commission that pervading societal attitudes towards them and assumptions about their quality of life and/or value to society can influence decision-making concerning their health care and treatment. Professor Lennox said that this was one of the key challenges to ensuring that people with intellectual disability receive high quality health care.<sup>499</sup> He commented that the 'devaluing' of people with intellectual disability occurs across the Australian community and is reflected in our health care system and those who work in this system.<sup>500</sup>
199. Ms O'Neill told the Royal Commission that negative assumptions and cultural ideas about people with intellectual disability fundamentally affect their ability to make decisions about their own lives, as they are not viewed as having the ability or right to make those decisions.<sup>501</sup>
200. Ms Mills observed that while people with disability today have greater opportunities than ever before to live full and meaningful lives and to contribute to their communities, there is still a tendency for poorly informed, negative predictions to be provided to families by health professionals. These range from stating that a child is unlikely to survive even if the child is not medically unwell, to placing limitations on their lifetime potential.<sup>502</sup> She said, '[t]he more insidious side of this is that, unconsciously, the belief that people are better off dead than disabled may

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<sup>496</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-513 [2]–[7].

<sup>497</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [16].

<sup>498</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [111]–[112].

<sup>499</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [21].

<sup>500</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [21].

<sup>501</sup> Transcript, Justine O'Neill, Public Hearing 4, 18 February 2020, P-31 [5]–[14].

<sup>502</sup> Exhibit 4-19, 'Statement of Jacqueline Terri Mills', 12 February 2020 at [164].

be influencing medical decisions.’<sup>503</sup> Mr Simpson expressed a similar concern that there may be many medical practitioners who think that it would be ‘a blessed release’ for a person with intellectual disability to die, and for their families.<sup>504</sup>

201. Ms Regan related how a doctor recommended that her daughter, Erin, not be operated on when she was a baby to fix a heart defect, while telling her that without the operation ‘there would be a slow, painful decline for five years until Erin’s passing.’<sup>505</sup> Ms Regan said that the doctor was ‘not pleased’ when she and her husband decided to go ahead with the operation.<sup>506</sup> Based on her years of experience accessing health services for Ms Sheehy, Ms Regan said she worries that some doctors make decisions about how to treat people with intellectual disability based on the perceived relative value of their patient to society.<sup>507</sup>
202. This problem of devaluing can be compounded for First Nations people, who Ms Reynolds said always have to ‘show white people our own value’.<sup>508</sup> Dr Avery also observed that the quality of health care for First Nations people with disability can be particularly compromised when it intersects with institutional racism and that negative public stereotypes and prejudices can prevail over robust diagnostic procedures.<sup>509</sup>
203. In her witness statement, Ms Abi remarked that the only reason her children are ‘disabled’ is ‘because of the society we have set up around them’ and that ‘[a]ll the treatment is trying to ‘fix’ our kids, not fix the world so they can just be whoever they are.’<sup>510</sup> Both Mr Simpson and Professor Trollor commented that while the recent shift in Australia away from the medical model of disability is a welcome one, it may have had some unintended negative consequences,<sup>511</sup> including that there has been an ‘unskilling of the medical workforce and an unequipping of the health services sector around the health needs of people with intellectual and developmental disabilities.’<sup>512</sup>
204. Another witness who is herself an experienced doctor, Dr AAJ, told the Royal Commission that doctors and other clinicians can find it hard to understand that a person with a severe disability can still have a good quality of life.<sup>513</sup> She stated

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<sup>503</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [165].

<sup>504</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-515 [1]–[4].

<sup>505</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [25].

<sup>506</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [26].

<sup>507</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [99].

<sup>508</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [62].

<sup>509</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [51].

<sup>510</sup> Exhibit 4-7, ‘Statement of Giuseppina Cinzia Porte (Jo Abi)’, 26 February 2020 at [111].

<sup>511</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [11].

<sup>512</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-177 [17]–[24].

<sup>513</sup> Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [28].

that ‘all too frequently doctors and nurses seem unable to think outside their own life experiences when presented with a patient who has a disability.’<sup>514</sup> Dr Small also commented on the different life experiences of trained medical professionals compared to their patients and said that ‘decisions based on perceived quality of life can lead to decisions for conservative instead of active treatments.’<sup>515</sup>

205. It is important to note that the Royal Commission heard a number of accounts of excellent medical care provided to people with cognitive disability around Australia. These included references to health care professionals demonstrating that they view their patients with cognitive disability as meriting care and attention equal to any other patient.<sup>516</sup> For example, Jayne Lehmann described the approach of her daughter’s GP as ‘person-centred, respectful, knowledgeable and flexible’.<sup>517</sup> Similarly, Dr Kelly said that she ‘never had a moment of doubt’ that her son’s paediatrician ‘sees Ryan as a person of value’.<sup>518</sup>

### **Attitudes prior to and at the time of birth**

206. Several witnesses described how negative attitudes or assumptions affected them or their children from the moment their disability was detected, either *in utero* or shortly after birth. Margot Elliffe, Evelyn Scott and Ms Regan gave disturbing accounts of comments made to them by health professionals shortly after the birth of their respective daughters in the 1970s and 1980s.<sup>519</sup> While such attitudes may not be thought to be so prevalent today, Ms Mitchell’s description of being given an appointment for termination of her pregnancy in 2000<sup>520</sup> and Ms Browne’s recollection of comments made by a doctor following the birth of her son Finlay, also in 2000,<sup>521</sup> demonstrate that negative views of babies with intellectual disability and their long-term prospects persist.
207. Dr Kelly, whose own experience of learning that her son Ryan has Down syndrome was a positive one,<sup>522</sup> described how she still gets asked ‘didn’t you

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<sup>514</sup> Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [28].

<sup>515</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [37]; Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-242 [21] – P-243 [1].

<sup>516</sup> For example: Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [20]–[25]; Exhibit 4-34, ‘Statement of Margot Elliffe’, 13 February 2020 at [13]–[16]; Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-277 [33] – P-278 [3]; Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [51]–[53].

<sup>517</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [52].

<sup>518</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [23].

<sup>519</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [20]–[23]; Exhibit 4-33, ‘Statement of Evelyn Scott OAM’, 11 February 2020 at [5]; Exhibit 4-34, ‘Statement of Margot Elliffe’, 13 February 2020 at [11]–[12].

<sup>520</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [19].

<sup>521</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [21]–[22].

<sup>522</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [22].

have the test?’ by doctors and nurses when she first meets them.<sup>523</sup> She said that this makes clear to her that they think his life is one that could and should have been avoided.<sup>524</sup> She commented that:

*Women are often given the diagnoses in negative terms, so first of all talking about a ‘risk’. We don’t talk about the risks of winning Lotto, we talk about the risk of people dying of cancer. Risk is inherently associated with bad outcomes. Risk sends a message that Down syndrome itself – and intellectual disability more generally – is a negative thing and it reinforces these outdated concepts around disability.*<sup>525</sup>

### **Attitudes at times of grave illness and death**

208. The attitude that conditions causing cognitive disability, such as Down syndrome, are medical conditions that can themselves contribute to death may be reflected in a practice of recording a person’s disability as a cause of death on a death certificate. Finlay Browne’s death certificate includes Trisomy 21 as one of the causes of his death.<sup>526</sup> His mother told the Royal Commission, ‘but Finlay didn’t die of Down syndrome and this has caused me further distress. I do not think that a person’s disability should be stated as a cause of their death, when it is not.’<sup>527</sup> Ms Creevey similarly said that ABI (acquired brain injury) is listed as a cause of death for her son Harri.<sup>528</sup> During his evidence, Professor Trollor recognised that this practice ‘makes no sense and is very distressing for people.’<sup>529</sup> He said that it is very important for accurate data to be recorded and analysed about the deaths of people with cognitive disability and their actual causes.<sup>530</sup> This is discussed further below.<sup>531</sup>
209. Other witnesses described specific events or occasions where they felt that assumptions about quality of life and negative attitudes about the value of people with cognitive disability had very real consequences on the health care or treatment provided to members of their families. In witness statements and during Public hearing 4, the term ‘unconscious bias’ was sometimes utilised in this context.

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<sup>523</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [210].

<sup>524</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [210].

<sup>525</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [212].

<sup>526</sup> Exhibit 4-5.4, IND.0011.0001.0002.

<sup>527</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [144].

<sup>528</sup> Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-329 [10–12].

<sup>529</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-207 [41].

<sup>530</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-207-208.

<sup>531</sup> At [433]–[444].

210. Stark examples were provided by Ms Browne, Ms Regan and Ms Creevey. Of Finlay's experiences in the period leading up to his death, Ms Browne stated:

*His basic human right to be treated with a level of compassion, respect and dignity was taken away. It is very hard to measure or determine internal bias in the health system, but it does happen, and I believe it happened in Fin's case and led to his death.*<sup>532</sup>

211. Ms Regan provided a detailed account of Ms Sheehy's stroke in 2002 and of a doctor telling her about the usual nine-month stroke protocol for rehabilitation but not offering it to Ms Sheehy.<sup>533</sup> Ms Regan said:

*[T]here was no medical reason for her not to do rehabilitation. And this man was just going to send her home to a life of paralysis and no control and possibly an early departure from this world just because he had decided how important it was for her to be alive or something. I don't know, but it wasn't a medical decision.*<sup>534</sup>

212. Ms Creevey also stated her belief that on the majority of occasions when her son Harri was hospitalised he was subject to unconscious bias, compromising his medical care.<sup>535</sup> She and her husband feel strongly that when their son went into hospital for the final time before his death, his care was influenced by his disability and that they were asked if they wanted to 'let Harri go' because of assumptions made about the value and quality of his life.<sup>536</sup>

### **Diagnostic overshadowing**

213. Other witnesses described a process known as 'diagnostic overshadowing' where symptoms or behaviours are attributed to a person's disability rather than being considered indicative of particular health problems or conditions unrelated to the disability.<sup>537</sup> This can result in delayed or misdiagnoses of serious medical issues. Diagnostic overshadowing may be a consequence of insufficient education or training concerning cognitive disability and may also reflect an underlying culture within the health system in relation to people with disability. Dr Small stated that in her experience, diagnostic overshadowing is common within both paediatric and adult health care settings.<sup>538</sup>

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<sup>532</sup> Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [137].

<sup>533</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [44]–[46].

<sup>534</sup> Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-268 [11]–[15].

<sup>535</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [10].

<sup>536</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [20], [32].

<sup>537</sup> For example: Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [43]; Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [49].

<sup>538</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [35].

214. Ms Mitchell told the Royal Commission that she believes her son had suffered ‘fourteen years of agony and permanent internal damage because no one took his health problems seriously.’<sup>539</sup> She said he had been ‘in constant excruciating pain every single day and the doctors we saw had just dismissed it as “Down syndrome”.’<sup>540</sup>

215. Ms Mills also suggested:

*... if a person with disability suffers from something for long enough, momentum can be lost in terms of finding solutions. People become complacent and see health issues as just something that’s ‘part’ of the person or disability.*<sup>541</sup>

216. Professor Trollor described diagnostic overshadowing as a ‘major problem for people accessing services’ and said that ‘when frontline health services hear from a person with disability, often they may see or hear about the disability first and may prioritise that issue, rather than listening carefully to the range of symptoms someone may present with’.<sup>542</sup> He observed:

*... unless medical practitioners are aware of the systematised way of assessing people with intellectual disability or autistic people as they come forward with a concern, including a hierarchical approach that prioritises health issues and things like pain, through to psychiatric issues, through to careful health screening, before concluding that the change is related to the disability itself, we won’t get very far.*<sup>543</sup>

217. During their evidence, Ms Porter and Ms McKenzie noted that diagnostic overshadowing can also happen within disability accommodation, particularly residential care.<sup>544</sup> They said that in these environments disability workers can sometimes misattribute certain behaviours to a person’s disability rather than questioning whether they might indicate medical problems or conditions.<sup>545</sup>

### **Attitudes to parents, carers and support persons**

218. The Royal Commission also heard from several parents, carers and support persons about occasions when they tried to raise their serious concerns with

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<sup>539</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [82].

<sup>540</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [82].

<sup>541</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [85].

<sup>542</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-195 [5]–[8].

<sup>543</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-195 [23]–[28].

<sup>544</sup> Transcript, Kathryn McKenzie and Lyn Porter, Public Hearing 4, 26 February 2020, P-580 [33]–[35].

<sup>545</sup> Transcript, Kathryn McKenzie and Lyn Porter, Public Hearing 4, 26 February 2020, P-582 [23]–[37].

health professionals about a person with cognitive disability's condition. They said that doctors and other medical specialists often dismissed or ignored these concerns on the basis that they were 'just a mum', were 'overwrought', or had no formal medical training.<sup>546</sup> This culture of devaluing the knowledge and experience of parents, carers and support persons can also be compounded for First Nations people. During her evidence, Ms Reynolds said that doctors and other services are dismissive of her 'because I'm black' and due to a view that 'because they're the professional and they know better than me', which she finds very condescending.<sup>547</sup> The importance of health professionals listening to and communicating with people with cognitive disability and their parents, carers or support persons is discussed further in the following section.

## Communication and information sharing

219. Several issues falling within the umbrella of 'communication' were identified by witnesses as having a significant impact on access to and delivery of good quality health care to people with cognitive disability.

### Communication with the person with cognitive disability

220. A number of witnesses told the Royal Commission that it is important that health professionals communicate directly with people with cognitive disability and not only with their parents or support workers.<sup>548</sup> Tara Elliffe described occasions when this did not occur and doctors did not speak or look at her directly, but instead spoke to her parents.<sup>549</sup> Other witnesses gave evidence of similar examples where doctors and other health professionals did not even greet or acknowledge the person with cognitive disability.<sup>550</sup> Ms Regan spoke of an occasion when she took her daughter for an operation, stating:

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<sup>546</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [112]; Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [65]–[68]; Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [124]–[137]; Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [28]–[29].

<sup>547</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-443 [31]–[32].

<sup>548</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [31]; Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-21 [6]–[9]; Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-35 [30] – P-36 [2]; Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [50]; Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-878 [20]–[21]; Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [97]; Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [143].

<sup>549</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [42]; Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-342 [19]–[21], P-344 [27]–[28].

<sup>550</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [32]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [147]; Exhibit 4-5, 'Statement of Rachel

*When we went in for the operation, the doctors just spoke to me instead of first speaking to Erin. They weren't necessarily rude, but I did have to keep repeating 'Tell Erin. Speak to Erin' whenever they would give us information.*<sup>551</sup>

221. Some witnesses gave examples where health professionals did not explain to the person with cognitive disability what was happening, or said things in front of them which were inappropriate or unhelpful.<sup>552</sup> Evidence provided by witnesses showed that this occurred even when the receptive language of that person is good and they are capable of understanding what is occurring.<sup>553</sup> Ms Barnett gave evidence of how her brother was treated at the hospital. She said:

*I felt that, during his long stays in hospital, Grant was treated like an unintelligent piece of meat that was a burden on the health system. The majority of staff would not speak to him directly unless one of us were there to direct the question to him, they would act surprised that he could understand our questions, and only after that would follow our prompting.*<sup>554</sup>

222. Mr Kelly, Mr Strike and Dr AAJ gave evidence that if a doctor invests time with a person with cognitive disability, and that person does not feel rushed, the experience for that person is better and less stressful.<sup>555</sup>
223. Several witnesses said that health professionals can improve communication by listening to people with cognitive disability, explaining what is happening, asking short questions in plain English, and speaking clearly.<sup>556</sup> Ms Elliffe and Mr Strike commented that the use of pictures and Easy Read documents helps them

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Browne', 2 February 2020 at [34], [85]; Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [33]–[34]; Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [29], [45]; Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [26].

<sup>551</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [33].

<sup>552</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [11]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [114]–[116].

<sup>553</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [55]–[57]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [12]; Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [29]; Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [70]; Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [46]; Transcript, Robert Strike, Public Hearing 4, 28 February 2020 at P-874 [29]–[34].

<sup>554</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [54].

<sup>555</sup> Transcript, Jack Kelly, Public Hearing 4, 18 February 2020, P-33 [8]–[18]; Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-874 [3]–[6]; Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [26].

<sup>556</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [24]–[26]; Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-21 [10]–[12]; Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [50]; Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-35 [31] – P-36 [9]; Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-873 [20] – P-874 [6].

understand what is happening.<sup>557</sup> Mr Strike said that Easy Read is different from plain English. He described it as a 'picture book' that combines pictures and plain, simple words to help people understand.<sup>558</sup> Jayne Lehmann, herself a health professional and a parent of a person with cognitive disability and communication challenges, said that these types of tools facilitate improved communication<sup>559</sup> and have the effect of minimising anxiety.<sup>560</sup>

224. Better communication between health professionals and people with cognitive disability was also identified by expert and advocate witnesses as critical to improving the accessibility of health services for people with cognitive disability. These witnesses spoke of the lack of knowledge, skills and right attitude of some health professionals in learning about forms of communication or what the particular needs or issues might be for people with cognitive disability.<sup>561</sup> Dr Small said:

*Health professionals are important communication partners for people with IDD [intellectual and developmental disability]. However, health professionals in general have little understanding of the communication impairments experienced by people with IDD, or of the added impact of the unfamiliar, intrusive hospital or healthcare environment.*<sup>562</sup>

225. Professor Trollor observed 'at the coalface there's a lack of awareness of the health needs and the communication needs and how to interact with people with intellectual disability or autism or both'.<sup>563</sup> He said that health information is not routinely made available in formats accessible to people with cognitive disability, which is important to assist them in understanding and managing their own health needs.<sup>564</sup>
226. While Professor Lennox said he was aware of a range of strategies employed in various health settings and services, such as plain language material, visual images, and other strategies to assist people with cognitive disability to process

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<sup>557</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [50]; Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-877 [13]–[18].

<sup>558</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-877 [15]–[18].

<sup>559</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [53]–[60], [120].

<sup>560</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [120]–[124].

<sup>561</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-179 [9]–[12]; Exhibit 4-18, 'Statement of Dr Scott Avery', 14 February 2020 at [46]; Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [11]; Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [41]–[44].

<sup>562</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [43].

<sup>563</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-179 [9]–[11].

<sup>564</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [225].

and recall information, he did not know if there was an underlying policy in any health service about the use of these strategies.<sup>565</sup>

227. As discussed above, when discussing the concept of ‘person-centred care’ and what that means for a person with intellectual disability in NSW, Dr Lyons said that it includes directing questions to the person being cared for and taking extra steps to explain things clearly to them.<sup>566</sup> When asked about the steps taken by NSW Health to ensure that its resources and information are communicated in a manner accessible to people with cognitive disability, Dr Lyons responded that resources and information are written in plain English and comply with relevant accessibility guidelines.<sup>567</sup> He later clarified that while there is a range of ‘consumer material in either Easy Read formats, infographics or videos for use by people with an intellectual disability, their families, carers or staff’, there are no NSW Health policies developed in Easy Read format.<sup>568</sup>
228. Communication with people with cognitive disability was acknowledged by the witnesses from Commonwealth Health as an important element in delivering person-centred care. In particular, Dr Singer said it is important to teach medical students how to communicate with people with intellectual disability in an appropriate, respectful and compassionate way.<sup>569</sup> He noted that this skill may be further developed as health professionals start their early practice.<sup>570</sup>

### **Communication with parents, family members, carers and support persons**

229. A second issue that the Royal Commission heard about from a number of witnesses relates to the communication between parents or carers of people with cognitive disability and health professionals. Parents, carers, family members and support persons gave evidence that on many occasions they felt they were not listened to by health professionals when raising concerns about the health needs of people with cognitive disability. This was despite them having intimate understanding of the person with cognitive disability and being ‘an essential and informed source of knowledge’ as well as ‘experts’ in their care.<sup>571</sup>

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<sup>565</sup> Exhibit 4-21, ‘Statement of Professor Nicholas Gordon Lennox’, 11 February 2020 at [30]–[31].

<sup>566</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-725 [30–31], P-726 [5]–[7].

<sup>567</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-743 [6]–[12]; Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [98].

<sup>568</sup> Exhibit 4-453, NSW.9999.0004.0003 at 0011–0012.

<sup>569</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [21]–[24].

<sup>570</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [24]–[26].

<sup>571</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [178]; Exhibit 4-13, ‘Statement of Kim Letitia Creevey’, 7 February 2020 at [24]; Exhibit 4-22, ‘Statement of Karen Barnett’, 12 February 2020 at [26]–[27].

230. Several parents spoke of their attempts to take a proactive and coordinated approach with health professionals prior to their children attending medical appointments or before undergoing invasive procedures.<sup>572</sup> Other parents spoke about how they expressed their concerns about medical procedures with doctors at the time, and requested action to be taken or adjustments to be made.<sup>573</sup>
231. Ms Monaghan said that on several occasions she attempted to ensure that her son was pre-medicated before undergoing medical procedures, due to his challenging behaviours brought on by previous trauma.<sup>574</sup> Similarly, Dr Kelly described her multiple attempts to arrange pre-medication for Ryan.<sup>575</sup> Both parents said that their attempts were unsuccessful because they were not listened to, or were ignored. They said that this resulted in their children experiencing significant escalation in anxiety, regression in behaviour and trauma.<sup>576</sup> This is discussed in further detail below.
232. Other witnesses spoke of how their similar attempts and concerns were not taken seriously,<sup>577</sup> or in some instances were completely dismissed.<sup>578</sup> Some said that they were excluded,<sup>579</sup> not informed about procedures that were being administered, or asked about any adjustments that could have been made to minimise anxiety and trauma.<sup>580</sup>

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<sup>572</sup> Exhibit 4-17, 'Statement of Narelle Reynolds', 10 February 2020 at [32], [52]; Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [32].

<sup>573</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [23]; Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [65]; Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [80].

<sup>574</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [73]–[77], [88]–[92], [98]–[100].

<sup>575</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [161].

<sup>576</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [156]–[168]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [75], [81]–[84], [93]–[96].

<sup>577</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [31]; Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [38]; Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [80], [102].

<sup>578</sup> Exhibit 4-13, 'Statement of Kim Letitia Creevey', 7 February 2020 at [24]; Exhibit 4-17, 'Statement of Narelle Reynolds', 10 February 2020 at [23]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-430 [15]–[23]; Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [28]; Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [65]; Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [61]; Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [108], [112].

<sup>579</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [87].

<sup>580</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [68]; Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [61]; Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [35].

233. Several witnesses who have children with cognitive disability said that when health professionals respected, listened to and acknowledged them as holding important information, the health outcomes were much better for their children.<sup>581</sup> Ms Reynolds said that it has taken ‘extreme incidents’ for ‘some doctors to begin to listen to us and what we need’,<sup>582</sup> but that she has had to ‘put my boys on show for people to get it’.<sup>583</sup> Jayne Lehmann said that on one occasion it took her 24 hours to convince hospital staff to investigate the reasons why her daughter was uncomfortable swallowing drinks and food, which turned out to be because she had severely bitten her tongue during a seizure.<sup>584</sup>
234. Professor Lennox acknowledged that, given the communication challenges faced by many people with intellectual disability, it is often important for health professionals to be assisted by parents, carers or family members when working with a person with intellectual disability.<sup>585</sup> He said that this allows them to obtain key information and enables meaningful engagement, more accurate diagnoses and individually tailored management plans.<sup>586</sup>
235. Dr Lyons also said that the involvement of family members and carers to reassure people with cognitive disability who may have anxiety, reinforces the person-centred care approach taken by NSW Health.<sup>587</sup> When asked whether he expects NSW Health to implement policies at the frontline so that family members and carers can be involved in the care of people with cognitive disability, he responded ‘certainly’.<sup>588</sup>

### **Communication between health services and professionals**

236. A third issue relating to communication concerns communications between health services and professionals, which can be particularly important in relation to patients with cognitive disability and complex health needs. This issue is also related to that of record-keeping and the importance of complete, accurate records being taken and transmitted between health services and health professionals as well as being provided to parents and carers.
237. Dr Kelly gave evidence that health care can be compromised when there is little or no communication among health professionals, including within primary care

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<sup>581</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [53]; Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [72].

<sup>582</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [35].

<sup>583</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-436 [25]–[26].

<sup>584</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [82]–[83].

<sup>585</sup> Exhibit 4-21, ‘Statement of Professor Nicholas Gordon Lennox’, 11 February 2020 at [29].

<sup>586</sup> Exhibit 4-21, ‘Statement of Professor Nicholas Gordon Lennox’, 11 February 2020 at [29].

<sup>587</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-726 [11]–[21].

<sup>588</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-726 [25].

teams, and between hospitals and other medical and allied health professionals.<sup>589</sup> As an example, she spoke in detail about how an interstate family trip resulted in a hospitalisation for Ryan, with hospital staff unaware of the Care Plan for Ryan as they had no information from his specialist team.<sup>590</sup>

238. Ms Browne said that she had assumed that health professionals who shared involvement in the care of her son Finlay were connecting or communicating with each other, but sometimes there were ‘gaps’.<sup>591</sup> Ms Regan observed that a lack of communication between health professionals could also result in some specialists recommending treatments that directly contradicted treatments provided by other specialists.<sup>592</sup>
239. Some witnesses told the Royal Commission that their experience of accessing the health system for their child has involved a revolving door of health professionals with no continuity of care.<sup>593</sup> These parents spoke about how the system requires them to go over the full medical history of their child and ‘start again’ with each new doctor they see.<sup>594</sup> Dr Kelly said that this encourages a ‘wait and see’ approach, pushing difficult decisions on to the next health professional, making it their problem.<sup>595</sup>
240. Dr Kelly emphasised that difficulties accessing records and information had an impact on her ability to coordinate care for Ryan.<sup>596</sup> At the same time, she told the Royal Commission that in the absence of accurate and adequate records, she has become a conduit of information for Ryan’s health care.<sup>597</sup> She highlighted the importance of providing easy and timely access to records and information to people with cognitive disability and their primary caregivers,<sup>598</sup> and of information being easily accessible among health professionals in all states.<sup>599</sup>

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<sup>589</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [191]–[199].

<sup>590</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [65].

<sup>591</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-78 [3]–[12].

<sup>592</sup> Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [74].

<sup>593</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [179]; Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [74]; Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [117]; Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [72].

<sup>594</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [179]–[181]; Exhibit 4-7, ‘Statement of Giuseppina Cinzia Porte (Jo Abi)’, 26 February 2020 at [47].

<sup>595</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [179]–[181].

<sup>596</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [105], [187].

<sup>597</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [105], [186]–[190].

<sup>598</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [186].

<sup>599</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [204]; Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-58 [7]–[20].

241. Dr Kelly gave detailed evidence of multiple instances where records and information from a hospital had not been provided to her, to Ryan's primary care team, or even to other specialists at the same hospital.<sup>600</sup> She said that this resulted in delays in obtaining a surgical date for Ryan and, on some occasions, caused uncertainty about what care should be provided.<sup>601</sup>
242. Dr Kelly told the Royal Commission that on one occasion when she requested information from the hospital, her request was refused on the basis that parents were not entitled to that information under 'hospital policy'.<sup>602</sup> She said that at other times, information such as reports and test results could not be provided because it had not been released by the consultant who prepared the report or performed the test.<sup>603</sup>
243. Dr Kelly and Ms Mitchell both spoke of how they have had to submit requests under relevant *Freedom of Information* legislation to obtain records, in order to do their own research or provide this information to other members of their child's care team.<sup>604</sup> Dr Kelly noted that these efforts require considerable amounts of time and paperwork.<sup>605</sup>
244. The Royal Commission also heard evidence about medical records for people with cognitive disability which were inadequate, limited and omitted important information about the care to be provided to them.<sup>606</sup> Dr Kelly said that the medical records she has obtained contained errors and inaccuracies and there were no opportunities for input or oversight to check on the accuracy of the information or the assumptions underpinning decisions.<sup>607</sup> Ms Mitchell commented that she noticed that things were not recorded on her son's file properly, and her requests for corrections were not actioned.<sup>608</sup> She and Dr Kelly highlighted the importance

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<sup>600</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [64–66], [72], [81], [92], [100], [141], [188] and [193].

<sup>601</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [65], [99]–[100], [142], [152], [193] and [195].

<sup>602</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [68].

<sup>603</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [104].

<sup>604</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [106], [113], [188]; Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-46 [14]–[25]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-138 [27] – P-139 [3], P-146 [11]–[13].

<sup>605</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [105].

<sup>606</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [72], [141]–[142]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [103].

<sup>607</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [74], [180], [182], [190]; Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-46 [31] – P-47 [10].

<sup>608</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-138 [5]–[24].

of being able to correct errors to ensure that other health professionals do not rely on incorrect information.<sup>609</sup>

245. Expert witnesses agreed that information sharing is crucial and that it will require investment and new pathways to care. According to Dr Small, this would ensure that the ‘fractured system works more seamlessly, so we’re working together as a harmonised team. We know how to refer, when to refer and who to refer to’.<sup>610</sup> Professor Lennox said that information sharing ‘really improves the outcome, because it ensures the crucial information about the person sitting in front of you at the time you need it is there’.<sup>611</sup> He said that ‘without that information, mistakes occur’.<sup>612</sup>
246. Professor Leeder agreed that communication among health professionals requires improvement, particularly for complex patients or patients with a number of health conditions.<sup>613</sup> Dr Small also emphasised the importance of ‘integrated care’, which she described as ‘a mechanism for bringing together health providers from different sectors, to try and break down ... some of the silos’.<sup>614</sup>
247. Ms Elliffe said that seeing different doctors made her feel ‘like a yo-yo’ and that on one occasion when she had to go to hospital her ‘head was exploding from all the noise and different people’.<sup>615</sup> Ms Oslington emphasised the importance that ‘different professionals need to talk, work together ... communicate’.<sup>616</sup>
248. This need for better communication, co-ordination and integration between health professionals and services to improve the health care provided to people with intellectual disability is recognised in the Draft Roadmap prepared by Commonwealth Health in August 2019, described above. One of the ‘Key elements’ of the Draft Roadmap is headed ‘better care coordination and integration within the health system’.<sup>617</sup>
249. Ms Rishniw from Commonwealth Health stated that the ‘My Health Record’ initiative aims to ensure that important health information is available when and where needed for each person.<sup>618</sup> Ms Rishniw said that the intent of the My Health

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<sup>609</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-146 [10]–[20]; Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [180].

<sup>610</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-235 [28] – P-236 [4].

<sup>611</sup> Transcript, Professor Nicholas Lennox, 25 February 2020, P-560 [35]–[36].

<sup>612</sup> Transcript, Professor Nicholas Lennox, 25 February 2020, P-561 [1].

<sup>613</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-160 [24]–[26].

<sup>614</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-235 [14]–[17].

<sup>615</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [39]–[40].

<sup>616</sup> Transcript, Ruth Oslington, Public Hearing 4, 18 February 2020, P-37 [3]–[4].

<sup>617</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0177.

<sup>618</sup> Exhibit 4-29, ‘Statement of Tania Rishniw’, 5 February 2020 at [45].

Record scheme is 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'.<sup>619</sup> She said that the Commonwealth is working with the states and territories on a national strategy that integrates electronic information collected at state and territory level into the My Health Record.<sup>620</sup>

250. Other witnesses said that the effectiveness of a person's 'My Health Record' depends on information being documented, accurate and accessible.<sup>621</sup> Mr Simpson commented that the impact that My Health Record has had for people with cognitive disability is 'very little' at this stage, and there has been no targeted focus for those who have particular accessibility needs.<sup>622</sup>

## Health system challenges

*...there are big problems across the health system for everybody ... perhaps with the exception of people who have got, you know, a very high degree of social capital. But ... for people with intellectual disability, the problems are just so much greater.*<sup>623</sup> (Jim Simpson)

251. Professor Leeder described the Australian health care system as 'among the most humane and efficient systems in the contemporary world'.<sup>624</sup> At the same time, he commented on the size of the system in terms of expenditure and investment, and noted that 'an enterprise of this size is bound to be complex'.<sup>625</sup> He also pointed to the integration of public and private health care services<sup>626</sup> and to the need for coordinated finance and management between state and federal governments and organisations as among the reasons for the system's complexity.<sup>627</sup>
252. Professor Leeder expressed the view that this complexity inhibits the system's capacity to care for patients with complex needs, or those who require a long-term, integrated approach to treatment.<sup>628</sup> He agreed that the characterisation by Dr

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<sup>619</sup> Transcript, Tania Rishniw, Public Hearing 4, 27 February 2020, P-786 [4]–[7].

<sup>620</sup> Transcript, Tania Rishniw, Public Hearing 4, 27 February 2020, P-786 [7]–[10].

<sup>621</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-57 [32] – P-58 [3]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [181]; Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-537 [12]–[26].

<sup>622</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-537 [12]–[26].

<sup>623</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-518 [19]–[22].

<sup>624</sup> Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020 at [7].

<sup>625</sup> Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020 at [9]–[10].

<sup>626</sup> Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020 at [7].

<sup>627</sup> Exhibit 4-8, 'Statement of Professor Stephen Leeder', 12 February 2020 at [10].

<sup>628</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-160 [16]–[34].

Kelly of the health system as ‘fractured’ and requiring better coordination of care for complex patients was accurate.<sup>629</sup> He suggested that, to address this challenge, a focus on policy is needed, as well as for the ‘private providers and the state[s] and the Commonwealth to come together around the care of the individual.’<sup>630</sup>

### Health care in non-metropolitan areas

253. Dr Small stated that people with cognitive disability in rural and remote Australia experience ‘additional barriers and disadvantage in relation to their access to appropriate health care.’<sup>631</sup> She added that ‘there is a higher proportion of the rural and remote population with IDD [intellectual and developmental disability] and fewer specialised services in rural and remote areas.’<sup>632</sup> In her statement, Ms Rishniw from Commonwealth Health said that she is not aware of any Commonwealth Health programs that specifically target people with cognitive disability in rural and remote communities, aside from telehealth services for patients after a stroke or children with complex developmental and behavioural issues.<sup>633</sup>
254. Professor Leeder gave evidence that distance from care is ‘a critical variable when considering health care in Australia.’<sup>634</sup> He noted that the provision of health care to people in remote communities, and particularly First Nations people, can be ‘compromised, if not entirely ineffective’, unless their access to housing, transport, food and money when leaving hospital are addressed.<sup>635</sup>
255. Dr Avery gave an example from his research, where an elderly Aboriginal man with a disability lived a distance of 500 kilometres from the hospital. Dr Avery said that the man underwent a knee operation and then ‘had been discharged by the health system straight into homelessness’ with no assistance to get home to the community where he lived.<sup>636</sup> According to Dr Avery, this exemplifies how current approaches to health care resourcing disadvantage people with disability.<sup>637</sup>

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<sup>629</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-160 [24].

<sup>630</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-160 [40] – P-161 [4].

<sup>631</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [55].

<sup>632</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [55].

<sup>633</sup> Exhibit 4-29, ‘Statement of Tania Rishniw’, 5 February 2020 at [71], [76], [78].

<sup>634</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [17].

<sup>635</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder’, 12 February 2020 at [38].

<sup>636</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-463 [23]–[35]; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [54].

<sup>637</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-463 [23]–[35]; Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [54].

256. Dr Kelly and Ms Reynolds both told the Royal Commission that they had relocated from regional areas or travelled repeatedly to access appropriate health care for their children with cognitive disability.<sup>638</sup> Dr Kelly said that for Ryan to access suitable health care when he was diagnosed with leukaemia, she and Ryan had to move temporarily to Melbourne.<sup>639</sup> They later had to travel frequently to Melbourne for further health care.<sup>640</sup> However, Ryan's health care remained hampered as a result of 'very poor' communication between health care providers and a lack of adequate record keeping, as discussed above.<sup>641</sup> Ms Browne provided similar evidence that a lot of her son Finlay's early life was spent travelling to Sydney from Bathurst for medical appointments, and that their only clinical guidance in Bathurst was his paediatrician, who he had seen since birth.<sup>642</sup>
257. Both Ms Browne and Ms Mitchell told the Royal Commission that delayed or lengthy emergency transfers of their children from regional to metropolitan hospitals seriously compromised their health. In the case of Finlay Browne, who died in Westmead Hospital in December 2016, Ms Browne said that nurses planned to arrange a helicopter to take Finlay from Bathurst to Westmead, but the transfer did not happen until 13 hours after his presentation to the emergency department, while his condition 'continued to deteriorate'.<sup>643</sup> Ms Mitchell also gave an account of having to wait for hours to get a transfer from Toowoomba to Brisbane for her son when he was a baby.<sup>644</sup> Ms Mitchell said that he had gone into heart failure while they continued to wait, and that 'everyone was patting me on the shoulder but no one told me what was going on. All I was thinking was, 'Why weren't we already in Brisbane?''<sup>645</sup>

### **First Nations people with disability and the health system**

*For me, being Aboriginal on top of being a mother of children with intellectual disability is a double whammy. Being black and fighting through the health*

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<sup>638</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [52]–[53]; Exhibit 4-17, 'Statement of Narelle Reynolds', 10 February 2020 at [16].

<sup>639</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [34].

<sup>640</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [36].

<sup>641</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [191].

<sup>642</sup> Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [50].

<sup>643</sup> Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [100]–[101], [111].

<sup>644</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [26]–[32].

<sup>645</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [30]–[31].

*system is one thing, but fighting for sons with intellectual disability is another.*<sup>646</sup> (Narelle Reynolds)

*The policy inertia, and poor health outcomes that flow from it, can be expected to continue unless the institutionalised practices of avoidance and prejudice within the health system are disrupted.*<sup>647</sup> (Dr Scott Avery)

258. The Royal Commission heard some evidence addressing the particular failures of the health system to provide adequate care for First Nations people with cognitive disability, a group which experiences multiple forms of disadvantage.<sup>648</sup>
259. Dr Avery described the intersectional inequality faced by First Nations people with disability. He stated that First Nations people face double disadvantage where racism and ableism intersect and are experienced simultaneously.<sup>649</sup> Dr Avery observed that intersectional inequality exists for First Nations people with disability when institutional prejudice is present where health care and services are also delivered.<sup>650</sup> He stated that this leads to structural disempowerment.<sup>651</sup>
260. Professor Leeder also spoke about the notion of ‘double jeopardy’ faced by First Nations people with serious disability, describing the impact of social determinants of life as amplified.<sup>652</sup> He went on to say: ‘[p]rejudicial attitudes to their race and their disability may coalesce and do not seem to improve. Statistics indicate that life expectancies continue to lag.’<sup>653</sup>
261. Mr Simpson also commented on the theme of double disadvantage experienced by First Nations people with disability, stating:
- I want to emphasise the evidence yesterday in relation to the double whammy, as Narelle Reynolds talked about in relation to if you’ve got both an Indigenous status and disability. It can be double barriers in terms of values and other things.*<sup>654</sup>
262. Dr Avery told the Royal Commission that a finding of his research was that First Nations people with disability said they were routinely confronted with an underlying presumption from other people that they lacked the capacity to look

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<sup>646</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [61].

<sup>647</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [66].

<sup>648</sup> Transcript, Commissioner Sackville, Public Hearing 4, 18 February 2020, P-8 [10].

<sup>649</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-459 [13]–[15].

<sup>650</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [51].

<sup>651</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [36].

<sup>652</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder, 12 February 2020, at [39].

<sup>653</sup> Exhibit 4-8, ‘Statement of Professor Stephen Leeder, 12 February 2020, at [39].

<sup>654</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-516 [8]–[11].

after their health needs. He said that this presumption may be more common and acute for people with cognitive disability.<sup>655</sup>

263. As outlined above, Ms Reynolds told the Royal Commission about the particular challenges faced by people with cognitive disability who are also First Nations people. In particular, Ms Reynolds spoke about the stigma attached to having Fragile X in some First Nations families as well as the difficulties in sharing information among her community about what Fragile X means, stating:

*Back then, before it was known, I think, about what Fragile X meant or how you could get it, I had comments such as, 'Are you trying to tell me that some of my family is going to be spastic?' You know, that was just a given word back then. And that caused me to move away from all my family because it was hurtful to me and my family, yes.*<sup>656</sup>

264. Ms Reynolds told the Royal Commission that she moved her family to Coffs Harbour in order to seek access to a culturally inclusive health service for her sons.<sup>657</sup> Ms Reynolds observed, however, that a lot of health services do not know how to help people with disability who are also First Nations people.<sup>658</sup> She also stated that service providers still have a long way to go in learning about cultural inclusion.<sup>659</sup>

265. Ms Reynolds also spoke about her role in her community, where she assists First Nations people with disability to connect with health services,<sup>660</sup> and that sometimes 'black fellas have to interpret for each other.'<sup>661</sup> Ms Reynolds told the Royal Commission about her role as an advocate and intermediary between service providers, who she says can be dismissive. She said:

*So I generally work around trying to help – I will rather help you understand so that my sons can get better access. Rather than jump up and down and make a noise, I will work with the services. And I do that. I work – I will offer my services free to help them understand what it means to be Aboriginal, and what it means for my sons to have a disability.*<sup>662</sup>

266. She told the Royal Commission that she is aware of 'a lot of Aboriginal people with disability who do not remain connected with, or continue to seek services from,

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<sup>655</sup> Exhibit 4-18, 'Statement of Dr Scott Avery', 14 February 2020 at [20].

<sup>656</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-425 [25]–[30].

<sup>657</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-439 [23]–[26].

<sup>658</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-443 [10]–[13].

<sup>659</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-449 [5]–[6].

<sup>660</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-442 [24] – P-443 [6].

<sup>661</sup> Exhibit 4-17, 'Statement of Narelle Reynolds', 10 February 2020 at [60].

<sup>662</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-443 [32] – P-444 [4].

NDIS.<sup>663</sup> Ms Reynolds stated that she thinks the NDIS needs Aboriginal liaison officers who can work with carers and assist people with disability to access services, stating that most of the time First Nations people ‘need to have a familiar face, a black face, just to feel like they’re safe to talk to. And that’s what I do but there needs to be someone employed by NDIS to help that gap.’<sup>664</sup>

267. Dr Avery described a number of ‘system-wide failings’ of the health system in Australia for First Nations people with disability, including a refusal to accept that health inequalities for people with disability even exist.<sup>665</sup> For example, he noted that the Closing the Gap in Indigenous Health Framework (**Closing the Gap**) published in 2018 did not include the impact of disability on health, on the basis that data was not collected.<sup>666</sup> Dr Avery also expressed the view that another ‘mechanism of avoidance’ is where one part of the health system ‘disgorges’ responsibility on to another part of the system to address these inequalities, creating a ‘circular reference of avoidance.’<sup>667</sup>
268. As an example of this, he said that the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 (**Plan**) is administered by one Commonwealth government department, but gives responsibility for the mainstream health requirements of people with disability to the National Disability Strategy, administered by another Commonwealth government department.<sup>668</sup> The Plan assigns responsibility to the NDIS for some matters, and the National Disability Strategy delegates responsibility through to the ‘Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander Peoples with a Disability’, which gives responsibility back to the Plan and Closing the Gap to monitor progress on improvements.<sup>669</sup> Dr Avery described this as an example of a ‘policy merry-go-round in which no-one accepts responsibility.’<sup>670</sup> He said:

*Aboriginal and Torres Strait Islander people with disability are in need of a sophisticated approach to address their health needs, in which all parts of a health care system to come together collaboratively in accepting joint and several responsibility for attaining improvements in their health outcomes.*<sup>671</sup>

269. In her witness statement, Ms Rishniw of Commonwealth Health described the Indigenous Australians’ Health Program, but said that while it recognises the

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<sup>663</sup> Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [68].

<sup>664</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-448 [9]–[24].

<sup>665</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [61]–[62].

<sup>666</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [63].

<sup>667</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [65].

<sup>668</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [65].

<sup>669</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [65].

<sup>670</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [66].

<sup>671</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [66].

higher reported rates of disability in First Nations people, it does not specifically target First Nations people with cognitive disability.<sup>672</sup> During her oral evidence Ms Rishniw stated that Commonwealth Health's implementation plan for the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 was developed in consultation with Aboriginal and Torres Strait Islander people.<sup>673</sup> She said that the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 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 sure the system responds to that.*<sup>674</sup>

270. She said that she was not aware of any specifics in the plan that deal directly with Aboriginal and Torres Strait Islander people with cognitive disability.<sup>675</sup> Mr Cotterell further told the Royal Commission that there will be complementary implementation of plans such as these with the Draft Roadmap.<sup>676</sup>

### **The importance of strong advocacy**

*I don't feel like AAL is safe. I feel like I need to live forever. I'm the carpenter, the plumber, the lawyer, the nurse. I am full time advocate. I have had to be very strong and proactive to find suitable medical and health services for AAL. I have made many phone calls, sent many emails and spent many days, weeks, months and years, researching on the internet what is available and suitable for AAL. I should not have to fight for AAL's right to equal access to health care in our first world country.*<sup>677</sup> (Sabrina Monaghan)

*I am that mother. I am the mother they talk about ... to get Joshy seen I had to become 'that mother': the nagger, the yeller, the complainer, the swearer, the constant phone caller, emailer, photo-taker and report-maker, the fighter ... I wasn't that mother because I trusted the doctors and the system. If I didn't*

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<sup>672</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [57].

<sup>673</sup> Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-788 [12]–[13].

<sup>674</sup> Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-788 [17]–[20].

<sup>675</sup> Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-788 [20]–[23].

<sup>676</sup> Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-788 [34] – P-789 [2].

<sup>677</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [141].

*become this mother, Joshy would be dead. I wish I had become that mother sooner, because then he wouldn't be suffering like he is now.*<sup>678</sup> (Toni Mitchell)

271. A number of witnesses told the Royal Commission that strong advocacy is crucial to ensure that people with cognitive disability are provided with quality health care. Dr AAJ told the Royal Commission that in her experience, 'a patient with an intellectual disability needs a strong advocate within the health system; without one they may suffer, or at worst they may die.'<sup>679</sup> Some witnesses talked about the importance of people with cognitive disability being their own advocates, and developing the skills to do so. Other witnesses described the central role of parents as advocates for their children with cognitive disability. Several witnesses highlighted the difficulties faced by people with cognitive disability who are unable to advocate strongly for themselves and who have no family capable of doing so.
272. The Royal Commission heard from two witnesses who described themselves as self-advocates: Kylie Scott and Mr Strike. They spoke about what it means to advocate for their own health care, and told the Royal Commission that they have developed the skills and knowledge not only to make their own voices heard, but also to teach other people how to speak up for themselves.<sup>680</sup> Ms Scott said:

*For me, being an advocate means that I can spread my wings and put people with disability under my wing. I can get people with disability to realise what speaking out means and what families can do.*<sup>681</sup>

273. Ms Scott also said that while people with disability are learning how to self-advocate and speak up for themselves,<sup>682</sup> 'some people can't and that's a problem'.<sup>683</sup> Ms Scott told the Royal Commission that even with her self-advocacy and independent living skills, she needs some help from her mother in navigating the health system, particularly organising appointments and making decisions about her health.<sup>684</sup>

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<sup>678</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-146 [26]–[33].

<sup>679</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [77].

<sup>680</sup> Transcript, Robert Strike AM, Public Hearing 4, 28 February 2020, P-868–869; Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [36]–[40].

<sup>681</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [38].

<sup>682</sup> Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-23 [6]–[11].

<sup>683</sup> Exhibit 4-1, 'Statement of Kylie Scott', 7 February 2020 at [39].

<sup>684</sup> Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-20 [10]–[17]; Exhibit 4-1.1, IND.0024.0001.0001.

274. The Royal Commission heard from 16 parents who gave evidence about their experiences as advocates for their children with cognitive disability.<sup>685</sup> In some cases, parents advocate for their children by helping them communicate with health professionals so that they can speak up for themselves and make their own decisions.<sup>686</sup> Mr Strike said that he encourages his daughter to speak for herself and talk directly to doctors, but he is ‘always behind her or next to her.’<sup>687</sup> He said that it is important that people have their parent or advocate with them when talking to doctors, ‘to make certain they are being listened to’.<sup>688</sup>
275. Some parents described their advocacy as ‘fighting’ for their child’s right to quality care and treatment.<sup>689</sup> Ms Mitchell told the Royal Commission that from the moment that her son Joshy was born, she ‘had to start justifying my son’s right to live and to be treated’.<sup>690</sup> Ms Mills said that she feels that she has not been a good advocate for her son in medical settings but that she has at least kept him alive.<sup>691</sup> A number of parents told the Royal Commission about their experience advocating for the most basic, and in some cases life-sustaining, treatment for their children.<sup>692</sup>
276. The Royal Commission heard that parents can be strong and effective advocates for their children and in some cases become ‘de facto health professionals’.<sup>693</sup> Ms Mitchell said that after years of learning about her son Joshy’s health needs

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<sup>685</sup> Rebecca Kelly, Rachel Browne, Toni Mitchell, Giuseppina Porte (Jo Abi), Christine Regan, Lorraine Clark, Kim Creevey, Tara Elliffe, Sabrina Monaghan, Narelle Reynolds, Jaqueline Mills, AAJ, Jayne Lehmann, Evelyn Scott OAM, Margot Elliffe, Robert Strike AM.

<sup>686</sup> Transcript, Evelyn Scott, Public Hearing 4, 28 February 2020, P-857 [37] – P-858 [12].

<sup>687</sup> Transcript, Robert Strike AM, Public Hearing 4, 28 February 2020, P-874 [11]–[13].

<sup>688</sup> Transcript, Robert Strike AM, Public Hearing 4, 28 February 2020, P-874 [29]–[33].

<sup>689</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [120]; Transcript, Margot Elliffe, 28 February 2020, P-863 [14–16]; Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [61]; Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [61], [64].

<sup>690</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-117 [11]–[17].

<sup>691</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [58].

<sup>692</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-122 [3]–[13]; Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [65–67]; Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly, 9 February 2020 at [124–137]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-437 [24–29]; Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-83 [12] – P-84 [6]; Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [44–48]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020, P-322 [25] – P-324 [22]; Transcript, Sabrina Monaghan, Public Hearing 4, 24 February 2020, P-372-373; Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [28]–[29], [30]–[33].

<sup>693</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [105].

through care and research, 'I know what [doctors] are talking about' and 'I have questions that I expect answers to' when it comes to his care and treatment.<sup>694</sup>

277. Because of their extensive knowledge of their children's needs and preferences, and deficiencies in continuity and co-ordination of care within the health system, parents can also assume responsibility for the case management of their child's health. Dr Kelly described herself as the 'project manager' for the care of her son Ryan, and spoke about her role in identifying appropriate specialists,<sup>695</sup> organising appointments and important surgeries,<sup>696</sup> and developing Ryan's Care Plan and making sure that it is followed by the various medical practitioners involved in his treatment.<sup>697</sup> As discussed above, Dr Kelly said that she is the conduit of information between the six or seven different specialist clinics where Ryan is treated,<sup>698</sup> and that she is responsible for managing Ryan's records and medical information which is 'almost like a job in its own right'.<sup>699</sup>
278. During his oral evidence, Professor Leeder spoke about the importance of supporting parents to be advocates because 'there's nothing like the advocacy of an individual who understands the patient'.<sup>700</sup> For their advocacy to be effective, the Royal Commission heard that parents need support, education and training.<sup>701</sup> Dr AAJ said that despite being a doctor herself, on one occasion she felt unable to advocate adequately for her son on her own.<sup>702</sup>
279. For some parents, such as Lorraine Clark and Evelyn Scott, advocating for their child developed into systemic advocacy for the broader community of people with cognitive disability and their parents.<sup>703</sup> Ms Reynolds also said that she helps connect First Nations people with disability in her community with health services.<sup>704</sup> Ms Mills told the Royal Commission that she has engaged in supporting other parents to build advocacy practice and has engaged in systemic advocacy for significant and lasting change.<sup>705</sup> In addition, Ms Mills gave detailed evidence about her work developing the 'microboard' model of support, which is a

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<sup>694</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-139 [11]–[16].

<sup>695</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [30], [38]–[39], [41].

<sup>696</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-41 [19] – P-43 [12].

<sup>697</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [75]–[79].

<sup>698</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-43 [30] – P-44 [8].

<sup>699</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-45 [23]–[28].

<sup>700</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-160 [28]–[30].

<sup>701</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [173].

<sup>702</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [57].

<sup>703</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [95]; Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-846 [1]–[2].

<sup>704</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-442 [16]–[21]; Exhibit 4-17, 'Statement of Narelle Reynolds', 10 February 2020 at [60].

<sup>705</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [11].

group of people – including parents, friends and community members – who are incorporated as a board to help a person with disability make decisions. She said that microboards are designed to outlive parents and to uphold quality of life, safeguards and human rights for vulnerable people.<sup>706</sup>

280. In his witness statement, Mr Simpson emphasised the importance of such systemic advocacy to ‘highlight violence, abuse, neglect and exploitation, provide recommended solutions and promote take-up of those solutions.’<sup>707</sup>
281. The Royal Commission heard that advocating for their child’s health takes a toll on many parents. Evelyn Scott said that ‘there have been penalties to pay’ in her personal life for her advocacy for her daughter Kylie.<sup>708</sup> At least three witnesses described that penalty as ‘normal’ family life.<sup>709</sup> In some cases, it is their own physical and mental health.<sup>710</sup> Ms Barnett felt that her father, Norm, neglected treating his cancer because he was focussed on advocating for her brother Mr Barnett.<sup>711</sup> Jayne Lehmann said that her health suffered from a lack of time for herself, because so much of it was spent looking after and advocating for her daughter Sarah.<sup>712</sup> Ms Mills stated that the ‘trauma, exhaustion and struggle’ of advocating for her son inhibited her from being a good advocate.<sup>713</sup> At least two parents said that they feared passing away because there would be no-one to assume the role of advocating for their child.<sup>714</sup>
282. Ms Regan and Dr Kelly both told the Royal Commission that while navigating the health system for their children had been a challenge, they recognised that they had a level of privilege in their capacity to do so, and that many people with cognitive disability do not have the benefit of strong advocacy support from their parents.<sup>715</sup> Dr Kelly asked:

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<sup>706</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-474 [30]–[33]; Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [7]–[8].

<sup>707</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [129].

<sup>708</sup> Transcript, Evelyn Scott, Public Hearing 4, 28 February 2020, P-866 [5]–[6].

<sup>709</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [104]–[106]; Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [140]–[143]; Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [174]–[175].

<sup>710</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [169].

<sup>711</sup> Transcript, Karen Barnett, Public Hearing 4, 26 February 2020, P-676 [19]–[26].

<sup>712</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [101].

<sup>713</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [58].

<sup>714</sup> Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [141]; Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [153].

<sup>715</sup> Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-274 [9]–[11].

*What on earth happens to the child whose parents do not have the education, who are intellectually disabled themselves, who place their full trust in medical practitioners, or for whom English is not a first or even second language?*<sup>716</sup>

283. Some witnesses told the Royal Commission that there is a need for independent advocacy services for people with cognitive disability, and their families, to support them to navigate the health system. Dr AAJ stated that there is a ‘hidden community’ of people who do not have access to specialist care, and she spoke about decisions to palliate patients which she felt were made prematurely because they did not have an advocate to challenge that decision and push for specialist treatment.<sup>717</sup>
284. Ms Porter, who works as an OCV in NSW, said that people with cognitive disability who do not have a parent or support person capable of assuming the role of managing their health ‘are falling through the cracks because nobody’s connecting the dots’.<sup>718</sup> She also said that people in group homes may have less choice and control over their care and treatment because decisions are made on the basis of convenience for the staff.<sup>719</sup> Ms Mills said that isolated people who have no family or support person who knows them should have a skilled and experienced medical advocate ‘to make sure their basic needs are met, to help keep them safe, and to uphold their right to make decisions’.<sup>720</sup>
285. Mr Simpson also said that there is a need for a ‘funded complex health facilitation role’ for people with complex needs.<sup>721</sup> Professor Lennox said that people with cognitive disability would benefit from the advocacy of what he described as ‘facilitators’: trained health professionals who have experience in both disability and health and understand the risks that arise at their intersection in the health system.<sup>722</sup> Professor Lennox said it is important that facilitators are ‘in a powerful enough position to question when wrong decisions are being made and advocate in a powerful way’ for the patient.<sup>723</sup>
286. In addition, Dr AAJ and Ms Creevey suggested that it is important to have independent advocacy services available to people with cognitive disability in

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<sup>716</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [172].

<sup>717</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-620 [15]–[22].

<sup>718</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-582 [13]–[14].

<sup>719</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-583 [1]–[17].

<sup>720</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [160].

<sup>721</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-549 [21]–[23].

<sup>722</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-561 [19]–[31]; Exhibit 4-21, ‘Statement of Professor Nicholas Gordon Lennox’, 11 February 2020 at [53]–[57].

<sup>723</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-561 [29]–[31].

acute settings like emergency departments.<sup>724</sup> Ms Creevey said that when attending the hospital with her son, she often saw people with disability who had been admitted to hospital unaccompanied and without an advocate.<sup>725</sup> She noted that admission is a crucial stage in the treatment of a person, and that an independent on-call service should be available ‘to make sure that the child or the adult gets what they need’.<sup>726</sup>

## Lifetime health care

287. During Public hearing 4, the Royal Commission heard extensive evidence in relation to the provision of particular forms of health services to people with cognitive disability. These included preventative, emergency, dental, paediatric, and mental health services, as well as services providing end of life care.
288. The following section outlines some themes arising from the evidence of witnesses who described a series of challenges over a lifespan. They include: inadequate engagement in preventative health care leading to increased multi-morbidity for people with intellectual disability; the importance of dental health care for people with cognitive disability; the difficulties with system transitions from paediatric to adult health care; the overrepresentation of people with cognitive disability with co-occurring mental ill health; and failures in palliative care referrals, treatment, and information sharing.

## Preventative health care

*We know that people with intellectual disability and autistic people experience very high rates of risk factors for later compounding effects on health, for example, high rates of obesity, cholesterol, high blood pressure, lower participation in exercise programs, keep-fit programs. And so the needs in the preventative health domain are documented as very high. But when a person with many needs – and we’ve seen in Professor Beange’s seminal study on average five and a-half conditions – come[s] to the preventative health care settings, often primary care, general practitioners may struggle with the current model of service delivery and funding available for GPs to provide services, to address all of the relevant issues.*<sup>727</sup> (Professor Julian Trollor)

289. The Royal Commission heard evidence about the importance of effective preventative health care that reduces the onset and severity of multiple health

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<sup>724</sup> Transcript, AAJ, Public Hearing 4, P-619 [22] – P-620 [9]; Transcript, Kim Creevey, Public Hearing 4, 21 February 2020 at P-330 [33] – P-331 [17].

<sup>725</sup> Transcript, Kim Creevey, Public Hearing 4, 21 February 2020 at P-330 [37] – P-331 [1].

<sup>726</sup> Transcript, Kim Creevey, Public Hearing 4, 21 February 2020 at P-331 [1]–[11].

<sup>727</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-197 [7]–[17].

conditions for people with cognitive disability. This was highlighted by Professor Trollor, who described research conducted by the Department of Developmental Disability Neuropsychiatry at the University of NSW (**3DN**) which confirmed multi-morbidity as a strong predictor of death for people with intellectual disability.<sup>728</sup>

290. A recent research project commissioned by the NDIS Commission (see outline of evidence of Mr Head) and conducted by Professor Trollor, referred to as a Scoping Review, identified that in the NSW sample for the 2012-13 and 2014-17 reporting periods respectively, 26 per cent and 20 per cent of deaths involved people with disability who had not had a comprehensive health check in the preceding 12 months.<sup>729</sup> Mr Head also noted the finding in the Scoping Review that the date of the last comprehensive health assessment was unknown for a number of the people who died.<sup>730</sup>
291. Professor Trollor told the Royal Commission that Australian disability data highlights gaps in the provision of basic health prevention methods such as influenza and pneumococcal vaccinations, comprehensive annual health examinations and preventative dental care.<sup>731</sup> Professor Trollor stated:

*Despite an elevated risk profile, access to and uptake of preventative health care measures among populations with disability is generally poor. A recent international review of data published between 2011 and 2015, for example, found that people with intellectual disability have a significantly higher number of unmet needs and lower uptake of preventative health services compared to the general population.*<sup>732</sup>

292. With respect to preventative dental care (discussed further below), Professor Trollor stated that, despite having a higher prevalence of poor oral health, people with intellectual disability have less access to preventative dental services.<sup>733</sup> He stated that, given tooth loss and poor gum health are correlated with increased risk for certain diseases, all-cause mortality, and mortality associated with aspiration pneumonia, 'these gaps in preventative dental care represent a pressing issue for people with intellectual disability.'<sup>734</sup>

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<sup>728</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [140].

<sup>729</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [139].

<sup>730</sup> Exhibit 4-32, 'Statement of Graeme Head AO', 11 February 2020 at [257].

<sup>731</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [135].

<sup>732</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [131].

<sup>733</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [142].

<sup>734</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [144].

293. Specialist dentist Dr Zylan also stated:

*... there's preventative measures in place to help develop overall health and oral health for people with cognitive disabilities, and that we should really view that every tooth that's extracted where preventative measures were not taken should be considered as neglect and ... an injustice.*<sup>735</sup>

294. A joint written submission to the Royal Commission prepared by the Disability and Oral Health Collaboration, Your Dental Health project team, and the Australasian Academy of Paediatric Dentistry, identified that the ability to provide familiarisation and continuity of care with familiar clinical and support staff facilitates the provision of regular care and is of utmost importance to early identification of oral disease and implementation of early intervention procedures.<sup>736</sup> During his evidence, Mr Cotterell of Commonwealth Health recognised that oral health care is a critical area of preventative health for people with cognitive disability that needs to be looked at and addressed at the Commonwealth level.<sup>737</sup>

295. With respect to health assessments, the Royal Commission also heard from Professor Lennox about the development of the CHAP. Professor Lennox stated:

*... this came out of the realisation I had from Helen Beange and other people's work in the mid-90s that there was a whole lot of things that this population that I had suddenly been looking at that were poorly managed, unrecognised ... We know that you need to do pap smears and you need to do other checks and we do something about it. But here we had a population of around 400,000 Australians, maybe more. We knew that they suffered all this, and we were doing nothing about it.*<sup>738</sup>

296. Professor Lennox described the CHAP as a tool which 'minimises barriers to primary health care for people with intellectual disability by prompting health care and screening.'<sup>739</sup> He noted that the process of a health assessment empowers all participants, including people with intellectual disability, their support persons, primary care staff and GP.<sup>740</sup> Professor Lennox outlined other benefits of comprehensive health assessments, including allowing health history to be obtained in an accessible form, initiating consultation for overall review, prompting GP and primary care staff to consider commonly missed or poorly managed

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<sup>735</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-412 [17–21].

<sup>736</sup> Exhibit 4-16, SUB.100.00532.0001 at 0013.

<sup>737</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, PP-780 [3–11].

<sup>738</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-558 [10–17].

<sup>739</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [7].

<sup>740</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [44].

conditions, and improving the integration of primary health care with disability support services.<sup>741</sup>

297. The importance of health assessments was reiterated by Professor Trollor who stated:

*Annual health assessments support early detection of emerging diseases and improve monitoring and effective treatment of existing conditions. They are an especially important evidence-based primary care recommendation for people with intellectual disability in the context of this population's complex co-morbidities and documented difficulties identifying emerging health threats and communicating changes in health status.*<sup>742</sup>

298. Despite these benefits, as noted above in the outline of his evidence, Professor Lennox stated that there is evidence to suggest poor implementation of health assessments for people with intellectual disability in Australia.<sup>743</sup> Professor Trollor similarly stated that while annual health assessments represent best practice, they are often not done.<sup>744</sup>

299. Ms Mills also stated:

*Health assessments such as the Comprehensive Health Assessment Program, is a well-evidenced and preventative health strategy that has been shown to be a precursor to good quality health care, but is rarely used or mentioned to individuals and families who could benefit.*<sup>745</sup>

300. Ms Porter told the Royal Commission that while she sees examples of the CHAP tool effectively used in disability-supported accommodation, she also sees it used as a 'tick box exercise,'<sup>746</sup> with no follow-up:

*... instead of it becoming ... a living document and a document that is enduring and people are looking at that and making sure that any recommendations or any outcomes are addressed, is just filed. And some group homes I go into, they're out of date ... they're two years out of date.*<sup>747</sup>

301. A number of witnesses described the absence of health assessments for their children and others with cognitive disability. Ms Monaghan stated that her son, referred to as AAL, has 'never had a proper health assessment since his

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<sup>741</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [44].

<sup>742</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [138].

<sup>743</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [45].

<sup>744</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [138]–[139].

<sup>745</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [18].

<sup>746</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-588 [6]–[7].

<sup>747</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-588 [16]–[20].

challenging behaviours have been evident since pre-adolescence'.<sup>748</sup> Ms Reynolds recounted her experience assisting a First Nations woman in Coffs Harbour who had 'been to the doctors for a lot of years and never had one health assessment.'<sup>749</sup>

302. Some witnesses noted that where health assessments were made available, they were valuable. Jayne Lehmann stated that her daughter's GP did yearly health assessments for her 'that were specifically tailored for Sarah's intellectual disability and also did regular health checks.'<sup>750</sup>
303. Some witnesses also discussed Care Plans. Ms Monaghan stated that AAL's 'neurologist works collaboratively with me to develop a Care Plan for AAL. He has a vision for where AAL will be in a year, and the year after that.'<sup>751</sup> Margot and Tara Elliffe stated that Tara's GP has a Care Plan for her.<sup>752</sup> Margot Elliffe also stated that she is 'aware of some of Tara's friends with Down syndrome who do not have a Care Plan and their families are unaware of this Medicare funded plan.'<sup>753</sup>
304. Dr Singer of Commonwealth Health outlined the early development of health assessment requirements, including through direct engagement with professional colleges, consumer organisations, and stakeholder forums.<sup>754</sup> As noted above, Mr Simpson stated that CID's initial advocacy was for the creation of annual health assessment Medicare items for people with intellectual disability:

*In view of the communication challenges and other factors that impede diagnosis of health conditions in people with intellectual disability, there was an obvious case for GPs to do a thorough assessment on an annual basis.*

*There already existed similar assessment items for aged people and we worked with our intellectual disability health professional colleagues to press for action by the federal government.'*<sup>755</sup>

305. In his written statement, Dr Singer asserted that several MBS items were introduced in 2007 'to assist health professionals when conducting health assessments for people with disability, including intellectual disability.'<sup>756</sup>

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<sup>748</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [118].

<sup>749</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-442 [29] – P-443 [1].

<sup>750</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [48].

<sup>751</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [24].

<sup>752</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [27]; Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [15].

<sup>753</sup> Exhibit 4-34, 'Statement of Margot Elliffe', 13 February 2020 at [15].

<sup>754</sup> Exhibit 4-30, 'Statement of Dr Andrew Singer', 5 February 2020 at [22]–[24].

<sup>755</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [53]–[54].

<sup>756</sup> Exhibit 4-30, 'Statement of Dr Andrew Singer', 5 February 2020 at [20].

Mr Simpson told the Royal Commission, however, that there was no substantial implementation strategy by the federal government, and in 2010 the intellectual disability items were rolled in with other annual health assessment items.<sup>757</sup>

306. Professor Lennox similarly noted that health assessments were never adequately implemented in Australia, with changes to the specific Medicare item number for people with intellectual disability to a generic item number that included a variety of other patient groups.<sup>758</sup> This meant monitoring implementation of health checks for people with intellectual disability as a separate group was no longer readily available.<sup>759</sup> Ms Rishniw acknowledged that '[a]vailable MBS data does not provide the ability to distinguish health assessments provided to patients with intellectual or cognitive disability from health assessments provided to other eligible patients.'<sup>760</sup>
307. Dr Singer accepted at Public hearing 4 that it 'may be the case' that annual health assessments require further promotion among health practitioners.<sup>761</sup>

### **Dental health care**

308. The Royal Commission received evidence during Public hearing 4 that oral health is central to overall wellbeing and is a 'whole of life' issue where everyone, including those with cognitive disability, benefits from ongoing professional and preventative care and maintenance.<sup>762</sup>
309. The Joint Submission prepared by the Disability and Oral Health Collaboration, Your Dental Health project team, and the Australasian Academy of Paediatric Dentistry states that '[g]ood oral health is required if people with intellectual disability are to experience good general health, participate in their communities, and function to the best of their abilities'.<sup>763</sup>
310. Professor Trollor gave evidence that dental problems and gum disease are more common among people with intellectual disability,<sup>764</sup> and said that poor oral health is correlated with increased risk for ischaemic heart disease, peripheral vascular disease, all-cause mortality and mortality associated with aspiration pneumonia.<sup>765</sup>

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<sup>757</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [58]–[59].

<sup>758</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [45].

<sup>759</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [45].

<sup>760</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [42].

<sup>761</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-767 [36]–[37].

<sup>762</sup> Exhibit 4-16, SUB.100.00532.0001 at 0002, 0004; Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-393.

<sup>763</sup> Exhibit 4-16, SUB.100.00532.0001 at 0002.

<sup>764</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [57].

<sup>765</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [144].

311. Dr Zylan said that if oral health is neglected, the consequences are serious and can lead to systemic health issues. He said that for people with cognitive disability, poor oral health can lead to loss of teeth, digestion problems, and obesity.<sup>766</sup>
312. For people with cognitive disability who are also non-verbal, oral pain may not be communicated in a manner that is immediately understood, but instead, communicated through ‘behaviours of concern’.<sup>767</sup> Ms Mills told the Royal Commission that her son displayed significant challenging behaviours that lasted for 12 months. She said that it took a long process to work out that these behaviours were caused by wisdom teeth pain.<sup>768</sup> Ms Mills said that a number of families with children (including adults) with cognitive disability have not had a dental assessment in years because these ‘behaviours of concern’ make it difficult to participate in dental assessments and treatment.<sup>769</sup>
313. During Public hearing 4, access to dental assessments and treatment was identified as a particular issue that caused a significant barrier to oral health care for people with cognitive disability.
314. Dr Zylan told the Royal Commission that for children with disability, access to dental care is different depending on whether the public or private pathway chosen. In the private system, a child with a disability may be seen by a paediatric dentist and stay with that dentist until early adulthood or transition to a special needs dentist at the age of 18. In the public system, Dr Zylan said that the rules are stricter in that a child with disability will only be seen by a paediatric dentist until they are 18.<sup>770</sup>
315. The Joint Submission described Special Needs Dentistry (**SND**) as a dental discipline in Australia that supports ‘the oral health care needs of people with an intellectual disability, medical, physical or psychiatric conditions that require special methods or techniques to prevent or treat oral health problems, or where such conditions necessitate special dental treatment plans’.<sup>771</sup> There are only 17 SND specialists in the country.<sup>772</sup>
316. Dr Zylan said that access to a special needs dentist is through a referral made by a general dentist which has long waiting times.<sup>773</sup> He commented that it could take

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<sup>766</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-393 [13]–[18].

<sup>767</sup> Exhibit 4-16, SUB.100.00532.0001 at 0004–0005.

<sup>768</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [44].

<sup>769</sup> Exhibit 4-19, ‘Statement of Jaqueline Terri Mills’, 12 February 2020 at [46].

<sup>770</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-394 [14]–[18].

<sup>771</sup> Exhibit 4-16, SUB.100.00532.0001 at 0006.

<sup>772</sup> Exhibit 4-16, SUB.100.00532.0001 at 0006.

<sup>773</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-406 [23]; Exhibit 4-16, SUB.100.00532.0001 at 0008.

anywhere between 12 and 18 months to see a special needs dentist from the date of referral, or 18 months to two years if the treatment requires general anaesthetic.<sup>774</sup>

317. Ms Monaghan gave evidence that her son, AAL, attended a SND clinic from about the age of 12 and continued to attend every six months to yearly for check-ups.<sup>775</sup> She spoke of the challenges she faced seeking a referral to a dental hospital so that AAL could have a proper dental examination and have his teeth cleaned.<sup>776</sup>
318. Another concern expressed by a number of witnesses during Public hearing 4 was the view that dentists do not have adequate skills in managing people with a cognitive disability. For example, Jayne Lehmann told the Royal Commission that her daughter Sarah was seen by a dentist who did not attempt to scale or clean her teeth and left Jayne Lehmann to manage the environment to make it comfortable for her daughter.<sup>777</sup>
319. Ms Monaghan said that the dentist at the special needs clinic attended by AAL only looked at his front teeth, and only after being aided by Ms Monaghan to hold his lips open.<sup>778</sup> Ms Monaghan said that appointments with this dentist only lasted 10 minutes, and no suggestions or alternative methods were offered to facilitate proper examination of AAL's teeth.<sup>779</sup>
320. Ms Monaghan told the Royal Commission that 'hands-on practical experience' and training for dentists is warranted to improve their ability to manage people with cognitive disability.<sup>780</sup>
321. The Joint Submission asserts that there are significant financial impediments and time constraints that impact further education in SND.<sup>781</sup> These include SND training programs costing over \$130,000 in fees with no scholarships, limited availability of SND training programs at only four universities, and the need for significant investment of time in completing the course.<sup>782</sup>
322. Ms McKenzie and Ms Porter told the Royal Commission that access to oral health care is also a concern for people with cognitive disability in supported

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<sup>774</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-406 [24]–[27].

<sup>775</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [34]–[35], [46].

<sup>776</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [50]–[56].

<sup>777</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [73].

<sup>778</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [41]–[42], [46].

<sup>779</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [41], [43]–[44].

<sup>780</sup> Transcript, Sabrina Monaghan, Public Hearing 4, 24 February 2020, P-382 [11]–[12].

<sup>781</sup> Exhibit 4-16, SUB.100.00532.0001 at 0008.

<sup>782</sup> Exhibit 4-16, SUB.100.00532.0001 at 0008; Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-406 [33] – P-407 [10].

accommodation settings.<sup>783</sup> Ms Porter told the Royal Commission that access to the public dental system is ‘appalling’ for residents because of significant waiting lists as well as the attitudes of some support staff at the supported accommodation setting.<sup>784</sup>

323. Ms Porter said that when residents are placed on waiting lists, some support staff take no further action or dismiss alternative pathways for oral care, such as access to oral hygienists.<sup>785</sup> She also identified a tendency for support staff to have all residents seen by one dentist,<sup>786</sup> and a reluctance of support staff to ensure good oral health care of residents where there is resident resistance to that care.<sup>787</sup> Ms McKenzie confirmed that this observation was consistent with concerns received from other community visitors in the NSW OCV scheme.<sup>788</sup>
324. The attitude of support staff was also identified by Mr Despott as being a significant impediment to access to oral health care for people with cognitive disability.<sup>789</sup> Mr Despott said that while physical access is an issue, planning and procedural gaps enable the barriers to access.<sup>790</sup> He said that there is ‘inconsistency’ in supported accommodation settings because it is ‘rare to find a support organisation whose workers are experienced in planning for appointments regularly and making sure they then continue to happen for years to come’.<sup>791</sup> Mr Despott also said that some support staff do not have experience in looking out for basic signs of poor oral health and identifying when to take action.<sup>792</sup>
325. Interdisciplinary communication is a particular issue identified in the Joint Submission as having an impact on access to oral health in supported accommodation settings. It states that it is often the view of oral health professionals that the disability support sector does not have the capacity to consistently engage with oral health processes and, similarly, many dentists do not have sufficient understanding of the structure, roles and practices of the disability support sector.<sup>793</sup>

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<sup>783</sup> Exhibit 4-26.1, ISS.001.0038.0001 at 0002; Transcript, Katherine McKenzie and Lyn Porter, Public Hearing 4, 26 February 2020, P-600 [26] – 601 [33].

<sup>784</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-600 [32]–[36].

<sup>785</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-601 [7]–[21].

<sup>786</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-584 [3]–[7].

<sup>787</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-600 [33]–[36].

<sup>788</sup> Transcript, Katherine McKenzie, Public Hearing 4, 26 February 2020, P-601 [28]–[33].

<sup>789</sup> Transcript, Nathan Despott, Public Hearing 4, 24 February 2020, P-395 [27]–[34].

<sup>790</sup> Transcript, Nathan Despott, Public Hearing 4, 24 February 2020, P-395 [18]–[20].

<sup>791</sup> Transcript, Nathan Despott, Public Hearing 4, 24 February 2020, P-399 [20]–[22].

<sup>792</sup> Transcript, Nathan Despott, Public Hearing 4, 24 February 2020, P-399 [26]–[29].

<sup>793</sup> Exhibit 4-16, SUB.100.00532.0001 at 0005.

326. The Joint Submission suggests the need for collaborative pathways to promote the connection between disability support staff and dentists to overcome access barriers, reduce neglect, and improve the oral health of people with cognitive disability.<sup>794</sup>
327. Mr Despott and Dr Zylan spoke about one such pathway.<sup>795</sup> They described two forms contained in the *Oral Health and Intellectual Disability Guide (Oral Health Guide)*, a publication developed by Inclusion Designlab and Your Dental Health project team,<sup>796</sup> and endorsed by the Australian Dental Association.<sup>797</sup> These forms are aimed at facilitating communication and treatment planning between dentists, people with cognitive disability and their support staff (**Home Oral Care Plan Form**), and between dentists and GPs (**Oral Health Assessment Form**).<sup>798</sup>

### Transition from paediatric to adult health care

328. Several witnesses informed the Royal Commission that the transition from paediatric to adult health care for people with cognitive disability can pose particular challenges. Some witnesses described how they were assisted by a paediatrician in co-ordinating or case managing the medical care of their children with cognitive disability and complex health care needs.<sup>799</sup> Dr Small, herself a specialist paediatrician, noted that paediatricians have training in development and thus an understanding of the functional implications of intellectual disability.<sup>800</sup> She said that ‘within the adult health care system there is a recognised shortage of both generalist physicians and doctors specialising in the care of people with IDD [intellectual and developmental disability].’<sup>801</sup>
329. Professor Trollor suggested that the fragmentation of adult medical care in the Australian health system among various specialities and sub-specialities is felt very starkly by people with cognitive disability as they transition to adult care.<sup>802</sup> Dr Small also described the adult health care system as fragmented and indicated that young people with intellectual disability in particular can fall through service gaps and experience poorer health outcomes during the transition to adult care.<sup>803</sup>

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<sup>794</sup> Exhibit 4-16, SUB.100.00532.0001 at 0005.

<sup>795</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-409 [11] – P-410 [34].

<sup>796</sup> Exhibit 4-223, EXP.0022.0001.0046.

<sup>797</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-410 [23]–[24].

<sup>798</sup> Exhibit 4-223, EXP.0022.0001.0046 at 0051–0053.

<sup>799</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [23]; Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [115].

<sup>800</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [76].

<sup>801</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [75].

<sup>802</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-193 [29]–[31].

<sup>803</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [71], [78].

330. Dr Small explained that, typically, the transition to adult care occurs in the few years leading up to the end of school or when a person turns 18 years of age.<sup>804</sup> Often, paediatric hospitals have specific rules around not admitting a person beyond a certain age. However, some paediatricians or adolescent physicians may continue to treat someone into their early 20s.<sup>805</sup> Dr Small noted that it is a vulnerable stage for many young people with cognitive disability, particularly considering the fact that the majority are not supported by a planned process of transition and may experience substantial service gaps and disruptions, loss of coordinated care and limited or no health services with specialty cognitive disability interest and skills for referral to support their complex needs.<sup>806</sup>
331. Dr Small emphasised that it is important for this transition to be a ‘planned and purposeful’ process.<sup>807</sup> While some services have been established to support transition,<sup>808</sup> Dr Small suggested systematising transition with evidence-based policy and a well-trained workforce.<sup>809</sup>
332. Ms Browne gave evidence that she was ‘fearful’ of what the transition from paediatric to adult health care would look like for her son Finlay, and of what services would be available.<sup>810</sup> She said that this was a source of great anxiety for her.<sup>811</sup> Ms Mitchell told the Royal Commission that her son Joshy’s transition from paediatric to adult care took place over a two-year period as he ‘aged-out’ of the paediatric system starting at age sixteen.<sup>812</sup> She said that each medical specialist Joshy was seeing as a child had to send a referral letter to their adult counterpart, each of whom also required a referral from their GP.<sup>813</sup> She also said that the adult specialists did not have access to Joshy’s children’s records and so relied on her copies.<sup>814</sup> When asked by Counsel Assisting whether she had received an explanation of what the transition to adult care meant for Mr Mitchell’s health care management through his adult life, she replied that she was just managing it herself.<sup>815</sup>

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<sup>804</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [70].

<sup>805</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [70].

<sup>806</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [71].

<sup>807</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [70].

<sup>808</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [72].

<sup>809</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [118]; Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-244 [21–26], P-245 [6]–[25].

<sup>810</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-95 [6]–[8].

<sup>811</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-95 [11].

<sup>812</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-140 [15]–[17].

<sup>813</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-140 [12]–[15].

<sup>814</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-140 [17]–[18].

<sup>815</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-140 [24]–[29].

## Mental health care, including children and young people

*Sometimes I think that if kids with autism don't have mental illness already, they'll get a mental illness eventually, because they're made to feel so stupid. And they're not, they're brilliant.*<sup>816</sup> (Jo Abi)

*What I want to say is that everybody deserves good mental health care. That means care that addresses the practical, physical, social and psychological aspects of illness rather than focussing only on medication. Nobody should need to be scared of mental health services. Awareness of some of the problems in the current mental health system is really needed around mental health, and governments should be committing to improving these services.*<sup>817</sup> (Ruth Oslington)

333. During Public hearing 4, the Royal Commission heard from a number of witnesses about the overrepresentation of mental ill health in people with cognitive disability, as well as about barriers to quality mental health care and treatment.

334. Professor Trollor told the Royal Commission that people with intellectual disability and autism experience very high rates of mental health conditions, well in excess of the rates experienced by the general population, stating:

*Best estimates suggest that for common disorders such as schizophrenia, affective and anxiety disorders and dementias, prevalence in people with intellectual disability is 2 to 3 times that of the general population.*

...

*Very high rates of mental ill health have also been reported in people on the autism spectrum. Depression and anxiety disorders are the most common conditions experienced.*<sup>818</sup>

335. Professor Trollor identified data relating to mental health management of Australians with intellectual disability which indicates 'problems with detection and active mental health management,' citing a study of Australian children and adolescents with intellectual disability and mental ill health that found only 10 per cent received mental health interventions in a 14-year period.<sup>819</sup> In relation to people with autism, Professor Trollor stated that very high rates of mental ill health are observed in autistic adults internationally and in Australian adults on the autism

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<sup>816</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [113].

<sup>817</sup> Exhibit 4-461, IND.0017.0002.0001 at 0002.

<sup>818</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [39], [41].

<sup>819</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [149–150].

spectrum.<sup>820</sup> He also noted very high rates of suicidal ideation experienced by this group.<sup>821</sup>

336. In relation to mental health service use, Professor Trollor stated that 3DN linked data analysis had found that, subsequent to a first ever admission for a mental health issue:

*... people with intellectual disability were three times as likely as people without intellectual disability to present to emergency departments, and between 55% and 75% more likely to be readmitted at 1 month, 2-5 months, and 6-24 months after discharge.*<sup>822</sup>

337. Professor Trollor considered that this data demonstrates the ineffectiveness of acute and post-acute care for people with intellectual disability and co-morbid mental ill-health.<sup>823</sup>

338. A number of witnesses spoke about their experiences attempting to seek access to mental health services for their children. Ms Abi, who gave evidence on her attempts to seek mental health services for her son, Philip, stated that she has 'had to take him out of several mental health facilities because they're no good at looking after my son.'<sup>824</sup>

339. Ms Abi told the Royal Commission about difficulties attending appointments at one mental health facility;<sup>825</sup> about Philip's unexpected transfers between mental health units;<sup>826</sup> and their experiences in hospitals, including having to recount his history to different medical staff on every visit to hospital.<sup>827</sup> Ms Abi recounted one occasion where, after Philip was admitted to hospital, she was separated from him:

*So my child, who has almost died, like, is going to be on the other side of a locked ward, like, you know? ... [H]e was sicker than he had ever been, closer to death than he had ever been, and I was – he was being taken away from me. I wish I could have stayed with him. And, yes, it was – it was awful. And the next day when I went back, after crying all night, I went back to see him and he was on the other side of the glass and we were just looking at each other and just holding our hands up to each other. I think that the system just*

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<sup>820</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [41–42].

<sup>821</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [43].

<sup>822</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [167].

<sup>823</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [167].

<sup>824</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [76].

<sup>825</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [74–75].

<sup>826</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [86–87].

<sup>827</sup> Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [85].

*sort of underestimates how much you need your person when you're that sick.*<sup>828</sup>

340. Ms Monaghan also described two occasions on which she attempted to get mental health services for her son, describing barriers to eligibility to receive mental health services, a focus on medication rather than therapy, a reluctance to make home visits, and high costs.<sup>829</sup>

341. Kylie Scott told the Royal Commission:

*... it is important to assess mental health. People with Down syndrome are vulnerable, they need more psychologists for people with intellectual disability. There are a fair few people with intellectual disability with mental health problems.*<sup>830</sup>

342. Ms Scott's mother, Evelyn Scott, also detailed the difficulties of accessing quality mental health care and support for her daughter.<sup>831</sup> She said:

*Well, we went through a never-ending series of psychologists, even psychiatrists, for a while. They suggested medication. We tried that for a while, but it was not helping and she felt she was just, yes, not herself. We had a lot of counsellors that we went to. We weren't getting through to the nub of what her problem was, because she kept wanting to relive what had been happening to her. It certainly wasn't helping her ... I don't think any of the experiences she had made a significant difference to her wellbeing.*<sup>832</sup>

343. Evelyn Scott stated her view that pathways through the mental health system for people with intellectual disability are not clearly defined by the mental health profession.<sup>833</sup>

344. Professor Trollor outlined 3DN's work on the *Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers (Guide)* as developed collaboratively with representatives from health, mental health, advocacy and other relevant agencies in 2014.<sup>834</sup> He said that its development

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<sup>828</sup> Transcript, Giuseppina Cinzia Porte, Public Hearing 4, 28 February 2020, P-834 [29] – P-835 [1].

<sup>829</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [123].

<sup>830</sup> Transcript, Kylie Scott, Public Hearing 4, 18 February 2020, P-22 [16]–[20].

<sup>831</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-854 [29] – P-856 [9], P-865 [10]–[35].

<sup>832</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-855 [37] – P-856 [2], P-856 [8]–[9].

<sup>833</sup> Transcript, Evelyn Scott OAM, Public Hearing 4, 28 February 2020, P-865 [26]–[28].

<sup>834</sup> Exhibit 4-56, EXP.0015.0002.0605; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-209 [20]–[21].

was funded by Commonwealth Health, with the purpose of ensuring that, at each level of the mental health services system, practitioners and organisations were aware of how to accommodate the needs of people with intellectual disability, to make the health services accessible around mental health.<sup>835</sup>

345. Ms Rishniw stated that the Commonwealth funds a range of mental health initiatives and programs that are available to the general population, including people with cognitive disability who also have a mental illness.<sup>836</sup> Professor Trollor noted that while the development of The Guide was funded by Commonwealth Health, its implementation was not.<sup>837</sup> He expressed the view that although published in 2014, the recommendations in the Guide are still valid today.<sup>838</sup>
346. One of these recommendations is for 'reasonable adjustments' in the context of mental health services, which Professor Trollor said should be universally adopted in clinical practice.<sup>839</sup> Mr Simpson stated that he is not aware of any concerted action to implement the Guide developed by Professor Trollor and others.<sup>840</sup>
347. Mr Simpson also described parts of CID's advocacy work on improving mental health services for people with intellectual disability. He stated that in July 2016, Commonwealth Health gave PHNs a key role in leading regional planning, integration and commissioning of mental health services at a local level, and told CID that it encouraged PHNs to be inclusive of people with intellectual disability and to contact CID and/or Professor Trollor for further information.<sup>841</sup> Mr Simpson stated, however, that 'CID did not receive any approach from a PHN, apart from Central and Eastern Sydney PHN which has a longstanding interest in intellectual disability issues.'<sup>842</sup>
348. Mr Simpson further stated that the 2016 draft Fifth National Mental Health Plan did not mention people with intellectual disability 'even in a list of groups whose specific needs should be considered when implementing actions identified in the plan.'<sup>843</sup> Mr Simpson stated that CID continued to vigorously advocate for a substantial focus on people with intellectual disability in the plan, and acknowledged that the final Fifth National Mental Health and Suicide Prevention

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<sup>835</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-209 [20]–[25].

<sup>836</sup> Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [70].

<sup>837</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-209 [34]–[35].

<sup>838</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-210 [1]–[3].

<sup>839</sup> Exhibit 4-56, EXP.0015.0002.0605; Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [222]–[223]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-215 [29]–[30].

<sup>840</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [51].

<sup>841</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [81]–[82].

<sup>842</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [83].

<sup>843</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [87].

Plan, released in October 2017, included a paragraph specifically acknowledging the mental health inequalities faced by people with intellectual disability and a statement that implementation of the plan ‘requires specific and appropriate application to groups with specific diverse needs.’<sup>844</sup>

349. Professor Trollor provided evidence about a National Roundtable, convened in 2018 by 3DN and research partners, which developed a Communiqué entitled ‘Recommendations from the National Roundtable on the Mental Health of People with Intellectual Disability’ (**Communiqué**).<sup>845</sup> Professor Trollor stated that the Communiqué represents the response of sector leaders to the mental health needs of people with intellectual disability and contains a ‘series of actionable recommendations for the sector under each of eight elements of an effective health care system for people with intellectual disability.’<sup>846</sup> Professor Trollor told the Royal Commission that each recommendation has a suggested pathway with a proposed set of steps, ‘but the majority of the recommendations require resourcing.’<sup>847</sup>
350. Dr Lyons stated that NSW Health broadly supported the 24 recommendations in the Communiqué, and has fully or partially implemented 16 of them, noting that ‘responsibility for implementing the remaining eight recommendations resides with the Commonwealth Government.’<sup>848</sup>
351. Dr Lyons further stated that in response to *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024*,<sup>849</sup> the NSW Government supported the development of specialised services for people with intellectual disability and mental health conditions.<sup>850</sup> Key service elements agreed upon in a 2018 workshop included clear pathways to access more specialised knowledge, assessment of people with complex intellectual disabilities and mental health conditions, and specialist support to inpatient mental health units and community health teams.<sup>851</sup> Mr Simpson commented that while there has been some progress in relation to mental health care for people with intellectual disability in NSW there has been ‘nowhere near the full implementation’ of the actions set out in the ‘Living Well’ strategic plan.<sup>852</sup>

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<sup>844</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [88].

<sup>845</sup> Exhibit 4-118, EXP.0016.0001.0611.

<sup>846</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor, 11 February 2020, at [210]–[211].

<sup>847</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor, 11 February 2020, at [212].

<sup>848</sup> Exhibit 4-27, ‘First Statement of Dr Nigel Lyons’, 13 February 2020 at [96].

<sup>849</sup> Exhibit 4-111, EXP.0016.0001.0960.

<sup>850</sup> Exhibit 4-28, ‘Second Statement of Dr Nigel Lyons’, 13 February 2020 at [30].

<sup>851</sup> Exhibit 4-28, ‘Second Statement of Dr Nigel Lyons’, 13 February 2020 at [31].

<sup>852</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-533 [12]–[13].

352. Dr Lyons also told the Royal Commission that NSW Health is in the process of establishing two state-wide Intellectual Disability/Mental Health Tertiary Specialist Hubs for adult and child and adolescent patients who have an intellectual disability and co-morbid mental illness.<sup>853</sup> These are intended to, amongst other things, 'improve state-wide access to specialist, multidisciplinary mental health assessment and consultative care for people with co-morbid intellectual disability and complex care needs.'<sup>854</sup> At Public hearing 4, Mr Lyons stated that these hubs are 'well-established and almost up and operating.'<sup>855</sup>

### End of life care

353. Dr AAJ gave detailed evidence about cases she is aware of from her experience as a palliative care physician in NSW where people with cognitive disability were referred to palliative care services rather than being offered other available medical treatment, a matter which has greatly concerned her.<sup>856</sup>
354. Dr AAJ outlined her views on poor decision-making by clinicians treating people with intellectual disability,<sup>857</sup> including decisions not to get a second opinion<sup>858</sup> or investigate further;<sup>859</sup> failure to offer alternative or active treatment;<sup>860</sup> assumptions about quality of life;<sup>861</sup> and referrals of patients with cognitive disability to palliative care when they are not imminently dying.<sup>862</sup>
355. Dr AAJ recounted one occasion when a patient with intellectual disability presented to the emergency department bleeding heavily from her cervix.<sup>863</sup> Dr AAJ said a colleague asked her to see this patient who was going to be sent home and, if she was to return, was to be treated under palliative care.<sup>864</sup> Dr AAJ saw that the patient's clinical notes said 'mental age of five.'<sup>865</sup> Dr AAJ stated that she was sure this was 'just a random statement' saying she had an intellectual

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<sup>853</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020 at [30]–[96].

<sup>854</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [42].

<sup>855</sup> Transcript, Dr Lyons, Public Hearing 4, 27 February 2020, P-717 [7]–[8].

<sup>856</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-605 [7]–[28].

<sup>857</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-604 [20]–[25]; Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [12].

<sup>858</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [20]–[21].

<sup>859</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [30]–[31].

<sup>860</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [26], [35].

<sup>861</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [28].

<sup>862</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [39], [42].

<sup>863</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [19]–[26].

<sup>864</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-607 [4]–[6].

<sup>865</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-607 [10]–[11].

disability without proper assessment or knowledge of a previous diagnosis.<sup>866</sup> Dr AAJ described the health system as a 'conveyer belt', suggesting that more time needs to be spent on communication and planning before deciding on appropriate treatment, such as this case, where Dr AAJ said the patient required modified treatment.<sup>867</sup>

356. During Public hearing 4, Mr Cotterell was asked by Counsel Assisting whether Commonwealth Health could look at some of the evidence that had arisen in the public hearing about people with intellectual disability being referred inappropriately early for palliative care. Mr Cotterell stated that Commonwealth Health would 'look at the evidence that's arisen from the ... Royal Commission. It was shocking evidence.'<sup>868</sup>

357. Ms Barnett and Ms Nash also expressed the view that there should be greater information sharing between palliative care and emergency services. Ms Nash stated that despite a palliative care team informing her and Mr Barnett's family of what to do if he passed away once discharged home under palliative care, and organising a Do Not Resuscitate form, after Mr Barnett died:

*The paramedics rushed into the house and were going to try to resuscitate Grant. Luckily, I had been warned that this might happen by the palliative care team and had the Do Not Resuscitate paperwork ready to show them. Grant's family and I then waited a long time for the Police.*

*I understand that the police and the paramedics had to do their jobs but this was quite a traumatic experience for myself and Grant's family.<sup>869</sup>*

358. Ms Barnett, Mr Barnett's sister, similarly stated:

*Having to inform both the police and paramedics of Grant's palliative care situation prior to his death was extremely difficult, given we were all very upset. It felt like there was a complete lack of information sharing between the police and paramedics. In my view, there should have been some communication between them prior to the police arriving at the house.<sup>870</sup>*

359. While Dr AAJ described people with intellectual disability being inappropriately referred for palliative care in circumstances where she believed medical treatment could and should be provided, Professor Trollor told the Royal Commission that

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<sup>866</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-607 [21]–[23].

<sup>867</sup> Transcript, AAJ, Public Hearing 4, 26 February 2020, P-609 [16]–[39].

<sup>868</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-781 [30] – P-782 [2].

<sup>869</sup> Exhibit 4-23, 'Statement of Tracey Nash', 10 February 2020 at [89]–[91].

<sup>870</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [61].

people with intellectual disability who do require palliative care may not being referred for that care. He stated:

*Despite a rapidly expanding aging population with intellectual disability and an overrepresentation of life-limiting conditions among this population, there is a paradoxical under-referral of people with intellectual disability to palliative care services.*<sup>871</sup>

360. Professor Trollor's evidence also noted pilot data from 3DN's current NSW intellectual disability health linkage project which showed that across the most common diagnoses for which palliation is provided, 'only 13% of hospitalisations for people with intellectual disability who died as inpatients with one of these diagnosis were palliative care-related.'<sup>872</sup> Professor Trollor pointed out that 'this compares poorly with the 51.6% palliative care referral rate in the general population.'<sup>873</sup> Professor Trollor also noted that there is no specific mention of people with intellectual disability in the National Palliative Care Strategy.<sup>874</sup>

## **Integration of the health and disability service sectors**

361. A number of witnesses told the Royal Commission that quality health care and better health outcomes for people with cognitive disability not only require improvements to the health system itself, but also changes to and better integration with the disability services sector. Mr Simpson stated:

*[T]he health system is responsible for health services to all people with disability. However, the disability support system has very important complementary roles for people receiving disability support, including promoting healthy lifestyles, being alert to signs of illness, facilitating access to and communication with appropriate health professionals and supporting action on recommended treatment.*<sup>875</sup>

362. According to the ADC, in 2018/19 its OVC scheme identified that issues 'relating to the health care and/or personal care of residents accounted for 20 per cent of issues raised in OCV visit reports to disability accommodation services.'<sup>876</sup> These issues included concerns about 'health, medical, dental, optical, auditory, nutritional, psychological and/or development needs not being addressed.'<sup>877</sup> As has been noted,<sup>878</sup> Ms Porter, an OCV in NSW, said that people with cognitive

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<sup>871</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020 at [170].

<sup>872</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020 at [171].

<sup>873</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020 at [171].

<sup>874</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020 at [170].

<sup>875</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [104].

<sup>876</sup> Exhibit 4-26.1, ISS.001.00038 at 0002.

<sup>877</sup> Exhibit 4-26.1, ISS.001.00038 at 0002.

<sup>878</sup> Report at [284].

disability in group homes who lack family or support persons capable of managing their health are at risk of falling through the cracks.

363. Professor Trollor noted that because people with intellectual disability and those on the autism spectrum have complex health care needs, coordination between disability and health services is particularly important.<sup>879</sup> He expressed the view that currently there is 'limited connectivity' between the health system and disability supports, which has been exacerbated by the individual funding model of the NDIS.<sup>880</sup> He also stated that further research may be needed so 'we could also understand where people are living and its impact on health outcomes and on access to health care'.<sup>881</sup> Dr Small also said that, despite the need for a holistic approach, there is 'little sustained collaboration and few shared models of care between disability and health services'.<sup>882</sup>
364. Similarly, Mr Despott told the Royal Commission that he and Dr Zylan were surprised and dismayed by the 'lack of interdisciplinary awareness between the dental and disability systems'.<sup>883</sup> Dr Zylan and Mr Despott also coordinated the joint submission from the Disability and Oral Health Collaboration, Your Dental Health project team and the Australasian Academic of Paediatric Dentistry, which stated that a focus on the 'broader systemic gaps across the oral health and disability sectors is needed.'<sup>884</sup> The joint submission noted that dental professionals are unable to effectively utilise the disability support network of a person with intellectual disability, because they do not have the training to understand the systems and communication pathways that exist.<sup>885</sup> It contends that effective training and more inter-disciplinary communication tools are required to connect the oral health and disability sectors.<sup>886</sup>
365. Mr Simpson explained that the implementation of the NDIS has meant that it is now the national funder of disability support services.<sup>887</sup> Thus, in NSW, the state government has ceased its role as a disability service provider and has closed the NSW Department of Ageing, Disability and Home Care (**ADHC**), whose services have been tendered to the non-government sector.<sup>888</sup> Funding of these services is

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<sup>879</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [95].

<sup>880</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-170 [1]–[7].

<sup>881</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-175 [15]–[19].

<sup>882</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [81].

<sup>883</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-392 [4]–[7].

<sup>884</sup> Exhibit 4-16, SUB.100.00532.0001 at 0010.

<sup>885</sup> Exhibit 4-16, SUB.100.00532.0001 at 0010.

<sup>886</sup> Exhibit 4-16, SUB.100.00532.0001 at 0010.

<sup>887</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [106].

<sup>888</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [106]–[107].

now administered via individual NDIS participant plans.<sup>889</sup> Mr Simpson suggested that, as an immediate priority, the National Disability Insurance Agency (**NDIA**) should establish a system to include a health facilitation role in the funding of NDIS plans for people with complex health support needs.<sup>890</sup>

366. Mr Simpson also expressed serious concern about the ‘minimal coverage of health in the standards of the NDIS Quality and Safeguards Commission’ as compared with the requirements of the previous ADHC health policies and procedures.<sup>891</sup> He recommended that the NDIS Commission should prioritise establishing ‘standards setting out expectations on disability support services, in particular those providing supported accommodation, in relation to supporting healthy lifestyle and health care for people with intellectual disability.’<sup>892</sup>
367. Dr Small said that while the NDIS has ‘provided much welcome opportunities for some people’, for those with complex needs ‘there’s been significant breakdown in existing relationships and partnerships, and to some extent ownerships and accountability’ for their needs.<sup>893</sup> She said that the new drivers within the NDIS are ‘market-driven individual business models’, which pose challenges to re-establishing lost partnerships.<sup>894</sup> She also expressed the view that high-level accountability across governments has changed with the introduction of the NDIS.<sup>895</sup> Dr Small also said that with the loss of the ADHC, there is no longer a ‘unifying agency in NSW that draws together the myriad of non-government services and individual disability therapists’.<sup>896</sup>
368. Some witnesses told the Royal Commission that there can be support co-ordination problems between health service providers and disability service providers. In a written submission, the ADC observed that this can affect decisions made when a person with disability is admitted to hospital and can pose significant risks to them as a result.<sup>897</sup> Ms Porter, who works as an OCV in NSW, said that there also needs to be better discharge planning and communication between service providers and hospitals.<sup>898</sup>
369. The ADC’s submission also said that OCVs continue to report concerns about the adequacy and quality of support provided to people with cognitive disability by

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<sup>889</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [106]–[107].

<sup>890</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [138.2].

<sup>891</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [120].

<sup>892</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [138.1.1].

<sup>893</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-246 [19]–[25].

<sup>894</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-246 [31]–[33].

<sup>895</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-246 [39]–[41].

<sup>896</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [87].

<sup>897</sup> Exhibit 4-26.1, ISS.001.00038 at 0005.

<sup>898</sup> Transcript, Lyn Porter, Public Hearing 4, 26 February 2020, P-599 [23]–[32].

health staff in hospitals, particularly during mealtimes.<sup>899</sup> Jayne Lehmann expressed similar concern and explained that during one of Sarah Lehmann's hospital admissions the support of her disability workers 'was essential', and that the 'medical and nursing staff acknowledged they were unable to provide the same quality of care.'<sup>900</sup>

370. Ms McKenzie of the ADC emphasised the importance of disability workers providing support and critical information, such as through a hospital support plan, to hospital staff so that they can meet a person's support needs in hospital.<sup>901</sup> In its written submission, the ADC noted that while some disability services develop hospital support plans prior to a resident's admission to hospital, they are not always followed and 'the necessary discussions do not routinely occur' between hospital staff and support workers.<sup>902</sup>
371. In relation to discharge planning, Ms McKenzie explained that a misconception rife within hospitals and health is that disability accommodation settings are medical environments staffed by health practitioners and nurses.<sup>903</sup> She said that there is an assumption that people can be discharged back home despite some kind of a significant change in their health needs, because once they're back home they will be supported by nursing care, when in fact that is not the case.<sup>904</sup>
372. Dr AAJ said that hospitals routinely fail to recognise that disability workers often cannot manage acute medical or psychiatric issues in group homes.<sup>905</sup> She also said that she knew of cases when people with severe autism have been admitted to community respite beds, which are staffed by disability support workers who usually cannot appropriately manage the person's health needs.<sup>906</sup>
373. The Royal Commission also received evidence that the level of training and competence of disability service staff can be relevant to how well the disability and health sectors coordinate. Professor Trollor stated:

*... [D]isability professionals represent critical players in access to health care and continuity of health care for people with disability. It is, therefore, important that professionals working in the disability system are equipped with basic*

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<sup>899</sup> Exhibit 4-26.1, ISS.001.00038 at 0005.

<sup>900</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [86].

<sup>901</sup> Transcript, Kathryn McKenzie, Public Hearing 4, 26 February 2020, P-596 [21]–[28].

<sup>902</sup> Exhibit 4-26.1, ISS.001.00038 at 0005.

<sup>903</sup> Transcript, Kathryn McKenzie, Public Hearing 4, 26 February 2020, P-599–600; see also Exhibit 4-26.1, ISS.001.00038 at 0005.

<sup>904</sup> Transcript, Kathryn McKenzie and Lyn Porter, Public Hearing 4, 26 February 2020, P-600 [12]–[14].

<sup>905</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [60].

<sup>906</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [60].

*competences in disability health care so that they are supported to do a good job.*<sup>907</sup>

374. Both Jayne Lehmann and Professor Trollor told the Royal Commission that disability support workers need to be given basic health training and education, so that they are supported to deliver quality services.<sup>908</sup>
375. In addition, the NDIS Commissioner, Mr Head, described a 'Scoping Review' of the causes and contributors to deaths of people with disability commissioned by his office and recently conducted by Professor Trollor and another researcher.<sup>909</sup> He noted that the findings and recommendations of the review shed light on the need for training in the disability services sector.<sup>910</sup> He said that key issues identified by the Scoping Review were a lack of proactive support for preventative health care, limited use of communication plans, a failure to proactively manage emerging and chronic health risks, and unfamiliarity with best practice standards in responding to medical emergencies.<sup>911</sup>
376. Mr Head gave evidence that the NDIS Commission intends to reduce the risks identified in the Scoping Review with a number of measures, including increasing the skills of NDIS providers and workers.<sup>912</sup> Mr Head also noted that the NDIS Commission will issue new Provider Practice Alerts,<sup>913</sup> and add some health-related measures to address quality and safety in mealtime support to the NDIS Practice Standards.<sup>914</sup>

## Reduction of distress and trauma

*Over Finlay's 16 years he had multiple encounters and interactions with members of the health system; every poor encounter is remembered. This, in turn, creates a sense of unease and fear going into the next encounter; combine that with an environment that assaults your senses and scares you and on top of that, that you are also sick or in pain. Anyone's level of compliance is going to be sorely tested, but given the right skills and a true*

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<sup>907</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [286]–[287].

<sup>908</sup> Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [113]; Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [287].

<sup>909</sup> Exhibit 14-32, 'Statement of Mr Graeme Head AO', 11 February 2020 at [234]–[267].

<sup>910</sup> Exhibit 14-32, 'Statement of Mr Graeme Head AO', 11 February 2020 at [322]–[325].

<sup>911</sup> Exhibit 14-32, 'Statement of Mr Graeme Head AO', 11 February 2020 at [263].

<sup>912</sup> Exhibit 14-32, 'Statement of Mr Graeme Head AO', 11 February 2020 at [322].

<sup>913</sup> Exhibit 14-32, 'Statement of Mr Graeme Head AO', 11 February 2020 at [314]–[319].

<sup>914</sup> Exhibit 14-32, 'Statement of Mr Graeme Head AO', 11 February 2020 at [327].

*sense of compassion and a desire to help in the health system's staff, it is not unattainable.*<sup>915</sup> (Rachel Browne)

377. The Royal Commission heard evidence about the trauma and distress that can be associated with health procedures and treatment for people with cognitive disability. Dr Kelly stated that this is a particularly important issue because a person with intellectual disability is likely to develop more trauma from the same experience as a person without intellectual disability, and this trauma can have lifelong impacts.<sup>916</sup> Ms Monaghan told the Royal Commission that, like a lot of people with autism, her son has an incredible memory, which means that if something bad happens he cannot shake it off.<sup>917</sup> She said that the cumulative effect of repeated hospital visits that traumatise him negatively impacts his physical, psychological and emotional health.<sup>918</sup>
378. Several witnesses gave evidence about the impact of the sensory environment on a person with intellectual disability and/or autism. Dr Small said that presenting to an emergency department in particular can be a 'stressful, anxiety-provoking situation' for anyone, which can lead to 'increased challenging behaviours or distress' for a person with intellectual disability.<sup>919</sup> Ms Monaghan suggested that all major hospitals should have a sensory room or quiet space with soft textures and dim lighting for people with 'developmental delays or autism'.<sup>920</sup>
379. Tara Elliffe spoke about a recent presentation to hospital where she felt that her 'head was exploding from all the noise and different people. It was building and crushing down on me.'<sup>921</sup> The Royal Commission heard that the sensory overstimulation that Ms Elliffe described is a feature of other clinical settings, including dental environments.<sup>922</sup> In Ms Elliffe's case, the sensory overstimulation of the emergency department cause her to dysregulate by 'slowly, slowly withdrawing and shutting down.'<sup>923</sup> Margot Elliffe felt that because Ms Elliffe 'shut down', her pain was overlooked despite her critical condition.<sup>924</sup>
380. The Royal Commission also heard that distress-induced 'challenging behaviours' can include resisting treatment and attempting to remove medical devices such as

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<sup>915</sup> Exhibit 4-5, 'Statement of Rachel Browne', 2 February 2020 at [140].

<sup>916</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [156].

<sup>917</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [137].

<sup>918</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [133].

<sup>919</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-241 [16]–[19].

<sup>920</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [161].

<sup>921</sup> Transcript, Tara Elliffe, Public Hearing 4, 21 February 2020, P-344 [1]–[2].

<sup>922</sup> Transcript, Sabrina Monaghan, Public Hearing 4, 24 February 2020, P-370 [25]–[30].

<sup>923</sup> Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-860 [23].

<sup>924</sup> Transcript, Margot Elliffe, Public Hearing 4, 28 February 2020, P-860 [25]–[36].

cannulas.<sup>925</sup> This may be detrimental to the person's care, particularly if it prevents treatment. It may also result in staff, carers or support workers using restrictive practices.<sup>926</sup>

381. In addition, the Royal Commission received evidence about the accumulation of trauma through repeated distressing experiences in hospitals and other clinical settings. Ms Browne said that it became more and more difficult for her son Finlay to have a routine blood test because generally the procedure was not well managed, adjustments were not made for his distress and, consequently, it became increasingly traumatic for him.<sup>927</sup>
382. A number of witnesses also spoke about the unnecessary trauma caused by decisions to deny pain relief to a person with cognitive disability.<sup>928</sup> Ms Mills said that she felt that these decisions were based on the 'common but dangerous' assumption that people with cognitive disability have a high pain threshold, and a failure to recognise that pain can be communicated in different ways.<sup>929</sup>
383. Traumatic experiences in the health system have implications for every aspect of life for people with cognitive disability. Dr Kelly said that the trauma of her son Ryan's hospitalisation meant that he 'experienced a significant escalation in his anxiety and regression in his behaviour over a whole term at school.'<sup>930</sup> Ms Mitchell said that after a traumatic procedure, it could take months or years to rebuild trust between the doctors and her son.<sup>931</sup> In other cases, trust can never be regained. Ms Monaghan commented that her son has developed 'a fear of people', particularly medical staff, to the extent that 'he will need intervention for everyday treatment like a dental or physical exam.'<sup>932</sup> Ms Elliffe stated that she never wants to go back to a hospital,<sup>933</sup> and Ms Oslington said that her bad experiences in hospital have made her distrustful of the health system.<sup>934</sup>
384. The Royal Commission heard that the parents of a child with cognitive disability may also experience trauma from witnessing their distress and suffering. For Jayne Lehmann and Ms Browne, trauma compounded the grief of losing a child.

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<sup>925</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [134]–[135].

<sup>926</sup> Transcript, Jaqueline Mills, 25 February 2020, P-493–494.

<sup>927</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-91 [21] – P-93 [29].

<sup>928</sup> Transcript, Jaqueline Mills, Public Hearing 4, 25 February 2020, P-497 [20]–[27]; Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [158–160]; Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [96]–[97].

<sup>929</sup> Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [152].

<sup>930</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [161].

<sup>931</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [110].

<sup>932</sup> Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [134].

<sup>933</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [49].

<sup>934</sup> Exhibit 4-461, IND.0017.0002.0001 at 0002.

Ms Browne said that the ‘trauma [of Finlay’s passing] has completely covered my memory of [Finlay] and what he was.’<sup>935</sup> She and Jayne Lehmann said that trauma related to their children’s hospitalisation contributed to their decisions to stop working in hospital settings.<sup>936</sup> Jayne Lehmann also noted that witnessing her daughter Sarah’s experiences in hospital and not being listened to with respect to Sarah’s care has resulted in trauma for herself and a loss of trust in accident and emergency hospital care.<sup>937</sup> Similarly, Ms Mitchell told the Royal Commission that because of the trauma of her son Joshy’s past experiences, she has an anxiety attack when she gets the smell of a hospital.<sup>938</sup>

385. It may be the case that any medical treatment, procedure or visit to hospital is likely to be a source of some distress, particularly for people with cognitive disability and those requiring frequent medical intervention. Similarly, witnessing the serious ill-health, distress, or death of a child is inherently traumatic for a parent.

386. The Royal Commission heard from several witnesses that adjustments to procedure or environment could and should be implemented to try to minimise distress and trauma for people with cognitive disability when accessing health services.

387. Professor Trollor explained this could include:

*... making reasonable adjustments related to the person’s disability within clinical interactions, adapting and ensuring effective communication, involving the person in decision-making, and working with family and carers according to the preferences of the individual.*<sup>939</sup>

388. Other witnesses talked of the need for simple modifications or adjustments in a clinical setting, to minimise distress for people with cognitive disability. For example, Ms Browne emphasised the need for simple adjustments to be made when patients with intellectual disability and autism are treated in hospitals and by health professionals.<sup>940</sup> She specifically referred to changes that could be implemented to make it easier to take blood for routine testing, such as

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<sup>935</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [138].

<sup>936</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [139]; Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [94].

<sup>937</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February at [66].

<sup>938</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [15].

<sup>939</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [222].

<sup>940</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [143].

‘desensitisation’ work in advance, home visits, and taking extra blood to reduce the need for additional blood draws.<sup>941</sup>

389. Other witnesses suggested additional ways in which their (or their family member’s) experiences of going to hospital or having medical interventions could be improved by simple adjustments. Some also described how such adjustments could improve health outcomes.
390. Several witnesses spoke of familiarisation and preparation as an important way to reduce distress for a person with intellectual disability. Tara Elliffe said that people with disability should be given tours of hospital when they are well, so that they know what to expect if they have to present during an emergency.<sup>942</sup> Ms Reynolds said that to get her son Luke to the hospital, it is ‘all about preparation’ which starts ‘months and months ahead’.<sup>943</sup> Ms Mitchell gave an example of a time where medical staff refused to allow her son Joshy time to process his new environment, after which he had a ‘meltdown’ resulting in tests being left undone.<sup>944</sup> Ms Browne recounted how a dentist had spent 18 months familiarising her son, Finlay, with the dentistry environment, until he was finally comfortable to sit in the dentist’s chair, as an example of good practice.<sup>945</sup>
391. Some witnesses stated that the use of simple, picture-based resources such as ‘social stories’ are valuable in assisting people with cognitive disability to understand new environments<sup>946</sup> and the types of procedures they may need to have.<sup>947</sup> Jayne Lehmann explained:

*[L]ow literacy pictures or information with symbols in addition to easy-read would help to de-escalate anxiety levels and prevent the behaviours that can be triggered in these circumstances, for example, hitting, kicking, and biting as a way to self-protect.*<sup>948</sup>

392. Ms Mitchell noted that for people on the autism spectrum in particular, information needs to be broken down in order for them to process it.<sup>949</sup> Professor Trollor gave evidence that health services do not routinely have consumer health information or

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<sup>941</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [37]–[41].

<sup>942</sup> Exhibit 4-14, ‘Statement of Tara Kate Elliffe’, 13 February 2020 at [52].

<sup>943</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-438 [9]–[15].

<sup>944</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [117].

<sup>945</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [51].

<sup>946</sup> Transcript, Rachel Browne, Public Hearing 4, 19 February 2020, P-92 [22]–[25]; Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [42].

<sup>947</sup> Exhibit 4-34, ‘Statement of Margot Elliffe’, 13 February 2020 at [45].

<sup>948</sup> Exhibit 4-25, ‘Statement of Jayne Ann Lehmann’, 13 February 2020 at [121].

<sup>949</sup> Exhibit 4-6, ‘Statement of Toni Mitchell’, 10 February 2020 at [116].

promotional materials available in accessible formats for people with intellectual disability.<sup>950</sup>

393. Ms Monaghan proposed modifications to the hospital environment<sup>951</sup> and ‘novel and flexible approaches’ to sedation such as with the use of pre-medications in a less threatening environment.<sup>952</sup> Dr Kelly emphasised the importance of pre-medication for Ryan before certain medical procedures, but said she often struggles to get her requests for pre-medication taken seriously.<sup>953</sup> Ms Reynolds told the Royal Commission that on eight occasions her son Luke had been unable to have a biopsy because doctors refused to give him medication to help with his anxiety.<sup>954</sup> On the most recent occasion, he was able to have Valium prior to the biopsy and it greatly assisted in calming him down.<sup>955</sup>
394. Ms Browne also stated that, at times, sedation is unavoidable.<sup>956</sup> Ms Monaghan contended that if a patient needs to be sedated, then all treatments should be done at once.<sup>957</sup> This decreases the number of visits that the patient would need to make if going to the hospital gives them severe anxiety.<sup>958</sup>
395. Ms Monaghan also provided a list of ‘adjustments or accommodations’ that could be made by dental clinics for check-ups for people with autism.<sup>959</sup> Mr Despott told the Royal Commission about animated videos developed by his project Inclusion Designlab, which were designed to prepare people with intellectual disability for going to the dentist.<sup>960</sup>
396. Dr Small told the Royal Commission that she believes it would be viable for the health system to implement adjustments that are most frequently needed for people with intellectual disability, such as longer appointment times, appointments being booked at certain times of day, or the use of visual aids to overcome communication difficulties.<sup>961</sup> She said that a suite of easily achieved adjustments

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<sup>950</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [225].

<sup>951</sup> Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [153]–[161].

<sup>952</sup> Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [164]–[165].

<sup>953</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [160]–[161].

<sup>954</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-436 [17]–[23]; Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [53].

<sup>955</sup> Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-436 [23]–[25]; Exhibit 4-17, ‘Statement of Narelle Reynolds’, 10 February 2020 at [54].

<sup>956</sup> Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [43].

<sup>957</sup> Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [158].

<sup>958</sup> Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [158].

<sup>959</sup> Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [162].

<sup>960</sup> Transcript, Nathan Despott, Public Hearing 4, 24 February 2020, P-398 [34]–[40].

<sup>961</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-239 [24]–[30], P-240 [20]–[23].

for people with intellectual disability could be identified and mandated, with scope to tailor those adjustments depending on the individual and on their overall care plan. She said that these adjustments could be made in every health context and that health funding models would need to allow for their implementation by health professionals.<sup>962</sup>

## Training and education of health professionals

*The current health care landscape in Australia is one of lack of preparedness for the needs of people with developmental disabilities. This lack of preparedness manifests on every level (practitioner, services, policy); in each health care compartment (primary, specialist and acute care settings); and in services across the life span (from childhood to later life).*<sup>963</sup> (Professor Julian Trollor)

397. Throughout Public hearing 4, the Royal Commission heard from parents, family members, carers, support persons and people with cognitive disability, as well as advocates and experts, about their perception that some health professionals did not have the knowledge, skills or attitude to provide quality care to people with cognitive disability.
398. Several witnesses expressed their view that these issues could be addressed by better education and training to eliminate the health inequities faced by people with cognitive disability. Mr Simpson said that education and training of health professionals is a central component to ensure that people with cognitive disability have the same opportunity to lead long and healthy lives as other people.<sup>964</sup>
399. Another aspect of health education and training that was raised by some witnesses as an important issue at Public hearing 4 relates to the knowledge and skills of those who work in the disability sector.<sup>965</sup> The evidence presented to the Royal Commission on this subject has been discussed above.
400. As set out above, a strong theme from the evidence is the urgent need to change people's assumptions about and attitudes towards people with cognitive disability. At least nine witnesses told the Royal Commission that they believed health professionals need education and training to ensure that health decisions are not

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<sup>962</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-240 [24] – P-241 [27].

<sup>963</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [15].

<sup>964</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [133]–[134].

<sup>965</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [286]–[287]; Exhibit 4-25, 'Statement of Jayne Ann Lehmann', 13 February 2020 at [113]; Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [135]; Transcript, Nathan Despott, Public Hearing 4, 24 February 2020, P-400 [9]–[33]; Transcript, Narelle Reynolds, Public Hearing 4, 24 February 2020, P-449 [9]–[17].

informed by their perceptions, attitudes and assumptions about cognitive disability.<sup>966</sup> Ms Creevey said:

*There needs to be a concerted effort to provide substantial training and education for all medical staff about unconscious bias and the impact that it might have on their decision making about treating a person with disability.*<sup>967</sup>

401. Dr Kelly, Ms Browne, Ms Mitchell and Dr AAJ told the Royal Commission that education and training should involve exposure to people with disability to challenge the attitudes and assumptions of health professionals.<sup>968</sup> Dr Kelly said:

*There is a clear need for greater exposure of trainee doctors and nurses to people with disability and their families to challenge their perceptions that our lives are tragic and that people with intellectual disability have limited potential.*<sup>969</sup>

402. Both Dr Kelly and Ms Mitchell told the Royal Commission that they make efforts to contribute to the education and training of medical students and doctors by showing them that their children are not defined by their disability. Dr Kelly said that on occasions she has taken her son Ryan on talks with fourth year medical students to ‘put front and centre his humanity first’.<sup>970</sup> Ms Mitchell said that she gives talks to junior doctors in Toowoomba, and has taken graphic photos of Mr Mitchell with her to show them that they need to look beyond the Down syndrome.<sup>971</sup> Both described these moments as ‘powerful’ training tools.<sup>972</sup>

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<sup>966</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [208]; Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [146]; Exhibit 4-11, ‘Statement of Christine Regan’, 13 February 2020 at [101]; Exhibit 4-12, ‘Statement of Lorraine Gaye Clark’, 12 February 2020 at [103]–[105]; Exhibit 4-13, ‘Statement of Kim Letitia Creevey’, 7 February 2020 at [51]; Exhibit 4-15, ‘Statement of Sabrina Monaghan’, 12 February 2020 at [146]–[151]; Exhibit 4-22, ‘Statement of Karen Barnett’, 12 February 2020 at [68]; Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [66]; Exhibit 4-34, ‘Statement of Margot Elliffe’, 13 February 2020 at [40]–[44].

<sup>967</sup> Exhibit 4-13, ‘Statement of Kim Letitia Creevey’, 7 February 2020 at [51].

<sup>968</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [208]; Exhibit 4-5, ‘Statement of Rachel Browne’, 2 February 2020 at [146]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-143 [20]–[25]; Exhibit 4-24, ‘Statement of AAJ’, 8 February 2020 at [65].

<sup>969</sup> Exhibit 4-4, ‘Statement of Dr Rebecca Anne Kelly’, 9 February 2020 at [208].

<sup>970</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-53 [32].

<sup>971</sup> Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-143 [20] – P-144 [33].

<sup>972</sup> Transcript, Rebecca Kelly, Public Hearing 4, 18 February 2020, P-53 [34]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-144 [14].

403. Mr Strike and Tara Elliffe said that people with cognitive disability should be involved in educating and training health professionals.<sup>973</sup> Margot Elliffe said:

*I also think doctors and nurses should have disability training. Any disability training would be good, and to have people with disability doing some of the training.*<sup>974</sup>

404. Ms Elliffe's suggestion was shared by several advocates and experts. Dr Small said that the training of health professionals currently involves limited exposure to people with intellectual and developmental disability and their poorer health outcomes.<sup>975</sup> In her written statement, Ms O'Neill stated that an intentional, cultural change is required which facilitates people with intellectual disability being included in the development of legislation, policy, practice and training.<sup>976</sup>

405. Professor Lennox gave evidence that education programs should be developed and delivered by people with intellectual disability and their families.<sup>977</sup> Professor Trollor also stated that as educators, people with intellectual disability can change attitudes and encourage young future doctors to develop skills in this area.<sup>978</sup> He said:

*[P]erhaps the most potent tool there are people with intellectual disability and autistic people themselves, because their very presence as teachers in universities ensure that barriers are immediately broken down.*<sup>979</sup>

406. Mr Simpson emphasised values-based training for health professionals, an approach agreed to by Professor Trollor.<sup>980</sup> Mr Simpson said that this approach focuses on recognising the equal value of people with intellectual disability, identification of an intellectual disability, communication skills, reasonable adjustments to standard clinical practice and relevant clinical issues.<sup>981</sup>
407. A second area of education and training that several witnesses suggested needs to be addressed, and one that is linked to changes in attitudes and assumptions, is communication by health professionals with people with cognitive disability and their families, carers and support persons. As discussed above, problems with

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<sup>973</sup> Transcript, Robert Strike, Public Hearing 4, 28 February 2020, P-878 [25] – P-879 [14].

<sup>974</sup> Exhibit 4-14, 'Statement of Tara Kate Elliffe', 13 February 2020 at [51].

<sup>975</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [34].

<sup>976</sup> Exhibit 4-2, 'Statement of Justine O'Neill', 11 February 2020 at [46(d)].

<sup>977</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [69].

<sup>978</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-214 [4]–[12], [25]–[29].

<sup>979</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-214 [23]–[25].

<sup>980</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-214 [13]–[18].

<sup>981</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [134.1].

communication were identified by several witnesses as having a significant impact on access to quality health care for people with cognitive disability.

408. Several witnesses agreed that education and training in communication is important to improve access to health care for people with cognitive disability.<sup>982</sup> Ms Mills also said that education and training should focus on communication being made accessible through visual supports and aids.<sup>983</sup> Some parents said that training should cover behaviour as a means of communication, and how pain responses can be linked to certain types of behaviour.<sup>984</sup>
409. Professor Trollor stated that the health workforce needs to be equipped with sufficient knowledge and training to tailor standard practice to the complex needs and communication requirements of people with cognitive disability.<sup>985</sup> According to Dr Small, this could be achieved by way of tools and resources.<sup>986</sup> Dr Small spoke about how simple photo stories and visuals can be used as a communication aid by health professionals.<sup>987</sup> Dr Small also said that the whole health profession, including clerical and secretarial staff in health services, should be trained in communicating with people with cognitive disability.<sup>988</sup>
410. A third area of education and training that was suggested by several witnesses is the need to address gaps in knowledge about cognitive disability to ensure that health care needs are being met and correct diagnoses are being made.
411. Several parents told the Royal Commission that, in their experience, health professionals did not appear to have much knowledge about cognitive disability and this did not inspire trust that the health care needs of their children were being met.<sup>989</sup> Ms Monaghan and Ms Mitchell said that health professionals should complete compulsory training on autism and cognitive disability, with learning modules that delve deep into strategies that can be used.<sup>990</sup> Ms Regan expressed

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<sup>982</sup> Exhibit 4-22, 'Statement of Karen Barnett', 12 February 2020 at [68]; Exhibit 4-19, 'Statement of Jacqueline Terri Mills', 12 February 2020 at [136].

<sup>983</sup> Exhibit 4-19, 'Statement of Jacqueline Terri Mills', 12 February 2020 at [136]–[137].

<sup>984</sup> Exhibit 4-4, 'Statement of Dr Rebecca Anne Kelly', 9 February 2020 at [215], [217]–[220]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [151]; Exhibit 4-19, 'Statement of Jacqueline Terri Mills', 12 February 2020 at [154].

<sup>985</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [128]–[129].

<sup>986</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [84]–[85].

<sup>987</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [83]–[85].

<sup>988</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-239 [3]–[7].

<sup>989</sup> Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020 at [103]–[104]; Exhibit 4-7, 'Statement of Giuseppina Cinzia Porte (Jo Abi)', 26 February 2020 at [115], [118].

<sup>990</sup> Exhibit 4-6, 'Statement of Toni Mitchell', 10 February 2020 at [123]; Transcript, Toni Mitchell, Public Hearing 4, 19 February 2020, P-145 [32]–[37]; Exhibit 4-15, 'Statement of Sabrina Monaghan', 12 February 2020 at [150].

concern that intellectual disability is optional learning for health professionals, and suggested that training in this area be made mandatory.<sup>991</sup>

412. These views were shared by Dr Small who said that further skills and knowledge enhancement is needed to provide high level specialised care for people with intellectual disability.<sup>992</sup> She said that there is insufficient inclusion in specialty and general practice curricula of relevant modules about intellectual and developmental disability.<sup>993</sup> She was not aware of any training programs or opportunities for general medicine physicians who have an interest in training in this area.<sup>994</sup>
413. As discussed above in the outline of Mr Simpson's evidence, in 2017 the NSW Agency for Clinical Innovation Intellectual Disability Network published *The Essentials* guide.<sup>995</sup> Dr Small told the Royal Commission that this harnessed together a range of useful resources, tools and information including from people with cognitive disability, to assist and support health professionals to improve health care, training and skills.<sup>996</sup> The lack of implementation of *The Essentials* was a matter of evidence before the Royal Commission.
414. Several witnesses gave evidence that better education and training should be embedded at all levels of theoretical study and clinical practice, from undergraduate study to practical training to continuing professional development. Some witnesses said that education and training should apply to all of the health profession, from clerical and administrative staff to clinical health professionals.
415. Dr Singer explained that there are effectively four phases where education and training can be embedded for health professionals: undergraduate training; prevocational training; vocational training; and continuing professional development.<sup>997</sup>
416. The first phase where education and training can be embedded is through undergraduate training in medical and nursing schools. Professor Trollor told the Royal Commission that training is an important 'opportunity to shape attitudes, teach skills and provide direct experiential learning with people with intellectual and other developmental disabilities'.<sup>998</sup>

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<sup>991</sup> Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020 at [101].

<sup>992</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-245 [4]–[25].

<sup>993</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [34].

<sup>994</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-245 [16]–[18].

<sup>995</sup> Exhibit 4-64, EXP.0014.0001.0096.

<sup>996</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-228 [7]–[17].

<sup>997</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [5]–[19].

<sup>998</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [234].

417. Professor Trollor and Professor Lennox gave evidence that national audits that have been conducted of the curricula at undergraduate medical and nursing schools found that there was limited content in relation to the specific health care needs of people with intellectual disability.<sup>999</sup> Professor Lennox stated that two audits revealed about 2.5 hours of education at medical schools and that fewer than half of nursing courses included units of study on intellectual disability and health care.<sup>1000</sup> Professor Trollor said that this meant that the majority of future nurses and doctors will graduate with inadequate or no understanding of the specific health care needs of people with intellectual disability.<sup>1001</sup>
418. Dr Small, Dr Avery, Ms Mills and Dr AAJ also emphasised the importance of education at the undergraduate phase to better address the needs of people with cognitive disability.<sup>1002</sup> Dr AAJ said that the education provided to doctors and nurses requires an overhaul,<sup>1003</sup> and Dr Avery said that medical and health training curricula should respond to social and other prejudicial influences in health care outcomes for people with cognitive disability.<sup>1004</sup> Dr Zylan told the Royal Commission that such education and training should also be made mandatory in undergraduate dentistry courses.<sup>1005</sup>
419. The Royal Commission heard that Commonwealth Health has identified the redevelopment of curricula and initiatives at the undergraduate phase of medical education as a key element in the Draft Roadmap.<sup>1006</sup>
420. In September 2019, the Commonwealth Minister for Health wrote to the Medical Deans, Council of Deans of Nursing and Midwifery and other stakeholders seeking engagement on curriculum development to increase the level of specific dedicated content relating to health care and treatment of people with intellectual disability in undergraduate education and training.<sup>1007</sup> The Medical Deans, Council of Deans of

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<sup>999</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [235]–[236]; Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [61]–[62].

<sup>1000</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [61]–[62].

<sup>1001</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [236].

<sup>1002</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [116]; Exhibit 4-18, 'Statement of Dr Scott Avery', 14 February 2020 at [69]; Exhibit 4-19, 'Statement of Jaqueline Terri Mills', 12 February 2020 at [177]; Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [65].

<sup>1003</sup> Exhibit 4-24, 'Statement of AAJ', 8 February 2020 at [65].

<sup>1004</sup> Exhibit 4-18, 'Statement of Dr Scott Avery', 14 February 2020 at [69].

<sup>1005</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-401 [36]–[40].

<sup>1006</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0177.

<sup>1007</sup> Exhibit 4-237, CTD.0001.1000.0029; Exhibit 4-238, CTD.0001.1000.0031; Exhibit 4-239, CTD.0001.1000.0033; Exhibit 4-240, CTD.0001.1000.0035.

Nursing and Midwifery and other stakeholders all expressed willingness to be involved.<sup>1008</sup>

421. Professor Trollor said that while he acknowledges this support at the Commonwealth level, ‘no timeline, process or funding has been assigned’.<sup>1009</sup> He stated that mandated training for all medical and nursing students should be developed and implemented as soon as possible, and that minimum capacities in intellectual disability knowledge and skills should be included in future revisions of the standards set by the Medical and Nursing and Midwifery Councils.<sup>1010</sup>
422. The second and third phases are prevocational and vocational training. Dr Singer said that prevocational training encompasses junior doctors who are in their early postgraduate years predominantly working in hospitals. He said that for most doctors in this phase, the theoretical knowledge they learnt is turned into practical effect.<sup>1011</sup> The vocational training phase, according to Dr Singer, involves training towards one of the specialty qualifications available. Dr Singer said that completion of specialty qualifications leads to fellowship of one of the medical colleges, which qualifies them for specialist registration.<sup>1012</sup>
423. Dr Singer said that the education and training in the vocational phase includes the development of skills every doctor is expected to have, and the development of a deeper level of knowledge for those doctors who have a special interest.<sup>1013</sup>
424. Dr Small said that during the vocational training phase of her career she did not receive specific training on intellectual disability.<sup>1014</sup> However, she said that today there is a very reasonable expectation that all health practitioners should have a baseline level of skills, knowledge and awareness of the health needs of people with intellectual disability.<sup>1015</sup>
425. Professor Leeder said that there is value in investing in education and training efforts in both these phases.<sup>1016</sup> Professor Lennox said that embedding education

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<sup>1008</sup> Exhibit 4-241, CTD.0001.1000.0037; Exhibit 4-242, CTD.0001.1000.0043; Exhibit 4-243, CTD.0001.1000.0071.

<sup>1009</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [238].

<sup>1010</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [239].

<sup>1011</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [10]–[13].

<sup>1012</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [13]–[16].

<sup>1013</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [28]–[34].

<sup>1014</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-237 [3]–[4].

<sup>1015</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-237 [6]–[9].

<sup>1016</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020, P-161 [34] – P-162 [6].

within the context of everyday clinical practice while the practitioner is consulting with the patient would be more likely to change practitioner behaviour.<sup>1017</sup>

426. Professor Trollor shared a similar view and suggested there be mandatory training for all clinical and non-clinical professionals. He stated that all staff in public facilities should undertake mandatory minimum basic training to ensure they adopt appropriate attitudes and know how to adjust their practice to meet the needs of people with disability.<sup>1018</sup> Professor Trollor suggested that this could be incorporated as a component of existing mandatory training in public and community health system settings.<sup>1019</sup>
427. Professor Trollor also suggested specific training in some 'clinical compartments' such as emergency departments and acute in-patient settings for staff who frequently encounter people with intellectual disability.<sup>1020</sup> He proposed that training be based on an overarching national framework and that it should be tiered in complexity depending on the role of the staff member.<sup>1021</sup> He further suggested that specific medical specialty groups, such as general practitioners, paediatricians, psychiatrists, rehabilitation and emergency physicians, should receive enhanced training.<sup>1022</sup>
428. Some experts told the Royal Commission that programs of continuing education should incorporate content regarding cognitive disability and that this should be mandatory. Professor Leeder gave evidence that many large teaching hospitals have sophisticated programs of continuing education which could incorporate treatment of people with various disabilities.<sup>1023</sup> Dr Zylan said that for dental practitioners, while there is no current component of continuing professional education that addresses the needs of people with cognitive disability, there should be scope to embed this as a compulsory component.<sup>1024</sup>
429. Dr Singer said that education and training does not have to be radically different between one phase and another.<sup>1025</sup> He encouraged 'appropriately-created learning modules' that apply to all phases and which provide learning and encourage practitioners to evaluate and change their own attitudes 'in the right

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<sup>1017</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [59].

<sup>1018</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [241].

<sup>1019</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [241].

<sup>1020</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [242].

<sup>1021</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [242]–[243].

<sup>1022</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [244]–[246].

<sup>1023</sup> Transcript, Professor Stephen Leeder, Public Hearing 4, 20 February 2020 P-162 [4]–[6].

<sup>1024</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-408 [17]–[30].

<sup>1025</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [36]–[37].

direction'.<sup>1026</sup> He said that the design of modules is a matter for each individual organisation.<sup>1027</sup>

430. During his oral evidence, Professor Trollor supported the proposal that the Royal Commission should look specifically at training on a national basis across all health disciplines and address the need for funding.<sup>1028</sup> He said it would be 'enormously helpful to accelerate progress', but that the development of relevant curriculum tools should be trialled before a full-scale implementation.<sup>1029</sup>
431. Professor Lennox said that while development of relevant curricula in the Draft Roadmap heads in the right direction,<sup>1030</sup> it should not be done for the 'sake of doing education' that ultimately goes nowhere.<sup>1031</sup> He said that there has to be some real rigour because of limited funding and appropriate evaluations to make sure curriculum development is effective.<sup>1032</sup>
432. Dr Singer stated that, as far as training and curriculum development for health professionals is concerned, the Commonwealth government does not currently provide any specific funding in relation to training around intellectual disability.<sup>1033</sup> He agreed that any initiatives in training will necessarily require the participation and cooperation of the states and territories, together with medical schools and relevant colleges, if the initiatives are to be successful.<sup>1034</sup> Mr Cotterell said that this is to be discussed at the second Roundtable.<sup>1035</sup> He also emphasised that the Commonwealth Minister for Health has written to relevant bodies including the Medical Deans of Australia and New Zealand, the Council of Deans of Nursing and Midwifery and the Australian Medical Council, seeking to engage with them about curriculum development.<sup>1036</sup> Further, the Chief Medical Officer has invited the Council of Presidents of Medical Colleges to engage with the Department and other relevant bodies to enhance medical education and training in the health care and treatment of people with intellectual disability.<sup>1037</sup>

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<sup>1026</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-774 [37]–[41].

<sup>1027</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-775 [6]–[7].

<sup>1028</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-213 [17]–[33].

<sup>1029</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-213 [17]–[33].

<sup>1030</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [68].

<sup>1031</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-566 [19]–[23].

<sup>1032</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-566 [23]–[26].

<sup>1033</sup> Transcript, Dr Andrew Singer, Public Hearing 4, 27 February 2020, P-776 [11]–[13].

<sup>1034</sup> As well as nursing and allied health schools at universities, as the case may be: Transcript, Dr Singer, Public Hearing 4, 27 February 2020, P-776 [14]–[18].

<sup>1035</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-777 [33]–[37].

<sup>1036</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [19].

<sup>1037</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [21].

## Collection of data and research

433. During Public hearing 4, the Royal Commission heard evidence about the importance of data collection and research into the health of people with cognitive disability: to expose disparities in health outcomes and highlight population health needs; to assist governments; to equip advocates with a foundation for their advocacy;<sup>1038</sup> and to design and evaluate health services and policy.<sup>1039</sup> As noted by Professor Trollor, data also confirms the lived experience of people with cognitive disability such as those whose stories were heard during the course of the public hearing.<sup>1040</sup>
434. The Royal Commission commends the State of NSW for establishing the Chair in Intellectual Disability Mental Health in 2009, as described by Dr Lyons of NSW Health and Professor Trollor. Dr Lyons acknowledged the valuable role played by that position and several witnesses described the importance of the research work being conducted by Professor Trollor and his team and the need for ongoing funding for that and similar research elsewhere.<sup>1041</sup>
435. Despite many years of valuable research projects, the Royal Commission heard accounts from witnesses in Public hearing 4 about the scarcity of appropriately funded, targeted, comprehensive, and reliable research in Australia into the health of people with intellectual disability<sup>1042</sup> and people on the autism spectrum. Evidence suggests that these deficiencies in research and data may be attributed to the exclusion of people with cognitive disability from population health surveys,<sup>1043</sup> gaps in tracking and publishing data, insufficient funding,<sup>1044</sup> and disconnected datasets held in various repositories.<sup>1045</sup>

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<sup>1038</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [92]; Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [77].

<sup>1039</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [77].

<sup>1040</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-206 [11]–[15].

<sup>1041</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-750 [7]–[11].

<sup>1042</sup> By way of example, on the topic of the interaction between the low dose contraceptive pill and strokes in women with Down syndrome: Exhibit 4-11, 'Statement of Christine Regan', 13 February 2020, at [95]; Transcript, Christine Regan, Public Hearing 4, 21 February 2020, P-278 [4]–[34]. On the topic of the lack of data on the prevalence of Alzheimer's or dementia in people with Down syndrome: Exhibit 4-12, 'Statement of Lorraine Gaye Clark', 12 February 2020, at [101]; Transcript, Lorraine Clark, Public Hearing 4, 21 February 2020, P-311 [11]–[37].

<sup>1043</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020, at [40]; Exhibit 4-16, SUB.100.00532.0001 at 0002–0003.

<sup>1044</sup> Transcript, Dr Richard Zylan and Nathan Despott, Public Hearing 4, 24 February 2020, P-394 [32]–[36].

<sup>1045</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-170 [22]–[25].

436. The Royal Commission heard about the need for comprehensive national data collection.<sup>1046</sup> In his expert evidence, Professor Trollor stated:

*To date, exposure of health outcomes has largely been left to the research community. However, there are multiple barriers, very large costs and significant time delay in the creation of the necessary data linkage infrastructure when undertaking such research.*<sup>1047</sup>

437. Evidence from Professor Trollor outlined the present limitations in Australian data relating to the prevalence of physical and psychiatric comorbidities experienced by people with intellectual disability<sup>1048</sup> and people on the autism spectrum.<sup>1049</sup> Dr Zylan and Mr Despott similarly noted that there is no reliable national data in relation to the oral health of people with intellectual disability.<sup>1050</sup> Further, where data is collected, they said it is not given as much weight as required given the small data sets used.<sup>1051</sup> Professor Trollor also stated that research on the health of people with intellectual disability and people on the autism spectrum is often ‘undervalued, making it difficult to compete for competitive funding from major organisations.’<sup>1052</sup> In addition, Dr Avery stated that there are very few acknowledgments in government about the statistical profile of Aboriginal people with disability.<sup>1053</sup>
438. In his oral evidence, Professor Trollor explained the difficulty with disconnected data systems in the following manner:

*The difficulty is, I think, linking all of the information systems together to ensure we capture all people with disabilities of different types, because they’re represented variously – often enter into data systems because they’re receiving a specific service from that funding body.*

*We know from [the Department of Developmental Disability Neuropsychiatry at the University of NSW] linkage that it was only when we put eight different datasets together that we came up with what we thought was a near population capture of people with intellectual disability receiving services of some sort ... [I]f we had just relied on one of those datasets ... we would have*

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<sup>1046</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [136]; Exhibit 4-19, ‘Statement of Jacqueline Terri Mills’, 12 February 2020 at [181]–[182].

<sup>1047</sup> Exhibit 4-9, Statement of Professor Julian Trollor, 11 February 2020 at [256].

<sup>1048</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [55], [83], [90], [277].

<sup>1049</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [43], [48], [53], [66], [87], [90], [163], [277].

<sup>1050</sup> Exhibit 4-16, SUB.100.00532.0001 at 0002–0003.

<sup>1051</sup> Transcript, Dr Richard Zylan, Public Hearing 4, 24 February 2020, P-394 [30] – P-395 [11].

<sup>1052</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [278].

<sup>1053</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-456 [35]–[37].

*concluded very limited representation of people with intellectual disability in New South Wales.*<sup>1054</sup>

439. One data linkage project was undertaken by Dr Avery, who gave evidence that he needed to ‘pool’ together disability data and Aboriginal data,<sup>1055</sup> using a mixed methodology approach which included both qualitative data and stories through ‘yarning pieces’ which describe human experience,<sup>1056</sup> drawing together many themes into a single person’s story.<sup>1057</sup> Dr Avery described this as coupling a statistical profile with the personal, a process which meant human impact and data validated one another.<sup>1058</sup>
440. Dr Lyons acknowledged limitations in data collection in the State of NSW. As noted above in the outline of his evidence, Dr Lyons told the Royal Commission that a lack of system-wide data identifying patients with cognitive disability<sup>1059</sup> presents a challenge in assessing the care provided to people with cognitive disability and for planning and developing specific policies which are appropriately targeted to the health care needs of people with cognitive disability.<sup>1060</sup>
441. The Draft Roadmap to improve health services for people with intellectual disability that is being developed by Commonwealth Health in collaboration with various experts and advocacy groups recognises that research, data and measurement ‘will also be a key platform for tracking the health outcomes of people with intellectual disability, and assessing the efficacy of initiatives to improve them’.<sup>1061</sup> Among other things, it recommends the building of a national data asset on the health of people with intellectual disability.<sup>1062</sup> When asked about this element of the Draft Roadmap during the hearing, the witnesses from Commonwealth Health told the Royal Commission that this was an area discussed ‘very briefly’ at the August 2019 Roundtable and that it requires further development.<sup>1063</sup> They also said that there were ‘tensions and trade-offs around collecting data’ and noted that the Australian Institute of Health and Welfare is tasked with collecting a national disability data asset.<sup>1064</sup>

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<sup>1054</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-207 [26]–[36].

<sup>1055</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-457 [17]–[20].

<sup>1056</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-457 [28]–[32].

<sup>1057</sup> Exhibit 4-18, ‘Statement of Dr Scott Avery’, 14 February 2020 at [28]–[30].

<sup>1058</sup> Transcript, Dr Scott Avery, Public Hearing 4, 24 February 2020, P-456 [40]–[42].

<sup>1059</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-737 [34]–[35].

<sup>1060</sup> Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-738 [25] – P-740 [12].

<sup>1061</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0178.

<sup>1062</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0178.

<sup>1063</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-779 [7]–[8].

<sup>1064</sup> Transcript, Tania Rishniw, Public Hearing 4, 27 February 2020, P-779 [23]–[30].

442. The Royal Commission also heard from Professor Trollor that despite research attention and publication of data highlighting substantial disparities in health outcomes, the life expectancy of people with cognitive disability has not significantly improved,<sup>1065</sup> a matter which he describes as cause for significant concern and ‘speaks to an ongoing critical neglect of the health care needs of this group of Australians.’<sup>1066</sup>
443. Professor Trollor described the data linkage research undertaken by the Department of Developmental Disability Neuropsychiatry at the University of NSW in 2017 which found a stark disparity between the life expectancy of people with cognitive disability and the general population. This research also found that a high proportion of ‘excess mortality among people with intellectual disability and autistic populations is potentially avoidable.’<sup>1067</sup> Professor Trollor gave evidence that, based on his extrapolation from NSW data, there are approximately 400 people with intellectual disability over the age of 20 who die in Australia each year and whose deaths are preventable.<sup>1068</sup> However, he stated that there has been a limited amount of research examining the cause of death among people with intellectual disability or among autistic populations in Australia to date,<sup>1069</sup> as well as a lack of consistent method for tracking and publishing mortality data,<sup>1070</sup> which would detect gaps in care and care pathways, and direct future health care spending.<sup>1071</sup> He also described existing gaps in tracking and publishing mortality data, including through the National Australian Coronial Information System,<sup>1072</sup> through varying state regimes<sup>1073</sup> and through the reportable deaths function of the NDIS Commission.<sup>1074</sup>
444. The Royal Commission also heard from the NDIS Commissioner about the data collected by the NDIS Commission through its reportable incidents function.<sup>1075</sup> Reportable deaths data is only collected by the NDIS Commission where a death has occurred or is alleged to have occurred in connection with the provision of supports or services by a registered NDIS provider, and involve an act or omission

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<sup>1065</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [177].

<sup>1066</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [178].

<sup>1067</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [195].

<sup>1068</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-214 [31] – P-215 [1].

<sup>1069</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [189].

<sup>1070</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [198].

<sup>1071</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020, at [291].

<sup>1072</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [198]–[199], [299]; Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-207 [3] – P-208 [21].

<sup>1073</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [200]–[206].

<sup>1074</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [293]–[297];

Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-199 [8] – P-200 [26].

<sup>1075</sup> Exhibit 4-32, ‘Statement of Graeme Head AO’, 11 February 2020 at [95], [222]–[233].

defined in section 73Z(4) of the *National Disability Insurance Scheme Act 2013* (Cth). Professor Trollor gave evidence that defining reportable deaths in this manner poses significant limitations in collating, analysing, and understanding deaths.<sup>1076</sup> As noted above in the outline of his evidence, Mr Head acknowledged the limitations of this NDIS Commission function in how it presently collects national mortality data.<sup>1077</sup>

## Initiatives to improve health care

*My sense is what we need at the very highest levels is a whole of government response that helps drive some of these good ideas. There's plenty of ideas. There's known solutions to the problems.*<sup>1078</sup> (Professor Julian Trollor)

445. As discussed above, the health disparities between people with cognitive disability and the general population are well documented in both the research literature and health policy. These disparities have been known in empirical data since at least 1995.<sup>1079</sup>
446. The Royal Commission received evidence of recent or planned initiatives by both NSW and Commonwealth government health departments to address the large gaps in health outcomes and the capacity of health care professionals and systems to respond to the needs of people with intellectual disability in particular. This included evidence from representatives of the respective health departments about expected timeframes for and manner of implementation of the main initiatives.
447. In their responses to the Counsel Assisting's Submissions, the Commonwealth and the State of NSW both emphasise these recent initiatives. NSW argues that the existence of these initiatives demonstrates that people with cognitive disability are not currently neglected in the NSW health system and lists the favourable evidence from some of the witnesses at the hearing about them. These arguments are addressed further below.

## NSW initiatives

448. Mr Simpson told the Royal Commission that it is important to acknowledge that there have been 'some good steps forward' in recent years with respect to health care and services for people with intellectual disability in NSW.<sup>1080</sup> However, he

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<sup>1076</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor, 11 February 2020, at [295].

<sup>1077</sup> Transcript, Graeme Head, Public Hearing 4, 27 February 2020, P-806 at [33] – P-808 at [8].

<sup>1078</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-205 [35]–[37].

<sup>1079</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [33].

<sup>1080</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-512 [31].

also said that ‘there is just so much more that needs to happen’.<sup>1081</sup> Professor Lennox described NSW as ‘leading the pack’ at the present time in relation to state-level initiatives to improve health care for people with intellectual disability.<sup>1082</sup>

449. As outlined above, during his evidence Dr Lyons was asked about implementation of *The Essentials* framework developed by the Intellectual Disability Network of the NSW Agency for Clinical Innovation (**ACI**). In its written response to questions taken on notice at Public hearing 4 by Dr Lyons, NSW Health stated that this is not mandatory NSW health policy, but rather was developed by the ACI to support people with intellectual disability to access health services in NSW and to build the system’s capacity for providing high quality care to people with intellectual disability.<sup>1083</sup> NSW Health informed the Royal Commission that data on the use of *The Essentials* is not collected at a state-wide level. However, it said that *The Essentials* has been presented, demonstrated and discussed at many levels, including at the LHD level, and other external provider forums such as PHNs and disability service providers, and that some LHDs have linked *The Essentials*, and particular resources within it, to their own websites.<sup>1084</sup>
450. Dr Small described *The Essentials* as a unique set of resources in Australia that provides training resources, skills-based resources and information to support health professionals in caring for people with intellectual disability, as well as a self-assessment tool which LHDs could use to evaluate how effective they are at supporting people with intellectual disability.<sup>1085</sup> She also said that there are currently efforts to extend *The Essentials* to national application.<sup>1086</sup> However, as described above, Mr Simpson told the Royal Commission that he was not aware of any robust action to implement *The Essentials* across LHDs in NSW.<sup>1087</sup> Among the ‘immediate priorities for action’ suggested by Mr Simpson in his witness statement was full implementation of *The Essentials* in NSW and that ‘other states and territories should similarly take comprehensive action to enhance their health services’ response to people with intellectual disability.’<sup>1088</sup>
451. Recognising that people with intellectual disability have poorer health outcomes and greater difficulty obtaining health services when compared to the general population, NSW Health has had a ‘Service Framework to Improve the Health

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<sup>1081</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-512 [34].

<sup>1082</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-556 [22]–[23].

<sup>1083</sup> Exhibit 4-453, NSW.9999.0004.0003 at 0009.

<sup>1084</sup> Exhibit 4-453, NSW.9999.0004.0003 at 0009–0010.

<sup>1085</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-228 [7] – P-230 [30].

<sup>1086</sup> Exhibit 4-10, ‘Statement of Dr Jacqueline Small’, 12 February 2020 at [21].

<sup>1087</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [45].

<sup>1088</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [137.2].

Care of People with Intellectual Disability' since July 2012 for reducing these health inequalities.<sup>1089</sup> Mr Simpson described the Service Framework as 'an illustration of how we at times have been able to work really collaboratively with government in developing strategies for action.'<sup>1090</sup> In his statement to the Royal Commission and written responses to questions taken on notice during Public hearing 4, Dr Lyons described how three new specialist intellectual disability health teams for patients with 'complex and chronic health conditions'<sup>1091</sup> were funded on a recurrent basis in the 2018-2019 budget and are in the process of being established. These additional three teams build upon three pilot teams previously set up in accordance with the Service Framework.<sup>1092</sup>

452. Dr Small told the Royal Commission that she expects that referrals will be made to her specialist intellectual disability health team from the hospitals and primary health care providers in her LHDs.<sup>1093</sup> Dr Small also explained that the team is yet to determine how patients will be prioritised and how to capture unmet needs, which she anticipates being substantial.<sup>1094</sup> She said that her team expected to commence seeing patients in late April 2020.<sup>1095</sup>
453. Dr Small said that one area of current uncertainty is how well other parts of the health system will be able to continue to care for people with complex and chronic health care needs who are to be provided with only a single assessment and short term follow-up care by the new multidisciplinary specialist teams.<sup>1096</sup> She said that her team is seeking to build capacity, including by building relationships with PHNs, delivering training sessions to GPs and increasing the skills of mainstream health professionals through supportive work and the provision of tools.<sup>1097</sup>
454. Dr Small expressed the view that the small but significant injection of new funds to establish these specialised teams for intellectual disability has already had a positive impact in NSW.<sup>1098</sup> She said that while still at an early stage, the work has drawn in mainstream health professionals and embedded accountability at the highest levels for improving the health of people with intellectual disability.<sup>1099</sup> She

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<sup>1089</sup> Exhibit 4-86, EXP.0014.0004.0231.

<sup>1090</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-524 [31]–[33].

<sup>1091</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020 at [25].

<sup>1092</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020 at [14]–[29]; Exhibit 4-453, NSW.9999.0004.0003 at 00005–0006.

<sup>1093</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-227 [8]–[16].

<sup>1094</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-227 [8]–[16].

<sup>1095</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-225 [30]–[31].

<sup>1096</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-225 [15] – P-226 [31].

<sup>1097</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-226 [15]–[31].

<sup>1098</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-231 [10]–[32].

<sup>1099</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-231 [18]–[20].

highlighted that the teams are still being established and that their work must be reported against indicators to ensure that the model leads to meaningful outcomes and a reduction in avoidable health gaps experienced by people with intellectual disability.<sup>1100</sup>

455. Mr Simpson stated that while there would be an evaluation of the specialist intellectual disability health teams by NSW Health, he could ‘confidently predict’ that CID would be advocating strongly for an extension to their funding and for their implementation in all 15 LHDs in NSW.<sup>1101</sup> He stated that other states and territories should fund specialised intellectual disability health teams consistent with the network established in NSW.<sup>1102</sup>
456. Professor Trollor also said that access to specialist intellectual disability health services in Australia varies substantially across jurisdictions. He noted that they are most developed in NSW and that where such services do exist, they form a valuable component of comprehensive health services for people with intellectual disability.<sup>1103</sup> Professor Lennox said that the NSW initiatives have ‘picked up the need for increasing actual physical services’ for people with intellectual disability, which are accessible and can provide specialist care.<sup>1104</sup> He noted, however, that there is a risk that specialist services may be focussed upon large metropolitan centres, and less on rural and regional areas.<sup>1105</sup>
457. Dr Lyons told the Royal Commission that NSW Health is also in the process of establishing two state-wide tertiary intellectual disability and mental health hubs, in response to the recommendations of a 2014 report from the NSW Mental Health Commission, titled *Living Well: a Strategic Plan for Mental Health in NSW 2014-2024*.<sup>1106</sup> Mr Simpson commented that it was ‘refreshing’ that this plan specifically covered people with intellectual disability.<sup>1107</sup> However, he said that while there has been some progress in relation to mental health care for people with intellectual disability in NSW there has been ‘nowhere near the full implementation’ of the actions set out in the strategic plan.<sup>1108</sup> In particular, he noted that there had not been concerted action to implement the *Accessible Mental Health Services for*

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<sup>1100</sup> Transcript, Dr Jacqueline Small, Public Hearing 4, 20 February 2020, P-231 [22]–[25].

<sup>1101</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-526 [22]–[28].

<sup>1102</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [137.1].

<sup>1103</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [231].

<sup>1104</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-555 [29]–[31].

<sup>1105</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-556 [24]–[35].

<sup>1106</sup> Exhibit 4-28, ‘Second Statement of Dr Nigel Lyons’, 13 February 2020 at [30]–[96]; Exhibit 4-111, EXP.0016.0001.0960.

<sup>1107</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-532 [27].

<sup>1108</sup> Transcript, James Simpson, Public Hearing 4, 25 February 2020, P-533 [12].

*People with an Intellectual Disability: A Guide for Providers*<sup>1109</sup> written by Professor Trollor, nor 'universal training in intellectual disability mental health'.<sup>1110</sup>

458. During his evidence, Professor Trollor commented that the Guide:

*provides some useful recommendations. But like many documents that are developed with good intent, it tends to be relegated to a shelf after several years. And I think the actual implementation part of it was, really, never funded.*<sup>1111</sup>

When asked where funding for the implementation of the recommendations would come from, Professor Trollor stated that it should be Commonwealth Health.<sup>1112</sup>

459. Another initiative first funded by the NSW government in 2009 was the creation of the Chair in Intellectual Disability Mental Health, a position which is held by Professor Trollor at the University of New South Wales.<sup>1113</sup> According to Professor Trollor, the Ageing, Disability and Home Care part of the then Department of Family and Community Services 'recognised a gap between health, particularly mental health, and the disability sector and thought that we needed to develop a response to that that involved equipping of a workforce and upskilling practitioners in the area and developing a bridge between disability and health.'<sup>1114</sup> When asked about similar initiatives in other states, he said that there was no equivalent, although there had been good initiatives in Queensland and Victoria. He expressed the view that in the three states with these initiatives, there is a 'spin-off', meaning 'more of a focus in health policy and in health services development'.<sup>1115</sup>

460. Professor Trollor agreed that a national body should be established and suggested that this could act as a 'clearing house of resources in this area that enables practitioners to be properly equipped to do a good job.'<sup>1116</sup> He also recommended that this national training centre and resource clearing house could produce training materials for nursing and medical schools and provide some consultation and input into policy and services development and service models.<sup>1117</sup> He noted that such a national body had been recommended previously, in the Communiqué

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<sup>1109</sup> Exhibit 4-56, EXP.0015.0002.0605.

<sup>1110</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [51].

<sup>1111</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-209 [32]–[35].

<sup>1112</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-210 [20]–[21].

<sup>1113</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020 at [97].

<sup>1114</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-204 [10]–[14].

<sup>1115</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-204 [29]–[37].

<sup>1116</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-205 [5]–[6].

<sup>1117</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-205 [6]–[11].

issued following the National Roundtable on the Mental Health of People with Intellectual Disability held in 2018.<sup>1118</sup>

### Commonwealth initiatives

461. Mr Simpson told the Royal Commission that the ‘whole mainstream health system’ in Australia needs to lift its capacity to respond appropriately to people with intellectual disability.<sup>1119</sup> This should occur at the same time as a network of specialised intellectual disability health services is created, as has begun in NSW.<sup>1120</sup> CID hoped that the adoption of the National Disability Strategy in 2011 would be a key driver of improved health care for people with intellectual disability, but Mr Simpson said that they saw little evidence of this being so.<sup>1121</sup>
462. Professor Trollor said that while national advocacy efforts have been made for many years, through groups like CID, the government response, although sympathetic and understanding, has been one of incremental and slow steps, whereas what is needed is fast-paced reform.<sup>1122</sup> He suggested that a common issue is that ‘people are prepared to do something but not prepared to take a step back and look at the population health needs and make strong recommendations and act’.<sup>1123</sup>
463. Mr Simpson told the Royal Commission how, in the lead up to the 2019 federal election, CID worked together with Inclusion Australia and in collaboration with Professor Trollor, Dr Small and others to develop its ‘Our Health Counts’ campaign.<sup>1124</sup> As part of this campaign, CID produced a detailed and costed proposal and sought commitments from various political parties as to its implementation.<sup>1125</sup> The Commonwealth Minister for Health directed his department to work with CID on planning a National Roundtable to address the issue, and this took place in August 2019.<sup>1126</sup>
464. MrCotterell of Commonwealth Health provided detailed evidence about the Roundtable and resulting Draft Roadmap.<sup>1127</sup> He said that a second Roundtable

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<sup>1118</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [254].

<sup>1119</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [15].

<sup>1120</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [15].

<sup>1121</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [26].

<sup>1122</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-212 [22]–[24].

<sup>1123</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-212 [25]–[27].

<sup>1124</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [91]–[93].

<sup>1125</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [96]–[98]; Exhibit 4-128, EXP.0016.001.0941.

<sup>1126</sup> Exhibit 4-20, ‘Statement of James Simpson’, 12 February 2020 at [99]–[100].

<sup>1127</sup> Exhibit 4-31, ‘Statement of Simon Brook Cotterell’, 5 February 2020 at [13]–[18]; Transcript, Tania Rishniw, Dr Andrew Singer and Simon Cotterell, Public Hearing 4, 27 February 2020, P-758–782.

was planned to further develop the Draft Roadmap, and that state and territory government representatives had been invited to attend.<sup>1128</sup>

465. The 'key elements' of the Draft Roadmap resulting from the 2019 Roundtable are: A. Better models of care for people with intellectual disability and their families; B. Better support for health care professionals to provide better care for people with intellectual disability; and C. Research, data and measurement to support continuing improvement.<sup>1129</sup> These are further divided into specific elements marked as 'short term' (1-2 years), 'medium term' (3-5 years) and 'long term' (6-10 years).<sup>1130</sup> These include matters such as better use of MBS items, better care coordination and integration within the health system, curriculum development in medical and nursing schools, a Primary Care Enhancement Program and a national network of Centres of Excellence on intellectual disability.<sup>1131</sup> Mr Cotterell gave evidence that decisions about funding of the elements of the Roadmap are future decisions for the Commonwealth, state and territory governments and relevant non-government organisations.<sup>1132</sup> As noted above, during the hearing the Minister for Health made an announcement that \$6.5 million had been allocated over four years to fund the PCEP.<sup>1133</sup>
466. Mr Cotterell emphasised the draft nature of the Roadmap and said that the timeframes for some of the elements were 'based on instinct or the best guess at the time' of the 2019 Roundtable.<sup>1134</sup> For example, putting the development of a network of Centres of Excellence into the long-term category was because such centres are currently funded by the states, only some states fund them and no state was represented at the first Roundtable.<sup>1135</sup> Ms Rishniw, also of Commonwealth Health, said that it would not be recommending that the Commonwealth fund its own Centres of Excellence, nor wish to duplicate already existing infrastructure and expertise funded by the states, if state-funded Centres of Excellence already exist and are successful and robust.<sup>1136</sup>
467. Professor Trollor told the Royal Commission that he was very supportive of the development of the Draft Roadmap but expressed the view that there is a gulf

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<sup>1128</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [15].

<sup>1129</sup> Exhibit 4-130, EXP.0016.0001.1106 at 1106.

<sup>1130</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0176.

<sup>1131</sup> Exhibit 4-68, EXP.0014.0001.0168 at 0176–0179.

<sup>1132</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [16]; Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-763 [11]–[34].

<sup>1133</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-763 [11]–[34].

<sup>1134</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-764 [30]–[32].

<sup>1135</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-765 [3]–[10].

<sup>1136</sup> Transcript, Tania Rishniw, Public Hearing 4, 27 February 2020, P-766 [17]–[25]; Exhibit 4-29, 'Statement of Tania Rishniw', 5 February 2020 at [83].

between what needs to be done and what is currently on the plan to be done.<sup>1137</sup> He also said that the timeframe for the implementation of its elements is inadequate.<sup>1138</sup> Professor Lennox gave evidence that he is similarly concerned that the Draft Roadmap does not respond urgently enough to the deficits in health care and systemic shortcomings in the health and disability systems.<sup>1139</sup> In his view, the initiatives set out in the Draft Roadmap can be achieved much more rapidly than 10 years.<sup>1140</sup>

468. When asked why the Draft Roadmap makes no reference to dental services for people with intellectual disability, Mr Cotterell stated that this also requires both Commonwealth and state government cooperation, given their shared responsibilities in this area.<sup>1141</sup> He gave evidence that the Commonwealth provides two streams of funding for public dental services delivered by the states and territories.<sup>1142</sup> He agreed that Commonwealth Health needs to look at this issue as an important area of preventative health and said that the Australian Dental Association has been invited to the second Roundtable.<sup>1143</sup>
469. Mr Cotterell also described the Commonwealth Health 10 Year Plan, which he said is under development and on track to be completed by September 2020.<sup>1144</sup> Mr Cotterell stated that development of this 10 Year Plan has involved extensive consultation involving a group comprising 90 or more stakeholder organisations, a public discussion paper process and a series of targeted consultations in the health system.<sup>1145</sup> He agreed that the 10 Year Plan is intended to be a plan for primary health care in all areas of health. He said further that the 10 Year Plan is intended to address the interactions of primary health systems with other parts of the health system including public hospitals and mental health services, and social support systems including the aged care system, the NDIS and other disability supports.<sup>1146</sup>
470. According to Mr Cotterell, the 10 Year Plan and the Draft Roadmap are intended to work together.<sup>1147</sup> Importantly, however, Mr Cotterell informed the Royal Commission that the Draft Roadmap is not restricted to primary health care and is

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<sup>1137</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-212 [40] – P-213 [1].

<sup>1138</sup> Transcript, Professor Julian Trollor, Public Hearing 4, 20 February 2020, P-213 [1]–[2].

<sup>1139</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-557 [25]–[26].

<sup>1140</sup> Transcript, Professor Nicholas Lennox, Public Hearing 4, 25 February 2020, P-557 [21]–[22].

<sup>1141</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-780 [3]–[4].

<sup>1142</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-778 [4]–[5].

<sup>1143</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-780 [5]–[11].

<sup>1144</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-758 [3]–[4].

<sup>1145</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-758 [4]–[9].

<sup>1146</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-758 [10]–[21].

<sup>1147</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-758 [35].

capable of addressing the health needs of people with intellectual disability in the public hospital setting and other areas not traditionally falling under primary health care.<sup>1148</sup>

471. We understand that the outbreak of the COVID-19 pandemic has required the postponement of the second Roundtable intended to finalise the Roadmap. The pandemic has undoubtedly impacted the work of all government departments and agencies, as well as that of non-government entities, and has required a redirection of resources. However, as observed by Mr Simpson, the finalisation and implementation of the Roadmap should be a priority.<sup>1149</sup>

472. According to Dr Small:

*[T]he absence of national leadership must end with the government finalising, funding and implementing the proposed Roadmap that addresses many aspects that are currently deficient in the health sector's national response to the unmet health needs of people with IDD [intellectual and developmental disabilities].*<sup>1150</sup>

Dr Small expressed the view that this national strategy must also include states' health care responsibilities for hospital and community based health care.<sup>1151</sup>

473. Professor Lennox also commented that the Draft Roadmap 'does not ensure timely, adequate and widespread implementation.'<sup>1152</sup> He recommended that it be amended to include an implementation strategy which is 'more immediate and includes detailed initiatives in each phase of the plan' to drive the use of comprehensive health assessments for people with intellectual disability, which he described as a 'proven intervention'.<sup>1153</sup>

474. While the Royal Commission received a great deal of evidence about the Draft Roadmap, it should be emphasised that this Commonwealth initiative is focused specifically on improving health care for people with intellectual disability and not people with cognitive disability more broadly. As explained by Professor Trollor, the two largest groups in the category of patients with 'developmental disabilities' are people with intellectual disability and people on the autism spectrum.<sup>1154</sup>

475. Despite the challenges experienced by people with autism in accessing and receiving health care described by a number of witnesses, including Professor

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<sup>1148</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-758 [28]–[30].

<sup>1149</sup> Exhibit 4-20, 'Statement of James Simpson', 12 February 2020 at [137.3].

<sup>1150</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [111].

<sup>1151</sup> Exhibit 4-10, 'Statement of Dr Jacqueline Small', 12 February 2020 at [112].

<sup>1152</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [47].

<sup>1153</sup> Exhibit 4-21, 'Statement of Professor Nicholas Gordon Lennox', 11 February 2020 at [47].

<sup>1154</sup> Exhibit 4-9, 'Statement of Professor Julian Trollor', 11 February 2020 at [16]–[17].

Trollor, there appears to be a dearth of initiatives directed towards this particular group. Mr Cotterell suggested that consideration of the specific needs of people with autism may require a different focus from that of the Draft Roadmap.<sup>1155</sup> He agreed that having a parallel process to that of the Draft Roadmap for people with autism would require more resourcing and would need to be considered by the Minister.<sup>1156</sup>

## Part 4: Neglect

476. As noted in the Introduction to this Report, Public hearing 4 marked just the beginning of the Royal Commission's inquiry into people with disability and the health system. We will continue to investigate the key themes identified in this Report in a number of ways. In particular, we are likely to conduct further public hearings to explore specific issues that arose in Public hearing 4 and to investigate broader questions relating to the experiences of people with disability in the health system. In addition the Royal Commission's research and community engagement programs will provide important information, as will the continuing flow of submissions and responses to Issues Papers.
477. Counsel Assisting's Submissions contended that the Royal Commission should not make findings about incidents that were the subject of evidence or as to whether a particular government, institution, agency or individual engaged in conduct amounting to violence, against or abuse, neglect or exploitation of people with cognitive disability. We accept Counsel Assisting's contention that it is not appropriate to make any such findings. Nor do we consider it appropriate to make findings about the experiences recounted by individual witnesses, although much of their evidence is not likely to be controversial.
478. Submissions made by interested parties after Public hearing 4 cautioned against making general findings about the health system (or systems) in Australia based on the experiences of individual witnesses. They also pointed out that the evidence at Public hearing 4 did not examine in detail the health system of every Australian state and territory.
479. We accept that these submissions have force and any finding should not go further than the evidence permits. Nonetheless it is open to the Royal Commission to consider the totality of the evidence presented during Public hearing 4, including the evidence admitted after the public sessions concluded.
480. The evidence from numerous people with cognitive disability, their families, carers and support persons, and from disability advocates, was powerful and consistent. This evidence, although based on individual experiences, demonstrates that there

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<sup>1155</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-761 at [38] – P-762 at [2].

<sup>1156</sup> Transcript, Simon Cotterell, Public Hearing 4, 27 February 2020, P-762 [3]–[8].

have been and are now formidable barriers to quality health care in Australia for people with cognitive disability. Far too often these barriers lead to people with cognitive disability receiving poor quality or inappropriate health care, often with serious and sometimes tragic consequences.

481. It is important to appreciate that the evidence at Public hearing 4 was not limited to individual experiences or anecdotal accounts. Extrapolating from his research findings in relation to NSW, Professor Trollor suggested that each year about 400 Australians with intellectual disability aged 20 or above suffer potentially avoidable deaths. His research also found that, in NSW, the median age of death for adults with intellectual disability is 27 years lower than that of the general population. He attributed the significantly poorer health outcomes of people with intellectual disability and people with autism to a combination of poor preventative health care, missed diagnosis and lack of evidence based disease management.<sup>1157</sup> Professor Trollor described the ‘mismatch’ between the health care needs of people with cognitive disability and the health care services they currently receive as ‘systemic and pervasive in nature’.<sup>1158</sup>
482. Dr Small, the President of the Australasian Association of Development Disability Medicine, considered that the absence of collaborative and integrated care and other measures necessary to improve the health of people with “intellectual and developmental disability” (IDD) reflects systemic neglect of such people by the health system.<sup>1159</sup> Dr Small also pointed to the lack of a comprehensive and evidence based paediatric strategic health care plan either in NSW or nationally for children and adolescents with IDD.<sup>1160</sup>
483. The Commonwealth acknowledged in its response to the Counsel Assisting’s Submissions that reforms are needed to improve the quality of health care and services provided to people with cognitive disability in Australia. However, it submitted that the evidence at Public hearing 4 does not support a finding by the Royal Commission that people with cognitive disability are currently subject to systemic neglect in the health care system in Australia.
484. The response to the Counsel Assisting’s Submissions on behalf of NSW recorded favourable evidence given by expert and advocate witnesses at Public hearing 4 about recent initiatives that have been implemented or are under consideration in NSW. We have referred to those initiatives in Part 3 of this Report.<sup>1161</sup> NSW contended that the official recognition of the barriers to quality health care for people with cognitive disability, together with the initiatives designed to improve

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<sup>1157</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [160].

<sup>1158</sup> Exhibit 4-9, ‘Statement of Professor Julian Trollor’, 11 February 2020 at [301].

<sup>1159</sup> Report at [139].

<sup>1160</sup> Report at [141].

<sup>1161</sup> Report at [448]-[460]

their health outcomes, are inconsistent with a finding of current systemic neglect of people with cognitive disability in NSW.

485. The Royal Commission accepts that both the Commonwealth and NSW have supported initiatives that may lead to improvements in the quality of health care and services to people with cognitive disability. The initiatives include the National Roundtable organised in August 2019; the Draft Roadmap of action to improve health care for people with intellectual disability;<sup>1162</sup> the Specialised Intellectual Disability Health Teams and Intellectual Disability Health positions in NSW;<sup>1163</sup> and the Intellectual Disability/Mental Health Specialist Hubs in NSW.<sup>1164</sup> While these initiatives, if implemented effectively with sufficient resources, offer hope for improvements, they rather suggest that substantial barriers prevent a substantial proportion of people with cognitive disability receiving good quality health care and that measures are urgently needed to dismantle those barriers. Indeed, the evidence shows that many of the initiatives have resulted from the concerted advocacy of individuals and organisations, some of whom gave evidence at the hearing.
486. The evidence also is clear that a great deal more needs to be done if people with cognitive disability are to receive in practice, as well as in theory, the right recognised in Article 25 of the CRPD, namely, the right to enjoyment of the highest attainable standard of care without discrimination on the basis of disability.
487. It will also be necessary for governments to provide the resources to ensure the robust implementation of the initiatives that have been developed. These initiatives must be implemented nationally; data must be gathered systematically and research undertaken to evaluate their success in improving the health of people with cognitive disability; steps must be taken to change entrenched negative attitudes and assumptions made by many health professionals and institutions about people with cognitive disability; health professionals must acquire the specialised skills required to equip them to care for and support people with cognitive disability; and active steps must be taken to address the particular health care needs of people with autism.
488. In these circumstances it would be premature to conclude that people with cognitive disability are no longer subject to systemic neglect in the health system(s) in Australia. We acknowledge that the evidence at Public hearing 4 did not address in detail the position in each Australian jurisdiction. We also acknowledge that practices are in the process of change in some parts of the health system. **Nonetheless the evidence justifies the Royal Commission**

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<sup>1162</sup> Exhibit 4-31, 'Statement of Simon Brook Cotterell', 5 February 2020 at [13], [15].

<sup>1163</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [13]–[29], [107]–[109]; Transcript, Dr Nigel Lyons, Public Hearing 4, 27 February 2020, P-747–749.

<sup>1164</sup> Exhibit 4-28, 'Second Statement of Dr Nigel Lyons', 13 February 2020, at [30]–[96], [110]–[114].

**finding that people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system. We make that finding.**

## **Part 5: Future inquiries and directions**

489. Other than the finding recorded in Part 4 of this Report, the Royal Commission does not intend to make formal findings or recommendations based on evidence presented at Public hearing 4. However, the key themes identified earlier and the evidence on which they are founded will guide the future work of the Royal Commission as we consider the measures needed to end the systemic neglect experienced by people with cognitive disability in their interactions with the health system.

### **Quality health care**

490. Witnesses at Public hearing 4 consistently stressed the importance of a ‘person-centred approach’ in addressing the health needs of people with cognitive disability. At the very least, a person-centred approach requires health professionals and institutions to be flexible and ready to adjust standard procedures to minimise distress and trauma often experienced by people with cognitive disability when they interact with the health system in Australia.<sup>1165</sup>
491. Quality health care for people with cognitive disability clearly involves more than minimising distress and trauma. People with cognitive disability need to be supported to make informed decisions about their own care and treatment. That support can only be produced if there is a relationship of trust and confidence between the person with cognitive disability and their family or support persons and the health professionals providing medical treatment or other forms of health care. The evidence is overwhelming that trust and confidence, from the perspective of people with cognitive disability, depends on health professionals and staff having the time, patience and understanding necessary to communicate clearly and appropriately with people with cognitive disability. Once trust and confidence are established, collaborative planning that allows people with cognitive disability to exercise choice and control over their health care needs becomes possible.<sup>1166</sup>

#### *Further inquiries*

492. The Royal Commission will investigate the measures needed to enable people with cognitive disability, where possible, to make informed decisions about their

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<sup>1165</sup> See [187] of this Report above.

<sup>1166</sup> See [189] of this Report above.

care and treatment and to exercise choice and control in their interactions with the health system. Consideration will be given to:

- the practical significance of a ‘person-centred approach’ of health professionals and institutions to people with cognitive disability and how such an approach can be implemented more widely;
- the training and other measures required to encourage health professionals and staff to acquire the understanding and skills necessary to communicate clearly and effectively with people with cognitive disability; and
- how collaborative planning between people with cognitive disability and health professionals can be encouraged within the health system.

## Attitudes, assumptions and culture

493. Numerous witnesses recounted examples of negative assumptions and cultural attitudes held by health professionals towards people with cognitive disability. These assumptions and attitudes can influence the treatment provided to people with cognitive disability and limit their opportunity to understand their condition and make informed decisions about their health care. People with lived experience of cognitive disability and their supporters made it crystal clear at Public hearing 4 that they are valued and loved members of their families and that with appropriate support they can enjoy a very good quality of life. We were given examples of people with cognitive disability making important contributions to the life of the community and obtaining great personal fulfilment in doing so.<sup>1167</sup>
494. Negative attitudes and assumptions are by no means universal within the health system.<sup>1168</sup> But they are sufficiently widespread to influence the nature and quality of care received by people with cognitive disability. Diagnostic overshadowing leads to symptoms or behaviour being attributed to a person’s cognitive disability, rather than to underlying health conditions unrelated to the particular disability.<sup>1169</sup> The result can be a delayed diagnosis or a failure to diagnose a treatable condition. When a person with cognitive disability dies great distress can be caused if the cause of death is attributed inappropriately in a death certificate to the disability, rather than to a discrete medical condition.

### *Further inquiries*

495. The Royal Commission will investigate the ways in which negative attitudes towards people with cognitive disability within the health system reflect outcomes and inflict distress. We will investigate:

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<sup>1167</sup> See [197] of this Report above.

<sup>1168</sup> See [205] of this Report above.

<sup>1169</sup> See [213] of this Report above.

- the nature and extent of diagnostic overshadowing and how it can be reduced and, so far as feasible, eliminated;
- the education and training necessary to enable health professionals and staff address to better address negative attitudes and assumptions; and
- the changes required in the policies and practices of the authorities in each state and territory to ensure that the cause of death of a person with cognitive disability is accurately recorded and not wrongly attributed to the disability.

## Communication and information sharing

496. The evidence at Public hearing 4 demonstrated the importance of open and effective communication at three levels, if the health needs of people with cognitive disability are to be adequately met:
- between health professionals and the person with cognitive disability;
  - between health professionals and parents or support persons of the person with cognitive disability; and
  - between health professionals and health services (including communications between different health professionals).
497. Effective communication between health professionals and people with cognitive disability (not merely with their parents or support workers) is critical to reducing distress and anxiety and to improving the accessibility of health services to people with cognitive disability.<sup>1170</sup> As has already been noted, health professionals need to acquire the knowledge, skills and attitudes to enable effective communication to occur as a matter of course.
498. The evidence referred in some detail to the techniques that can be employed to improve communication with people with cognitive disability. The techniques include providing material in plain English or Easy Read, conveying information by visual images and using other forms of communication accessible to people with cognitive disability.<sup>1171</sup>
499. Techniques are also available to ensure that the parents, carers and support persons of people with cognitive disability are listened to and, equally important, feel that health professionals are listening to them when they raise issues related to the health needs of their children or the people whom they care and support.<sup>1172</sup> In the absence of effective and respectful communication with

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<sup>1170</sup> See [220]-[228] of this Report above.

<sup>1171</sup> See [226]-[228] of this Report above.

<sup>1172</sup> See [233]-[235] of this Report above.

parents, carers or support persons, health professionals may overlook or simply not receive information important for accurate diagnosis and effective treatment strategies. As a result, health outcomes for people with cognitive disability can be adversely affected and levels of stress and anxiety increased.<sup>1173</sup>

500. The benefits of effective communication among health professionals and between hospitals and health professionals are self-evident. Lack of continuity in health care for people with cognitive disability can be a significant barrier to coordination between professionals, create a risk of incorrect diagnosis and lead to ineffective or even harmful treatment.<sup>1174</sup>
501. Accurate and complete record keeping is integral to continuity of care and rapid intervention in a health crisis which people with cognitive disability may experience because of their co-occurring health conditions. Evidence at Public hearing 4 suggested that the standard of record keeping for people with complex conditions is sometimes seriously deficient and a source of great frustration particularly to people with cognitive disability, their families and support persons.<sup>1175</sup>

#### *Further inquiries*

502. In addition to investigating the means of improving communication at the three levels referred to above, the Royal Commission will request Commonwealth, state and territory Health Departments and PHNs to:
- undertake a review to identify their policies, practices and information relating to the health needs and care of people with cognitive disability;
  - assess whether the policies, practices and information are available in formats that can be readily accessed and understood by people with cognitive disability, their families and support persons; and
  - report on actions that can and should be taken to make the policies, practices and information available in formats that are capable of being more readily accessed and understood by people with cognitive disability, their families and support persons.
503. In approximately 12 months time the Royal Commission will:
- seek an update from Commonwealth, state and territory Health Departments and PHNs in relation to the reviews referred to above;

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<sup>1173</sup> See paragraphs [231]-[233] of this Report above.

<sup>1174</sup> See paragraphs [239], [247] of this Report above.

<sup>1175</sup> See paragraphs [240], [244] of this Report above.

- determine what recommendations should be made in relation to the issues raised by the reviews;
- seek an update from Commonwealth Health as to the steps it has taken to improve the accessibility of My Health Records to people with cognitive disability and to promote the use of My Health Records by people with cognitive disability including through PHNs; and
- determine what recommendations it should make in light of the update from Commonwealth Health.

## Health system challenges

504. The Australian health system faces a significant challenge in providing adequate health care for people with cognitive disability who live in regional, rural and remote areas.<sup>1176</sup>
505. If anything, the challenges are even greater when it comes to providing health care for First Nations people with cognitive disability, especially those who live in regional and remote areas. The multiple forms of disadvantage experienced by First Nations people with cognitive disability were outlined in the evidence and require careful investigation.<sup>1177</sup>
506. People with cognitive disability, their parents and other family members, support persons, experts and advocates were unanimous in emphasising the critical part played by advocates in assisting people with cognitive disability to access quality health care. It is often parents who take on the role of advocate on behalf of their children. As we have recorded, 16 parents recounted their experiences as advocates for their children. In other cases, independent advocates assist people with cognitive disability to navigate the complexities of the health care system. We also heard from two self-advocates who explained how important it is for them to develop the skills required to make their own voices heard.<sup>1178</sup>

### *Further inquiries*

507. The Royal Commission will investigate:
- the particular barriers limiting the access of people with cognitive disability living in regional, rural and remote areas to quality health care and the measures required to break down those barriers;
  - the multiple forms of disadvantage experienced by First Nations people with cognitive disability, particularly those living in regional, rural and remote areas;

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<sup>1176</sup> See paragraph [253] of this Report above.

<sup>1177</sup> See paragraphs [259] – [262] of this Report above.

<sup>1178</sup> See paragraphs [272]-[273] of this Report above.

- the barriers to adequate health care faced by First Nations people with cognitive disability and the extent to which these barriers contribute to disparities in health outcomes for this group of people;
- the culturally appropriate measures that should be taken to improve access to health services for First Nations people with cognitive disability in the light of the multiple forms of disadvantage they experience; and
- the means by which people with cognitive disability, their families, carers and support persons can be supported in advocating for health care and treatment, including support for independent advocacy and self-advocacy.

508. The Royal Commission also will request the Commonwealth, state and territory governments to provide comments and advice on:

- whether health facilitators or independent advocates for people with cognitive disability could be funded through the public health system; and
- how such a scheme could work, for example through services provided by GPs or through NDIS funding.

509. In light of the comments and advice received, the Royal Commission will consider what recommendations, if any, should be made.

## Lifetime health care

510. The evidence addressed a series of issues that can affect the health of people with disability over the course of a lifetime.<sup>1179</sup> The issues in brief are as follows:

- inadequate attention within the health system to preventative health care, leading to the onset or increased severity of multiple health conditions experienced by people with cognitive disability;<sup>1180</sup>
- the links between poor oral health and systemic health issues (including a higher risk of mortality), and the lack of strategies designed to overcome the barriers to adequate oral health care for people with cognitive disability;<sup>1181</sup>
- fragmentation of the adult health care system, creating difficulties for young people with cognitive disability as they transition from paediatric to adult health care;<sup>1182</sup>

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<sup>1179</sup> See paragraph [289] of this Report above.

<sup>1180</sup> See paragraphs [290]-[298] of this Report above.

<sup>1181</sup> See paragraphs [310]-[327] of this Report above.

<sup>1182</sup> See paragraphs [328]-[332] of this Report above.

- high rates of mental health conditions among people with intellectual disability and people with autism, and the associated obstacles to people with intellectual disability or autism gaining access to mental health services;<sup>1183</sup>
- inappropriate referrals of people with cognitive disability to palliative care;<sup>1184</sup> and
- integration of the health system (including the oral health system) and the disability services sector.<sup>1185</sup>

### *Further inquiries*

#### Preventative health care

511. The Royal Commission will request Commonwealth Health to consider:

- devising and implementing a strategy to encourage greater uptake of annual health assessments for people with cognitive disability both through primary health networks and key health services that reach people in First Nations and culturally and linguistically diverse communities, or who live in regional, rural and remote communities;
- revising MBS item numbers applicable to comprehensive health assessments for people with intellectual disability and people with autism, and devising and implementing a strategy to encourage uptake of the revised MBS items.

512. In approximately 12 months time the Royal Commission will:

- seek an update from Commonwealth Health as to its consideration of the matters identified above; and
- after receiving the update determine what recommendations the Royal Commission should make in relation to those matters.

#### Oral health

513. The Royal Commission will investigate:

- the measures required to increase awareness among dentists, other health professionals and disability support workers of the oral health needs of people with cognitive disability;

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<sup>1183</sup> See paragraphs [333]-[352] of this Report above.

<sup>1184</sup> See paragraphs [353]-[360] of this Report above.

<sup>1185</sup> See paragraphs [361]-[376] of this Report above.

- the establishment of pathways to promote collaboration and co-ordination between disability support workers and dental services, as a means of improving the oral health of people with cognitive disability; and
- training programs to increase awareness among dentists and other health professionals of practices that reduce stress and anxiety among people with cognitive disability who seek or receive oral health care.

#### Transition to adult health care

514. The Royal Commission will investigate the measures required to establish a planned process for the transition of young people with cognitive disability into the adult health system, including a process for addressing sexual and reproductive health for people with cognitive disability.

#### Mental health

515. In approximately six months' time the Royal Commission will seek an update from Commonwealth Health concerning:
- implementation of recommendations made in *Accessible Mental Health Services For People with Intellectual Disability: A Guide For Providers* and the additional measures Commonwealth Health proposes to take to ensure full implementation of those recommendations;
  - implementation of the Communiqué, including the resources that have been allocated for that purpose, including an assessment of additional measures and funding required to ensure full implementation of those recommendations; and
  - further initiatives that are required at a national level to improve mental health care for people with autism.
516. In approximately six months' time the Royal Commission will seek an update from NSW Health concerning:
- further implementation of *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024* in relation to the particular needs of people with cognitive disability (including people with autism);
  - the functioning, resourcing and further roll-out of the Intellectual Disability/Mental Health Tertiary Specialist Hubs; and
  - action taken by NSW Health in light of the evidence at Public hearing 4 in relation to the mental health care needs of people with autism.
517. The Royal Commission will also request primary health networks to provide information concerning regional planning, integration and commissioning of mental health services for people with cognitive disability (including people with

autism) at a local level, and the extent to which this planning work has involved the participation of people with cognitive disability.

518. In the light of responses and information received from Commonwealth Health, NSW Health and the primary health networks, the Royal Commission will determine what recommendations the Royal Commission should make on these issues.

#### Palliative care

519. The Royal Commission will investigate the inclusion of people with cognitive disability in the National Palliative Care Strategy and the measures needed to prevent referrals to palliative care in circumstances where medical treatment can and should be provided.

### Integration of health and disability services

520. The Royal Commission will investigate:
- the means by which coordination can be achieved between health care and disability services to address the complex health needs of people with intellectual disability and people with autism;
  - the extent to which the individual funding model of the NDIS militates against co-ordination between the health care and disability sectors; and
  - how violence against, and abuse, neglect and exploitation of, people with disability can be minimised through the quality and safeguards system of the NDIS Commission, including how that system can encourage and facilitate the integration of health care and disability support services.<sup>1186</sup>
521. The Royal Commission will also inquire into the practices and systems adopted in closed settings such as group homes that may limit people with cognitive disability from accessing appropriate health care.

### Reduction of distress and trauma

522. The Royal Commission heard a good deal of evidence about the trauma and distress experienced by people with cognitive disability as they undergo health procedures or treatment, whether in clinical environments or in hospital.<sup>1187</sup> So-called 'challenging' behaviour induced by stress can be extremely detrimental to good health care, for example if treatment has to be postponed or abandoned.<sup>1188</sup> Repeated distressing experiences can intensify, and lead people with cognitive

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<sup>1186</sup> See paragraphs [375]-[376] of the Report above.

<sup>1187</sup> See paragraphs [377]-[378] of the Report above.

<sup>1188</sup> See paragraph [380] of the Report above.

disability and their families to lose trust in the health system and indeed fear further interactions.<sup>1189</sup>

*Further inquiries*

523. The Royal Commission will investigate adjustments that should be made to the hospital and clinical environment and to clinical procedures in order to minimise stress for people with cognitive disability consulting health professionals, undergoing tests, receiving treatment or being admitted to hospitals.

## **Training and education of health professionals**

524. As we have noted, at least nine witnesses expressed the view that health professionals need education and training to ensure that their decisions about diagnosis and treatment are not informed by preconceptions about people with cognitive disability or the nature of cognitive disability.<sup>1190</sup> It was also said that training and education are needed to improve communication between health professionals and people with cognitive disability, their parents, carers and support persons.<sup>1191</sup> Several advocates and experts remarked on the limited exposure of health professionals to people with cognitive disability in the course of their training and clinical work, resulting in limited knowledge of the nature and complexities of cognitive disability and of practices likely to foster trust and understanding between doctor and patient.<sup>1192</sup>

*Further inquiries*

525. The Royal Commission will consider how training and education of health professionals can result in better quality health care and outcomes for people with cognitive disability. In particular, the Royal Commission will investigate further:
- the nature and content of training relating to cognitive disability currently provided to people studying to become health professionals or already practising as health professionals;
  - the extent to which training programs currently involve the participation of people with cognitive disability, their families, carers or support persons;
  - the effectiveness of education programs designed to improve communication between health professionals and people with cognitive disability and to address unconscious bias and negative assumptions held by health

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<sup>1189</sup> See paragraphs [381]-[384] of the Report above.

<sup>1190</sup> See paragraphs [400]-[402] of the Report above.

<sup>1191</sup> See paragraphs [407]-[409] of the Report above.

<sup>1192</sup> See paragraphs [410]-[412] of the Report above.

professionals about the value of lives led by people with cognitive disability;  
and

- the nature of training and education required to equip health professionals with the skills, knowledge and understanding necessary for the correct diagnosis of conditions experienced by people with cognitive disability and to avoid diagnostic overshadowing.

526. In the light of these investigations, which may require a further short public hearing, the Royal Commission will determine the recommendations it should make on these matters.

## Collection of data and research

527. The systematic collection of data relating to the health needs and health care of people with cognitive disability is fundamental to the development of sound policy addressing issues such as the prevalence of physical and psychiatric co-morbidities experienced by people with intellectual disability and disparities in health outcomes.<sup>1193</sup> So, too, rigorous research into the health needs and health care of people with cognitive disability is essential to identify weaknesses or gaps in the health system and to design and evaluate programs to improve the health outcomes for people with cognitive disability.<sup>1194</sup>

528. The Royal Commission has had the benefit of extremely important research undertaken by Professor Trollor and his team, with financial support from NSW. However, the evidence at Public hearing 4, including that of Professor Trollor himself, exposed the limitations of data collection at a national level and the scarcity of appropriately funded, targeted and reliable research into the health needs and health care of people with cognitive disability.<sup>1195</sup>

### *Further inquiries*

529. In approximately six months the Royal Commission will seek an update from Commonwealth, state and territory Departments of Health as to measures taken since Public hearing 4:

- to improve the collection and analysis of data relating to the health care and health needs of people with cognitive disability, including data collected on a national basis;

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<sup>1193</sup> See paragraph [433] of the Report above.

<sup>1194</sup> See paragraphs [434]-[435] of the Report above.

<sup>1195</sup> See paragraphs [436]-[443] of the Report above.

- to ensure that data is collected and presented in a form that can be usefully analysed by research centres and institutes for the purposes of research into the health needs and health care of people with cognitive disability; and
- to provide ongoing funding to independent centres or institutes capable of conducting high quality research or data analysis relating to the health care and health needs of people with cognitive disability.

530. The Royal Commission will also request information from government and non-government agencies about their capacity to collate and publish accurate data on mortality rates and causes of death of people with cognitive disability, with a view to collecting and publishing data on a national basis.
531. In the light of the information received, the Royal Commission will determine the recommendations it should make in relation to data collection and research.

## Initiatives to improve health care

530. As has been pointed out in Part 4 of this Report<sup>1196</sup> and explained in some detail in Part 3,<sup>1197</sup> both NSW and the Commonwealth have introduced programs intended to enhance the responses of health services to the needs of people with cognitive disability. The initiatives in NSW attracted praise from expert witnesses and advocates who acknowledged that NSW has been a leader in Australia. However, the praise was qualified by observations that implementation of the initiatives has been somewhat slow and that substantially more resources are required to produce significant reductions in the health gaps experienced by people with cognitive disability.
531. Potentially significant Commonwealth initiatives, notably the Draft Roadmap and the 10 Year Plan,<sup>1198</sup> have yet to be implemented. Moreover, experts and advocates express reservations about the scope of the proposed actions. To adopt Professor Trollor's language, there is a gulf between what needs to be done and what is currently proposed to be done. Experts and advocates also noted the dearth of initiatives to ensure that people with autism can access and receive appropriate health care.

### *Further inquiries*

532. The Royal Commission will request information from state and territory Departments of Health, other than NSW Health, about:

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<sup>1196</sup> See paragraphs [484]-[485] of the Report above.

<sup>1197</sup> See paragraphs [445]-[475] of the Report above.

<sup>1198</sup> See paragraphs [464]-[470] of the Report above.

- whether they operate specialist health services for people with cognitive disability or have plans to create any such services; and
- whether they have resources similar to *The Essentials* used in NSW or could implement *The Essentials* or similar resources.

533. In approximately six months, the Royal Commission will seek an update from NSW Health about:

- the proposed timetable for evaluation of the specialist intellectual disability health teams;
- progress in implementing a state-wide service model for specialist intellectual disability health teams and whether this model will cover all LHDs;
- plans to ensure that people with intellectual disability in non-metropolitan areas have access to the specialist intellectual disability health teams; and
- further measures that will be taken to ensure more comprehensive implementation of *The Essentials*.

534. The Royal Commission has requested information from Commonwealth Health about the date set for the second National Roundtable and progress that has been made in developing the Draft Roadmap.

535. In approximately 12 months the Royal Commission will seek an update from Commonwealth Health about:

- the measures it has taken to implement the National Roadmap endorsed at the second National Roundtable; and
- the steps it has taken to develop similar initiatives focussed on the health and health care needs of people with autism.

536. In the light of the information received, the Royal Commission will consider what recommendations should be made in relation to initiatives to improve health care and services for people with cognitive disability.

## Part 6: Appendices

### Appendix A – Parties granted leave to appear

	Parties
Leave to appear	<p>Commonwealth of Australia</p> <p>State of New South Wales</p> <p>State of Queensland</p> <p>Royal Children's Hospital Melbourne</p> <p>Victorian Department of Health and Human Services</p> <p>Giuseppina Porte (Jo Abi)</p> <p>Sabrina Monaghan</p>
Legal representatives	<p>K Eastman SC with G Wright and S Fraser, instructed by the Office of the Solicitor Assisting the Royal Commission, appearing as Counsel Assisting the Royal Commission</p> <p>K Morgan SC with A Munro, instructed by A Floro and S Byng, appearing for the Commonwealth of Australia</p> <p>K McMillan QC instructed by P Clohessy, appearing for the State of Queensland</p> <p>G Furness SC with I Fraser, instructed by K Hainsworth, appearing for the State of New South Wales</p> <p>B Fogarty appearing for Rachel Browne</p> <p>S Healy appearing for AAJ</p> <p>S Lawrence appearing for Dr Rebecca Kelly</p> <p>G Willis appearing for Sabrina Monaghan and Giuseppina Porte (Jo Abi)</p> <p>C Hunter appearing for Karen Barnett</p> <p>M McKenzie appearing for Tracey Nash</p>

## Appendix B – Links to exhibits and transcripts

Key document	Hyperlink
Terms of Reference	<a href="#">Commonwealth</a> <a href="#">Commonwealth as amended</a> <a href="#">New South Wales</a>
Transcripts for Public hearing 4	<a href="#">Day 1</a> <a href="#">Day 2</a> <a href="#">Day 3</a> <a href="#">Day 4</a> <a href="#">Day 5</a> <a href="#">Day 6</a> <a href="#">Day 7</a> <a href="#">Day 8</a> <a href="#">Day 9</a>
Exhibits for Public hearing 4	<a href="#">Exhibit List</a> <a href="#">Day 1</a> <a href="#">Day 2</a> <a href="#">Day 3</a> <a href="#">Day 4</a> <a href="#">Day 5</a> <a href="#">Day 6</a> <a href="#">Day 7</a> <a href="#">Day 8</a> <a href="#">Day 9</a> <a href="#">Chambers</a>

## Appendix C – List of Acronyms

Acronym	Definition
ACI	Agency for Clinical Innovation
CHAP	Comprehensive Health Assessment Program
CID	Council for Intellectual Disability
DIAP	Disability and Inclusion Action Plan 2016-2019
ENT	Ear, Nose and Throat
FPDN	First Peoples Disability Network
GP	General Practitioner
IDD	Intellectual/Developmental Disability
LHD	Local Health District
MBS	Medicare Benefits Schedule
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Commission	National Disability Insurance Scheme Quality and Safeguards Commission
NHRA	National Health Reform Agreement
NSW	New South Wales
OCV	Official Community Visitors
PCEP	Primary Care Enhancement Program
PHNs	Primary Health Networks
SND	Special Needs Dentist and Special Needs Dentistry



**Royal Commission**  
into Violence, Abuse, Neglect and  
Exploitation of People with Disability