JURISDICTION	**:**	STATE ADMINISTRATIVE TRIBUNAL
ACT	**:**	GUARDIANSHIP AND ADMINISTRATION ACT 1990 (WA)
CITATION	**:**	DAH [2023] WASAT 102
MEMBER	**:**	JUDGE H JACKSON, DEPUTY PRESIDENT MS N FINDSON, MEMBER MR J MANSVELD, SENIOR SESSIONAL MEMBER
HEARD	**:**	19 SEPTEMBER AND 11 OCTOBER 2023
DELIVERED	**:**	11 OCTOBER 2023
PUBLISHED	**:**	6 NOVEMBER 2023
FILE NO/S	**:**	GAA 3812 of 2023
		DAH Represented Person
		MAP Applicant

Catchwords:

Guardianship - Represented person proposing to participate in medical research - Application for amendment of current orders to make guardian research decision-maker - Construction of Part 9E of *Guardianship and Administration Act 1990* (WA) - Jurisdiction where represented person does not suffer from medical condition the subject of medical research - capacity - orders made

Legislation:

Guardianship and Administration Act 1990 (WA), Pt 5, s 4, s 43, s 43(2), s 45, s 45(1), s 45(2), s 45(2)(i), s 46, s 46(2)(i), s 86,
Guardianship and Administration Amendment (Medical Research) Act 2020 (WA), Pt 9E, s 3, s 3AA, s 3AA(1), s 3AA(3), s 110ZP, s 110ZR, s 110ZR(1), s 110ZR(1)(c), s 100ZR(2), s 110ZR(2)(b), s 110ZR(2)(c), s 110ZR(2)(c)(iii), s 110ZR(2)(c)(iv), s 110ZU, s 110ZU(1), s 110ZU(1)(b)(i), s 110ZU(1)(c), s 110ZU(1)(d), s 110ZU(2), s 110ZW, s 110ZW(1)(b), s 110ZW(1)(c)

Result:

Public Advocate appointed limited guardian with function of research decision-maker

Category: A

Representation:

Counsel:

Represented Person	:	N/A
Applicant	:	N/A

Solicitors:

Represented Person	:	N/A
Applicant	:	N/A

Case(s) referred to in decision(s):

Minister for Aboriginal Affairs v Peko-Wallsend Ltd (1986) 162 CLR 24

REASONS FOR DECISION OF THE TRIBUNAL:

(These reasons were delivered orally and have been taken from the transcript of the hearing. They have been edited to make necessary corrections or annotations for the purposes of correcting grammatical errors or infelicity of expression.)

Introduction

1 This is an application under s 86 of the *Guardianship and Administration Act 1990* (WA) (**GA Act**) for the review of a guardianship order.[1]

2 The orders the subject of review were made on 25 February 2021. Those orders confirmed previous orders made on 20 February 2020.

3 The orders concern DAH, who is a represented person under that Act. The orders declared that DAH is, in effect, incapable of looking after her own health and safety and in need of a guardian. By those orders Public Advocate was appointed as a limited guardian with the function of determining the services to which DAH should have access.

4 DAH has been subject to orders since January 2015, when orders were made in anticipation of her leaving State care on her 18th birthday.

5 The 2015 orders were broader than the current orders. They gave the Public Advocate additional functions of accommodation, medical treatment and contact.

6 Orders were also made in both 2015 and 2021 granting powers of administration to the Public Trustee.

7 We have been advised that there is frequent, or even constant, tension between DAH and the Public Trustee in that DAH frequently runs out of money and asks the Public Trustee for additional funds for reasons which include that she is financially vulnerable, which condition is not infrequently exploited.

8 It is in that context that the applicant, as DAH's support coordinator, has become aware that DAH has applied to participate in a medical research trial in return for which she will be paid quite a substantial sum of money.

[1] All references to sections in these reasons are, unless the context requires otherwise, references to sections in the GA Act.

9 The applicant is concerned that DAH lacks the capacity to make such a decision and seeks review of the current orders, asking that the Public Advocate be granted the additional function of what is known in the GA Act as a 'research decision-maker'.

10 That is, the applicant seeks orders granting the current guardian the additional power to make what is known in the GA Act as a 'research decision'.

11 We emphasise at this stage that it is not the Tribunal's role to decide whether or not DAH can or should participate in the medical research trial, although we will make some comments in that regard below.

12 Rather, it is our role simply to determine whether a substitute decision-maker should be granted the power to make that decision. If so, we are obliged to grant that function to the Public Advocate if there is no-one else who consents to that role, as the guardian of last resort.

13 It is therefore necessary for us to address three questions.

1) First, does DAH lack the capacity to make the decision in her own best interests as to whether or not she should participate in medical research;

2) Second, is there a need for such a function to be granted to a guardian as substitute decision-maker for DAH; and

3) Third, is there any other person available to play that role.

14 We will turn to those three matters shortly. Before then, however, we will make some preliminary observations about the legislative regime in place to address those issues.

15 We do so because this is, to our knowledge, the first application of its type. We adjourned this matter on 19 September 2023 (which was the date for which the matter was originally listed for hearing) in order to allow the Office of the Public Advocate to put on submissions as to the legal scope of Part 9E of the GA Act.

16 In particular, we were concerned that Part 9E may have been drafted in such a way as to be limited to circumstances where the medical research in question is concerned with a medical condition from which the represented person suffers.

17 That is, in circumstances where we understand that DAH does ***not*** suffer from the condition which is the subject of the medical research that she wants to participate in, we were concerned with whether or not we have jurisdiction to make the orders sought.

18 For the reasons that follow, we are satisfied that we do have that jurisdiction.

Legislative regime

19 Part 9E of the GA Act is headed Medical Research.

20 It provides for decisions to be made on behalf of those who cannot make such decisions for themselves to participate in medical research. In doing so, it limits the ability of such decisions to be made in a manner that clearly seeks to protect the represented person.

Introduction and legislative history

21 Part 9E was inserted into the GA Act by Act Number 14 of 2020, the title of which was *Guardianship and Administration Amendment (Medical Research) Act 2020* (WA) (**Amendment Act**).

22 That Act was assented to on 6 April 2020. It is notorious that in April 2020 the world was in the very early stages of the COVID-19 pandemic.

23 The Minister's Second Reading Speech includes the following passage:

> Currently in Western Australia, if a person has lost capacity to make his or her own decisions, even if for only a short period, medical practitioners are not authorised to seek consent for medical research from a patient's enduring guardian, guardian or next of kin. This, effectively, denies critically ill or otherwise incapacitated COVID-19 patients access to the cutting-edge treatments that are on trial throughout the world. If we are to provide the best healthcare possible for Western Australians, we must keep pace with the various treatment responses that could save our most vulnerable COVID-19 patients from serious harm or death.

24 However, as is also noted in the Second Reading Speech, while COVID-19 provided the impetus, the matters the subject of the amendment had in fact, been the subject of recommendations in a 2015

statutory review.[2] Recommendation 6.1 of that review was that the GA Act be amended to include:

> …that in addition to treatment decisions, a decision may be made on behalf of a person, including a represented person, for that person to participate in medical research, ***including treatment that is part of research when***:
>
> - it is deemed to be in the person's best interests
> - the research will not involve any known or substantial risks to the participants or if there are existing treatments for the condition concerned, will not involve material risks greater than the risks associated with those treatments
> - the research has been approved by a human research ethics committee
>
> and consideration is given to:
>
> - the wishes of the person so far as they can be ascertained
> - the nature and degree of any benefits, discomforts and risks for the person in having or not having the procedure
> - any other consequences to the person if the procedure is or is not carried out
> - any other prescribed matters.

25 As will be seen, Part 9E of the GA Act clearly implements that recommendation, but we emphasise that our task is one of statutory construction and the start and end point of that task is the words of the statute itself. The statutory review document can assist in understanding the statutory text, but it cannot do more than that.

The statutory text

26 Turning then to the statutory text itself, Part 5 of the GA Act deals with guardianship.

27 Within that Part, s 43 provides that, upon satisfaction of certain preconditions, the Tribunal has the power to declare that a person is in need of a guardian and, if it does so, it shall appoint either a plenary or limited guardian.

[2] *Statutory Review of the Guardianship Administration Act 1990* (November 2015).

28 Section 45(1) provides, in effect, that where a person is appointed as a plenary guardian, they 'have all of the functions in respect of the person of the represented person' that a parent has over a child, as if the represented person were a child lacking in mature understanding, save that they do not have the right to chastise or punish the represented person.

29 Without limiting those very broad functions, s 45(2) of the GA Act identifies the specific functions that a plenary guardian has which, following the passage of the Amendment Act in 2020, includes s 45(2)(i) which provides as follows:

> if the plenary guardian is a research decision-maker for the represented person – subject to subsection (4A)(a) and sections 110ZR and 110ZT, make research decisions in relation to the represented person.

30 Section 46 addresses the powers of a limited guardian. It provides that a limited guardian shall have 'such of the functions mentioned in section 45 as the … Tribunal vests', in them in the guardianship order.

31 On one view, the making of a limited guardianship order leaves the represented person with the legal capacity to make decisions about those matters concerning their person other than those covered by the functions granted to the guardian by the Tribunal. That view exists notwithstanding that a particular guardianship order might be limited in its scope because, although the represented person lacks capacity, there is no need for an order in relation to a particular function.

32 That view is not without doubt in circumstances where s 43(2) requires the Tribunal to declare certain matters as to capacity (but not as to need) which are very broadly expressed and do not descend to the specifics of functions.

33 It has not been necessary for us to resolve that issue here. Amongst other things, as we have already said, we have determined that we have jurisdiction to determine the matter and make the order sought.

34 We merely note here that in our consideration of the matter we have proceeded on the basis that if we lacked the power to vest the function described in s 45(2)(i) in the Public Advocate as guardian then DAH would have retained the legal capacity to make her own decisions to participate in medical research.

35 To repeat, s 45(2)(i) provides that the relevant function is, 'to make ***research decisions*** in relation to the represented person' subject to certain limits, the only relevant one of which is set out in s 110ZR, to which we will refer in detail.

36 Section 3 defines the term ***research decision*** as a decision to consent or to refuse consent to the participation by a ***research candidate*** in ***medical research***.

37 That section also defines ***research candidate***. It means an individual whose participation is sought in ***medical research***; in this case, DAH.

38 The term ***medical research*** is defined very broadly in s 3AA of the GA Act. That section provides as follows:

> (1) For the purposes of this Act, ***medical research*** —
>
> (a) means research conducted with or about individuals, or their data or tissue, in the field of medicine or health; and
>
> (b) includes an activity undertaken for the purposes of that research.
>
> …
>
> (3) Despite subsections (1) and (2), ***medical research*** does not include —
>
> (a) research conducted about individuals, or their data or tissue, in the field of medicine or health that
>
> (i) only involves analysing data about the individuals; and,
>
> (ii) does not result in the disclosure or publication of personal information;
>
> and
>
> (b) any other activity prescribed by the regulations not to be medical research.

39 It is to be noted that the statutory definition of ***medical research*** relies upon (incorporates) the term ***research*** which is not defined in the GA Act. Its ordinary meaning according to the *Macquarie Dictionary Online* is as follows:

> (*noun*) … diligent and systematic inquiry or investigation into a subject in order to discover facts or principles: *research in nuclear physics*.
>
> (*verb, intransitive*) … to make researches; investigate carefully.
>
> (*verb, transitive*) … to investigate carefully: *to research a subject exhaustively*.
>
> (*adjective*) … of or relating to research.

40 That definition is very broad indeed.

41 Putting to one side the carve-out in s 3AA(3), which does not appear relevant, the definition of ***medical research*** contains no limits on what the subject of the ***research*** can or must be, save that firstly:

(a) the ***research*** must be 'with or about' individuals, their data, or tissue; and

(b) secondly, the ***research*** must be in the field of medicine or health.

Section 110ZR

42 As noted above, the power of a guardian to make ***research decisions***, as provided by s 45(2)(i), is subject to section 110ZR.

43 That section establishes two primary requirements:

(a) Firstly, subsection (1) of that section provides that a ***research decision-maker*** for a ***research candidate*** **may** make a ***research decision*** in relation to the candidate's participation in ***medical research*** if three things are satisfied.

(b) Secondly, subsection (2) provides that a ***research decision-maker*** for a ***research candidate*** **must not** make a ***research decision*** in relation to the candidate's participation in ***medical research*** unless three more things are satisfied.

44 We will return to those criteria in a moment. Before we do, we note that:

(a) firstly, ***research candidate*** and ***research decision*** are both defined terms which we have just referred to.

(b) secondly, the third term used in s 110ZR(1) is ***research decision-maker***. That term is defined in s 110ZP. It is also the

> term used in s 46(2)(i). It means someone who makes a decision for a ***research candidate*** if they – that is the ***research candidate*** – is unable to make reasonable judgments in respect of their proposed/possible participation in ***medical research***.

45 As we noted, s 110ZR(1) provides that the ***research decision-maker*** **may** make a decision **only** if three criteria are met.

46 Firstly, the ***research*** in question must have been approved by a Human Research Ethics Committee (**HREC**) established in accordance with the National Statement on Ethical Conduct of Human Research issued under the National Health and Research Council (**NHRC**).

47 We need not concern ourselves with this here.

48 Secondly, the ***research candidate*** must be unable to make reasonable judgments in relation to participating in ***research***. We will turn our attention to that shortly, but that is clearly a matter that must be addressed by the ***research decision-maker*** at the time he or she makes their own decision.

49 Thirdly, the ***research decision-maker*** must have before them the opinion of a medical practitioner to the effect that the represented person is:

> … not likely to be able to make reasonable judgments within the timeframe for the research approved by the HREC.

50 The third criteria goes to circumstances where the loss of capacity is or may be temporary. That was a matter addressed in the 2015 statutory review. In particular, the Department of Health submitted to that review that substitute decision-making arrangements should not be put in place where the lack of ability to provide consent is only temporary. Section 110ZR(1)(c) appears to address that issue.

51 Turning then to s 110ZR(2), that section prohibits the ***research decision-maker*** from granting consent to the ***research candidate's*** participation in ***medical research*** unless they receive a determination of an independent medical practitioner that addresses two matters:

(a) firstly, whether the ***research*** will be in the best interests of the ***research candidate*** or will not be adverse to their interests; and

(b) secondly, the nature of the ***research*** and in particular whether it will involve substantial risks to the ***research candidate*** and how those risks compare to other risks.

52 It is not express whether or not this independent medical practitioner is separate, distinct, and indeed independent from, the first independent medical practitioner who is concerned with whether the lack of capacity is temporary or not.

53 The first issue – that is, the best interests of the represented person – is to be determined by the medical practitioner in accordance with s 110ZU. That section provides that in making the determination the medical practitioner must take into account certain matters that include:

(a) the wishes of the ***research candidate*** to the extent that they can be determined, which is the 'paramount consideration';

(b) the likely effects of the ***research candidate's*** participation in the trial, including the existence, likelihood and severity of any risks and whether those risks are justified by any benefits to the ***research candidate*** or the broader community;

(c) any consequences for the ***research candidate*** if they are involved in the ***research***; and

(d) any alternative treatments available to the ***research candidate***.

54 Sub-section 110ZU(2) provides that the fact that the ***medical research*** may involve the use of placebos does not prevent the medical practitioner being satisfied that participation is in the best interests of the candidate.

55 The second matter that the independent medical practitioner must determine concerns the nature of the ***medical research*** and its associated risks.

56 In accordance with s 110ZW, the practitioner must determine, effectively, that the candidate's participation in the ***medical research*** will satisfy one of the following:

(a) whether the participation will involve any known substantial risks to the candidate;

(b) whether there is an existing treatment available to the candidate; and

(c) if there is an existing treatment available to the candidate, whether that treatment carries substantial risks and, if so, whether they are greater than participation in the ***medical research***.

57 Having received those two determinations from the (perhaps more than one) independent medical practitioner, the ***research decision-maker*** must not consent to the represented persons participation in ***medical research*** unless they are satisfied of two matters:

(a) firstly, that, to do so would be in the best interests of the ***research candidate*** or is not adverse to their interests: s 110ZR(2)(b); and

(b) that, pursuant to s 110ZR(2)(c), the ***research candidate's*** participation in the ***medical research*** will satisfy one of the following criteria.

(i) that the ***medical research*** is non-invasive;

(ii) that if it is invasive, it will not involve any known substantial risks;

(iii) if it is invasive and involves known substantial risks those risks will not be greater than those of any other treatment that exists; or

(iv) that if none of the three previous circumstances apply, the ***medical research*** will not involve substantial risks greater to the candidate than if they did not participate.

Commentary Analysis

58 As is evident from the preceding description, several of the relevant sections appear to proceed on the basis that the ***research candidate*** suffers from a medical condition which is the subject of the ***medical research*** in which it is proposed that they participate.

59 For example:

(a) Section 110ZR(2)(c)(iii) requires consideration of risks where 'an existing treatment' is available. If that subparagraph does not apply then subparagraph s 110ZR(2)(c)(iv) requires

consideration of whether the participation will involve substantial risks greater than not participating in the research. Both of those paragraphs appear to assume that the participant suffers from a medical condition that would be the subject of the ***medical research***.

(b) Section 110ZU(1)(c) and (d) provide that when assessing whether participation in the ***medical research*** would be in the candidate's best interests (or will not be adverse to their interests), the independent medical practitioner is required to consider:

(i) any consequences for the ***research candidate*** if they are not involved in the ***medical research***; and

(ii) any alternative treatments available to the ***research candidate***. Again, both paragraphs appear to assume that the participant suffers from the medical condition the subject of the ***medical research***.

(c) Section 110ZW requires a medical practitioner to inform the substitute decision-maker as to whether or not the ***medical research*** will involve any known substantial risks to the candidate, whether there is an existing treatment available to the candidate; and:

(i) if there is, whether the risks associated with participation in the ***medical research*** are greater than those associated with any existing treatment; and

(ii) if there is **not**, whether the risks associated with participation in the ***medical research*** are greater than those associated with not participating.

60 Again, those provisions appear to proceed on the basis that the candidate suffers from a medical condition that would be the subject of the ***medical research***.

61 So too does s 110ZU(2), which provides that the chance that a participant in the ***medical research*** will be provided with a placebo does not preclude a decision that participation is in the represented person's best interests.

62 However, in our view, the better view is that those provisions **do not** narrow the scope of the definition of either ***research decisions*** or ***medical research***.

63 As noted previously, s 45(2)(i) refers to a power to make a ***research decision***, which is defined by reference to ***medical research*** which is defined very broadly by s 3AA.

64 That definition is not limited in its terms to particular forms of ***medical research***. In particular, the definition does not limit the meaning of the term ***medical research*** to that which is concerned with medical conditions suffered by those participating in it.

65 Neither does s 45(2)(i) limit the function of a guardian to make a ***research decision*** about a represented person participating in ***medical research*** that is concerned with medical conditions suffered by the represented person.

66 Also, s 110ZR(1) grants the power to make a ***research decision*** if three criteria are met, none of which are concerned with the type of medical research.

67 Most significantly, in our view, the provisions that speak of existing treatment – that is, s 110ZR(2), s 110ZU and s 110ZW – are capable of being applied despite the ***research candidate*** not suffering from the condition the subject of the ***medical research***.

68 So if the candidate does **not** suffer from the relevant medical condition and the ***medical research*** is invasive and carries substantial risks, s 110ZR(2)(c)(iii) would not apply, and s 110ZR(2)(c)(iv) would require the medical practitioner to advise that the substantial risks to the candidate associated with the ***medical research*** are greater than the risks associated with **not** participating because there **are** no risks to the candidate if they do not participate.

69 When we say there are no risks, we understand that subsection to refer to medical risks. Equally, if the candidate does not suffer from the relevant medical condition, the medical practitioner's opinion under s 110ZU(1) is unlikely to address any of:

(a) the medical benefits to the candidate by participation in the research under subparagraph (1)(b)(i) because there is unlikely to be any;

(b) the adverse medical consequences for the candidate if they do not participate under subsection (1)(c) because there is unlikely to be any; or

(c) any alternative treatments under subparagraph (1)(d) because there will not be any.

70 And if the candidate does **not** suffer from the relevant medical condition, the medical practitioner will not be able to address s 110ZW(b) and (c) but that does not prevent an opinion being expressed that there are risks associated with participating in the ***medical research***, (which, we assume, will be the situation in many cases), and that those risks exceed those associated with not participating, (which, we assume, will be so in all such cases).

71 It must be acknowledged that to construe these provisions in this way is somewhat clumsy, but that result arises due to what we consider to be the unusual, and perhaps unforeseen, circumstances that we are considering in this case.

72 That is, we consider it most unusual that someone who lacks capacity to consent to participate in ***medical research*** might be proposed as a ***research candidate*** for ***medical research*** that concerns a medical condition not suffered by that candidate.

73 But in our view, when construed in the manner described above, Part 9E can and does address those unusual circumstances.

74 In particular, as we have noted, the definition of ***research decision*** and ***medical research*** are very broad and are not limited to any particular type of ***medical research***, and, for the reasons we have just described, the provision of a recommendation and the forming of an opinion can occur even if there is no medical condition that would benefit from the research.

75 It is also, in our view, not without significance that such an approach will facilitate the protection of those that lack capacity to make such decisions in their own best interests, consistent with the purpose of the GA Act.

76 Accordingly, we are satisfied, and we find, that we have jurisdiction to determine the application before us, notwithstanding that DAH does not suffer from the medical condition which is the subject of the ***medical research*** in which she proposes to participate.

Further Thoughts On The Statutory Regime

77 Having done so – that is, having made that finding, it is necessary or at least convenient and appropriate to make two further comments in relation to the statutory regime, both of which may appear obvious from our previous comments but which we feel compelled to make in any event.

78 The first point is that, in our view, the independent medical expert when expressing their views pursuant to s 110ZU and s 110ZW is, in our view, limited in the expression of their opinions to medical matters.

79 In s 110ZU(1)(b)(ii) where the medical practitioner is asked to opine as to whether any risks are justified by any likely benefits of the ***medical research*** to the ***research candidate***, the practitioner is limited to expressing his or her views as to the medical risks to the candidate and the medical benefits to the candidate. That is so because the person that the Parliament has said shall express the relevant opinion or, indeed, more accurately, recommendation is a **medical** practitioner. Accordingly, in our view, that qualification ought to limit the scope of the opinion.

80 The second point is that when considering what constitutes a represented person's 'best interests', it seems to us that the financial interests of the represented person ought to play either no part at all, or a very limited part. That is for at least two reasons.

81 First, the GA Act divides responsibility for a represented person between a guardian, who is concerned with decision-making related to the represented person, and an administrator, which is concerned with decision-making related to the represented person's estate. It seems to us unlikely that Parliament intended a guardian to weigh the financial aspects of a decision when considering the represented person's best interests.

82 Secondly, s 110ZR(2)(b) by its terms requires the ***research decision-maker*** to make a decision as to the best interests of the represented person having regard to the determination of a medical practitioner, where that determination is whether, in the practitioner's view, the represented person's participation in the ***medical research*** will be in the represented person's best interests. Consistent with what we said a moment ago, the medical practitioner, in making that determination or, perhaps more accurately, recommendation ought to be limited to consideration of medical matters.

83 While the ***research decision-maker*** is not bound to follow the medical practitioner's recommendation, that recommendation must be given due weight, and while the section does not expressly limit the matters, other than the recommendation, which the ***research decision-maker*** must and may consider, such matters are, pursuant to the test in ***Peko-Wallsend***,[3] necessarily constrained by the scope, purpose and subject matter of the legislation.

84 Given the nature of the decision being made – that is, participation in ***medical research*** – and given the nature of the decision-maker – that is the guardian and its analogues – and given the factors which must be considered – that is, the recommendation by a medical practitioner – it seems to us unlikely that Parliament intended to allow financial benefits to be considered in determining whether participation is in the represented person's best interests although, given the lack of submissions on this issue, we refrain from making a formal finding in that regard.

Capacity

85 Having expressed those matters, we now turn to the question of capacity. In relation to capacity, we have several medical reports before us, but none of them are very recent or, with respect, very relevant.

86 None of them address the question of DAH's capacity to make reasonable decisions in her own best interests in relation to her participation in ***medical research***.

87 The Tribunal in this regard sought the evidence of a particular general practitioner whom we were advised was DAH's general practitioner but he or, rather, his practice advised that he was not DAH's general practitioner, and we have heard today that DAH has not had a general practitioner, or at least not had a consistent one, for some time.

88 The first of the reports is dated 17 June 2009, so DAH was 12 years old at that time. That report is a psychological report, and it was prompted by DAH having some difficulties at school. It is very comprehensive. It was based on multiple interviews with DAH as well as interviews with her parents and teachers, and it applied multiple assessment methodologies and assessed a range of matters.

[3] ***Minister for Aboriginal Affairs v Peko-Wallsend Ltd*** (1986) 162 CLR 24 at 39 - 40.

89 Most relevantly, it stated that DAH has a mild intellectual disability and that she has particular and severe difficulties with language and memory and that she also has difficulties with attention, concentration and memory.

90 The second medical report before us is dated 26 March 2010, so DAH was 13 years old. It is a letter from a psychiatrist, and it goes to DAH's suitability for educational assistance and again describes her as having a mild intellectual disability.

91 The third medical report is dated 21 March 2013, when DAH was 16 years old. It is from a clinical psychologist and was prepared for the purposes of a possible criminal injuries compensation claim. It really does not assist us a great deal other than to say that overall, in the author's opinion, DAH did not appear to have difficulties understanding and answering the questions posed to her during the interview.

92 The fourth report is dated January 2014 when DAH was 17 years old and is again from a clinical psychologist. It quotes an interview with a teacher who described DAH as performing at a level of approximately high primary school and who has the ability to get through tasks with support. It said that DAH has some independent living skills, but that budgeting will be difficult for her and that while she has developed some basic literacy and numeracy skills, she is reported to experience difficulty in tasks such as filling out forms, which is plainly relevant to the issue before us.

93 In its conclusion the report says that there were grounds for concern as to her capacity for functional decision-making and says that DAH is a concrete thinker who has significant deficits in her capacity to understand abstract concepts, understand a problem, and to plan a sequence of actions to competently evaluate persons or situations.

94 The final medical report is dated 4 August 2018 which was prepared by a general practitioner who had known DAH for five months. Again it reports a mild intellectual disability and makes a broad statement that DAH is unable to make decisions regarding her living situation.

95 We also have several reports prepared by service providers.

96 The first is dated 5 March 2013 which adds little, and we will not deal with that in any more detail.

97 A report of 15 October 2013 was completed by two psychologists who focused on DAH's feelings of anxiety and again that is of little utility.

98 A report prepared by a Parkerville caseworker dated 24 October 2013 says that DAH demonstrated an inability to apply knowledge imported during educational sessions to distinguish between safe and unsafe situations and help her maintain personal safety.

99 The fourth report was prepared by DAH's caseworker. It is undated, but she describes herself as being DAH's caseworker since 2014. It is a comprehensive report that was obtained from departmental files of conversations with DAH's care team and meetings with DAH and her carers. Under the heading 'Do They Follow Instructions' the report states:

> As a result of [DAH's] receptive language difficulties, instructions sometimes need to be simplified or explained in order for her to understand them.

100 Under the heading 'Concerning the Ability to Make Reasoned Decisions' the report states that:

> [DAH] is at significant risk of abuse and exploitation because of her inability to make reasoned decisions due to [her] below average cognitive and adaptive functioning[.]

101 It also says that:

> [DAH's] limited ability to communicate her wants, needs and feelings is a result of her speech and language deficits.

102 Under the heading 'Health' it states that the author has some concern about DAH's capacity to effectively manage certain aspects of her health and she questions her capacity to:

> Seek appropriate treatment and make reasoned decisions about any significant non-routine health issues that may arise in the future.

103 The fifth report is a report of 24 August 2023 by the applicant which says that DAH is unable to budget without assistance, constantly asks the Public Trustee for more money, that DAH understands she has an intellectual disability but not the impacts that it has on her and that she is unable to perceive or understand risk and consequently puts herself in unsafe situations.

104 The sixth report is a functional assessment report of 15 September 2023 which was completed for the purposes of National Disability Insurance Scheme (NDIS) funding. It is a comprehensive document of 28 pages plus annexures. Under the heading 'Communication Skills' it says that:

> [DAH] can understand language of a simple nature but struggles with more complex language.

105 It also says that DAH requires information to be presented in a simple and condensed format and that when learning a new task DAH requires step by step instructions and that each step must be shown and completed before teaching the next step. Under the heading of 'Self-Management Skills' it says that:

> there appears to be reduced understanding and realistic consideration of the pros and cons and the long-term implications [of significant life decisions].

106 And that:

> [DAH] has significant challenges making decisions and is unable to draw from past explicit teaching or extrapolate a solution from similar past events secondary to her disability.

107 And under the heading 'Cognitive and Learning Skills', perhaps most significantly, the report says that:

> [DAH] has significant challenges with attention and focus, impulsivity, executive functioning difficulties, and a lack of understanding of consequences, which means she cannot solve problems to maintain her safety.

108 It also says that:

> [She] struggles to recall information and provide an accurate timeframe for events in her past and has poor long-term memory. Her poor executive functioning means her working memory is problematic, secondary to her disability, impacting her attention and ability to retain information.

109 We also have several reports from the Public Advocate, one dated 20 February 2020, which we do not need to address. The second is dated 18 February 2021, which, again, we do not need to address. The most recent is dated 12 September 2023 which states that DAH has a mild intellectual disability that has minimal impact on daily living, but causes her to struggle with more complex matters.

110 That report also states that DAH has signed up for medical research which is obviously the subject of these proceedings.

111 We also have reports before us from the Public Trustee which are not really relevant to the issue before us, save that as we have already outlined, there are concerns that due to DAH's lack of capacity dealing with complex financial matters, she often runs out of money which has prompted the interest in participating in the trial.

112 Finally, we have obtained a copy of the form of consent documentation from the medical research company that proposes to run the medical research which DAH expressed an interest in. It runs to 19 pages of information and it starts by inviting a proposed candidate to take the time to read the 19 pages, discuss it with a doctor, and that:

> You should not sign the documentation until you understand all of the information presented.

113 It says that participants will have an initial screening visit and examination to investigate eligibility, and, if the candidate is considered appropriate and suitable, that the trial will consist of 11 days of confinement during which participants will live in a clinic, eat meals provided and will be tested throughout by way of physical examinations and blood tests. It requires the participants to provide personal and medical information and refrain from certain activities.

114 The notes set out two and a half pages of possible risks of treatment and expressly state that there will be 'no clear benefit' to participants in the study, although it is said that the information obtained as a result of the study may help others.

115 We also heard from several people during the hearing.

116 We heard from DAH herself, who answered a series of questions as to how she became aware of the medical trial, what she understood of it, and why she wanted to participate in the trial.

117 In that regard, she said that she wanted to participate in the trial because it is something different and she is interested in seeing how her body reacts to the medication. She also said that as at today's date she still holds an interest in understanding that reaction of her body.

118 She also said that she understood that the applicant had concerns about her participation in the trial that went to possible impacts on her health, but she declined the opportunity to say anything about

her capacity to make the decision in question; i.e. to participate in the medical trial.

119 We also heard from Ms D, who is DAH's mother, who said that she attended primarily to support DAH, but did speak to us about DAH's capacity to make certain decisions.

120 She said that in her view DAH had the capacity to make decisions concerning everyday living activities, but that in her view – that is, Ms D's view – DAH did not have the capacity to make the decision in question, that is, the decision to participate in a medical trial.

121 We also heard from the applicant and her colleague, Ms S, who have both worked with DAH. They did not really take the matter much further in that they spoke only to matters that were already in the written materials. In so saying we do not express any criticism of either of them.

122 Equally, the current guardian (being a delegate of the Public Advocate) also gave evidence without going much beyond what was already in the written materials, save that she said that in her role she had only limited involvement with DAH. She said that her functions are limited to the determination of the provision of services and in that capacity she deals mainly with the applicant, that she has only met DAH once, although she has spoken with her several times over the phone, and that most of the information about DAH comes from the applicant.

123 The view of the current guardian is that DAH can make decisions about daily living but a decision to participate in ***medical research*** was complex and involved, amongst other things, an understanding of ethical approval; in particular, whether the research had been approved by a HREC. For those reasons, it was her view that the application should succeed and that a decision-making function should be granted to the Public Advocate.

124 Following all of that oral evidence, DAH was then given another opportunity to say anything, including by way of response, but she did not take that opportunity up. Again, we make no criticism in that regard.

125 As is obvious from our description of the written materials from the drug research company, participation in medical research requires informed consent.

126 That is, participation can only occur if a candidate agrees to participate in circumstances where they have previously been advised of what the trial involves, including what the risks are to them. But the provision of advice to the candidate is only sufficient if they are able to:

(a) understand what has been said or been read;

(b) sit through the provision of that information to ensure they understand all of it;

(c) place that information within a body of knowledge and understanding about their own circumstances;

(d) recognise any gaps in the information or concerns about what the information might mean for them given their own circumstances;

(e) be able to identify someone suitable with whom they can discuss the issue;

(f) be able to both choose the words necessary to ask the questions relevant and be able to understand the answer;

(g) then place the questions and their answers back into the whole body of information, assess it all, weigh up the risks against any benefits; and

(h) then be capable of independently making a decision.

127 Both the applicant and the current guardian have real concerns that DAH is not able to do all of that. We are satisfied and we find that DAH is unable to do so. We make that decision conscious of the presumption of capacity in s 4 of the GA Act.

128 In our view, that presumption is displaced for the following reasons. Firstly, those that know DAH well, including the applicant and DAH's mother, are both of the view that DAH lacks that capacity.

129 Secondly, it seems accepted, and certainly the medical evidence that we have referred to is clear, that DAH suffers an intellectual disability.

130 Thirdly, it also seems clear that particular aspects of DAH's intellectual disability identified in childhood and young adulthood are concerned with language and concentration and functional

decision-making so, for example, several reports spoke of her inability to understand what was being said.

131 The medical report of June 2019, we have outlined, notes that DAH has particular and severe difficulties with language and memory and also has difficulties with attention, concentration and memory.

132 The report of January 2014 spoke of particular difficulties in filling out forms.

133 The undated report spoke of DAH's difficulties with receptive language and the need for instructions to be simplified or explained, spoke of significant language delays, spoke of limited ability to communicate her wants, and spoke of a real concern as to DAH's capacity to seek appropriate treatment and, 'make reasoned decisions about any significant non- routine health issues that may arise'.

134 As we have also said, the very recent NDIS report speaks of significant difficulties with language and communication, concentration and functional decision-making, the last of which, again to quote, said that:

> [DAH] struggles to recall information and provide an accurate timeframe for events and has poor long term memory. Her poor executive functioning means her working memory is problematic and impacts on her attention and ability to retain information.

135 The evidence speaks of DAH's inability to concentrate, of her limited ability to understand complex language and concepts, speaks of a lack of awareness of her own limitations so that she overestimates her abilities, and her inability to recognise and weigh up risks.

136 DAH's limited capacity in these areas make it most unlikely, in our view, that:

(a) she will be able to sit, read and understand the 19 page document or its equivalent,

(b) place the information contained in it within knowledge of her own circumstances;

(c) identify issues that require clarification and formulate questions;

(d) identify a suitable person to ask, and understand their answer;

(e) weigh up pros and cons of participation; and, then

(f) make a reasoned decision.

137 It is also clear that DAH is vulnerable to financial abuse for a variety of psychological factors, together with her intellectual disability. That raises further concern about her ability to make reasoned decisions in her own best interests where large sums of money form part of the factual context for the decision.

138 For these reasons we are satisfied that DAH is unable to make decisions in her own best interests as to whether or not to participate in ***medical research*** trials, and we find, therefore, that she lacks capacity to do so.

139 We are also satisfied and we find that there is a need for formal orders to be made granting a substitute decision-maker a function of making decisions on her behalf in this regard.

140 There are several aspects to our conclusion.

141 Firstly, DAH clearly has an interest in participating in such trials. She has approached one firm and, in her oral answers to us in the hearing, as we have said, expressed an ongoing interest in how medication impacts her physical body.

142 Secondly, we are told that at a superficial level, DAH's disability may not be immediately apparent, and she may well be able to persuade others that she understands what she is doing.

143 Thirdly, formal orders will have the effect of putting beyond doubt that DAH does not have capacity and it will have the effect of nullifying any decisions made by her to participate in any clinical trials, should they have been made, so as to prevent participation in the first place or end participation if it has begun.

144 We see the need for formal orders as protective, which is plainly the purpose of the legislation.

145 Turning then to the question of who ought to be granted the relevant function. We note that granting guardianship functions to the Public Advocate must only occur as a last resort. That is, when no one else consents.

146 Given the ongoing guardianship role played by the Public Advocate, we have assumed that no one else consents and, indeed, no

one has put themselves forward to consent. As we have said, the Public Advocate has been the guardian since January 2015.

147 For those reasons, we will grant the function of ***research decision-maker*** to the present guardian, that is the Public Advocate, for a term ending not later than 20 February 2025, that date being the date for review of the current orders.

148 Accordingly, we make the following orders:

Orders

The Tribunal declares that the represented person, DAH is:

(a) incapable of looking after her own health and safety;

(b) unable to make reasonable judgments in respect of matters relating to her person;

(c) in need of oversight, care or control in the interests of her own health and safety; and,

(d) in need of a guardian.

The Tribunal orders:

Guardianship

The guardianship order dated 25 February 2021 is revoked and substituted with an order in the following terms:

1. The Public Advocate of David Malcolm Justice Centre, Level 23, 28 Barrack Street, Perth, Western Australia is appointed limited guardian of the represented person with the following functions:

    (a) to determine the services to which the represented person should have access; and,

    (b) as the research decision-maker for the represented person – subject to subsection 45(4A)(a) and sections 110ZR and 110ZT, to make research decisions in relation to the represented person.

2. The Tribunal approves delegation by the Public Advocate of her functions as guardian of the represented person to an officer or employee employed in the Office of the Public Advocate.

3. The guardianship order is to be reviewed by 20 February 2025.

I certify that the preceding paragraph(s) comprise the reasons for decision of the State Administrative Tribunal.

RM
Associate to Deputy President Judge Jackson

6 NOVEMBER 2023