Neutral Citation Number: [2023] EWCA Civ 1262

Case Number: CA-2023-002011

In The Court Of Appeal (Civil Division)
On Appeal From The High Court Of Justice (Family Division)
Mr Justice Peel
Fd23p00452

Royal Courts Of Justice
Strand, London, Wc2a 2ll

Date: 23/10/2023

Before:

Lady Justice King
And
Lord Justice Birss

- -

Between:

Dean Gregory	**Defendant/ Appellant**
- And -	
(1) Nottingham University Hospitals NHS Foundation Trust **(2) Indi Gregory (By Her Cafcass Guardian, Kathleen Cull-Fitzpatrick)** **(3) Claire Staniforth**	**Applicant/ Respondents**

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Bruno Quintavalle (instructed by **Andrew Storch Solicitors**) for the **Appellant**
Emma Sutton KC (instructed by **Browne Jacobson LLP**) for the **First Respondent**
Katie Scott (instructed by **CAFCASS**) for the **Second Respondent**
The Third Respondent did not attend and was not represented

Hearing date: 23 October 2023

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Approved Judgment

This judgment was delivered ex-tempore on 23 October 2023 and the perfected judgment finalised on 30 October 2023 by circulation to the parties or their representatives by e-mail and by release to the National Archives.

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Lady Justice King:

1. This is the judgment of the Court.

2. This is an application for permission to appeal against orders made by Peel J ('the judge') in respect of a baby girl, Indi, who was born on 24 February 2023 and is a patient in the Paediatric Intensive Care Unit ('PICU') of Nottingham University NHS Trust ('the Trust'). Indi is the much-loved child of devoted parents and as the judge said: 'this case is about the precious life of a very young person, a family member and an individual in her own right'.

3. On 16 October 2023 the judge sitting in the Family Division of the High Court made the following order:

> "1. By reason of her minority, Indi is unable to consent to her medical care and treatment.
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> 2. It is in Indi's best interests to be cared for in accordance with the compassionate care plan dated 9 October 2023, and such other treatment as her treating clinicians in their judgment consider clinically appropriate to ensure that Indi suffers the least pain and distress and retains the greatest dignity, and the court consents to the implementation of the compassionate care plan on her behalf.
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> 3. It is not in Indi's best interests to continue to be intubated and invasively ventilated, she will be extubated as soon as practicable, and no later than 7 days from the date of this order (the exact day to be determined by Indi's treating clinicians, in consultation with her parents), and the court consents to the withdrawal of intubation and invasive ventilation on her behalf.
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> 4. It is not in Indi's best interests (once extubated) to again be intubated and provided with any aggressive care or painful interventions including (but not limited to) blood tests, inotropic support, cardiopulmonary resuscitation, bag/mask ventilation or any new vascular or intraosseous access, and the court consents to this ceiling of care on her behalf.
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> 5. It is in Indi's best interests to be provided with non-invasive ventilation (including High Flow Nasal Cannula, CPAP, or BiPAP), as clinically indicated, for a period of up to 7 days post extubation, and the court consents to this treatment on her behalf.
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> 6. Non-invasive ventilation will be provided to Indi in accordance with paragraph 5 above unless:
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> i) Indi shows any sign of distress (based on clinical judgment), such that non-invasive ventilation will cease post extubation before 7 days expires; or

> ii) There is a significant improvement in Indi's overall clinical presentation (for instance if she is weaning off non-invasive ventilation and would only need a short extended time, based on clinical judgment) such that 7 days may be extended. Once Indi is weaned off non-invasive ventilation, this will not be restarted.
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> 7. If Indi continues to require non-invasive ventilation after a period of 7 days post extubation (and paragraph 6(2) does not apply), it is in her best interests to be provided with compassionate care only, including any appropriate pain relief, in accordance with the compassionate care plan dated 9 October 2023, and the court consents to the implementation of the compassionate care plan in such circumstances on her behalf. For the avoidance of doubt, this does not prevent Indi's treating clinicians continuing to provide non-invasive ventilation to Indi after a period of 7 days post extubation (in accordance with paragraph 6(2) above), if, in their clinical judgment, it is appropriate so to do, but they cannot be compelled to do so."

4. Mr Quintavalle in seeking permission to appeal on behalf of the applicant Dean Gregory ('the father'), was in both his opening and closing remarks frank as to his position saying that the father accepted that the decision that the judge had made now reflected in the declarations and order set out above 'may well be right' and that he was not saying that the judge had been wrong in his conclusion, but rather that absent the father having adduced his own independent expert evidence, the judge did not have a sufficient evidential basis upon which to reach his conclusion, the more so in such a serious case.

5. For this court to grant permission to appeal, it must be persuaded that an appeal against the making of that declaration would have a real prospect of success or that there is some other compelling reason for an appeal to be heard: CPR 52.6. If that test is not satisfied, permission must be refused.

Background

6. It was known before her birth that Indi had serious health difficulties and in particular that she had a hole between the two main chambers of her heart. After birth it was almost immediately found that her heart had a tetralogy of Fallot which is a combination of heart defects. This was then followed by a diagnosis of intestinal malrotation for which she underwent surgery. In June 2023 the devastating diagnosis of Combined D-2,L-2 hydroxyglutaric aciduria, a mitacondrial condition was made. In summary, Indi suffers from the following disorders:

    i) Combined D2, L-2 hydroxyglutaric aciduria, a metabolic disorder that causes progressive damage to the brain. The disorder is characterised by epileptic encephalopathy, respiratory insufficiency, abnormalities in the brain, developmental arrest, and early death;

    ii) Severe bilateral progressive ventriculomegaly which lead to enlarged brain ventricles from a build-up of spinal fluid;

iii) Tetralogy of Fallot which affects normal blood flow through the heart;

7. Indi is provided with multi-organ support and has the highest level of intensive care, that is to say one to one care 24 hours a day.

8. The judge set out the progress of Indi's various medical conditions. She has been on full life support since 6 September 2023 and is critically ill, intubated, ventilated, and sedated. What is uncontroversial is that the nature of her various conditions has meant that this tiny baby has, all her short life measured in months not years, undergone extensive invasive treatment in order to keep her alive. This has included surgery for intestinal malrotation, the fitting of a shunt in her brain to assist with the build-up of fluid and the drilling of a needle into her bones on numerous occasions to deal with her challenging IV access. On eight occasions she has required PICU or NICU ventilation, she has suffered from frequent and serious desaturation episodes and on three occasions she has had Cardiopulmonary Resuscitation ('CPR') when she went into cardiac arrest. On at least two occasions she had blood transfusions. It is now too dangerous for an MRI scan to be carried out in order to see the extent of further deterioration of her brain.

9. It is common ground that the Trust have sought advice both nationally and internationally from a range of experts and have been open to and attempted novel and experimental treatment, none of which has succeeded in arresting the downward trajectory of her condition.

10. Following a serious desaturation episode on 6 September 2023, Indi was fully intubated and has been intensely ventilated ever since. The evidence from the clinicians who gave evidence before the judge was that the current level of intensive care might prolong her life for a few weeks or months, whereas without such treatment her life expectancy can be measured in days or a week or two.

Pain:

11. No parent would wish to see their child in pain and this father is no different. In his composed and dignified evidence before the judge, he expressed his belief that Indi experiences pleasure and he was adamant that she does not experience significant pain. His view is that '*any minor distress is outweighed by the benefit from continued life'*. Unhappily that understandable view is contrary to the overwhelming evidence. The judge set out the evidence of Dr E at [32] vii**:**

> "Dr E has himself observed episodes of distress and agitation, which the bedside team sees multiple times a day. The current treatment causes [Indi] pain, exposing her to harmful procedures and therapies which provide no long-term benefit. She displays signs of distress during interventions (such as handling, suctioning, use of IV lines, blood tests) and reacts to painful stimuli, including crying (tears well up in her eyes), increased heart rate and mottled skin, wincing and gasping. These episodes of distress can last up to 10 minutes."

12. The judge also set out the evidence of one of the nurses at [36]:

> "I asked to hear from one of the nursing staff who was present in court, but had not provided a witness statement. Nobody objected. She told me that [Indi] is distressed by the various interventions. She struggles to breathe, winces, coughs and her eyes fill with tears. This takes place several times a day, often lasting several minutes, in response to medical interventions."

13. The judge held at [43]:

> "I take the view that the parents do not recognise the pain she is suffering, perhaps because, as the Guardian put it, they see Indi through their own lens. That is completely understandable. They are hoping against hope for something positive to emerge. However, the evidence clearly establishes that she experiences significant pain and distress several times a day, and each painful episodes lasts up to ten minutes. It has been observed by Dr E, other clinical team members, the nursing staff and the Guardian, all of whose evidence I accept. The descriptions of her wincing, struggling to breathe, gasping and developing tears in her eyes are vivid. Such pain is caused by her multiple treatment interventions including invasive ventilation, suctioning, use of IV lines, blood tests and the like. It will continue for as long as the interventions continue."

14. This court will not go behind the judge's finding of fact as to the level of pain and distress suffered by Indi which finding was confirmed when, for the purposes of this hearing, at our request Dr E provided a short statement updating the court as to Indi's current condition. The statement charts an inexorable decline in relation to her distress and agitation. He said at [6]:

> "We attempted to wean her sedation at the beginning of the week, as she was a little calmer, but then needed to go back up (above her previous level) as she was significantly distressed and agitated. The nursing team have told me that she has had prolonged episodes of distress and being unsettled, especially linked to fevers and after large stool motions. Her continued and prolonged distress is exhibited by disordered breathing, grimacing, squirming, and crying.
>
> She is currently on ketamine and oxycodone infusions (the oxycodone was swapped from fentanyl as part of our standard rotation), regular promethazine, clonidine, and gabapentin, and as required chloral hydrate and paracetamol. This is a significant amount of pain relief/sedation, and as set out above, is above the previous level provided (as at the date of the final hearing).
>
> She continues to display no purposeful interaction with the world around her."

15. Indi's parents accept that she is fragile and has limited life expectancy, but say that she shows no signs of serious pain, that she is currently stable, and that the precise causes

of her presentation are unclear. She can, they believe, achieve some autonomy in the future.

16. The father had thought that the fever to which Indi is susceptible was caused by infection. In fact it is not and is part of the deterioration of her brain function. At the hearing on 3 October 2023, the father agreed for her antibiotics to stop as there had been no evidence of infection since 28 August.

17. It was against this desperate background that the hospital made their application on 7 September 2023 on the basis that continued invasive intervention was not in Indi's best interests.

18. In the great majority of these sad cases, doctors and family members are able to reach agreement about whether treatment should continue. Where, as here, there is disagreement, an application may be made to court.

19. As the judge observed, it is necessary at such a hearing to consider the entire picture of this profoundly sick little girl, by way of example, her heart condition on its own would be treatable, but as recently as 4 October 2023 at a joint cardiac conference at Birmingham Children's hospital, it was concluded that her presentation is not materially caused by her heart condition and the cardiac team were not willing to provide and treatment for her heart.

20. The judge found that Indi is on a rapid downward trajectory and is at the limits of what is medically available for her. That that is the case is confirmed by today's update on Indi's condition which sets out in detail her continued deterioration notwithstanding the administration at the request of the father, of a mitochondrial cocktail.

21. Against this background the judge held as follows at [40] and [41]:

> "As against that, the medical evidence is unanimous and clear. I accept what I was told by Dr E, Dr S and the nurse. I am satisfied there is no gap which needs further inquiry. Tragically, Indi has an incurable condition which, combined with her other morbidities, will lead to a fatal deterioration within, at the most, a few months even if she receives ongoing full critical care, and probably a few days if invasive interventions are withdrawn. Beyond prolonging life, which in itself has a value and to which I pay high regard, treatment is futile. There are no curative therapies. Indi is progressively deteriorating, and highly unstable. She has reached the limit of what medicine can achieve. She will not recover from, or even have minor improvement to, her life-limiting conditions. Her short life has consisted of cycles of stability, punctuated by episodes of acute care associated with painful stimuli, leading to the most severe episode of all in early September from which she has not recovered. Physiological deterioration is occurring regardless of treatment. Cardiac treatment will not address the underlying incurable disease. Nor, on the evidence, is it a feasible option as it is clear no cardiological treating team would be willing to provide any cardiac intervention. CPR would be without any

> purpose for the reasons outlined by Dr E. The parents' belief that her presentation has been caused by infections since early September is not supported by the evidence. The current fever spikes are not symptoms of infections, but a consequence of the progression of the mitochondrial disorder and evidence of ongoing damage to the brain. The reality in this case is that infection is not a cause of Indi's multiple diagnoses, but a consequence thereof. Tracheostomy ventilation is not practical or realistic. Whilst the ketogenic diet and administration of citrate may have some effect on reducing the number of desaturation episodes, they are still occurring.
>
> Although F's case, as presented through counsel, advanced the proposition that the causes of Indi's presentation are unclear, how the various morbidities interlink is unclear, and whether alternative treatment may provide better results is unclear, I do not agree. The medical evidence about this little girl is compelling. All her issues are interlinked, and her diagnoses and conditions, viewed in the round, lead to her current presentation. I am satisfied that there is nothing more than can be realistically done by the treating team. Similarly, on occasion questions were put to witnesses about the hypothetical treatment for a child not suffering from Indi's particular conditions, but ultimately the clinicians, and the court, are concerned with this particular child with this range of presentations".

22. Turning then to the proposed grounds of appeal: Grounds 1 and 2 relate to the judge's case management decision not to grant permission to the instruction of a raft of experts with the attendant significant delay which would result.

Ground 1: Anxious Scrutiny

23. Whilst Ground 1 is framed as a failure to provide 'anxious scrutiny' to the case in circumstances where the fundamental right to life is at stake, its focus is on the absence of extensive further expert evidence. The depth of the inquiry, it is submitted, was inadequate to decide a matter of life and death.

24. Having considered the judgment with care it is clear to anyone who may read it, [2023] EWHC 2556 (Fam), that this judge gave the case 'anxious scrutiny' and was at all times conscious of the importance of prolonging life, a matter to which the judge said at [40] he had 'high regard'.

25. Drawing on Macdonald J's summary of the law in *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426; [2021] 4 WLR 95, at [95] the judge reminded himself both that there is a strong presumption in favour of taking all steps to preserve life and also that there will be cases where it is not in the best interests of the child to subject him, or her, to treatment that will cause increased suffering and produce no commensurate benefit 'giving the fullest possible weight to the child and mankind's desire to survive'.

Expert Evidence

26. At the hearing on 3 October 2023, the father filed an application for leave to adduce evidence from experts in 4 disciplines:

    i) A mitochondrial expert;

    ii) A neuroradiological expert;

    iii) A consultant cardiologist;

    iv) A paediatric intensivist.

27. The test to be applied to applications such as the present, namely for declaratory relief under the inherent jurisdiction, is found in Part 25.4(3) of the Family Procedure Rules 2010. The test to be applied by a court when considering an application to obtain expert evidence is whether such evidence is 'necessary to assist the court to resolve the proceedings.' Mr Quintavalle mentioned s13 of the Children and Families Act 2014 but did not explain with any specificity as to how its application to the case would have made any difference, in any event he accepted that the test was essentially the same, namely 'necessary' rather than that found in the Civil Procedure Rules test under Part 35 which is whether such evidence is 'reasonably required'.

28. The judge refused the application for expert evidence in an ex-tempore judgment which he subsequently summarised in his substantive judgment at [20] as follows:

> "Save in one respect, at the hearing on 3 October 2023, I refused the application for expert evidence, and gave reasons in an ex-tempore judgment. In summary:
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> i) The application suggested that evidence would not be obtainable until 20 October, and that the proceedings should be adjourned to a date on or after 30 October. I did not consider that to fit within this child's timescale, given the urgency of the situation.
>
> ii) The medical evidence is extensive. There were three (now five) statements from Indi's lead consultant in paediatric critical care, a statement from a consultant in paediatric respiratory medicine, and a statement from a paediatric consultant with specialist interest in inherited metabolic disease; all are clinicians at the hospital where Indi is an in-patient. In addition, there are exhibited statements or letters from the cardiology teams at two nearby hospitals. The Trust has also commissioned a second opinion from a paediatric intensivist at another hospital in the form of two letters which are before the court.
>
> iii) The entirety of the medical evidence is unanimous. The medical evidence is that Indi is now almost certainly permanently intubated. Her conditions are irreversible and untreatable. The current treatment causes Indi pain, exposing

> her to harmful procedures and therapies which provide no long-term benefit. Life expectancy is severely limited and there are no curative therapies.
>
> iv) There was no medical evidence to the contrary offered by the parents. They said that Indi has an infection, but there was no evidence of that. All cultures were negative. In any event the parties agreed that Indi would cease to receive antibiotics, and further tests over the following few days should establish the position definitively.
>
> v) The application for expert evidence did not suggest what was incorrect, or might be incorrect, about the medical evidence currently before the court. There was no evidence of any alternative treatment which is theoretically possible, let alone practicable. There was nothing to indicate a gap in the evidence in any of the fields suggested.
>
> vi) I took the view that the application for expert evidence was somewhat speculative."

29. Although not considering it to be 'necessary', per Part 25 FPR 2019, the judge on the 3 October 2023 granted permission for the instruction by the father of a paediatric intensivist who had been identified by the father's legal team. Permission was granted on condition that the report was available no later than the 7 October 2023. The report was not ready and no application for an adjournment was made at the start of the hearing.

30. The judge, it should be borne in mind, was making these decisions against the backdrop of this being an urgent medical treatment case in respect of a critically ill baby.

31. As part of the same directions, the judge arranged for questions to be asked by the father at the Cardiac conference at the Birmingham Children's hospital, referred to at [18], convened for the following day. The two questions were: i) whether Indi's current presentation could be attributed to her heart condition; and ii) would the cardiac team be prepared to offer any treatment for her heart defect. The answer to both questions was 'no'.

32. The Trust identified four clinicians upon who they relied on and were to be available to give evidence. The principal evidence was given by Dr E, a paediatric intensivist, but Dr S a paediatric intensivist from another hospital also gave evidence. A paediatric respiratory consultant and a paediatric consultant with interest in inherited metabolic disease were each available to give evidence but were not required by Mr Quintavalle for cross examination.

33. The time estimates for oral evidence were agreed between the parties and no late application was made to suggest that the time estimate of one day was insufficient.

34. The judge found Dr E to be 'sensitive, thoughtful and compassionate' in his evidence wanting the best for Indi, but said the judge, ' his view of what is best is different from that of Indi's parents'. We should note that the judge had the clear impression that the

treating team as a whole is one of 'the utmost skill and dedication devoted to the care of Indi'.

35. The judge heard oral evidence from a Sister in the paediatric critical care team in relation to the levels of distress demonstrated by Indi and observed by the nursing team.

36. The judge also heard evidence from Dr S, the Paediatric Intensive Consultant from a different hospital. His conclusion was that:

> "Very sadly further ventilation, painful procedures or resuscitation is not appropriate, this is on the basis that physiological deterioration is occurring regardless of treatment and that the severity of her progressive neurological condition is such that she can no longer benefit from continued life".

37. The judge rightly took into account all the evidence including the written statements and the documents which were exhibited to them, all of which were properly before the court. Some extra material came in in relation to a diagnosis of diabetes insipidus after the judge had sent out his draft judgment. No objection to the judge taking this material into account was taken by any party. The evidence overall demonstrated not only Indi's parlous state, but also that the Trust had investigated treatment options for her not only locally but also nationally and internationally and had tried at least three experimental treatments.

38. It is not necessary to set out the full list of specialists who have considered Indi's case but in summary it amounts to:

    i) Four metabolic specialists including experts from Sheffield's Children's Hospital's specialist Centre for Metabolic diseases and a specialist Professor in Germany.

    ii) A paediatric intensivist from Birmingham, a consultant in paediatric respiratory medicine, a consultant in neuroradiology and consultant cardiologists from both Leicester and Birmingham.

39. Mr Quintavalle in his skeleton argument is not correct therefore to suggest that the consideration by the judge of Indi's best interests had been limited to '*The Applicant Trust's intensive care consultant'.*

40. Mr Quintavalle has set out at considerable length in his skeleton argument all the types of experts he would have wished to give opinions each to prepare a report written from the perspective of their own individual area of expertise, but as Dr E explained, Indi's life expectancy 'is not as the result of one particular diagnosis per se, it is a consequence of interlocked conditions and causes. Her problems are intertwined, impacting across various conditions and disciplines and cannot be compartmentalised'.

41. The hearing took place on 9 October 2023, no application was made on behalf of the father for a further adjournment either at the beginning of the case or after evidence was heard. The judge, however, said:

> "Nevertheless, throughout the hearing I bore in mind the possibility that the unfolding evidence might raise points or

> queries which would justify additional expert input. In the event having heard the case, I am quite satisfied that there is no need for any additional expert advice".

42. Nothing in the material before us shows that even if there had been further expert evidence, it would make any difference to the best interests decision made by the judge. The information before the judge was clearly more than sufficient for him to reach the decision he did and more than adequate to enable him to consider the case with the care necessarily required in any case involving the proposed withdrawal of medical treatment.

43. The fact that the evidence recognises there were uncertainties in relation to Indi's condition does not mean that further evidence was necessary. There are always, and inevitably will be, questions which remain unanswered in cases involving these vanishing rare mitochondrial diseases. The evidence that Indi's condition is incurable and that the medical intervention is causing her significant pain and distress is nonetheless clear and compelling.

44. According there is no real prospect of an appeal on Ground 1 succeeding should PTA be granted.

Ground 2: Equality of arms

45. Mr Quintavalle seeks to argue that, as only the trust had the realistic opportunity to adduce evidence about Indi's medical condition then, in order for the trial to have been fair, he should have been allowed on behalf of the father, to call a raft of experts. In this context, he referred the court to a series of European cases in relation to a party calling their own expert evidence in order to achieve equality of arms, most especially where the right to life is engaged.

46. Whilst equality of arms is the backdrop to any consideration of an application to adduce expert evidence, it is not suggested that the applicable rules and legislation which govern the admission of expert evidence into proceedings is not human rights compliant. The judge is therefore entitled to refuse an application for experts, as he did in this case for the careful reasons he gave whilst giving the father the opportunity to obtain a paediatric report, if it could be obtained within the timescales for Indi. It should be borne in mind that not only did the judge give the father every opportunity to test the evidence of all four of the clinicians but also, as is clear from the order of 3 October 2023, he facilitated arrangements to be made for him to have discussions with a consultant neurologist to help him and Indi's mother better to understand her prognosis and on 4 October 2023, the Joint Cardiac conference was held in Birmingham where the questions to be considered were agreed between the Trust and the father.

47. Mr Quintavalle seeks to compare Indi's case with that of the well-known case of Charlie Gard and a host of other medical treatment cases. It is not in our judgment helpful to attempt to draw on another case in this way relating as it does to a case involving a different patient in wholly different circumstances. This case is not a unique example of a court making a case management decision that no further medical evidence is necessary, see for example: *St George's NHS Foundation Trust v Casey* [2023] EWCA Civ 1092.

48. Notwithstanding Mr Quintavalle's submissions, in our judgment there is no real possibility of a court finding on appeal that the judge had been wrong in concluding that there was no gap in the medical evidence, and that he had accordingly been wrong in his case management decision that no further expert evidence was necessary in order to resolve the issues before him.

49. There is no real prospect of the father succeeding in an argument that the trial did not comply with Article 6 ECHR even when taking into account Article 2 ECHR.

Ground 3: Discrimination

50. Mr Quintavalle rightly submitted that the UN Convention on the Rights of Persons with Disabilities has an interpretive role in relation to Article 2 ECHR. However, he also argued that withdrawal of life-sustaining treatment amounts to discrimination. This proposition was advanced without authority or further exploration of in what way Indi has been discriminated against or what is the type or nature of discrimination she has suffered.

51. Permission to appeal is accordingly also refused on Ground 3.