An investigation based on a complaint regarding a HSE decision in relation to an application for funding for assistance for treatment abroad

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Ombudsman for Children

A statement under the Ombudsman for Children Act 2002

An investigation based on a complaint regarding a HSE decision in relation to an application for funding for assistance for treatment abroad

April 2013

Ombudsman for Children's Office
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1. Introduction

Ombudsman for Children Statutory role and remit

1.1 The Ombudsman for Children's Office provides an independent and impartial complaints handling service. The investigatory functions and powers of the Office are set out in Sections 8-16 of the Ombudsman for Children Act 2002. This provides that the Office may investigate the administrative actions of a public body, school or voluntary hospital where, having carried out a preliminary examination, it appears that the action has or may have adversely affected a child and where those actions come within the ambit of Sections 8 (b) or 9 (1) (ii) of the 2002 Act.

1.2 The Office can receive complaints directly from children and young people or any adult on their behalf. The Ombudsman for Children may also initiate an investigation of her own volition where it appears to her, having regard to all the circumstances, that an investigation is warranted.

1.3 The Office aims to carry out investigations and to make recommendations which are fair and constructive for both parties. In the context of an investigation, the Office is neither an advocate for the child nor an adversary to the public body.

1.4 In accordance with Section 6(2) of the Act, the Office is obliged to have regard to the best interests of the child and in so far as practicable, to give due consideration, having regard to the age and understanding of the child, to his or her wishes.

1.5 The principal issues to be addressed through an investigation are:

(a). whether the actions of the public body has, or may have had, an adverse effect on the child involved; and

(b) Whether those actions were or may have been:

- (i) taken without the proper authority;
- (ii) taken on irrelevant grounds;
- (iii) the result of negligence or carelessness;
- (iv) based on erroneous or incomplete information;
- (v) improperly discriminatory;
- (vi) based on undesirable administrative practice; or
- (vii) Otherwise contrary to fair and sound administration.

1.6 This statement has been prepared in accordance with Section 13 (2) of the Act, which requires the Ombudsman for Children to produce a statement outlining the results of an

investigation. In accordance with the Act, this statement is for distribution to the public body under investigation, the complainant, other relevant parties involved in the investigation and any other persons to whom she considers it appropriate to send the statement.

1.7 A copy of this draft statement was sent to the public body under investigation, in accordance with Section 13 (6) in order to provide them with an opportunity to consider the findings and make representations in relation to same. The response received has been considered and where appropriate, amendments or responses have been incorporated into the statement.

2. Complaint Details

2.1 In April 2011 a complaint was submitted to the Ombudsman for Children's Office by the parents on behalf of the child aged 7 years. The child concerned was born with limb abnormalities affecting his right leg and his arms. The child does not have a left arm and has abnormalities of his right arm together with a condition whereby the femur on his right leg does not grow on its own. The problem which is currently being addressed for him through treatment in the US involves his right lower limb. He has an absence of the upper end of his right femur including the hip joint and his leg is very short. He needs extensive reconstructive surgery to his right hip and leg. The parents explained that as their son's right leg does not grow properly, he requires limb lengthening surgery, which they contend can only be performed in the United States of America.

2.2 The parents advised that their son received two such operations in the US in 2006 and 2009 and funding for 70% of the costs associated with the operations and the trip to the USA were provided by the Health Service Executive (HSE) under its Treatment Abroad Scheme (TAS). The cost of the operations is paid by the parent's private health insurer and currently the cost of physical therapy is also covered by the insurer.

2.3 The parents state that their consultant orthopaedic surgeon advised them that their son had no hip and spoke about amputation for him. The parents advise that because the child does not have a left arm a prosthetic limb would be difficult for him to manage. The consultant encouraged the parents to complete their own research in limb lengthening for him. The parents met and contacted doctors in Dublin, Cork, Belfast, the UK, France, Germany, Russia and America. They were seeking physicians who would be experienced enough to undertake leg lengthening for their son. On completion of their research they discovered two doctors one in Baltimore, Maryland, USA and another doctor in Russia.

2.4 They chose the US consultant because their health insurer at the time had identified him as the best international doctor and he was also recommended by their consultant in Dublin.

2.5 In his consultations with the parents prior to treatment the US consultant advised them of the requirements on them to support the child's treatment. This involves

- Living in the USA for approximately 4 months at a time when surgery is performed for limb lengthening. The treatment involves cutting a bone to encourage tissue to grow and an applicator is used to support the surgery.
- The applicator has to be turned four times daily.
- The child has pool therapy and physical therapy daily.
- The parents have responsibility to clean and dress the wounds daily
- The child sees his doctor weekly whilst in the USA.
- The child has a fixator fitted to his leg for 8 months after the surgery.
  The US consultant assured the parents that the child would have two legs of equal length by the time he reached age 16 years.

2.6 The parents are aware that trainees of the US consultant may now be giving similar treatment in the UK, as was raised by the HSE. They are reticent about taking their son to a less experienced practitioner than his current doctor. Further they specifically express their understanding that there is a significant difference in relation to the clinical outcome of the treatment in the USA in regard to the level of length that can be achieved. The parents also contend that this surgery was not being carried out in the UK at the time of his diagnosis and indeed, at the time they commenced treatment under the US consultant. They had researched alternatives and according to the parents the only equivalent procedure at the time was being carried out in Russia.

2.7 The parents applied for funding from the HSE in 2006 in relation to subsistence and travel to the USA. The application was initially rejected as it did not come under the TAS but following a review was verbally granted in 2007. The parents had provided, upon request from the HSE, a care plan from the US consultant. The HSE sought further clarification on this plan directly from the US consultant in 2008. Following this clarification the parents received a letter dated February 2009 (considered further in paragraph 3.1) from the HSE and it was the parent's assertion that this letter provided that the following "appointments" for their son for treatment in the US were "covered" as follows:

- *Surgery in May 2009 and surgery at 12yrs and 16yrs of age*

- *One review visit per year between these dates was also covered*.

The letter also advised that any visits outside of these dates would require a new application and recommendation from the US consultant. There were no further restrictions in this letter. The letter stated that, subject to a means test, the HSE will provide funding for the costs associated with the travel to the USA.

2.8 An additional surgery is now required for the child due to an infection which occurred after surgery in 2009 which meant that he did not achieve the anticipated growth expected after the success of his 2006 surgery. After surgery in 2006 it was anticipated by the US consultant that four surgeries in total would be required however, following this infection, five surgeries are now required. This means a further trip for the surgery in 2013 which was not covered in the consultant's submission to the HSE for the approval received from the HSE in 2009. This additional surgery was also not provided for in the letter dated February 2009.

2.9 In their complaint, the parents highlighted concerns that, despite its previous commitment, the HSE had informed them in 2011 that their son was not entitled to funding under the Treatment Abroad Scheme as his treatment is being provided outside the EU/EEA. They were advised that a new National Travel Policy was introduced in November 2009, however the parents underline that they received approval for the surgeries prior to the introduction of this policy. They contend that this new policy does not negate agreements/ approvals made prior to its introduction.

2.10 The parents report that they were informed by telephone in April 2011 that they owed €5000 to the HSE for accommodation that was not covered by TAS scheme. The parents contend that funding to cover accommodation was agreed by HSE and supplied documentation to support their contention, in particular an email dated May 2009 which states that the HSE would provide funding up to the value of €1,200 per month.

2.11 The total costs to the HSE for travel and subsistence and other related costs such as shoe lifts, prescriptions and out patient treatment not covered by the private Insurer to date have been calculated by the HSE as €29,957.89, representing 70% of the associated costs. This sum also includes an amount calculated as overpayment. The child had two surgeries completed over this time in 2006 and 2009. The child has attended for yearly review visits and costs have been covered. The plan for the child is three further surgeries in 2013, 2016 and 2020.

2.12 The parents do not accept the recent estimates of overpayments made by the HSE. They believe the matter of €5000 owed for accommodation costs to be a mistake by the HSE as they have evidence in writing that these costs were agreed with the HSE. The HSE have written to the parents with respect to the need to submit a P60 for the year 2009/2010 to process their later claims. The parents believe that they have provided all the necessary information for processing of their claim in relation to 2009 surgery and 2010 expenses. The parents contend that the means testing in relation to the grant of 2009 which covered surgery in 2009 and the fixator removal in 2010 has already been completed by the HSE through the information provided for their household income in 2008. They have submitted the receipts for the expenses claimed for 2009 and 2010 for the grant of 2009. They understand that the outstanding claim is the expenses for the review visit of 2011. According to the HSE there are claims outstanding for 2010 and 2011 and they are seeking to complete a means test of household income for 2009 and 2010 in relation to these later claims.

2.13 In response to the draft statement the HSE contend that a number of the issues detailed in the parents' complaint are untrue and inaccurate.

3. The Investigation

3.1 The parents applied to the HSE TAS in September 2006 for financial assistance towards expenses associated with treatment outside the State for their son. The parent's application included letters from their consultants in Ireland and the USA as well as estimated costing for treatment. The parents advised the HSE in their letter of application that their Health Insurer had agreed to cover the inpatient costs but did not cover physical therapy. The parents also advised the HSE about the duration of treatment until the child was 14 to15 years old.

3.2 Although the child was not referred to the USA via the TAS Office, in this case the application made by the parents was submitted to the HSE medical advisor and approval was given for the treatment plan as outlined by the child's consultant in the USA. An internal memorandum in the Overseas Section (TAS) to the medical advisor dated October 2006 shows that the file was sent to the medical advisor at the time requesting a recommendation on the application in relation to financial assistance towards the cost of medical treatment outside the state not covered by model form E112 (IRL) funding. The medical advisor recommended approval.

3.3 In October 2006 the Overseas Section wrote to the parents advising them to complete a means test form and enclosed a description of the means tested discretionary Hospital

Services Scheme for their information. These application forms for payment under the HSE scheme for Hospital Services, Travelling and Subsistence Expenses were returned completed by the parents in October 2006. A letter included with the forms from the parents stated that the operation at that time was only stage one of the treatment procedure which would be ongoing until the child was fully grown. The documentation in this case shows that a General Manager, now retired, instructed his staff member to process this application under TAS.

3.4 The parents received a letter dated November 2006 from the Overseas Section advising them that their application for financial assistance towards the cost of lawfully permitted medical treatment or examination outside the State did not qualify under the HSE Overseas Section's Treatment Abroad Scheme under the EEA Social Security Regulations 1408/71 and 574/72 as amended. This letter stated that their application for travel and subsistence was also outside the Scheme.

3.5 The HSE then referred the case in November 2006 to the Director of the Disabilities HSE for that area. This service replied to the HSE in December 2006 stating that Disability Services *are not funded to cover the cost of overseas treatment* and *that this would have been the remit of the overseas section to provide funding for this as was the case in the past.* The letter stated that the Disability Services would *strongly support* the parents' application for funding to the HSE Overseas Section.

3.6 In November 2006 the parents made an appeal to the HSE Customer Services, Information and Appeals against the decision of the Hospital Services Scheme which had issued via the letter in November 2006.

3.7 An email dated December 2006 from the General Manager to a staff member states that the family have been to the US for treatment and advises the staff member to contact them to *submit their costs and we will make a decision about the extent to which we can fund*.

3.8 In December 2007 an email to the parents from the staff member informed them of the approval of their application made in 2006 and stated what was admissible for claim was accommodation, car hire, flights and they had approval for 70% of the claim.

3.9 The parents submitted claims after this initial approval for 70% funding for subsequent years for travel and subsistence. These claims were processed and the parents were reimbursed for costs associated with the USA visits. The HSE reimbursed the parents

€12,678.00 for travel and subsistence and €5000.09 for treatment costs for 2006 -2007. In 2008 the HSE reimbursed the family €2,131.09 travel only. In 2009 the HSE prepaid the parents €10,438.90 based on estimates submitted by the parents for travel and subsistence.

3.10 In December 2008 the HSE Overseas Section wrote to the US consultant seeking clarification from him about the child's treatment. The email indicated that the HSE "*wished to assess the possibility of providing additional funding"* to the family for the child's treatment and travel and subsistence costs. The HSE requested the consultant to provide "*an up to date medical report, outlining the child's progression, based on the treatment provided and a clear plan on the child's continuing treatment over the coming years*". The email stated that the HSE would endeavour to give the parents a decision on the provision for the child's treatment. The consultant replied in January 2009. The Irish consultant who originally saw the child had written to the HSE previously in support of the parents' application for treatment outside the state.

3.11 The HSE having confirmed the treatment plan with the US consultant wrote to the parents by letter dated February 2009 and outlined that the HSE intended to fund travel and subsistence for the USA. The funding was subject to a means test. The letter sets out that the funding would be provided in respect of specific appointments only, namely those appointments pursuant to the US consultant's recommendation. The appointments which would be covered under this approval were a surgery in May 2009, surgeries at 12 and 16 years of age and one follow up visit per year between these dates. Any visits outside of these dates would require a new application and recommendation from the US consultant.

- *The level of costs which would be covered during these appointments were as follows:*
    - *Costs for two accompanying parents provided a referring consultant certified the need for two parents to travel.*
    - *Transport costs for the patient and approved accompanying escorts, from point of departure air/ferry port. Transport costs in Ireland are not covered.*
    - *The cost of car hire within the US provided there are no other travel expenses claimed for- taxis, trains, buses etc. Fuel is not covered.*
    - *Outpatient prescriptions, Shoe lifts and Brace subject to a copy of prescriptions and receipts being supplied.*
    - *Advised the parents were to apply to the Community Welfare Officer with regard to inadmissible expenses.*

The matter of cover for accommodation costs was not mentioned in this letter. The family had stayed in Ronald Mc Donald accommodation for the first surgery in 2006 as the costs were low relative to renting other types of accommodation. However the treating consultant moved his practice to a new location in Florida in 2009 and this type of accommodation was not available to the family there. In an email dated May 2009, the HSE advised the family that funding was available for accommodation up to the value of €1200 per month for the trip in 2009.

3.12 In February 2010 the parents advised that they submitted receipts to the HSE for the 2009 trip and at that stage they were informed of a new travel policy in a telephone call with an official from the HSE which they understood covers 100% of the cost of flights. The parents asked for a copy of the new policy which was emailed to them subsequently. The parents' state that they understood that this conversation with the HSE official related to the costs for the further operation required by the child that was not detailed on the original treatment plan submitted by the US consultant and is scheduled to take place in 2013. The parents believed that approval remained in place for all other treatments as outlined in the letter of February 2009 from the HSE.

3.13 The parents state that the first time they realised that this might not be the case was after a further conversation with a HSE official about receipts in March 2010. This official is reported to have said that shoe lifts were not covered for their son and referred the parents to the new policy. The parents responded by sending the official a copy of the letter dated February 2009 which showed that shoe lifts were covered.

3.14 When the parents submitted a bill for the flight costs for the child's next review in May 2011, they received a letter in March 2011 from the current General Manager of the HSE TAS. This letter informed them that the child's treatment was outside the criteria for TAS and "*as such no approval can be given for any funding under this scheme*". The letter stated that on a once off basis TAS would fund air fares for the child and one escort. However the letter further stated that the authorisation of this payment should not be interpreted as any indication that further approvals for such payments would be made by TAS.

3.15 The parents contacted the HSE to seek clarification on this matter and to appeal this decision. They received a letter from the Assistant National Director of the HSE dated March 2011 which concurred with the General Manager's decision that the child was not entitled to funding under the TAS as his treatment was being provided outside the EU/EEA and a once off payment for airfares would be made to the parents.

3.16 The parents now believe that the only costs which will be covered by the HSE will be flight costs for their son with one parent to the USA as outlined in the new 2009 travel policy of the TAS.

3.17 The parents dispute the statement by the HSE that they owed €5000 for accommodation costs for which they had not given approval. The parents have correspondence (see Para 3.11) from the HSE confirming that accommodation costs are covered.

3.18 As already stated at para 2.12 the parents are in dispute with the HSE in regard to a request for means testing and do not accept the recent estimates of overpayments by the HSE. The parents' perception is that this request for means testing constitutes a second means test for the grant of 2009. The HSE state that the claims of February 2010 and May 2011 are awaiting a means test. There is considerable confusion on this matter as the parents were advised in a letter of March 2011 of a "once off payment for flights" for 2011 under the new HSE policy on travel. This new policy on travel (see para 4.7) states that no means testing is required. There has been correspondence on this matter between the HSE and parents and the HSE have continued to seek information for the purposes of means testing for 2010 and 2011 with the parents contending that the HSE have all the information required with respect to their claims to date except for 2011 costs for the review visit. Consequently the parents' further argue that there should be no requirement for a means test to be carried out at this time. The HSE argue that the means test is required to meet expenses claimed in 2010 while the parents'' argue that this would fall under the 2009 grant and thus the means test for 2010 is not required. It is not disputed that the means test for 2009 was submitted. Notably the new policy does not require a means test.
The parents have informed the HSE that they are awaiting the outcome of the investigation by this Office before providing any further information to the HSE on the matter of their claim for the review visit of May 2011 and have clarified that they are not claiming for February 2010 as they understood the grant of 2009 was intended to cover this.

3.19 The parent's primary concern is that the HSE would honour the contents of the letter of the February 2009. The parents have indicated in an email dated May 2011 to the HSE their willingness "*to keep the lines of communication open*" in relation to clarifying the matter of their claims for travel and subsistence.

They believe the HSE statement that they were not entitled to claim is incorrect and their perception of this is that it warrants an apology. Notably the letter of February 2009 was subject to a means test.

3.20 Having carried out a preliminary examination into this complaint, a decision was made in July 2011 to proceed with an investigation. The investigation focused on the administrative actions of the HSE in regard to the administration of this child's application for funding made under the Treatment Abroad Scheme.

3.21 The reasons for proceeding to investigation and the specific administrative actions identified at that time (by letter of July 2011) as requiring investigation relate to;

- The HSE approval in 2009 to provide funding for certain costs associated with the treatment for this child in the USA and their decision now in relation to this funding.
- The HSE contention that overpayment has been made to the family for costs incurred for treatment to date which is disputed by the family.
- That no information had been provided in relation to the policy and procedures followed regarding travel costs for treatment outside the EU, specifically the policy operational at the time of this application.

3.22 The investigation involved a review of the Health Service Executive files received in relation to the matter and documentation regarding the Treatment Abroad Scheme and information provided by the parents.

Investigation meetings took place with;

- The parents and the child
- Representatives of the HSE Treatment Abroad Office in the Overseas Section of HSE.

4. The Investigation and Analysis

Policy and Procedures

4.1 The Treatment Abroad Scheme (TAS) E112, administered by the HSE, provides financial assistance for hospital treatment that cannot be provided in this country. In this case the parents were not seeking treatment costs under the TAS as treatment in the USA is not covered by EEA Social Security Regulations 1408/71 and 574/72 as amended.

4.2 The Department of Health and Children (DoHC) Guidelines state:

"Article 22 (1) (c) of Regulation 1408/71 governs the referral of patients for public services to another European country. In accordance with this article, a person eligible for

health services in Ireland may be authorised by the HSE to go to another country for treatment in the public system there. When a person is authorised to receive abroad under the above provisions, Form E112 is issued by the HSE. Issue of this form by the HSE involves a commitment by the Executive to pay the costs of the treatment". The HSE has no statutory framework in which to approve treatment for patients outside the EU/EEA.

4.3 During the investigation the HSE stated that there is no legal basis of entitlement within the DoHC guidelines for applicants to the E112 scheme for travel and subsistence. However, there was an unwritten policy that applicants who qualified under the E112 scheme could be considered for travel and subsistence funding. The application on behalf of the child did not qualify under the scheme and the HSE advised this Office that the application was dealt with through the use of a discretionary function available to it through the DoHC which the HSE states as follows:
"Paragraph three of the DoHC guidelines allows the HSE to use discretion where applications do not meet the criteria for the Scheme. It is the use of this discretion that the policies, procedures and funding of the TAS are applied" to this child's case.

4.4 The regional TAS had responsibility for dealing with this child's application in 2006. During the investigation the HSE in correspondence with this Office dated July 2011 advised that prior to October 2009 the HSE had no written policies and procedures for staff operating the scheme and that administration of the scheme was conducted in line with the relevant EU regulations and Department of Heath and Children Guidelines. At that time each TAS office operated independently and there was no national standard approach to travel and subsistence. In 2009 in an effort to standardise access to and implementation of the E112 scheme, the HSE introduced the HSE TAS National Travel Policy, to standardise the approach to the provision of travel and subsistence to approved applicants.

4.5 When the scheme was reviewed in 2009, it was decided to fund travel only for all applicants where approval was given under TAS. This means that subsistence is no longer available through TAS. This review was intended to cover all applicants to the TAS meaning both applicants to the E112 scheme for treatment under the public health system in another country, those who had private health insurance and applied for financial assistance towards treatment and others seeking treatment outside the EU/E112 scheme.

4.6 The HSE advise that the rationale for the change in policy in November 2009 was to introduce a system that would be transparent and equitable for all applicants.

4.7 A protocol regarding travel approval for eligible E112 applicants was then introduced. The new policy means there is no requirement for means testing and those who qualify under the E112 scheme will be entitled to have their travel costs paid for in line with the criteria and conditions set out in the travel policy.

4.8 When the application on behalf of the child was made in 2006, there were no specific criteria used for determining access to discretionary funding for travel and subsistence in the TAS office for cases which did not fall within the E112 scheme.

4.9 The HSE advise that where treatment was sought outside the EU/EEA applications were referred to the Assistant National Director or the General Manager at TAS office and were examined on a case by case basis. There was no written guidance for the staff on how cases which involved the use of discretion should be processed other than that the application was referred to senior management for a decision.

HSE processing of this application

4.10 The officials at the TAS office in 2009, having confirmed the treatment plan for the child with the US consultant, issued the letter of February 2009 to ensure that the file showed a formal record of the decision reached by the General Manager following the application in 2006 for funding (for travel and subsistence) as this was not recorded properly at that time. The family were receiving on going funding (for travel and subsistence) on submission of receipts for costs associated with the child's treatment in the USA up to that time.

4.11 There are different views among HSE personnel with respect to the discussions and meetings that took place regarding the authorisation process for the issue of the letter of 2009. The staff who issued the letter point out that the initial decision to fund was made by a senior manager and they were following his authorisation. In internal correspondence of May 2011, the staff also state that consultation did take place with the then line manager/ acting General Manager at the time the letter of February 2009 was issued. This consultation concerned the issue of an approval letter (as outlined at Para 4.10). The staff claim that there were reservations expressed by the team in the TAS office as the case did not meet the criteria for the scheme but the recommendation at previous General Manager level and the expertise of the then section manager was accepted as sufficient seniority and expertise in relation to the approval of funding for the child's application.

4.12 The person who was acting as the General Manager at the time the letter issued, has stated more recently that while he does not recall this particular case, he does not dispute the staff contention that a discussion took place with him. He says that it was customary for the staff member to have many passing conversations on cases in general. He stated that at all times he would have insisted on the correct procedures and governance being adhered to and sought approval from the Assistant National Director on a case where a patient was travelling outside the EU Treatment Abroad scheme, in this instance the USA. In regard to this particular case he states that it appears that approval was given prior to his time in the Treatment Abroad Office and subsequently the letter of approval granted on the previous General Manager's recommendation.

4.13 The HSE senior management acknowledges that there were was no system of appropriate recording in the TAS office at that time. This is the case both when the first decision was made with respect to funding (for travel and subsistence) of this case and when the letter of 2009 was issued. Senior management in the HSE are of the view that proper procedures were not followed at the time this matter arose and that this has subsequently been addressed.

4.14 During the investigation the HSE advised that it was the practice at the time in the TAS that most cases were considered for the duration of a particular treatment and the funding covered this. The difference with this child was that the treatment went over a much longer period than the normal application. No guidance however, existed for staff in relation to cases where treatment was of longer duration. The question of treatment becoming available within the EU was not addressed when the file was being regularised in 2009. In response to the statement HSE state that it is not TAS role or function to seek to influence the referral for treatment of any patient and even more specifically so a private patient. Therefore the availability of treatment in the EU would not have been addressed on the file.

4.15 The staff stated that they followed procedures which they understood were appropriate to the applications at the time. The issue of a formal decision letter to the parents was standard practice for such applications at the time and as stated earlier staff sought the appropriate information pertaining to the child's treatment plan and issued the letter following confirmation of this by the US consultant. In commenting on the draft statement the HSE advise that the issuing of decision letters is standard practice but the content of this letter goes beyond standard practice and is an administrative error.

4.16 The HSE senior management have stated that the issue in this case is not about cost; rather it is about HSE policy and the risk of setting of a precedent. The HSE have also stated that this case has been given an approval for funding (for travel and subsistence) that is no longer available under current policy to other applicants and that no other cases have been issued with such a letter of approval.

4.17 Since 2009 the HSE have introduced a standardised process for all such applications to TAS and a standardised appeals process for applicants. All applicants are now assessed in line with the E112 scheme criteria.

The TAS sends all applications to medical advisors who offer

- Clinical guidance on applications
- Advice on the availability of treatment in Ireland and elsewhere.
- Give recommendations on applications to the E112 scheme.
- The file on an application for funding outside the E112 scheme is sent directly to the Assistant National Director.
- Decisions on applications by the Assistant National Director are communicated to applicants in writing and a file copy is maintained.

4.18 According to the HSE the child is now entitled to the same costs as any other applicant under the E112 scheme. This means that the same travel policy applies and that he will get outpatient costs funded. Receipts will have to be submitted for each claim. This matter has not been fully clarified with the parents to date. The child will continue to be entitled to funding (for travel and subsistence) as above as long as it is available to all other applicants.

Current position of the HSE in relation to the application of the child

4.19 The HSE contend, in their letter of May 2011, that this case does not qualify for funding (for travel and subsistence) for the following reasons:

- Treatment outside the EU is not covered by the E112 Scheme.
- The treatment in question is available within the EU.
- Patient was not referred to the USA via the Overseas Office.
- There is no precedent for blanket approval of ongoing overseas care. In every case without exception where ongoing care is required, each visit is a separate application requiring a new referral and consultant sign off.
- Letter of February 2009 was issued by an error in judgement and was a mistake.
- The signatory of the letter did not and does not have the authority to do so under the HSE financial regulations.

- Authorisation of the Assistant National Director should have been obtained and without this authorisation the letter issued is null and void.

4.20 The treatment for this child is funded by private insurance and the parents did not apply for treatment costs under the E112 scheme. The issue in this case is not about treatment costs but about subsistence and travel costs associated with the treatment. The HSE were fully cognisant of this when the decision to apply the DoHC guidelines paragraph 3 with respect to discretionary funding for this child was made. The child's application was clearly outside the criteria for TAS from the outset (see para 3.4) and this Office considers the HSE position in arguing that the funding (for travel and subsistence) does not apply for reason that the treatment is outside the E112 scheme is untenable and contributes to confusion on the matter.

4.21 The HSE have contended that this case is outside their remit as the treatment is outside the E112/EEA scheme and have claimed that it would not receive approval for treatment in the USA as it is available in the UK. The current policy as stated by the HSE is that approval for treatment in the USA is solely at the discretion of the HSE. The HSE further states that a decision to refer a patient outside the EU will be made, only after detailed consultation with a patient's consultant, health intelligence consultants and sometimes independent experts. The HSE state in reply to the draft statement that they extended the same consideration of travel and subsistence funding to this case as would have been made to a public patient who met the criteria.

4.22 In this case it was the medical advisor at the time of application in October 2006 who recommended approval and he was fully cognisant of the fact that the child's treatment was outside the EU/EEA (see para 3.2). The file was referred to the medical advisor, and the HSE made available to them all the information relevant to the child's treatment plan in the USA at the outset of this application. There is no evidence on the file that the matter of treatment becoming available within the EU/EEA was raised with the parents at the time of application or subsequently. The General Manager at the time of processing the application was fully aware that the child had been to the USA for treatment (see para 3.7) when he instructed his staff to contact the parents to submit costs. In response to the draft statement, the HSE clarified that they were not per se approving treatment as treatment was availed of in a private capacity and funding for same was not applied for. However in order to consider travel and subsistence the HSE reviewed the application to ensure that it would have met the criteria for approval as if the HSE were funding it.

4.23 When further clarification of the treatment plan was sought by the HSE from the US consultant in 2008, the purpose of the correspondence from the HSE was to specifically address the funding requirement over the duration of the treatment (as outlined para 3.10) in respect of travel and subsistence costs.

4.24 In this case the statement by the HSE that each visit is a separate application requiring a new referral and consultant sign off would not appear to have been clear to staff processing this application. It appears that there was a lack of guidance for staff with respect to cases for treatment abroad applications. The HSE has outlined (see para 4.17) the standardisation now occurring in relation to such cases. There would not appear to have been such a template for processing cases where treatment was of long duration at the time of this child's application.
In response to the draft statement the HSE do not accept that there was a lack of guidance. HSE advise that it is agreed that there were not formal written policies or procedures in the office but in these exceptional cases the practice of referral for individual review by a senior manager was the norm and the report reflects that this did in fact occur.

4.25 The matter of valid authorisation is disputed by staff involved in issuing the letter (see paras 4.11- 4.12). There was no written guidance on procedures and protocols and in this context officials were operating on understandings locally derived which dictated what was the normal practice at the time. In the absence of clear written procedures this Office would hold that such decisions have to be accepted as legitimate in that context.

4.26 The HSE also contend that the financial regulations within the HSE allow staff to approve funding up to specific amounts depending on the grade of the staff member. An approval letter covering a number of treatments over a period of time could exceed the funding approved by a particular grade of staff. In this case the member of staff who signed the letter was a Grade V1 so the commitment of the HSE to funding in this way is argued by the HSE as not appropriate. During the investigation staff stated they did not have responsibility for decisions on cases which were outside the E112 scheme. Applications were referred to senior management and decisions on funding (in this case on travel and subsistence) made by senior management. When authorisations had been given by the medical advisor and the General Manager for funding the travel and subsistence. the function of staff was to process claims arising from that decision. The letter was issued by staff processing the decision on the understanding that a decision on funding (for travel and subsistence) had already been made on the application by the appropriate senior manager at

the appropriate grade within the National Financial Regulations. Staff outlined this in a letter to senior management in May 2011.

4.27 During the investigation the HSE clarified that current practice in non standard cases outside the terms of TAS is that the General Manager discusses each application with the Assistant National Director and the decision letter is signed by the Assistant National Director. It appears from information provided during the investigation, that there was no written guidance for staff regarding the requirement for sign off by the Assistant National Director. At the time the case in contention was being dealt with, staff stated that their understanding was that decisions regarding treatment outside the EU are made by the General Manager or the Assistant National Director. In this case staff advise that approval for funding (for travel and subsistence) was given by the General Manager at the time and were of the understanding that this was sufficient. At the time there were no formal records or documentation regarding decisions made by the General Manager.

4.28 The information provided in the course of the investigation indicates that the decision to fund was made by a General Manager who had authority to make decisions on discretionary payments. He made the decision in 2007 to fund the child's application in respect of travel and subsistence, after he had explored alternative funding options for the child and in the full knowledge that the child had already been for treatment to the USA and that the treatment involved a number of surgeries and visits to the USA over a long period of time.

4.29 Different understandings exist among the HSE staff in relation to the decision to issue an approval letter in 2009 covering the associated costs for treatment for the child in the USA. There are no written records to validate the position taken by either side. However there are sufficient records to indicate that the HSE undertook to pay the costs associated with the travel and subsistence for the treatment plan for this child over a period of time from 2006 to 2010, subject to a means test. The issuing of a letter was a confirmation of what was already taking place in relation to funding for travel and subsistence in respect of this child's treatment.

4.30 The HSE note that the parent's have not submitted documentation with regard to the Means Test for 2010. The parents' contend that this information is not required.

5. Overpayment by the HSE

5.1 The final account presented by the HSE in relation to overpayment to the parents is €5,971.90. The parents' contend that the first communication of the overpayment was by telephone on the April 2011 where they allege they were advised that they owed circa €5000 for accommodation costs they were not entitled to claim. The HSE dispute that this phone call occurred as reported. The parents were able to provide evidence to show that they were approved for accommodation for the 2009 trip.

5.2 However, HSE state that overpayment does not relate to accommodation but to flights taken by the family which were not authorised or covered by the scheme. The account of overpayment provided by the HSE shows there were nine flights (PO Number 76183) taken by the father and siblings (twin infants aged 9 months) to and from the USA for the period November 2006 and June 2007. This was the period in which the parents were in the USA and their claim had not been processed until they returned. An internal memorandum undated and unsigned seeking a once off payment based on the parents submission was drafted by a staff member for this General Manager for submission to the Assistant National Director. This memo detailed the application specifying that the travel would include the child's two baby siblings for travel to the USA. The child's father would travel back and forth for one week end a month with his family for the four months between 2006 and 2007. The documents on file indicate the family applied for the costs incurred. The HSE paid the parents on the basis of the costs submitted and there is no documentation on file indicating that the HSE advised the parents these costs were not admissible.

5.3 Three flights pertain to the period 2008 and 2009. In May 2008 air fares relate to flights for two parents, the child and three siblings. The flights for the visit in May 2009 are claimed for the child and two parents. An internal memorandum dated December 2008 from the manager of the Overseas Section and addressed to the Assistant National Director, National Hospitals Office shows the claim by the parents for travel in 2008 to include their other children was receipted and accepted by the HSE. This memo also requests the first pre payment of flights for the child and two escorts for flights for 2009 which were subsequently funded.

5.4 The parents were advised in a letter from the HSE in December 2008 that their claim, which included the flights for parents and siblings, was approved. There is evidence on file that the HSE sought information from the Irish consultant in September 2008 with respect to the inclusion of the siblings for the trip in 2009 and he supplied a recommendation to the HSE to facilitate the inclusion of the children for social and family reasons.

In response to the draft statement the HSE advise that the overpayment relates to unreceipted expenses paid in advance and additional flights which had not been approved. HSE state that the flights agreed and subject to means test at the time were for two accompanying parents and did not include providing for siblings or for additional return flights for the father. HSE reiterate that the family were receiving advance payments on the basis of their estimation of costs and were then required to submit supporting receipts.
As set out in paragraph 3.7 and 3.8 the files provided by the HSE indicates that the family were requested to submit receipts for the costs incurred and the HSE would then decide on the extent to which HSE would provide funding, which was advised to them in December 2007 for the costs relating to 06/07. As set out in paragraph 5.2 the HSE paid the parents on the basis of the costs submitted. As regards costs incurred in 2008, paragraph 5.4 sets out that a letter issued to the parents in December 2008 advising that a grant had been approved which included airfares for 2 escorts and 3 siblings. Thus on the basis of the information provided it appears that the costs for these trips were considered and paid by the HSE. If an issue of over payment arises, this appears to relate to the matter of authorisation.

5.5 Contrary to the HSE claim that the overpayments were facilitated by a system of pre payments to the parents, this occurred only for the first time for the 2009 visit. The parents estimate for costs for 2009 was submitted and the HSE paid a grant to them and they submitted receipts for the amount of the grant. The parents are only entitled to 70% of the receipts they had submitted. Currently the HSE claim there is a shortfall in the receipts submitted by the parents with respect to the grant which was pre paid to them. This shortfall is given as two amounts of €1,685.24 or €1,975. 64. The parents advised the HSE in a letter dated May 2011 that these costs were incurred in respect of the removal of the fixator in February 2010 are not being claimed as they took these costs as part of the prepayment for 2009 expenses. This information does not appear to have been taken into consideration in relation to the alleged overpayment in the prepayment of 2009 by the HSE. If the HSE had established a pattern of paying on receipts, it was the responsibility of the HSE to clarify any matter concerning entitlements with the parents and there is no evidence that the parents were ever approached on this matter. In response to the draft statement the HSE advise that proof of income is required for 2009 to process 2010 claim. This Office is of the view that this is a reasonable request.

5.6 Having considered the HSE's response on the draft statement and the points raised at paragraph 5.4 above this Office remains of the view that the case made in relation to overpayments by the HSE cannot be fully or clearly substantiated until the matter is clarified with the parents as claims made by the parents were made in good faith and paid for by the

HSE and no clarification was given with respect to these entitlements to the parents. The HSE in meeting with this Office have stated that the parents are understood to have acted in good faith.

6. Adverse effect on child

6.1 The parents believe that the decision by the HSE to withdraw its commitment to the agreement contained in the letter of 2009 is unfair as they understood that they had a written commitment for travel and subsistence funding from the HSE to allow them to continue their son's treatment plan of a long duration. This treatment plan had been explained to the HSE as being one which would take place over the course of a substantial period of time. The HSE demonstrated their understanding of this plan in an email from the HSE to the consultant dated December 2008. The decision to grant funding (for travel and subsistence) was made after all available information had been provided to the HSE, including a medical report from the consultant, which confirmed that the treatment plan would be staged up to the child reaching 16 years. The surgeries were commenced in 2006 and payment was discharged over the course of 2007 and 2008. The letter of February 2009 was, at that time, forwarded on the basis that the HSE wished to formalise their file. The decision was relied upon by the parents and the child and their commitment to a gruelling and intense programme was progressed.

6.2 The HSE contend, amongst other criteria, that this case does not qualify for funding (for travel and subsistence) on the basis that similar treatment is available in the UK (see para 4.19). The child's parents argue that this was not the case on entering into the treatment programme in 2006 and they state that only two countries offered this treatment at that time, Russia and the USA. They are now aware of a UK treatment, however the parents state that they sought a treatment programme which assured them of the best results for their child and the US consultant told them the treatment would ensure their son has legs of equal length when surgeries are completed at the age 16 years. The US consultant was also recommended by their Private Heath Insurer and the treatment was going to be covered by the same Insurer. No medical opinion has been provided or sought which would delineate whether a change in treatment provider at this stage would affect the results assured by the US consultant. Also, this Office notes that the issue of alternative treatment was never discussed with the parents. The parents believe that the treatment in the USA will have a better outcome for their son than the UK treatment centre. They cannot understand why the HSE have waited until now, five years later, to raise the option of treatment within the EU/EEA. The child is half way through this treatment programme and it appears unfair to

withdraw funding (for travel and subsistence) on the basis that alternative treatments are available in the EEA without any further information, medical opinion or assurances similar to the US consultant being given to the child. At this moment, the indication, in the absence of a medical view to the contrary, is that the child would stand a better chance of a positive outcome by continuing treatment in the USA.

In response to the draft statement the HSE advise that the statement about treatment being available in the EU was proffered as a rebuttal to the parents contentions that this specific treatment was only available in the USA and Russia. The family are availing of treatment in a private capacity and all decisions about treatment are a matter for themselves. The HSE state that they have never and would never recommend treatment be transferred to the EU. It was also stated that they would not recommend the transfer of the care of any patient from one provider to another mid treatment (particularly with such a specialised process) except in exceptional circumstances and they have no evidence of exceptional circumstances here. Again any such action would only occur where the HSE is the funder or co-funder of such treatment.

6.3 The child's parents state that the withdrawal of funding for travel and subsistence, which had been approved in the HSE's letter of February 2009 but provided since 2007, is causing considerable stress to the family as it introduces uncertainty in relation to the child's ongoing treatment. The HSE, in response to the draft statement, state that the HSE are not withdrawing funding (for travel and subsistence) but are seeking to apply the funding which is available to public patients (the same funding that the family have availed of up to now) in line with the new travel policy. Having considered the response, the Office remains of the view that the HSE position in relation to the 2009 letter has resulted in a change for the family in terms of the previous agreement given and created a situation of uncertainty for them.

6.4 The parents' report that with the treatment provided to date their son's quality of life has improved and he can participate in normal activities for his age such as cycling and karate. They believe that if the child does not complete this treatment it will be life limiting for him, that he would not be walking without the treatment and he needs the treatment to continue to walk. It is clear that he is progressing under the benefits being provided by this treatment. In the meeting with the child, he expressed his understanding of the meaning of the treatment for him stating that without these operations "I will be in a wheelchair until I am dead".

6.5 The letter granting funding (for travel and subsistence) to the parents issued after payments had been made for a three year period. The HSE note that the letter issued in order to regularise their file on the matter. Similarly the parents' note in correspondence to this Office that the letter issued after considerable work had been put into their application. The letter contained a number of clear reservations, (for example that any additional treatments outside the treatment plan would need a separate application) and a further email and letter issued subsequently supplementing the letter and setting out limitations on the specific funding that would be provided in general (by email dated the 6 May 2009) and as regards the grant being provided in 2009 (by letter dated 18 May 2009). Accommodation costs were provided for in these emails.

6.6 The HSE subsequently dealt with queries arising on foot of the withdrawing of this letter of offer in a confusing and contradictory manner. The parents contend they were not told that the letter of February 2009 was no longer valid at the time that the new TAS policy was forwarded to the parents. The HSE state that the new travel policy was notified to the parents via email and in a subsequent phone conversation. However there is no evidence of any written communication at that time advising the parents that the new travel policy would negate the February 2009 letter or that the payments would be made on a 'one-off' basis.
HSE staff knowledge or otherwise of proper procedure to be followed in issuing this letter is outside the scope of this investigation statement and is a matter for the HSE to address. The parents contend that they were told on a piecemeal basis that certain funding would not be provided, however some of this funding is now being provided.

- Initially the parents understood that out patient costs would not be covered (shoe lifts), however, this has been clarified as not being the case and out patient costs will be funded.
- it appeared that travel costs would not be provided, but now appears that this is now not the case and it seems airfares will be funded under the new TAS policy.
- The parents report that they were told they had been overpaid by the HSE and had to reimburse the HSE as their accommodation costs were not covered. It was subsequently determined that the alleged overpayment did not relate to accommodation costs.
- The parents were told subsequently that their flights were not fully vouched/covered and further ancillary expenditure was not receipted. The sum alleged to have been overpaid by the HSE varied each time the issue was raised.

The parents contend that they had provided all receipts and vouching as required and that they had accounted for all expenditure. This Office is of the view that the argument put forward by the HSE that funds are due and owing to the HSE is unclear and contradictory

and further added to the parents' and the child's stress and concern in relation to this issue overall.

7. Findings

7.1 In response to a draft statement the HSE state that original application was approved for travel and subsistence in line with the then policy but the letter issued to the family was not authorised, is an administrative error and the HSE like any other public body they must be allowed to correct administrative errors.

Having considered the HSE response, on the basis of the information provided and as set out in the statement, in particular in paragraphs 4.18 and 4.19, it appears to this Office that the HSE took a number of steps in relation to assessing this application, including liaising with the consultant treating the child, considering what would and would not be covered and discussing the matter with senior management, which is not disputed although there are no written records of same. In the absence of any written policies or procedures, it appears that sufficient steps were taken to consider and process the application.

The Office notes the facts and circumstances established in this investigation in relation to the administrative actions of the HSE. This Office acknowledges the considerable and significant changes the Treatment Abroad Scheme has brought about in the administration of its service. This Office has noted in meeting with the HSE senior management a concern to resolve this matter in a fair and equitable manner for this child. However, having had regard to the administrative actions of the HSE, it finds that the HSE's actions in resiling from the approvals given in 2009, for the provision of financial assistance to the parents to support the medical treatment of their child are based on undesirable administrative practice and are contrary to fair and sound administration. In that connection, the Office has had particular regard to the following:

- The HSE had available to it the requisite information from the applicants, including the care plan in respect of which assistance was being sought;
- The HSE had ample time to go through its own processes to determine the application;
- Senior HSE personnel considered and approved the application;
- The HSE issued a clear and explicit approval to the parents on foot of their application, with the only qualifications on the provision of assistance identified as relating to:

(i) Means test,

(ii) Certification by the referring medical consultant of the necessity for two adults to travel,

(iii) Submission of prescriptions and receipts; and

(iv) A reimbursement limit of 70% on the eligible expenditure.

7.2 The Office considers that current HSE thinking regarding the propriety, robustness, or any other aspects of the internal processes operated at the time does not constitute a valid or reasonable basis for overturning the informed approval previously issued to the parents. The HSE contend that funding is not being withdrawn, rather it is being applied under the new policy however the February 2009 letter does not contain any provision stating that the letter is subject to future changes in policies.

7.3 Fair administration requires that all conditions or reservations are made known to the applicants at the time of approving an application. Given that at the material time the HSE did not make its approval subject to periodic review or future policy change – particularly when the commitment to support the child clearly extended over a significant period of time – it is not equitable to impose such a fundamental condition after the commitment had been extended by the HSE and relied upon by the parents and the child.

7.4 The decision to fund travel and subsistence for this child and the preceding and subsequent actions by the HSE in providing for such funding which was explicitly linked to the treatment plan, has allowed the parents and the child to continue their commitment to this treatment plan for its duration and to rely on the fact that the written agreement stipulating this would be honoured. The letter of February 2009 which stated that funding would be provided for the child's travel and subsistence in relation to this treatment, together with the supplementary emails, indicated to the family that they were entitled to rely on the HSE as regards the provision of funding for travel and subsistence. The parents relied on this assurance for continuance of the child's treatment. There was a legitimate expectation by the parents that the HSE would provide the funding (for travel and subsistence) until the child's treatment was completed as per the February 2009 letter and that this written agreement would be honoured. The withdrawing of funding (for travel and subsistence) in the middle of the treatment programme would cause the treatment to be stopped as the child's parents assert that they cannot afford the costs associated with subsistence whilst the child remains in the USA for the necessary number of months after each operations.

7.5 The HSE contend that the family received over payments with respect to their claims under the discretionary funding scheme. The Office has found that this matter is unclear with respect to the claims made by the HSE. It is noted from the investigation that the HSE has yet to decide on the matter of alleged overpayment to the parents. The HSE has stated in response to the draft statement that the HSE had tried to resolve this matter but the family

did not provide the documents requested. In this regard the following course of action should apply:

- The HSE should decide, by reference to the nature of the support it has approved and the expenditure detailed to it by the parents, if there has or has not been overpayment and take appropriate steps to resolve the matter;

This Office is of the view that, the HSE requirements in relation to the carrying out of a means test is reasonable.

7.6 This Office finds that the administrative actions in relation to this matter have adversely affected the child at the centre of this complaint in that the HSE actions have:

- Placed at risk an established and previously supported course of medical treatment with no offer of alternative support of corresponding merit and prospects;
- Have resulted in stress for the family as a whole regarding a good medical outcome for the child;
- Have failed to adequately communicate with the parents in relation to the issues in question.

7.7 Following the conclusion of this investigation, pursuant to Section 13 of the Ombudsman for Children Act 2002, this Office found that the administrative actions of the HSE come within the ambit of Section 8 of the Act. Specifically Section 8 of the Act

(a) has adversely affected the child at the centre of this complaint

(b) and Section 8 (b) (vi) based on an undesirable administrative practice

(c) and Section 8 (b) (vii) contrary to fair or sound administration.

8. Recommendations

In light of this investigation, the Ombudsman for Children recommends that the HSE:

1. Honour the written agreement of 2009 to fund travel and subsistence or offer the family an alternative arrangement for funding (for travel and subsistence) that is no less advantageous as regards the child's medical treatment and clinical outcome.

   This Office is conscious that a new policy came into place which post dates the agreement between the HSE and the parents. The policy implements new guidelines as regards the TAS scheme. However this Office is of the view that the HSE has provided an assurance to the parents in written communication which had been reasonably relied on by the parents in the course of continuance of their child's treatment plan and as such the parents formed an expectation based on this communication which should now be adhered to by the HSE.

HSE response: The TAS will honour the contents of the letter as per this recommendation.

2. That any necessary but unplanned treatments (i.e. not comprehended by the care plan in respect of which approval was given e.g. additional surgery 2013) are a matter for the HSE to consider on foot of such supporting information it may require from the parents. Fair and sound administration would indicate that this be considered in the context of the established arrangements in place to secure the optimum medical outcome for the child and by reference to his best interests.

   HSE response: The TAS will consider funding for travel and subsistence for any such unplanned treatments in accordance with this recommendation.

3. The matter of over payments should be clarified through discussion and negotiation with the parents.

   HSE response: The matter of over payments will be clarified with the parents.