

Ombudsman Investigation – Long Term Illness Card Scheme

Complaint against the Health Service Executive

Summary

This was an investigation by the Ombudsman of a complaint about the refusal of the Health Service Executive (HSE) to award a Long Term Illness Card (LTI card) to a woman for her son who was diagnosed as having attention deficit hyperactivity disorder (ADHD) and autistic spectrum disorder (ASD). The HSE refused the application on the grounds that the applicant did not meet the medical criteria for eligibility. Following the investigation, the Ombudsman found that the decision to refuse the application was, among other things, improperly discriminatory.

The Ombudsman also found that the failure of the HSE to ensure a uniform approach to the administration of the scheme throughout the country was contrary to fair or sound administration.

The Case

In March 2010 Ms Kelly (not her real name) complained to the Ombudsman about the refusal of her application for a LTI card for her son. The HSE's refusal was on the basis that her son did not meet the relevant medical criteria. The applicant believed that her son's condition was such that he did meet the criteria and she also contended that, had they lived elsewhere in Ireland (they live in Wexford) her son would have been awarded a LTI card.

The LTI card scheme is a statutory one. The HSE has responsibility for its administration. Under the Health Acts the HSE has the power to make arrangements for the supply without charge of drugs, medicines or medical/surgical appliances to persons suffering from "a prescribed disease or disability of a permanent or long-term nature." Regulations list the diseases or disabilities which qualify an applicant for the card. The illness with which this case is concerned is simply listed as "mental illness." The relevant section says:

"Arrangements for the supply of drugs and medicines to persons suffering from mental illness ... shall be made only in respect of persons under the age of 16 years."

This means that mental illness in a child under the age of 16 is an illness which qualifies for the LTI scheme so that the medications prescribed for that child may be obtained free of charge.

The Investigation

The investigation looked in detail at the HSE's handling of Ms Kelly's application. The HSE acknowledged disparities in the way both ADHD and ASD are classified by individual medical officers in processing LTI card applications. In some geographical areas, children under 16 with these disorders are classified as having a mental illness and as such entitled to a LTI card, in others they are not. The HSE accepted that this system was inequitable and, in January 2013, informed the Ombudsman that the Department of Health was carrying out a review of the scheme. This wide-ranging policy review commenced prior to the Ombudsman's investigation and was not prompted by it.

In March 2012, as a result of the Ombudsman's intervention, the HSE issued a LTI card to Ms Kelly for her son which she has used since to obtain the prescribed medication for his conditions. At the time, the HSE refused to reimburse her for the cost of medication for the period July 2009 to February 2012. If the card had been awarded to her following her application at the end of June 2009, she would have received these medications free of charge.

In a response to a draft report of this investigation, the HSE decided to alter the approach of its medical officers who heretofore had accepted ASD and ADHD as conditions which conferred eligibility under the scheme. It said that it would no longer accept people onto the LTI scheme where ADHD is the disorder involved. The HSE also said that it would await the outcome of the Department of Health's review of the scheme.

The Ombudsman recognised that there is a continuing debate on the best approach to dealing with ADHD. The Ombudsman suggested that the HSE should have regard to the definition of "mental illness" set out in the Mental Health Act 2001, a definition that focuses on behaviour rather than the underlying causes of the behaviour. This definition is, "a state of mind of a person which affects the person's thinking, perceiving, emotion or judgement and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons."

In the context of the varying approaches to the treatment of ADHD the Ombudsman was of the opinion that a reasonable view would be that both the diagnosis of the illness and the treatment prescribed for it are decisions for the individual's own doctor.

The HSE decision not to accept people onto the LTI scheme where ADHD is the disorder involved and to await the outcome of the Department of Health's review of the scheme were judged by the Ombudsman not to be positions well supported by the law.

The fact is that ADHD is recognised as a mental illness by many HSE medical officers for the purposes of the LTI scheme. The HSE has acknowledged that children with ADHD have been accepted as eligible for the LTI card by medical officers in the greater part of the country; it is likely that this has been the approach for many years in these areas.

Findings

The investigation resulted in a number of findings about the handling of the individual case and in relation to the administration of the LTI scheme. The Ombudsman found that Ms Kelly was adversely affected by the refusal of her applications for a LTI card in July 2009 and in September 2010 and that the decisions to refuse her applications were based on erroneous or incomplete information, on irrelevant grounds and were improperly discriminatory.

The Ombudsman also found that the decision to refuse to recompense Ms Kelly for her son's medication for the period of her application prior to March 2012 was taken on irrelevant grounds, erroneous or incomplete information and improperly discriminatory.

In relation to the administration of the scheme, the Ombudsman found that the different treatment of cases depending on their geographical location, was improperly discriminatory, an undesirable administrative practice and contrary to fair or sound administration. The failure of the HSE to ensure a uniform approach to the administration of the scheme and in addition, the failure to provide the HSE administrators of the scheme with adequate and clear guidance in relation to it were contrary to fair or sound administration.

The Ombudsman also found that, in the light of the fact that the scheme is under review by the Department of Health and the outcome of that review is not yet known, the HSE proposal to alter the approach of its medical officers who heretofore had accepted ASD and ADHD as conditions which conferred eligibility under the scheme, was contrary to fair or sound administration.

Recommendations

Based on these findings, the Ombudsman made the following recommendations:

- that the HSE refund Ms Kelly the cost of medications for her son in the period from when she first made an application for him under the LTI scheme to the time when her application was granted. (approximately €3,000)
- that, as the outcome from the Department of Health Review Group is awaited by the HSE and in the absence of any substantive amendments to the governing legislation, the HSE continues to administer the LTI scheme as it has done for many years in the greater part of the country, thereby including ADHD as constituting a mental illness which, in the case of persons under 16 years, gives entitlement to a LTI card.
- that steps be taken to ensure that the LTI Scheme, as a national scheme, is administered in a uniform fashion throughout the country.
- that all of these recommendations are implemented before the end of October 2013.

The HSE accepted the findings and recommendations made to it.

Ms Kelly was reimbursed the cost of medications for her son for the period involved.

The HSE also developed new operational guidelines which, it says, take account of the available national and international clinical evidence. The new guidelines, issued to HSE staff on 18 October 2013, direct that ADHD be regarded as a mental illness for the purposes of the LTI scheme. The guidelines outline the factors which must be present in such cases. They are to be implemented on a national basis to ensure consistency and clarity in the administration of the scheme.

Local Rules for National Schemes

Inequities in the administration of the Long Term Illness Card
Scheme

Office of the Ombudsman

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Acronyms used in this Report

A/SAMO	Acting Senior Area Medical Officer
AMO	Area Medical Officer
ASD	Autism Spectrum Disorder
ADHD	Attention Deficit Hyperactivity Disorder
HSE	Health Service Executive
LTI	Long Term Illness

Introduction

This investigation report is concerned with a complaint made to the Ombudsman by a woman living in Co. Wexford. Her complaint centred on the fact that there are variations in the way the Long Term Illness card (LTI card) scheme is administered by the HSE in different parts of the country. The complainant believed that her son would have qualified for the card, which was refused at the time of the complaint, had he lived in a different region and that the refusal amounted to discrimination against him.

The HSE acknowledged that there are variations around the country in the assessment of certain illnesses for the purposes of the scheme. These variations meant that applications for the card from people suffering from the same type of illness could be treated differently depending on where the applicants lived; in some parts of the country they would qualify for the card while in others, they would not qualify for it. This report explores some of the issues arising from the case in addition to the circumstances of the case itself.

The Long Term Illness Card Scheme

The long term illness card scheme is a statutory scheme. Section 59(3) of the Health Act 1970 gives the health boards (now HSE) the power to make arrangements for the supply without charge of drugs, medicines or medical/surgical appliances to persons suffering from “a prescribed disease or disability of a permanent or long-term nature.” Regulations made by the Minister for Health under the Act, (The Health Services (Amendment) Regulations, 1971, S.I. 277/1971) listed the diseases or disabilities which would qualify an applicant for the card. The illness with which this case is concerned is listed in the Regulations as “mental illness. “ Article 9 of the Regulations stipulates that *“Arrangements for the supply of drugs and medicines to persons suffering from mental illness in pursuance of section 59(3) of the Act shall be made only in respect of persons under the age of 16 years.”*

This means that mental illness in a child under the age of 16 is an illness which qualifies for the LTI scheme so that the medications prescribed for that child may be obtained free of charge.

Complaint to the Ombudsman

Ms Kelly (not her real name) complained to the Ombudsman in March 2010 that the HSE had refused her application for a LTI card for her son who had been diagnosed with attention deficit hyperactive disorder (ADHD) and autism spectrum disorder (ASD). She said that children in other parts of the country with the same diagnoses had qualified for the card and that it was unfair and discriminatory that her application for it had been refused.

The LTI card was granted to Ms Kelly in March 2012 following the intervention of the Ombudsman, but the HSE refused to recompense her for the cost of her son's medications for the period from June 2009.

Details of the case

Ms Kelly first applied for a LTI card for her son, Sam, (not child's real name), in June 2009. Sam was then seven years of age. Her application form contains certification from her GP that Sam was under his care for the "treatment of ADHD and Aspergers." The GP said that the conditions were being treated with prescribed medication. The application was refused by the HSE's Acting Senior Area Medical Officer (A/SAMO) in July 2009. When Ms Kelly appealed this decision, she said that the family were finding it extremely difficult to afford the medication of almost €100 a month. The Appeals Officer wrote to her saying that he was of the opinion that the decision to refuse was correct but that he had been informed [by the A/SAMO] that her son might be diagnosed with Autistic Spectrum Disorder, "...and that should this diagnosis be made then he will be considered for the Long Term Illness scheme..."

When Ms Kelly complained to the Ombudsman (in March 2010, after the Appeals Officer refused her appeal) she said that she was aware of children living in Meath and Dublin "who have only ADHD and they are getting their medication on a long term illness card." She believed that the refusal of the card to her son amounted to discrimination against him.

In September 2010, Ms Kelly applied for the LTI card once more and supplied evidence from a HSE Consultant Child Psychiatrist that her son had been diagnosed with autism spectrum disorder. This application was also refused. The HSE wrote to her to say that "Autism and ADHD are not currently eligible under the current list of medical conditions listed for the scheme."

There followed a lengthy period of correspondence between the Office of the Ombudsman and the Health Service Executive. This resulted in the HSE issuing Ms Kelly with a LTI card for her son in March 2012. This was done, according to the HSE, on the basis of the individual circumstances of her case, it would not serve as a precedent and no recompense would be made for the costs of medications purchased by her for her son since June 2009 (when she had first applied for the card).

In March 2012, the Ombudsman's Office wrote to the HSE to say that the Ombudsman, when deciding on appropriate redress where maladministration has occurred, seeks to restore the complainant to the position he/she would have been in if the public body had acted properly in the first place. It was put to the HSE that in order to do this, Ms Kelly would have to be reimbursed the expenses of €3,000 she had incurred in the period prior to the issuing of the card to her. The HSE then wrote to Ms Kelly to say that "... given the 'good will' basis and particular circumstances on which the card has been awarded, the issue of retrospective payments does not apply."

Ms Kelly subsequently provided the Ombudsman's Office with a document from her pharmacy showing that she had spent over €3,000 on the medication prescribed for her son's conditions between the time of her application for the LTI card and the issue of a card to her. The document was forwarded by the Ombudsman's Office to the Health Service Executive. At the time of writing this report, the HSE had taken no further action in the matter.

The wider issues

On 24 January 2012, the HSE wrote to the Ombudsman to say that the case had raised wider issues for the administration of the LTI scheme. It said that the case,

“...highlights the disparity across the country in the way Attention Deficit Hyperactivity disorder (ADHD) and Autistic Spectrum Disorder (ASD) are classified by individual Medical Officers in processing Long Term Illness (LTI) card applications. In some areas children under 16 with these disorders are classified as having a mental illness and as such entitled to an LTI card, in others they are not.

It appears that individual Medical Officers have made their determination in relation to eligibility for an LTI card based on the clinical classification they use for ADHD and ASD. The two systems currently in use are the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and the World Health Organisation’s International Classification of Diseases (ICD 10). It would appear that Medical Officers using the ICD 10 have not recognised these conditions as mental illness, however those who use the DSM-IV have.”

These systems classify ADHD and ASD differently. The DSM-IV classifies them as mental illnesses. The ICD 10 classifies these conditions, using slightly different terminology to describe them, as a “behavioural and emotional disorder” (in the case of ADHD) and as a “disorder of psychological development” (in the case of ASD).

The use of different classification systems led to children in certain parts of the country qualifying for the LTI card on the basis that their illnesses were covered by the scheme while others, with the same conditions, were refused the LTI card. In November 2012, in response to the Ombudsman’s notification of this investigation, the HSE said,

“LTI cards for children with these conditions have been awarded in Dublin North East; Dublin Mid Leinster; North West; former Southern Health Board area; Midlands (some Local Health Offices) and have not been approved in the South East, Mid West, Dublin North and Midlands (some Local Health Offices)”

The HSE accepted that this system was inequitable and went on to say,

“The matter is under active consideration by the Department of Health, however the specific issue is being considered within the broader policy development of the Long Term Illness Scheme under the Programme for Government. This has not yet been finalised.

*In the absence of any formal policy direction in the matter, the HSE has convened a group of appropriate clinical and management personnel ... to agree an **interim operational policy** ... This group is expected to provide its recommendation before the end of November 2012 after which the decision and formal direction will be issued to the relevant clinical and management personnel across the HSE.”*

In January 2013, the HSE informed the Ombudsman’s Office that the group had held a number of meetings to consider the issues and “is currently consulting national experts to determine a definition for the condition, i.e. whether or not ADHD is a mental illness.” At the time of writing this report this particular issue was still undecided.

However, when asked for its comments on a draft of this Report, which is at Appendix 1, the HSE said in its submission to the Ombudsman of 15 April 2013 that as an interim operational policy, the issuing of new LTI books to children should be suspended, pending a formal decision from the Department on the matter.

Investigation

Confusion about the scheme

An examination of the HSE file in this case showed that there was a certain amount of confusion about the nature of the LTI scheme among the administrators charged with implementing it. Some of this confusion appeared to arise from the (mistaken) idea that the LTI card is provided to people in order to obtain certain prescribed medications and that it is the medications which are covered by the scheme, not the condition for which they are prescribed. The letter sent to Ms Kelly on 10 July 2009 by the A/SAMO in response to her application said:

“I acknowledge receipt of your Long Tern [sic] Illness Book for Sam. I regret to inform you that the following medication is not currently available for you [sic] medical condition under this scheme...”

The letter then went on to name the medication which had been prescribed for Sam Kelly and to give details of the address to write to if appealing the decision.

This letter is confusing in its terminology and import. Ms Kelly had not sent the HSE an LTI book: she was applying for one. The basis of the scheme, as provided by the legislation, is the provision of medications free of charge to persons who have certain prescribed diseases or disabilities: the medications prescribed are not part of the eligibility criteria.

Ms Kelly then made an appeal in which she pointed out that the HSE application form lists the conditions covered by the scheme and it includes “mental illness (under 16 years old).” She said that ADHD is a mental illness and her son was under 16 years of age. She said that they were awaiting an appointment for a specialist as there was a possibility her son also had Aspergers syndrome. The Appeals Officer to whom the case was sent noted the confusing nature of the decision letter which had issued and raised the question with the writer of the letter, pointing out that “Ms Kelly appears to be appealing the refusal of a Long Term Illness book ... but your decision appears to be that the particular medication is not available on the scheme.” In response, the A/SAMO replied:

“... a diagnosis of attention deficit hyperactive disorder is not regarded as a mental illness and as such does not qualify for a [sic] long-term illness scheme. This has always been the case. I also note ...that there is a possibility that he might be diagnosed with autism spectrum disorder...”

If he is diagnosed with autism spectrum disorder then he may well be eligible for an LTI and I would suggest the parents would reapply under those circumstances.”

The Appeals Officer accepted this information and refused the appeal on the grounds that “A diagnosis of ADHD does not qualify an applicant for the Long Term Illness Scheme.” Ms Kelly was told in the letter notifying her of the appeal decision that should Sam be diagnosed with Autistic Spectrum Disorder “... he will be considered for the Long Term Illness scheme” and she was told if

that happened she should apply again. However, when a diagnosis of ASD was made by the HSE Consultant Child Psychiatrist in Wexford, and evidence of that diagnosis provided to the HSE together with a new application for the LTI card in September 2010, the A/SAMO who had suggested that this might allow Sam to qualify for the scheme wrote to Ms Kelly to say:

“...Autistic Spectrum Disorder and ADHD are not currently considered eligible under the current list of medical conditions listed for the Long Term Illness Scheme. The medication...which is used for the treatment of ADHD is also not available on the above Scheme.”

It is notable that this letter came from the same person who had advised the HSE Appeals Officer that if Sam was diagnosed with autism “then he may well be eligible for an LTI...” The mention, again, of a particular medication not being available under the scheme is not in accordance with the terms of the scheme as provided by legislation.

The A/SAMO commented on the preceding paragraphs when she was sent a copy of this report in draft form. She said that:

“In the HSE South what was the old South Eastern Health Board area, ADHD was classified under ICD code 10 and as such was not regarded as mental illness, therefore was not deemed eligible for the LTI scheme. I was informed of the policy when I started doing the LTI books and hence I was following established policy.”

She also said that in relaying the suggestion to the Appeals Officer that if Sam were to be diagnosed with Autistic Spectrum Disorder, he *might* be eligible she did not intend to give the impression to his parents that he would be eligible; she wanted to check with her peers in the Southeast if the disorder was eligible for the LTI scheme. She was told that it was not and, consequently, had no choice but to refuse the second application which was made on the basis of that diagnosis.

Use of different classification systems

The HSE said in its November 2012 submission to the Office of the Ombudsman that,

“LTI cards for children with these conditions have been awarded in Dublin North East; Dublin Mid Leinster; North West; former Southern Health Board area; Midlands (some Local Health Offices) and have not been approved in the South East, Mid West, Dublin North and Midlands (some Local Health Offices)”

Dublin North East and Dublin Mid Leinster have the highest population centres in the current division of the HSE into four administrative regions. Thus, it appears that a large cohort of Medical Officers accept ADHD and ASD as falling within the category of “mental illness” where a child is concerned and that, consequently, LTI cards have issued for these children. The Medical Officers who do not take this approach (mainly in the South East) appear to be in the minority.

How did it come about that Medical Officers in the HSE use different disease/illness classification systems for the purpose of administering a national scheme? The answer probably lies in the historic separation of the former health boards into different functional areas. This however, is not a sufficient explanation. The LTI card scheme, from the time of its inception in 1971, was always a national scheme with a statutory basis. There should, therefore, always have been a uniform and standardised approach to its implementation.

Analysis

Initial decision to refuse application

It is generally accepted that good decision making entails the notification of a decision in clear language explaining the legal and other grounds for the decision. The notification of the decision should enable the applicant to make an informed appeal, where an appeals process is the next step. In this case, the A/SAMO decision letter of July 2009 (quoted above in the paragraph “Confusion about the scheme”) did not meet these criteria. The confusing nature of the terminology used and the errors in relation to law and facts (that is, the references to medications not being available under the scheme and to “receipt” of a LTI book) seriously undermined the validity of the decision. In the event, the appellant herself had regard to the terms of the scheme in making her appeal.

Appeal decision

The information supplied to the Appeals Officer by the A/SAMO in her letter to him of 4 December 2009 was incorrect on a number of counts:

- She said, “... a diagnosis of attention deficit disorder is not regarded as a mental illness and as such does not qualify... This has always been the case. ” The A/SAMO has told the Ombudsman’s Office that this statement was accurate insofar as it reflected the position of medical officers and management in the Southeast. She is correct in this. However, it has since become clear that it is not an accurate reflection of how ADHD is seen by the HSE in many other parts of the country where it is regarded as a qualifying condition for the LTI scheme.
- The suggestion that “If he is diagnosed with autism spectrum disorder then he may well be eligible for LTI and I suggest the parents would reapply...” was misleading as when the diagnosis was, in time, made by a HSE Consultant, the decision made by the A/SAMO was “ that Autism Spectrum Disorder and ADHD are not currently considered eligible...”

It is a matter of concern that factually incorrect information was supplied to the Appeals Officer, albeit given in good faith by the A/SAMO, which was relied upon by him in making his decision on the appeal. As he did rely on that advice, his decision on the appeal cannot be said to be soundly based.

There does not appear to have been any awareness of the national nature of the LTI scheme among the local administrators involved with this case. The information supplied by the HSE to this Office, which shows that in many parts of the country the condition of ADHD is regarded as a mental illness in a child less than 16 years of age, should have been available to the administrators dealing with this case. There should have been an awareness of the practices in other areas and the fact that a uniform approach to the classification of diseases/disabilities which qualify under the LTI scheme is the only equitable approach.

Decision on second application

The HSE suggested that the family should reapply for the card if Sam was diagnosed with autism spectrum disorder. The A/SAMO told the Ombudsman’s Office that she wished to check the position with her peers in the Southeast and she did not intend to give the impression that Sam would be eligible for the LTI scheme if he were diagnosed with this disorder. The refusal of the second

application was undoubtedly confusing to Ms Kelly in the light of the HSE's suggestion. If, as this later decision said, neither ASD nor ADHD were qualifying diseases/disabilities for the scheme then it was unfair and misleading to invite a further application on the basis of a diagnosis of autism spectrum disorder. Ms Kelly could have argued, with some justification, that the HSE had implied that her son would qualify for the card in these circumstances (as she was told "should this diagnosis be made he would be considered for the [LTI] scheme") and that she consequently had a reasonable expectation that she would receive it following that second application in 2010. Again, it was inaccurate to say that the particular conditions "are not currently considered eligible..." (as, in fact, children with these conditions in other parts of the country are regarded as eligible for the LTI card). This decision is also one which cannot be said to be soundly based.

Decision to award LTI card

In March 2012 the HSE issued a LTI card to Ms Kelly for Sam which she has used since April 2012 to obtain the prescribed medication for his conditions. The HSE refused to reimburse Ms Kelly for the cost of the medication for the period July 2009 to February 2012. If the card had been awarded to her following her application at the end of June 2009, she would have received these medications free of charge. She supplied documentary evidence from her pharmacy to this Office – which was forwarded to the HSE – which shows her costs have been in excess of €3,000.

The HSE wrote to this Office in February 2012 to say that the LTI card would be issued to Ms Kelly. In the letter the HSE said that the issue of the variations in the application of diagnostic classification systems was raised with the Department of Health for the purpose of getting clear national guidance on the appropriate classification system to be used. The HSE decided to issue a LTI card to Ms Kelly in recognition that for her:

- *"There has been a long delay in bringing the wider issue to a conclusion and that this has resulted in delays in addressing her complaint.*
- *A reasonable expectation may have been given that a card would have been awarded following Sam dual diagnosis of ADHD and ASD."*

In considering whether any recompense should be made for medication costs incurred by Ms Kelly since she first applied, the HSE said:

"This card will be issued strictly on the particular and individual circumstances of the case and will not serve as a precedent for other applicants until the wider issues in relation to clinical classification ... are resolved."

It is now 17 months later and no decision has been made on the adoption of a nationally applicable diagnostic system for the purposes of the LTI scheme.

There are some comments which must be made about the decision to award the card, but no payment of past medication costs, to Ms Kelly:

- The card could not be issued in accordance with the terms of this statutory scheme unless the HSE was satisfied that the applicant met the eligibility criteria for it. If Ms Kelly was eligible for the card in March 2012 on the basis of her son's conditions, it follows that she was eligible for it at an earlier time. She had supplied both application forms and documentation from the HSE Consultant psychiatrist who was treating her son, certifying his diagnosis of Sam's condition. While it is acknowledged that the card was said by the HSE to have issued on

a “good will” basis, following contact from the Office of the Ombudsman, there is no provision in the scheme for issuing a LTI card on such a basis. A determining factor in the original decision in her case was her residence in one of the few parts of the country which refused LTI cards to children with ASD and ADHD; this cannot be ignored.

- The HSE says that the card has issued to Ms Kelly on an “individual” basis and that the decision in her case should not serve as a precedent. The adverse financial implications of treating the case otherwise are mentioned in internal HSE memoranda on the case. Clearly, there are financial implications for extending the scheme to a class of persons who had been excluded from it in the past. However, there are two points to be made here: first, this is not a sound administrative basis for treating similar cases differently and second, the adverse financial implications would be limited to the extension of the system already in place in many local Health Offices whereby the conditions in question are recognised as qualifying for the issue of an LTI card.

Interpretation of “mental illness”

The HSE has sought direction from the Department of Health on the interpretation of the phrase “mental illness” as it applies to the scheme. The LTI scheme is a statutory scheme administered by the HSE and for which it has responsibility. Under Section 7(8) of the Health Act 2004 “the Executive has all the powers necessary or expedient for it to perform its functions”. This means that the HSE has the authority in law and the competence to decide on the interpretation of the phrase “mental illness”. It is not reliant on the Department (as is the case with administrative, non-statutory schemes) to give guidance on the implementation of the scheme. While it may be appropriate to seek guidance on particular issues, the scheme remains the statutory responsibility of the HSE to administer in a fair manner.

The HSE has not developed a consistent approach on the question of whether the disorders of ASD and ADHD are regarded as mental illnesses for the purpose of the LTI scheme. It attributes the variations in approach to the fact that two different diagnostic classification systems are in use. Again, it is not at all clear that it is necessary for the HSE to choose between the two systems for the purpose of the scheme. It is only necessary to decide if the disorders in question come within the terms of the scheme.

As noted earlier, this is a scheme with a legislative basis. Section 59 (3) of the Health Act 1970 provides that:

“A health board may make arrangements for the supply without charge of drugs, medicines or medical and surgical appliances to persons suffering from a prescribed disease or disability of a permanent or long-term nature”.

Regulations made by the Minister for Health under the Act, (The Health Services (Amendment) Regulations, 1971, S.I. 277/1971) provide:

“8. The following diseases and disabilities are hereby prescribed for the purposes of section 59(3) of the Act: mental handicap, mental illness, phenylketonuria, cystic fibrosis, spina bifida, hydrocephalus, haemophilia, cerebral palsy, diabetes mellitus, diabetes insipidus and epilepsy.

9. Arrangements for the supply of drugs and medicines to persons suffering from mental illness in pursuance of section 59(3) of the Act shall be made only in respect of persons under the age of 16 years.”

There are two points to make about this legislation which are of note; it refers to both diseases and disabilities and it does not provide a definition of “mental illness”. As mental illness is included in the list then it must be considered in the context of this legislation as either a disease or disability. There is, in fact, a definition of mental illness provided in the Mental Health Act 2001 to which the HSE has not referred in its communications with the Ombudsman’s Office on this matter. Section 3(2) provides that “mental illness” means:

“... a state of mind of a person which affects the person’s thinking, perceiving, emotion or judgement and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons”.

The Mental Health Act 2001 covers a range of issues unconnected with the LTI scheme. At the same time, it does seem likely that a person with ADHD or ASD may have a "state of mind" of a kind reflected in the Mental Health Act definition. It seems possible, therefore, that the question for the HSE is not which diagnostic classification system to use, but rather whether ADHD and ASD are conditions of a type whose consequences are in line with those set out in the statutory definition of mental illness. While it is a broad definition it is, nonetheless, an extant statutory definition of a term contained in the provisions for the LTI scheme. In the absence of amendment to the legislative provisions for the scheme this definition is of relevance to any discussion of the LTI scheme in its present form.

HSE response to draft report

A copy of this report, in draft form, was sent to the HSE on 15 March 2013. In accordance with section 6(6) of the Ombudsman Act 1980 the HSE was afforded the opportunity to make representations in relation to the draft findings and also to draw attention to any factual errors in the report. The full text of the HSE response, dated 15 April 2013, is at Appendix 1. The points made by the HSE may be summarised as follows;

- The HSE has been working for over a year to end the disparity with regard to ADHD in the context of the LTI scheme. The diagnosis of ADHD is difficult and agreement on the use of different classification systems is problematic internationally. There has been an increase in the recognition and treatment of children with ADHD.
- The issue is not an administrative one. Medical Officers are clinicians and their decisions (including the choice of an internationally accepted classification system) are clinical decisions. It is misleading of the Ombudsman to suggest that varying administrative practices (local rules) were used for a national scheme as in fact, medical officers were consistent in their use of classification schemes. The disparity arose because the choice of diagnostic classification schemes was not consistent across the country.
- The Ombudsman's report and findings could be considered as straying beyond her proper remit in that it denotes clinical decision makers as administrators and also questions the exercise of clinical judgement in connection with the diagnosis or illness in the care and treatment of a patient (a matter excluded by law from the Ombudsman's jurisdiction).
- The Department of Health says it is reviewing the LTI scheme and the question of whether ADHD should be considered a mental illness for the purposes of the scheme is a matter best resolved in the context of the overall review.
- As far as the individual case is concerned, while retrospective payment of medical expenses was not made, neither was it refused. The HSE did not receive a quantification of the amount involved until January 2013. The suggestion that the decisions taken locally were not soundly based is rejected as is the suggestion that staff in HSE South were unaware that the LTI scheme is a national scheme.
- It is unreasonable of the Ombudsman to seek to have one case dealt with in isolation and then, when the HSE acts, to accuse it of treating cases in inequitable or expedient fashion. The HSE is concerned to ensure a consistent and practicable policy for the LTI scheme.
- Applications under the LTI scheme are considered in two steps; diagnosis and approval of products. The section in the report which refers to confusion about the scheme is itself based on a misunderstanding of the LTI scheme.
- The Ombudsman's suggestion that reviewing other cases would be the fairest course does not take account of the fact the Department of Health has not completed its review of the LTI scheme and any HSE decisions will be taken in the context of the Department's policy

decision. Also, the HSE could not divert financial resources away from current services to cover LTI arrears without causing other service users to suffer as a consequence.

- The HSE does not have the authority to impose a matter of policy in place of the Department of Health. With the Department's agreement the HSE has decided as an interim measure that the issuing of new LTI books to children with ADHD should be suspended which will end the current disparity pending the Department's decision on the matter.

Analysis of HSE Response

It is important to recall the purpose of the LTI scheme; it is to assist people with prescribed long-term diseases and disabilities with their medication expenses. The HSE response conflates the treatment of long-term illnesses with the financial assistance available under the scheme. The primary decision regarding the diagnosis of an illness or the identification of a disability rests with the individual's own doctor; this is a clinical decision. The decision to grant or refuse an application, whether made by a medical professional or not, is an administrative decision. The medical professional in this circumstance is not acting in a doctor-patient role in relation to the patient. He/she is offering an opinion to a deciding/appeals officer on whether the diagnosis already made is within or without the terms of the scheme; this is an administrative function. If not offering an opinion, then he/she is deciding the issue him/herself, which, again, is an administrative decision. This is a factual situation long endorsed by the Courts in relation to cases involving medical professionals employed by the Department of Social Protection in the administration of schemes where an assessment of disability or illness is involved.

The actions of medical professionals employed by the HSE are within the Ombudsman's jurisdiction unless they come within the excluded category provided for in legislation. This exclusion refers to persons acting on behalf of the HSE who, in the opinion of the Ombudsman, act "solely in the exercise of clinical judgement in connection with the diagnosis of illness or care and treatment of a patient..." The medical professionals examining applications for the LTI scheme are not the applicant's doctor and do not have a doctor/patient relationship with that person. It is the Ombudsman's firm opinion that the actions in question are not excluded from her remit.

The HSE refers to the scheme covering both the "approval of products" and diagnosis. However, the legal basis of the LTI scheme, outlined in this report, does not set out limitations on the medications for which assistance under the scheme may be given. The Ombudsman recognises that there is a continuing debate on the best approach to dealing with ADHD. As regards the classification systems it appears that it is not necessarily the case that they are at odds with one another. While the WHO approach focuses on the behavioural dimension of ADHD, this does not mean that it cannot be seen as a "mental illness", particularly when one has regard to the definition of "mental illness" set out in the Mental Health Act 2001. In fact it is clear that the Oireachtas, in enacting the 2001 legislation, provided a definition that focuses on behaviour rather than aetiology. This is the legal framework to which the HSE administrators of the LTI scheme should have regard. To quote the Act again, "mental illness" means "a state of mind of a person which affects the person's thinking, perceiving, emotion or judgement and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons."

In the context of the varying approaches to the treatment of ADHD it seems reasonable to take the view that both the diagnosis of the illness and the treatment prescribed for it are decisions for the individual's own doctor.

The HSE says it will no longer accept people onto the LTI scheme where ADHD is the disorder involved. The HSE also says that it must await the outcome of the Department of Health's review of the scheme. However, neither of these positions are well-supported by the law. As noted earlier in this report, the LTI scheme has a statutory basis and the HSE is charged with its administration. While it may be appropriate to seek guidance on certain issues, the scheme remains the responsibility of the HSE to administer in an equitable manner.

The central fact of this investigation is that ADHD is recognised as a mental illness by many HSE medical officers for the purposes of the LTI scheme. The HSE has acknowledged that children with ADHD have been accepted as eligible for the LTI card by Medical Officers in the greater part of the country; it is likely that this has been the approach for many years in these areas. The HSE is now proposing to tell all of these medical officers that they may not follow this approach in future. In effect, the HSE is deciding that ADHD does not constitute a mental illness in circumstances where it has no strong basis for adopting the approach. There is no recognition of the practice of many of their own Medical Officers in recognising ADHD and ASD as meeting the LTI eligibility criteria nor is there any consideration of the existing statutory definition of mental illness. In proposing a change of this nature the HSE is also pre-empting the outcome of the Department of Health's review of the scheme.

This is the second investigation in recent times to uncover practises in one part of the country which are at variance with the rest¹. Given that one of the aims in establishing the HSE, more than seven years ago, was to promote consistency of approach and of standards, it is of great concern that such variation of approach could happen and could continue unchecked until this Office is alerted to the matter by a complainant and only then does it become an issue for the HSE.

Findings

Arising from this investigation the Ombudsman makes the following findings²

1. That Ms Kelly was adversely affected by the refusal of her applications for a Long Term Illness card in July 2009 and in September 2010 and that the decisions to refuse her applications were based on erroneous or incomplete information, on irrelevant grounds and were improperly discriminatory.
2. That the decision to refuse to recompense Ms Kelly for her son's medication for the period of her application prior to March 2012 was taken on irrelevant grounds, erroneous or incomplete information and improperly discriminatory.
3. That the administration of the Long Term Illness card scheme by the HSE, treating children differently depending on their geographical location, is improperly discriminatory, an undesirable administrative practice and contrary to fair or sound administration.
4. That the HSE failed in its responsibility to ensure a uniform approach to the administration of the LTI card scheme and failed also to provide the HSE administrators of the scheme with adequate and clear guidance in relation to the scheme and that these failures were contrary to fair or sound administration.
5. That, in the light of the fact that the scheme is under review and the outcome of that review is not yet known, the HSE proposal to alter the approach of its Medical Officers who heretofore had accepted ASD and ADHD as conditions which conferred eligibility under the scheme, is contrary to fair or sound administration.

Recommendations

Based on the findings set out above, the Ombudsman makes the following recommendations:

- that the HSE refund Ms Kelly the cost of medications for her son in the period from when she first made an application for him under the LTI scheme to the time when her application was granted. (The cost was approximately €3,000)
- that, as the outcome from the Review Group is awaited by the HSE and in the absence of any substantive amendments to the governing legislation, the HSE continues to administer the LTI scheme as it has done for many years in the greater part of the country, thereby including ADHD as constituting a mental illness which, in the case of persons under 16 years, gives entitlement to a LTI card.
- that steps be taken to ensure that the LTI Scheme, as a national scheme, is administered in a uniform fashion throughout the country.
- that all of these recommendations are implemented before the end of October 2013.

Peter Tyndall
OMBUDSMAN

January 2014

Endnotes

¹ [Investigation Report: Motorised Transport Grant - The Office of the Ombudsman](#)

² These findings reflect the language of section 4(2) (b) of the Ombudsman Act 1980 which identifies eight categories of maladministration. These apply where an action was or may have been (1) taken without proper authority, (2) taken on irrelevant grounds, (3) the result of negligence or carelessness, (4) based on erroneous or incomplete information, (5) improperly discriminatory, (6) based on an undesirable administrative practice, (7) a failure to comply with section 4A or (8) otherwise contrary to fair or sound administration.

Appendix 1

Submission to the Office of the Ombudsman On the Draft investigation report into inequities in the administration of the Long Term Illness Scheme

1. Clinical Judgment

As the Ombudsman is aware, the HSE has been working actively for over a year to end the disparity with regard to ADHD in the context of the LTI Scheme in Ireland, which is one manifestation of an on-going debate on the clinical nature of ADHD.

The NICE Guidelines on ADHD (September 2008) point out that the diagnosis of ADHD is difficult, and somewhat controversial, for a number of reasons. It is to be noted that there has been an increase in the recognition and treatment of children with ADHD and that high prevalence rates have been reported in some studies. This gives rise to questions given the differing criteria applied to determine the diagnosis.

The authors conclude that, on the basis of current evidence, ADHD is best conceptualised as the extreme of a continuous trait that is distributed throughout the population; the distinction from normality being made by the presence of high levels of ADHD symptoms when they are accompanied by significant impairments. This highlighted the importance of defining what amounts to a significant impairment and ensuring that impairment is fully evaluated when applying the diagnostic criteria. (<http://guidance.nice.org.uk/CG72/Guidance/pdf/English>).

The HSE made clear in its letter of 24 January 2012 and, most recently, in its submission of 14 November 2012 that agreement on the use of diagnostic classification systems continues to prove problematic internationally. Thus, the Ombudsman's Office is aware that the disparity is in fact explained by clinical decisions, taken by clinicians working as officers of the HSE, which were based on recognised, but differing, diagnostic classification systems. The draft report suggests that the issue is a simple administrative one (pages 0, 5, 8, 11). However, against the background of the ongoing debate on the clinical nature of ADHD, it is misleading to suggest that "local rules" (or varying administrative practice) have been employed for a national scheme.

Applications under the LTI Scheme are considered in two steps: diagnosis and approval of products. Medical Officers are clinicians; as such, the organisation expects them to carry out their work as professionals and they can legitimately expect to exercise clinical autonomy. This reasonably extends to their choice of internationally accepted diagnostic classification system. The fact that clinicians in the HSE elect to rely on one or other of two current systems is an inherent part of their clinical decision-making. Practice is not arbitrary; Medical Officers were consistent in their use of classification schemes, which formed a legitimate basis for their decision-making. The disparity arose because clinicians' choice of diagnostic scheme was not consistent across the country.

It is the HSE's view that this draft report and its findings could be considered as straying beyond the Ombudsman's proper remit, in that it consistently employs the terms "administrators" to denote clinical decision-makers (pages 5, 8, 11) and questions the exercise of clinical judgement in connection with the diagnosis or illness or the care or treatment of a patient (SI No 332 of 1984) -2 <http://www.ombudsman.gov.ie/en/About-Us/Policies-and-Strategies/FOI-Manuals/Section-15-Manual/Amendments-to-the-Act-and-Other-Legislation-Amending-or-Impacting-on-the-Act.html>

2. Interpretation of mental illness

In April 2013, the Department of Health (DoH) reiterated its position as relayed to the Ombudsman by the HSE in July of last year, i.e. that it continues to review the LTI Scheme and is not yet in a position to give a timescale for a Government decision. With regard to LTI policy, the Department has stated that is of the view that the question of whether ADHD should be considered a mental illness for the purposes of the LTI Scheme is best resolved in the context of its overall review (pages 9-10).

3. Individual case

The report states that an LTI book was given on a “good will” basis and that “there is no provision in the scheme for issuing an LTI card on such a basis” (page 9). The HSE’s letter of 24 February 2012 (quoted on page 8) clearly states that the basis for the decision was two-fold: long delay and reasonable expectation. It further states that this would “not serve as a precedent for other applicants until the wider issues in relation to clinical classification as described above are resolved”. While the letter of 29 March 2012 to Ms Kelly did not approve retrospective payment, it is inaccurate to

say simply that the HSE has *refused* to reimburse costs retrospectively in this case (page 8), as this letter does not constitute the HSE’s response to the Ombudsman’s letter of 26 March.

The report (page 3) omits to mention that the Ombudsman’s request for retrospection, dated 26 March 2012, was addressed by the HSE in its letter of 9 May 2012, and at a meeting the following day, to the effect that, while it was not possible to conclude that case in isolation pending a DoH policy decision, the HSE would “endeavour to provide a full response for Ms Kelly as quickly as possible”. On 27 July 2012, the HSE provided a comprehensive update and concluded that “in these circumstances” it was “*not yet* in a position to consider a full response” in the individual case. In the circumstances, it is difficult to see what further response the HSE could give to the Ombudsman’s letter of 4 January 2013 which, by the way, represents the first quantification of the 3,000€ suggested (page 3).

The HSE rejects any suggestion that the decisions taken locally in the individual case were not soundly based (pages 7 and 8) or that staff in HSE South were unaware that LTI was a national scheme (page 8). Again, the disparity in Ireland is in fact explained by clinical decisions, taken by clinicians working as officers of the HSE, which were based on recognised, but differing, diagnostic classification systems. It is one more manifestation of an on-going debate on the clinical nature of ADHD.

It is unreasonable of the Ombudsman to seek to have one case dealt with in isolation and then, when the HSE acts, to accuse it of treating cases in “manifestly inequitable” or “expedient” fashion (page 9). The HSE, on 9 May 2012, emphasised its concern “to ensure a consistent and practicable policy” in relation to LTI eligibility.

4. LTI Scheme

Applications under the LTI Scheme are considered in two steps: diagnosis and approval of products. The section “confusion about the scheme” (page 5) is thus itself based on a misunderstanding of the LTI Scheme.

To say that reviewing other possible cases at this stage “would be the fairest approach” (page 7) takes no account of current circumstances, i.e.:

- The DoH has recently informed the HSE that it is not in a position to indicate the outcome of its LTI review at this stage and that final decisions will be a matter for Government. Any HSE decisions should be taken in the context of their policy decision.
- The HSE could not divert financial resources away from current services to cover any LTI arrears without causing other service users to suffer as a consequence.

5. Report Findings

Re 1: Ms Kelly's child was found to be ineligible, based on the clinical diagnostic classification scheme utilised.

Re 2: A final decision has not been taken re retrospection for Ms Kelly.

Re 3: As clinicians' use of different clinical diagnostic classification schemes lies at the root of the disparity, the HSE does not accept that these clinical matters constitute administrative practice in the first instance. The HSE is of the view that this draft report and its findings could be considered as straying beyond the Ombudsman's proper remit, in that it questions the exercise of clinical judgement in connection with the diagnosis or illness or the care or treatment of a patient

Re 4: The HSE does not have the authority to impose a matter of policy in place of the DoH or to oblige clinicians to change how they take clinical decisions as part of their professional practice.

6. Interim Operational Policy

With DoH agreement, and after careful consideration, the HSE has decided an interim operational policy to the effect that the issuing of new LTI books to children with ADHD should be suspended.

This will end the current disparity in clinical practice pending a formal policy decision from the DoH on the matter.