

Medical Card Eligibility

*- Outline Reform Proposals
to take account of Medical Need*

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Context

The Health Act of 1970 is the overriding legislation that determines who should have “full eligibility” for health services. Those deemed to be fully eligible, i.e. those that meet the HSE’s income assessment guidelines, are awarded a medical card, granting full & free access to all publicly available health services in Ireland.

Any applicant that is deemed to be above the HSE’s income guidelines may be awarded a medical card on what has become known as a discretionary basis - subject to a single criteria as set down in the governing legislation –

“...persons considered to be unable, without undue hardship, to provide that service for himself or his dependants...” – Section 45 (7)

The term “undue hardship” refers to *financial considerations only*, as set out in the national assessment guidelines. Generally under these guidelines, applicants are assessed on their net income after income tax, USC, PRSI and mortgage / rent payment and certain expenses.

The means test for medical card applicants applies more stringent conditions than those set for a range of other State supports & allowances. Significantly, repayments on a home improvement loan (typically a credit union loan) were no longer accepted as an allowable expense from April 2013. Furthermore, any contributions to a pension scheme are not admissible. Frequently families are assessed based on last year’s income; disregarding the reality that a parent generally must leave their job in order to appropriately care for their child. The net effect is that the guidelines judge families to be better off than they actually are and increased numbers are forced to appeal for a medical card to be issued on a discretionary basis.

For those above the income threshold, somewhat ambiguous references within the guidelines to “include the nature and extent of personal, medical or social circumstances of the applicant...” all revert back to section 45 (7) of the act as above, and the HSE’s interpretation of what constitutes “undue financial hardship”. The legislation as it stands *precludes any other factors* from being taken in to account when establishing whether full eligibility is warranted.

For over 40 years, applications for medical cards were administered by approximately 100 local offices around the country until a centralised system was introduced in July 2011. All applications are now assessed, and medical cards issued, by a single office - the Primary Care Reimbursement Service of the HSE.

The locally administered system resulted in wild inconsistencies in the application of the rules across the country. The disparity in assessment procedures allowed some to be granted medical cards for very long periods, without review, while others in another part of the country found it considerably more difficult to obtain a medical card.

The local system fostered and was subject to intense lobbying on behalf of applicants deemed to be ineligible. ‘Who you knew’ was often a crucial deciding factor. The net effect was that although difficult, persistence often paid off, rules were bowed, and most with serious illness or conditions were eventually granted a medical card on a discretionary basis. As a country, we limped along with this malleable, deficient system and although it represented a frustrating process for many, as most applicants were eventually successful, calls for reform were largely contained.

The centralisation of the system was intended to ensure that a uniform approach was taken in the assessment of all applicants, under standardised national guidelines and consistent with the letter of the 1970 Health Act.

Ultimately, the centralisation of the system exposed the limited scope and purely financial basis for the assessment of applicants as determined by the 1970 Act itself. Increasing numbers with serious illness and conditions have found over the last 3 years that they are not eligible for a medical card under the existing system. The application process itself amounts to a rigorous financial audit of these people, causes significant distress to families struggling to deal with a serious diagnosis for their child, and in the end, deems that many children suffering with a serious illness or condition are ineligible.

The centralised office remains subject to intense lobbying - in just the first 6 months of 2014, over 21,000 phone calls and emails from TD's on behalf of their constituents were dealt with by the PCRS¹.

The continued prevalence of lobbying is symptomatic of, and underscores, the inadequacy of a system that fails to take account of medical need and the impact of a serious medical condition on a child or their family.

The number of medical cards in circulation has increased significantly over the last 10 years, such that almost 40% of the population now have a general medical card, equating to 1,790,438² medical cards as of June 1st. However, just 2.92%² of that total were issued on a discretionary basis.

Even after the return of many cards over the summer months, discretionary medical cards now account for just 3.9% of the total³. While the overall rise in the headline numbers holding a medical card is often cited by government, for the 3.9%, a fraction that includes many with serious & chronic conditions, they face an onerous application process, with many deemed ineligible from the outset or following review.

Most would agree that some form of universal health care is the ultimate answer to the difficulties faced in determining eligibility for medical services. However such a system is undoubtedly many, many years from implementation. In the mean time, we must prioritise those with the greatest medical need and most especially children.

While it may not be possible to devise a perfect system to take account of medical need, we believe it is possible to establish and introduce a vastly improved basis for assessment that takes account of the impact of a medical condition on a child and the implications for their family.

A means based system of awarding medical cards is necessary and fundamental. So too is a comprehensive, well funded and accessible primary care service. However, we cannot continue to have a situation whereby children with the most serious medical need coming from ordinary families with modest incomes and huge outgoings remain ineligible. This is simply wrong and unjustifiable.

Here we put forward our proposals divided into 5 key areas and endeavor to outline how a reformed system to take account of medical need might work. The following is based on our own research and experience of the system, our submission to the expert panel and intensive contact with parents over the last 160 days. We believe the suggested reforms to be not only feasible, but essential, to ensure every child in Ireland with a serious illness or condition is afforded full and free access to all public health services. We hope that in some way, this document may add to the on-going discussion and inform the pending changes to the medical card system.

¹ Sunday Business Post, July 14th

² Figures from briefing notes to the Minister for Health, www.health.gov.ie

³ Irish Independent, October 31st, based on quoted numbers holding a discretionary medical card at end September 2014.

Outline Reform Proposals & Current Practice

1

Assess every child in their own right, based on their *individual medical need*, consistent with obligations as set out in articles 23 and 24 of the 1992 UN Convention on the Rights of the Child, which Ireland is party to.

Currently under the legislation, no child can be assessed for medical eligibility in their own right. Any parent seeking a medical card for their child must submit an application for the entire family, listing the child among their dependants. Even when presenting with the most serious and acute medical need imaginable, the assessment for a medical card is in reality a comprehensive financial audit of the parents, often resulting in the application being denied. Each medical card in circulation costs money, whether used or not. Frequently, successful applicants receive 5 or 6 medical cards for the entire family, when a single card was required. Similarly, unsuccessful applicants for a general medical card commonly receive GP only cards for all members of the family, instead of the single card required, all resulting in unnecessary additional expense for the State.

2

Establish *clear criteria* relating to the impact of a medical condition, criteria that should outline the common characteristics of serious medical need and should in themselves grant full eligibility to certain categories, or at a minimum be taken into account when determining eligibility (see appendix (i)).

The current basis for assessment, whether an applicant is above or below the income guidelines, takes financial considerations into account only – for those above the threshold, seeking a card to be awarded on discretionary grounds, the test is whether “undue hardship” can be shown. The narrow financial criteria as set down in the national assessment guidelines fail to take any account of the impact of a medical condition on a child - what amounts to a significant departure from the normal life trajectory relative to their healthy peers or siblings, and the associated implications for the parent or guardian aiming to ensure they fulfil their potential. While listing conditions in isolation may not be possible or practicable, we consider that it is feasible to establish qualifying criteria and common characteristics of medical need, that if taken into account, would greatly improve the basis for assessment. Criteria and medical guidelines drafted to determine eligibility for the Domiciliary Care Allowance provide relevant precedent and may be of use in this context.

3

Establish a new *Medical Services Card* that will grant an individual child full eligibility for all medical services only. Additional social supports that form an integral part of the existing medical card for those below the income threshold are not particularly significant for those with serious illness and conditions and result in unnecessary additional cost to the State.

The existing medical card grants a range of social supports such as a reduced USC rate, exemption of payment for State exams and free school transport. Medical cards granted based on means assume financial need, medical cards based on medical need should not necessarily make the same assumptions. The key priority for parents is that their child is fully eligible for all medical services and that the period of eligibility is appropriate to their needs.

4 A ***streamlined application process***, facilitating an application for an individual child in their own right, with dedicated personnel to deal with each application, handled by a new medical need unit within the PCRS.

An application can be dealt with relatively quickly when an applicant meets the financial criteria. However, for applicants above the income threshold, the process is all too often slow, laborious and inefficient. Any new medical need assessment criteria should be handled by a separate department with dedicated case officers assigned, providing continuity in the assessment of an application. This separation will lead to a streamlining of the processes, adding efficiency and clarity for applicants and staff alike while alleviating frustration by ensuring the applicant does not have to recount the entire case history with every phone call.

5 The ***expertise of the professional*** treating the child with their associated medical and local case knowledge should be central to any application for eligibility based on medical need. Those trusted to treat the child should be trusted to recommend when eligibility is warranted, and in particular, recommend the duration as appropriate.

Many applications are accompanied by letters from clinicians detailing the extent, severity and likely duration of a condition, but such valuable input is effectively disregarded as it falls outside the scope for assessment. The lead clinician* charged with treating the child is in many cases best placed to recommend when full eligibility is warranted according to the qualifying medical criteria as established. Particularly in cases where diagnosis and/or prognosis is rare, uncertain or complicated, the medical professional involved will have the ability and experience to negotiate and understand a defined set of characteristics of serious medical need and know when a patient falls into this category.

Reviews

Reviews of medical cards; both scheduled and arbitrary as part of the recent 'probity exercise', appear to take no account of the severity or likely duration of a medical condition. The recommendation of the lead clinician should be central when determining the appropriate period for eligibility, and instructive in establishing an appropriate time scale for a review.

**It should be noted that in many cases of serious medical need, especially in relation to children, the treatment of a patient is not always carried out in a primary care setting. Many children are treated exclusively by a consultant lead team in a tertiary hospital, with little or no involvement from their GP. Input should be sought from the lead clinician as appropriate to each case.*

Medical Need

Establish Clear Criteria



A working group should be convened to establish the common characteristics of **Serious Medical Need**. These criteria should ultimately form the basis of awarding a Medical Services Card, to an individual child, centred on the impact and implications of a medical condition.

- **The following are no more than suggested examples of guideline criteria, by no means exhaustive, that may determine the common characteristics of serious medical need. Criteria that in our view, should in themselves warrant full eligibility for medical services, or at a minimum be taken in to account as part of the assessment process.**

→ **A child with a life-limiting or terminal condition;**

A life limiting condition in a child is defined as “any condition from which there is no reasonable hope of cure and from which the child or young adult will die”^{1,2}

¹Palliative Care for Children with Life Limiting Conditions in Ireland - A National Policy, Department of Health & Children, 2010.

²A Core Care Pathway for Children with life-limiting and life threatening conditions, 3rd Edition. – Together for Short Lives, UK, formerly Association for Children with Life threatening or Terminal conditions and their Families.

→ **A child with a life threatening condition;**

A life threatening condition in a child is defined as “a condition where curative treatment may be feasible, but can fail, such as cancer”¹

¹A Core Care Pathway for Children with life-limiting and life threatening conditions, 3rd Edition. – Together for Short Lives, UK, formerly Association for Children with Life threatening or Terminal conditions and their Families.

- Applications for children falling in to the above categories should be dealt with as swiftly and compassionately as possible, effectively an automated process, with particular regard paid to the appropriate period for eligibility.
- Children with life limiting and terminal conditions should not be subject to review and remain fully eligible for the duration of their lives.
- The UK body, Together for Short Lives, has established 4 broad categories of life-limiting and life threatening conditions, cited by both the Department of Health, and Irish Hospice Foundation, see Table 1.

Table 1	Categories of Life-limiting and Life-threatening conditions <i>Together for Short Lives UK (Reviewed February 2013)</i>
Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. <i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i>
Category 2	Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. <i>Examples: cystic fibrosis, Duchenne muscular dystrophy.</i>
Category 3	Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. <i>Examples: Batten disease, mucopolysaccharidoses.</i>
Category 4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. <i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i>

- **A child with a severe disability requiring continual or continuous care and attention which is substantially in excess of that normally required by a child of the same age;**

Consistent with the agreed qualifying criteria for the Domiciliary Care Allowance, as reviewed in March 2014¹

¹*Medical Eligibility Guidelines for Domiciliary Care Allowance, Report of the Expert Medical Group, March 2014.*

- **A child with a congenital condition resulting in cognitive developmental delay, related physical growth and intellectual impairments, and an associated high incidence of treatable medical disorders;**

As referenced in Medical Management of Children & Adolescents with Down Syndrome in Ireland¹

¹*Medical Management of Children & Adolescents with Down Syndrome in Ireland, Approved Guidelines Down's Syndrome Medical Interest Group (DSMIG) (UK & Ireland Department of Paediatrics University of Dublin, Trinity College The National Children's Hospital, AMNCH, Tallaght 2001)*

- **Where there is a necessity for on-going acute tertiary pediatric care, or treatment is required by a consultant led team on a prolonged basis.**
- **Where the frequency of required hospital and GP visits arising from a condition, as envisaged by the medical professional, exceeds an agreed threshold.**
- **Persistent and recurring absence from education due to the impact of a condition, or inability to participate in education resulting from a condition.**
- **Where there is an on-going requirement for equipment, physical aids & appliances to support & sustain functions relative to the normal of age of attainment, e.g. mobility.**
- **Where there is an on-going requirement for access to therapies to ameliorate the impact or symptoms of a condition; physiotherapy, occupational therapy, speech and language therapy, hydrotherapy etc.**
- **Inability to feed independently, whether resulting from a physical or intellectual disability, necessitating the insertion of a permanent gastrostomy tube.**
- **Where on-going treatment results in significant side effects, requiring a multidisciplinary response, necessitating additional treatment, aids or equipment.**
- **Where continuous pain management is required over a sustained period.**
- **Where extensive tests and investigation are necessary to determine appropriate diagnosis and treatment.**
- **Where medical services required are rare, unavailable or cost prohibitive privately.**

Summary

We have tried to capture in a concise way why the system and the legislation supporting it needs reform. In this context we have proposed 5 key areas where change is needed and how this can be done. While some may regard these changes as not going far enough, we have constructed and presented them in such a way that we believe to be realistic, possible and necessary.

Key Reform Proposals:

1. Assess children and their medical need in their own right.
2. Establish criteria for awarding medical cards on the basis of the common characteristics of serious medical need.
3. Introduce a new *Medical Services Card*, in addition to the existing Medical Card.
4. Establish a separate section of the PCRS to deal exclusively with *Medical Service Card* applications.
5. Expertise of medical professionals charged with treating the child should be fully utilised in determining eligibility based on medical need, and in particular, in establishing an appropriate review timescale.

We suggest that a working group of medical experts be convened to establish qualifying criteria based on the common characteristics of serious medical need. We have put forward some limited examples that are by no means exhaustive but included for illustrative purposes. Establishing clear criteria would provide a transparent and consistent basis for assessing the impact of a medical condition and ultimately determine eligibility based on a child's medical need.

We understand that following on from the Keane report, government will shortly set out reforms to improve the basis of assessment for medical cards and, we hope, reform access to medical services on the basis of medical need. It is in this context that we place our proposals in order to add to the debate and hasten much needed reform.

This document will be sent to all key members of Government and the Oireachtas, Parents, Interest groups, all media outlets and made generally available publicly. Ultimately this document aims to bring about real reform for the parents we have come to represent and their children. We believe that their fight on behalf of their children, their bravery, commitment and generosity towards their family should be reflected by the State in how it responds to these families and the difficult circumstances they find themselves in.

Our Children's Health will continue to campaign until such time as children are adequately awarded full eligibility to all necessary available medical services on the basis of their medical need but look forward to a day where our campaign is no longer necessary.



Peter Fitzpatrick



Kevin Shortall



Mark Fitzpatrick