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LTI or GMS Card for Chronically Ill Children? Or Both?

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The long term illness scheme (LTI) was both prescient and providential. Introduced in 1970 its aims and achievement were far seeing, relieving the burden of chronic illness for parents and their children. It has been extraordinarily successful. One hears reports of the HSE considering reining in or restricting "demand led services". One hopes that they will not curtail or cutback on the LTI scheme.

The LTI covers drug and equipment costs for children with specified long term illnesses (Table 1). The listed conditions are somewhat arbitrary and by no means cover all chronic debilitating illnesses in childhood. The scheme is hospital based and does not cover GP visits or services. The scheme has not been revised or updated. For example a child with diabetes mellitus is entitled to free influenza vaccine but may have to pay his/her GP to administer it. Most Irish people would be surprised to learn that children with cystic fibrosis (a condition of much frustration and recent furore) are not entitled to a medical card.

Table 1 Conditions covered by the long term illness scheme

Mental illness	Cystic Fibrosis	Cerebral palsy
(under 16 years only)	Spina Bifida	Epilepsy
Mental handicap	Hydrocephalus	Diabetes mellitus
Phenylketonuria	Haemophilia	Diabetes insipidus
Acute leukaemia	Muscular dystrophies	

The Faculty of Paediatrics RCPI (the voice of Irish paediatricians) voted unanimously in 2007 that all children entitled to the LTI scheme should be entitled as a right to a medical card. Some 30 new cases of cystic fibrosis are diagnosed each year and some 600 children attend CF units in Ireland. The GP (family doctor) is not part of their caring team. While it is imperative that children with CF attend a paediatric unit for most of their care, which by its nature must be multi-disciplinary including doctors, nurses, physiotherapists, dieticians, psychologists, social workers, etc. the family doctor has a definite role. The LTI effectively places the GP out of the loop, being a hospital based service. One suspects that many children on LTI schemes do not attend their GPs at all because of cost implication.

Table 2 lists the conditions covered by LTI, the estimated annual frequency of new cases and the cumulative number of cases attending childrens' units. Children with chronic conditions such as CF, diabetes mellitus, phenylketonuria, epilepsy, etc. tend to attend childrens' units until their 18th birthday as they are so entitled. Some will graduate to adult services at 16 years but most opt for the familiarity and trust of their paediatric team until 18 years old.

Table 2 Accounts to about 20,000 children or about 2% of 1 million Irish chidren

List to Include	New Cases Per Year	Total No. of Cases
Inborn Errors of Metabolism	140	1800
Cystic Fibrosis	35	600
Insulin dependent diabetes mellitus	150 – 200	2,500 – 3,000
Down's Syndrome	110 – 120	1,500 – 2,000
Haemophilia and inherited coagulopathies	18 – 20	480
Muscular Dystrophy	20 – 25	300 – 400
Cerebral Palsy	120	2,000
Epilepsy	200	3,000
Chronic Kidney Failure	10 – 15	50 – 70
Leukaemia	30 – 40	130
Childhood Malignancies	100	300 – 500

The GP should know and be familiar with children on LTI other than by hospital discharge reports, consult communications, or test reports. The HSE's own strategies would suggest that the GP should play a central role in providing care. Does this happen for children on LTI scheme? One suspects that many children on LTI schemes are given for a medical card and that the HSE is sympathetic to their needs but data are simply not available. One also suspects that the Irish public would be horrified to know that children with CF have to apply for a medical card. The CF association has been campaigning for a medical card for all CF patients for some time, without success. The Diabetic Federation of Ireland believes that all children with diabetes mellitus should qualify for a medical card, as a right, not as an arbitrary entitlement.

The Faculty of Paediatrics strongly advocates and exhorts that all children on the LTI scheme, should be entitled to free medications, free devices and equipment, free hospital services but additionally access to a free comprehensive health service including that provided by GPs. Children with listed LTI conditions are amongst the most vulnerable in society and need our support, succour and comprehensive health care. The LTI has served Irish children well. It must not be diminished or dismantled with withdrawal of provision. Instead LTI entitlement should progress to GMS entitlement. The Faculty of Paediatrics would welcome comments from the IMO, ICGP, patient organisations and the tax paying public on this issue. The issues are complex and the costs considerable.

Surely in 2009 Ireland can afford to provide a universally free health service to its chronically ill children, accounting for about 2% of its 1 million children? The provision of health care, medical devices and comprehensive therapy to Ireland's vulnerable chronically ill children needs review and revision.

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