

Best health for children: developing a partnership with families

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BEST HEALTH FOR CHILDREN

PREFACE

This document represents the first phase of a longer term project to develop work relating to children's health.

This initial step looks at promoting health in children aged 0-12 and in particular the role of screening and surveillance and the development of parenting, education and support.

Only part of the picture is presented here and should be viewed as work in progress. This work will continue to be developed and refined. For example, a group to look at adolescent health needs has recently been established.

However, there are many areas of child health services which would benefit from the ideas and suggestions within this initial report. There has been very strong interest in the work to date, a recognition of the need for change, and a desire to have support and backup for the change to occur.

This initial document should be viewed as a resource to help the change. Many services have already moved in the direction suggested by this report; others are making the first steps.

The Chief Executive Officers of the Health Boards have recognised the need for support for the change process and have set up a co-joint Child Health Committee to help in the development and quality improvement of child health services. A National Child Health Co-ordinator has also been funded and will take up post shortly.

These services will continue to develop the work in relation to the health of children and young people, but will rely very heavily on the contribution of clinicians and managers at local level, and the help and support of the Department of Health and Children. This recognises the aims we all share of wanting all children in Ireland to develop to their full potential.

The ideas and suggestions in this report go part of the way to showing how this may be achieved.

Mr. Denis Doherty
Chief Executive Officer
Midland Health Board

INTRODUCTION

BEST HEALTH FOR CHILDREN

Issues around Child Health Screening and Surveillance has not been examined in Ireland for over thirty years. During this period there have been rapid economic, social and health care advances and increased emphasis on quality, effectiveness and value for money in health and social services.

This report has a significant number of detailed recommendations.

These are underpinned by the development of a model which encompasses a more holistic child health promotion approach, and emphasises the role of families as partners in the process.

The report is in two sections.

Part one, A Vision for Child Health develops a vision for child health in the future, describes a model that would enable services to meet this vision, and outlines changes that will be need to be made in current practice to enable this model to become reality. It includes a summary of conclusions.

Part two, A Technical and Operational Report describes the evidence concerning screening and surveillance, looks at professional roles and responsibilities, and details the content and timing of a standardised national screening and surveillance programme. It includes a summary of recommendations.

Child health screening and surveillance programmes in Ireland developed out of a desire to ensure that children achieved the best possible health of which they were capable. Because of these services and the staff working in them, many children have had problems detected at a stage which has allowed much earlier intervention than would have been otherwise possible.

However in the last few years there have been several developments which meant an evaluation of current approaches was timely. New evidence about the effectiveness of

screening has been coming to light. There is increasing recognition of the roles and abilities of parents in detecting problems with their children's health. The value of a broadly based health promotion approach, which goes beyond the detection and treatment of disease and can contribute to improved health, has been recognised.

This report is an attempt to evaluate where we are now, and what needs to be done to get to where we want to be.

Using this report:

This report is presented in a ring binder format because:

1. It is likely that sections of it will need to be updated as our knowledge base improves.
2. There is room for practitioners to add material or articles relevant to child health.

In doing this we hope it will be seen as a resource which managers and practitioners can refer to, dip into and add to.

Table of Contents

PART ONE

PAGE

1.	Child Health Review – Conclusions	1 - 2
2.	A Vision for Health	3 - 5
3.	The Strengths of the Current System	7 - 10
4.	Listen to parents “You know yourself”	11 - 12
5.	Screening: Back to Basics	13 - 15
6.	A New Service Model	17 - 22
7.	Moving to the New Model	23 - 28

CONCLUSIONS

QUALITY OF SERVICE

1. Current programmes and services for children focus mainly on disease and physical ill health
2. The emotional and psychological health of children has hitherto received insufficient attention in surveillance programmes.
3. An effectively run screening and surveillance programme for children can make a significant contribution to the health and social welfare of children.
4. The current system for surveillance and screening for children is unacceptably varied in quality.
5. Some parts of current programmes of surveillance and screening are not evidence based and need to be changed or stopped.
6. There are considerable strengths and skills within the current arrangements. These should be acknowledged and built upon.
7. The Community Child Health Team can be a significant resource to schools in delivering Health Education Programmes.

A PARTNERSHIP WITH PARENTS

1. There is substantial evidence confirming the effectiveness of parents in detecting problems with their children. Current services give insufficient recognition to this fact.
2. Facilities for child health screening and surveillance are often inadequate and too little emphasis is placed on ensuring that surroundings are child or/and parent friendly.
3. First time parents are often particularly in need of support. Interventions with this group can be particularly effective.

4. Parents in vulnerable families may benefit from much more intensive levels of support than they currently receive.

SERVICES

1. There is a need for greater feedback to general practitioners in relation to child health surveillance. General Practitioners with appropriate training may be contracted to undertake developmental screening by the Child Health Co-ordinator.
2. There is potential for the development of greater nursing specialisation for children particularly those in vulnerable settings.
3. The potential of many community medical staff remains under-developed and the skills of this group are not being fully utilised.
4. Consultant Community Paediatricians in some areas would have a valuable role to play as part of a multi-disciplinary child health team.
5. Health Promotion support in school settings is inadequate in most regions given the size and potential of the task.
6. Schools value a link with named professionals with whom they have an ongoing relationship.

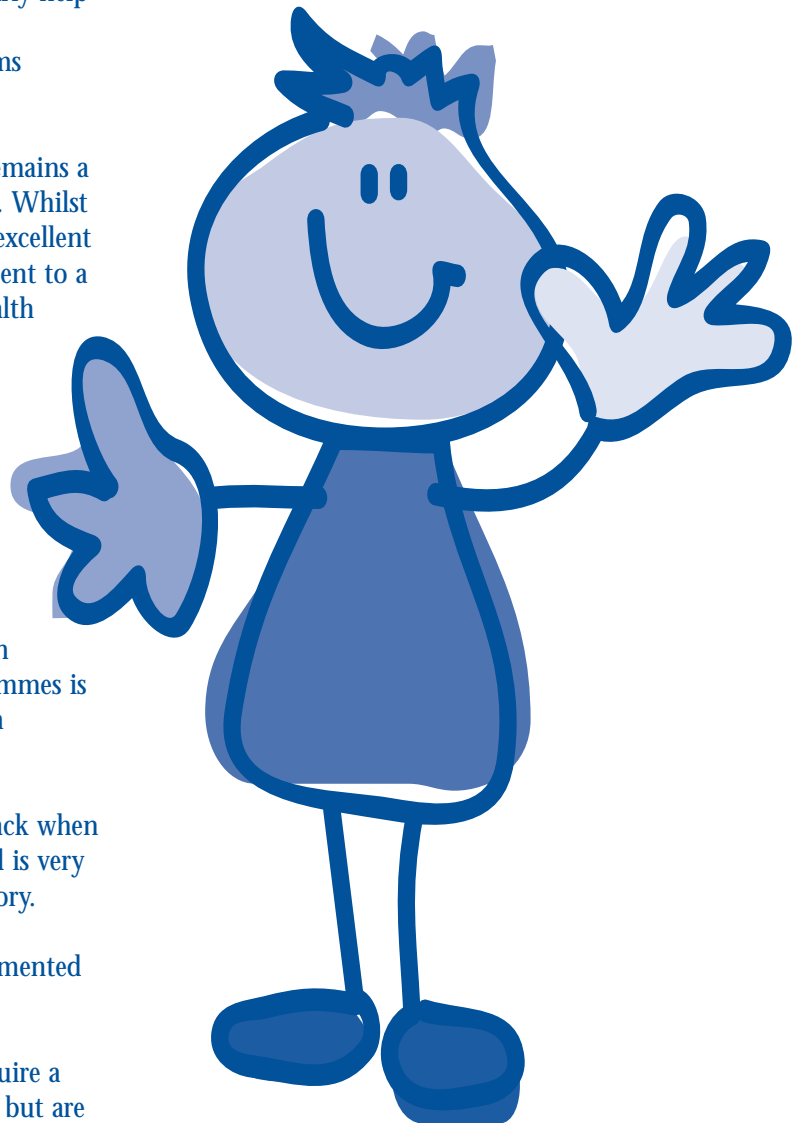
Teachers and parents have unacceptable difficulties in getting support from educational psychology services. Behavioural problems are a major problem and treatment services to respond to them are insufficiently developed in some areas.

TRAINING

1. Training and continuing education in the area of child health promotion including screening and surveillance are patchy at best and need to improve significantly.

EQUITY

1. The current system for surveillance and screening for children in Ireland is not equitable.
2. Programmes can be inflexible and not cater for different levels of need.
3. The lack of free access for all children under 5 to general practitioner services may act as a barrier for seeking early help in some circumstances, and may contribute to the delay in problems getting attention.
4. The health of traveller children remains a very significant cause for concern. Whilst there have been some pockets of excellent work, there seems little commitment to a comprehensive programme of health improvement.



ACCOUNTABILITY

1. Information currently gathered on screening and surveillance programmes is of poor quality and of little use in performance management.
2. The process of referral and feedback when a problem is detected with a child is very variable and too often unsatisfactory.
3. Roles and responsibilities are fragmented with variable co-ordination.
4. Children with complex needs require a seamless and co-ordinated service but are often not receiving it.
5. General Practitioners require much better feedback on screening and surveillance programmes than they are currently receiving.

Recommendations are given in the first part of the next section of the report.

A VISION FOR HEALTH

Of all European Union countries, Ireland has the highest level of children as a percentage of the total population. Investment in our children in terms of health and education is essential to ensure the future prosperity of the country.

Ireland has an impressive track record in acknowledging this fact, and health services have increasingly recognised the need to protect and treat children with problems.

However, services for the promotion of children's health and the prevention of ill health have not been the subject of sufficient attention in recent years.

"A Mother is nearly the next best thing to a doctor".

Quote from participant in study of user views

The last review was over 30 years ago. Since then there have been major developments in what we understand about the effectiveness of services, the influence of lifestyle, the role of consumers of services and the approaches that are likely to influence behaviour.

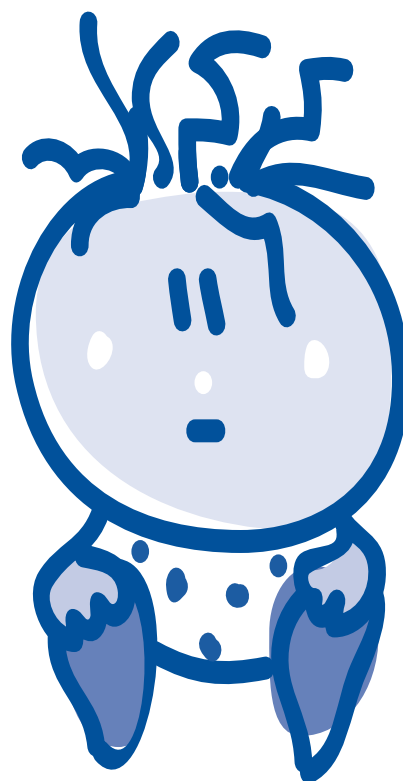
Although there is general agreement throughout the world regarding the importance of monitoring a child's growth and development, particularly in the early years of life, it has been difficult to achieve consensus on how best to do this.

This reflects the paucity of good quality research in this area, itself the symbol of a lack of importance sometimes given to these programmes.

Goals of a Child Health Surveillance Programme

- That all children have the opportunity to realise their full potential in terms of good health, well-being and development
- That remediable disorders are identified and acted on as soon as possible

These may be achieved principally by parental observation aided by professional support. Observation should be supplemented with a small core programme of screening tests of proven effectiveness.



A CHILD HEALTH REVIEW

At the request of the Chief Executive Officers of the Health Boards, the Directors of Public Health established a team to review the screening and surveillance services for children in Ireland.

The last comprehensive review of these services was carried out in 1965-1967 by a Working Group appointed by the Minister for Health.

The national health strategy document "Shaping a Healthier Future" in 1994 stated that there would be a review of the pre-school and school health services.

Terms of Reference

The terms of reference of this group were:

To define a programme for child health surveillance in the pre-school and primary school age group, the content of which would be based on the best available evidence.

The review covered the age group from birth to 12 years and addressed the following areas (outlined in the box below:)

Review Process

The review team was set up in September 1996 and used the following methodology:

Review of published and unpublished literature from Irish and international sources. This focussed particularly on the evidence base for screening and surveillance but also addressed issues of management, organisation and training.

A broad consultation process involving interviews with professionals working with children, service managers and representatives of consumer groups.

Qualitative research with consumers groups.

A multidisciplinary workshop.

A working group on parent held records.

A working group on the birth notification system.

A workshop on parent support.

Content and timing of programme
Roles and responsibilities, including accountability
Partnership with parents
Training
Information management
Resources
Opportunistic health promotion
Quality Assurance

Workshops were facilitated by Dr. Sarah Stewart-Brown and Professor David Hall, two of the leading experts in Europe on Child Health Surveillance.

The following services were excluded from the review in order to ensure it remained focussed:

Maternity services

Breastfeeding

Immunisation

Acute/episodic illness

Chronic illness

Dental health

Adolescent health

Disability - except in so far as it impinges on the screening services

Child protection - except in so far as it impinges on the screening services.

Some of the exclusions listed have already been the subject of national reviews, and some, such as improving adolescent health, are sufficiently complex to require a review of their own.

STRENGTHS OF THE CURRENT SYSTEM

The 1970 Health Act

Under section 63 of the Health Act 1970, the Health Board shall make available medical, surgical and nursing services for children up to the age of 6 weeks.

Under section 66 of the Act, a Health Board shall make available without charge a health examination and treatment service for pupils attending a national school.

Children who are referred for further specialist out-patient attention or for admission to hospital are treated free of charge.

In practice there is no standardised approach to the operation of the child health services around the country.

Child health services in Ireland were first set up in the early part of this century when childhood mortality and morbidity were high and most children did not have access to free medical care. These services subsequently developed in a rather ad hoc manner as needs arose or as remedies became available. Many services provided by a range of statutory and voluntary agencies have been continued, without any scientific evaluation of their relevance to present health needs.

However, it must be recognised that whilst critical examination is timely there are many strengths to the current child health screening and surveillance services in Ireland.

Accessibility and acceptability:

The pre-school and school health services operated by the Health Board community care staff have provided an opportunity for all children to receive a health service, regardless of income. For some children, particularly the most vulnerable whose parents may be reluctant to access other health services, it may be the only contact they have with health

professionals in their childhood. Traditionally the services have been considered very acceptable to parents, as evidenced by the high uptake recorded and by the results of consumer surveys.

Advocacy/facilitation:

There are many children who do not fit in easily to mainstream services, for medical, social, emotional or educational reasons. Traditionally the community care professionals, having identified such children through the screening services, have played a major advocacy role in facilitating these children to access appropriate services and thus to achieve their full potential.

The local knowledge and contacts developed over the years by these professionals is invaluable in this regard, as is the liaison with a multidisciplinary team at local level.

Capture of entire childhood population:

In the absence of a general practitioner registration system as exists in many other countries, the only opportunity to access the entire population of children is by using the birth notification registration system.

This is the basis of the system used currently for screening and surveillance services in Ireland.

These services thus allow unique access to the population at a critical age in life - to access not just the physical aspects of health but also the broader social, emotional and environmental influence on health of the child, and an important opportunity for introducing the concepts of health promotion.

Such a captive population base also holds the potential for valuable epidemiological analysis.

Expertise and experience:

The contact with such large numbers of children through these services has allowed the health professionals involved to develop a high

level of expertise in a wide range of areas of child health.

Cost:

The present salaried session based system has been run at a relatively low cost compared to that of the alternative of a fee-per-item system.

Building on Strengths

For a variety of reasons families have had to fit into the services the health boards chose to provide.

The approach has tended to depend heavily on the opinion of experts. It is increasingly recognised that a partnership approach with parents is likely to be much more effective in achieving health and social gain for children.

Health boards must develop this partnership with parents, one which enables both partners to recognise their responsibilities in an agreed way.

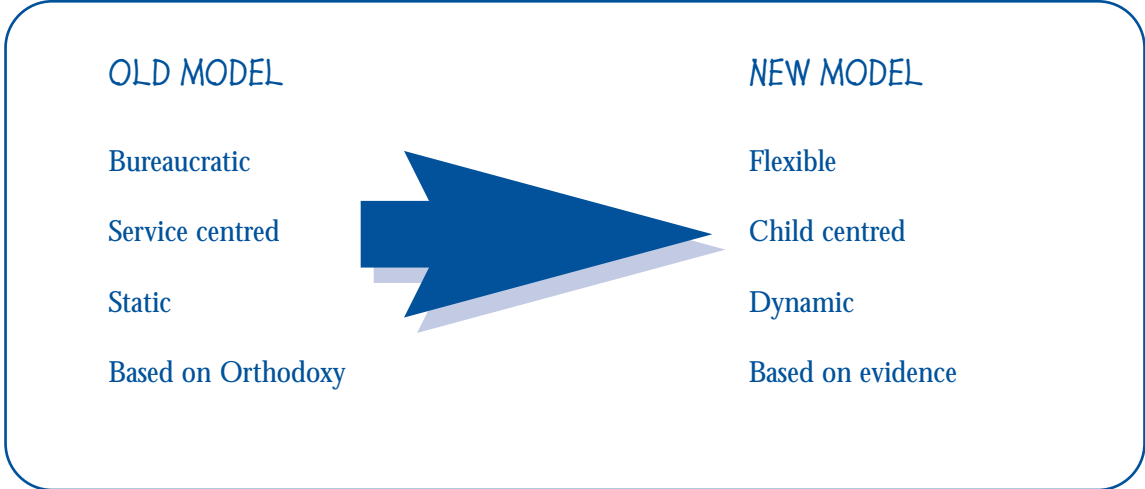
The Responsibility of Service Providers

The responsibility of service providers takes the form of key principles, given in the right hand column, which should underpin any quality service.

These principles, need to produce a shift in services from the left to the right of the diagram given below.

Key Principles of a Quality Child Health Programme

- Children should be enabled to achieve their maximum health potential.
- Parents or have the right to be actively involved in their children's health and supported in appropriate and effective ways.
- Services exist to serve the needs of children and parents
- Parents have a right to information about services
- Parents have a right to appropriate feedback from services
- Parents have a right to be consulted about how services are delivered.
- Parents and children have a right to services of high quality.



A VISION FOR CHILD HEALTH SERVICES

A new model needs to be developed which places children and carers or parents at the centre of the process and offers them a number of alternatives.

All parents should be strongly encouraged to make use of certain services, for example the core screening and surveillance check ups. Some children and parents may need additional services.

This process can be seen as completing a jigsaw. Some children will need a one or two piece jigsaw, other children will need jigsaws with many pieces.

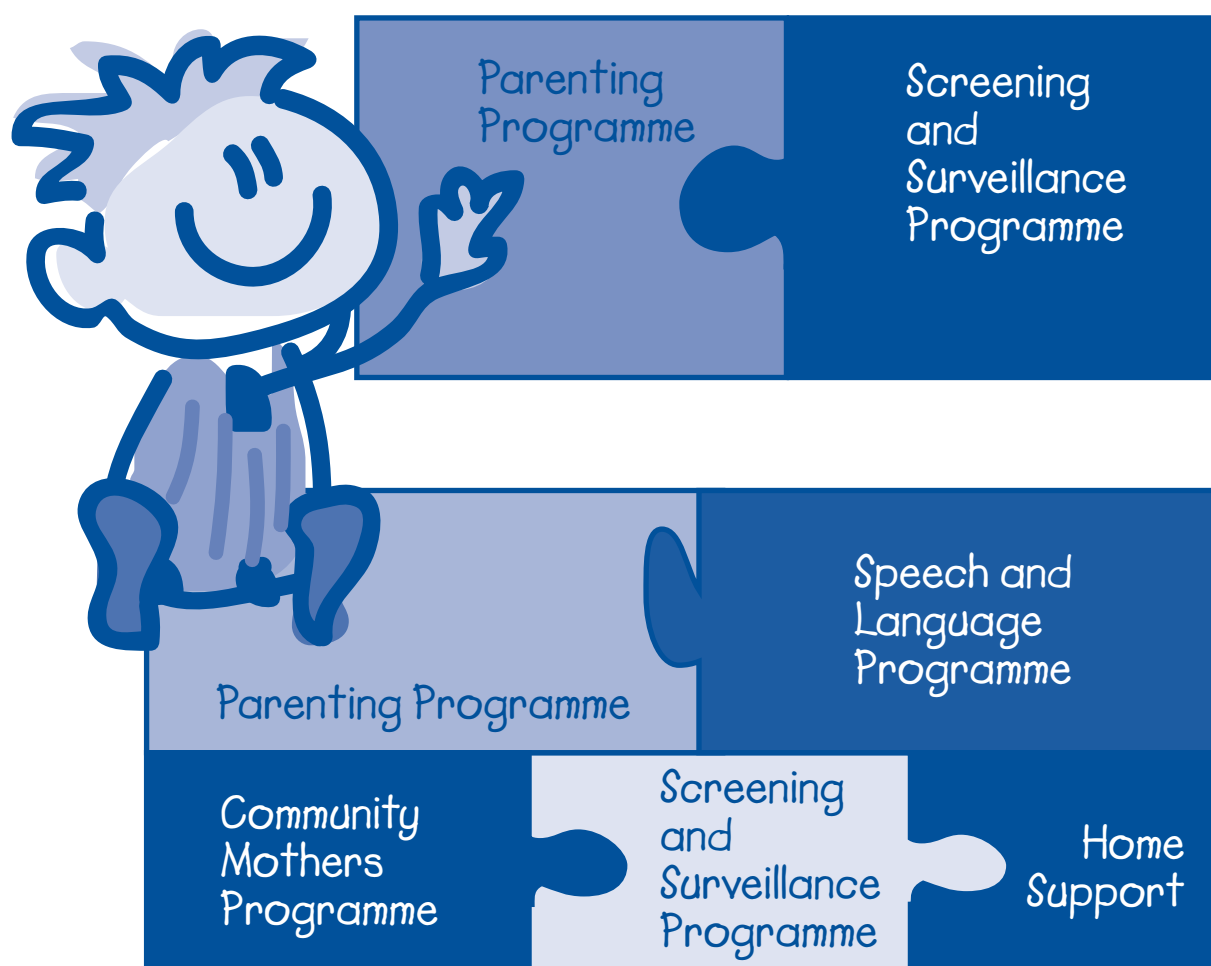
The role of services should be to facilitate the parents in deciding which bits of the jigsaw they need, and facilitating or providing services to meet those needs (of the highest quality).

Service components must link in with each other to provide an integrated, co-ordinated service.

Services must also be flexible and recognise that needs change, and what was once an appropriate package of services may not be in the future.

Finally all services, but particularly screening services need to be subject to rigorous quality control.

Some families will require only core parts of the service



Some families will require a comprehensive suite of programmes

Seven Key Questions

In order to strengthen this integrated approach to child health, it is helpful to outline a set of seven key questions which should be considered when considering where we are now and where we might want to go in the future.

1. What are the professional skills needed and to what extent are needs for training and continuous education being met?
2. How clear are areas of responsibility and lines of accountability ?
3. What emphasis is given to parental involvement?
4. What commitment is there to parental support and education?
5. What commitment is there to trying to achieve equality of outcomes for children?
6. To what extent do current practices in screening and surveillance programmes reflect current evidence?
7. To what extent have standards for quality and outcomes been defined and monitored?



LISTENING TO PARENTS

It has been increasingly recognised internationally that parents are very capable screeners of their children and are swift to identify developmental delays.

It is also recognised that families will usually use their own lay networks as their first source of advice.

A research project was commissioned by the review group to help further our insights into how parents access the service and how they view the services they have received.

In the study a qualitative approach was used amongst two groups of parents, one with children from 8 weeks to 18 months, the other with parents of primary school children.

Children 8–12 weeks: Main findings

- All children had received a pre-discharge and 6 week check plus at least one visit from the public health nurse.
- There was a certain perceived overlap between the hospital pre-discharge check and the first public health nurse visit.
- There are gaps in the information provided about the roles of professionals, particularly the role of the public health nurse.
- Communications between parents and GPs and PHNs is generally positive though communication gaps do exist particularly between the hospital and General Practice and PHNs.
- There are poor facilities such as toys, toilets, and buggy parking for families in most health centres.
- There is in existence a strong lay network which is the first point of help for most families.

“I never really worried but at the same time I would have known myself if he was developing normally”

“only because I already had a child, that I knew what was going on”

“If there was any difficulty I would probably ring my friend”.

Quotes from mothers interviewed for study

Children 6–18 months: Main findings

- The service provision is being experienced by parents in a very variable way.
- There appears to be very poor understanding and little formal notification of what developmental checks their children should have.
- There is a lack of clarity amongst parents of the roles and responsibilities of parents.
- There were poor facilities for families at clinics.

Primary School Children: Main Findings

- Generally parents expressed satisfaction with the service they received.
- There was a high level of confusion as to the aims and objectives of the service
- Little information was given to parents about the service and the people responsible for delivering it.
- Parents generally thought there should be more examinations as they believed this

would bring more benefit. This view was particularly held by parents without a medical card.

- Parents complained of differences in level and intensity of service over time or between different places.

“I just had a vague idea that they called out to see that everything is ok. I did not know at what stage she would be calling”

“It was packed.... I was waiting for an hour and a half”

“A few extra nappies would not go astray”

“It was great when she (the public health nurse) did call. She gave advice on feeding, checked weight, reflexes, sight etc...”

Quotes from mothers interviewed for study

SCREENING: BACK TO BASICS

Screening programmes, like any other intervention have the potential to do both good and harm.

However, the balance between good and harm will change with the frequency of testing and the quality of the programme

If the quality of the screening programme is low, the benefits are reduced and adverse effects increase. If an adequate level of quality is not achieved, there may be a point at which the harm done by screening is greater than the good.

The criteria for appraising screening were first put forward in the 1960's by Wilson and Jungner.

Criteria for appraising screening developed in the 1960's (Source: Wilson and Jungner)

- The condition sought should be an important health problem.
- There should be an accepted treatment for patients with recognised diseases.
- Facilities for diagnosis and treatment should be available
- There should be a recognisable latent or early symptomatic stage
- There should be a suitable test or examination
- The test should be acceptable to the population
- The natural history of the condition, including development from latent to declared disease, should be adequately understood
- There should be an agreed policy on whom to treat as patients

- The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole
- Case-finding should be a continuing process and not a 'once and for all' project.

Screening Programmes

A test or series of tests performed on a population that has neither the signs nor the symptoms of the disease being sought but where members have some characteristic that identify them as being at risk from that disease, the outcome of which can be improved by early detection and treatment.

However J. Muir Gray has argued that these are out of date and need to be built on.

- There is insufficient emphasis on the adverse effects of screening and the need to ensure that a programme does more good than harm.
- The criteria state that 'an accepted treatment' should be available, but many accepted treatments are either ineffective or of unproven efficacy.
- There is no discussion of the quality of the evidence upon which decisions are made.

He also suggests that in appraising screening programmes consideration of the financial costs of the screening programme and the health gain that may be obtained by using the resources in other ways should be considered, e.g.

- (a) Other ways of managing the health problem that the screening programme has been designed to tackle.

- (b) Alternative services for the population that the screening programme is designed to benefit, e.g. parenting programmes, parent and toddler groups.

Muir Grey has also put together a selection of aphorisms which he suggests people ponder about screening programmes, some of which are featured in the boxes in this section.

"A screening programme without false positives will miss too many cases to be effective. Like the tightrope walker above Niagara Falls, any screening programme must balance false negatives and false positives".

"For the distressed patient seeking help, the clinician does what she/he can; for the healthy person recruited to screening, only the best possible service will suffice".

"Screening programmes should be run with firm management".

J.A. Muir Grey

QUALITY, QUALITY, QUALITY

Perhaps more than any other services the effectiveness of a screening programme stands or falls by good management and a quality assurance system.

If a screening programme is not supported by quality assurance it should be stopped.

Quality assurance encompasses the essentials of

- standards
- information
- authority to act.

Screening programmes need competent and watchful management. If the quality falls, a programme that was doing more good than harm may then do more harm than good.

The Body of Evidence

The evidence in relation to child screening and surveillance has recently come under attack.

A recent upsurge of interest in systematic review of evidence is playing an increasingly important part in helping practitioners focus their skills on doing things based on evidence.

The programme of screening and surveillance recommended by Hall and his colleagues in the UK had diminished with each edition of his authoritative report "Health for All Children".

Even some of the "sacred cows" of screening such as screening for amblyopia have recently been questioned.

However as is often the case some research has been interpreted in different ways leading to researchers looking at the same evidence and coming to completely different conclusions! It is important that where the evidence for a test is strong should continue. Where there is evidence that it does more harm than good it should be stopped.

The problem with child health surveillance is that most of the activities lie in the gray areas in between where the evidence is not there or is conflicting. There is always some apprehension about stopping something which appears to do no harm and may be of some good, in the absence of evidence either way.

A Pragmatic Approach

A pragmatic approach needs to be taken which offers a rationalised screening programme which reflects current knowledge but errs on the side of caution. It cannot be stated too often that the quality assurance of the programme is vital. There is no point in having any programmes that are not tightly controlled.

Part 2 of this report outlines the core programme of screening and surveillance which can be justified as things stand.

It should be recognised that this is very unlikely to remain static and that further

changes are likely as the evidence becomes available.

This is one of the reasons why there needs to be an advisory group at national level which can disseminate evidence and oversee the quality of the programme, as without a national steering group it is very unlikely that modifications would occur in a planned way.

The table in Part II represents the core programme. It should be recognised that there may be settings or groups where the programme should be enhanced in the light of evidence relating to particular groups of children.

“If quality falls, a screening programme that was doing more good than harm may then do more harm than good”.

“If a quality assurance programme is not generating at least one major public inquiry every 3 years, it is ineffective”.

“At best, screening is a zero gratitude business”.

“The harm from a screening programme starts immediately; the good takes longer to appear. Therefore, the first effect of any programme, even an effective one, is to impair the health of the population”.

J.A. Muir Grey



A CHILD CENTRED MODEL

In this section an attempt is made to describe a model of services which fits the requirements for the next century, bearing in mind the evidence of effectiveness and examples of good practice.

This model:

- Recognises that the services are concerned with children and their parents, and that they should be at the centre of them.
- Acknowledges and respects the importance of communities and lay support as the first port of call.
- Recognises that primary care should be the main focus for health care.
- Works to increase the knowledge and skills of families and communities to enable them to continue to take responsibility for the health of their children.
- Facilitates a system to identify and support families who need help in fulfilling their responsibilities.
- Recognises the principle that it is health and well being which should be the focus but acknowledges the importance of a swift and effective response to problems of ill health or potential ill health.
- Recognises that families have most contact with the play group, the crèche, the school, the community centre, the health centre and so on and that therefore services should be built around these locations.
- Operates in a co-ordinated way to deliver a flexible package of care.
- Accepts the need for high quality specialist services to back up local services, which would have excellent communication between these services and the families needing them.

- Recognises that Health Boards and the Department of Health need high quality information on which to plan and develop policy. They need to ensure resources are being used effectively and that outcome indicators for services are developed and understood.
- Promotes links with other departments or services to ensure health issues in relation to children are acted upon.

A young population

Almost 25% of the Irish population is aged under 14 years.

Ireland has the highest proportion of the population under 15 in the EU.

The prevalence of breastfeeding in Ireland is amongst the lowest in Europe at 33% (1992)

In 1996 over 40% of all childhood deaths (aged 5-14) were due to injury.

A COMMUNITY CHILD HEALTH SERVICE

The following describes, in broad terms, what the new model service would look like.

Before Birth

Having presented for maternity services all new parents should receive a visit from the public health nurse. This would serve as an introduction to her and to the child health service which the parents would encounter after the birth. It would also allow an opportunity for the nurse to outline the services that would be anticipated in the future.

The nurse would give the parents the Patent Held Child Record and any other leaflets, books or videos that are appropriate in assisting the parents in identifying any support available.

The Parent Held Child Health Record: acts as a record of the developmental checks and screening that has taken place; contains information on services; gives information on children's health and the developmental stages that children pass through; contains health promotion messages on a range of topics from accident prevention to diet; and gives details of local community groups and activities.

After Birth

Before leaving hospital the child will have a check-up including hearing testing. In the first few days after discharge the PHN would call to discuss the process of child health surveillance, and complete any screening procedures e.g. the Guthrie test.

The parents would be automatically asked to attend scheduled check-ups through the child health system which is initiated through the birth notification system.

A range of community based options including parent and baby and toddler groups, community mothers scheme, parent training programme should be available and easily accessible in each locality. The information given on these, combined with advice from the PHN, and GP and AMO, will allow parents to avail of help and support when needed.

Particular emphasis will be given to first time parents as they have particular needs which, if addressed, will ensure they are more confident with this child and subsequent children.

Children will be seen for surveillance or screening within a local setting whenever possible. This will be undertaken by doctors and nurses with special training in child development and screening.

Children with complex needs and/or in particularly vulnerable families will receive additional support from Community Child

Health Nurses who specialise in working with children. Traveller families may need extra support.

In areas where the family GP is not directly involved in screening, there will be excellent feedback mechanisms established which would allow the GP to have a full understanding of any problems found, and of any referrals thought to be necessary. This will enable the GP to be prepared when parents call to her seeking help or advice.

The Community Child Health Team

Community Child Health Teams will provide the hub for the child health system.

The Community Child Health Team (CCHT) is multi-disciplinary with nursing, medical and paramedical input and having strong links with other children's services, such as child protection and children's mental health services.

It provides the main clearing house for children identified as having problems identified by the screening and surveillance programme, whether this be via a formal developmental check up or opportunistically by General Practitioners.

A child referred to the team will be able to have a full and comprehensive assessment made of its needs, and a treatment and rehabilitation package developed in conjunction with the parents with the family's General Practitioner.

The CCHT serves as the link between primary care and tertiary services, and ensures children receive an appropriate and co-ordinated package of care.

The CCHT will develop explicit standards in relation to child health services, and take responsibility for a programme of clinical audit to improve standards.

High quality tertiary services in Centres of excellence will provide diagnostic and treatment services for the most complex problems. Again the local CCHT will have a close involvement in tertiary referrals to ensure

a cohesive package of care is delivered and that parents and their child's General Practitioner are fully informed.

Parenting Support

As the child develops parents will be able to avail of a network of parenting supports, both formal and informal. This will range from Community Mothers type programmes and Fathers Groups to Parent and Toddler groups.

Purchasing Developmental Screening

The Community Child Health Co-ordinator should be given flexibility in ensuring that children in their population have access to high quality developmental checks.

They should be enabled to 'purchase' checks for their population from health staff with appropriate skills and training. In most cases this will be Area Medical Officers and PHNs, but may include GPs who have equivalent experience.

They should also ensure that staff undertaking checks have adequate continuing education to remain on the panel for undertaking checks.

These will be "purchased", supported and developed by the CCHT in conjunction with other services such as the social work service or the health promotion service. This will be done on the basis of analysis of local needs and priorities.

All parents will have the opportunity to receive parenting education pitched at the appropriate level.

At school

Routine physical examination of children will be replaced by a more holistic approach to school health. Universal vision and hearing testing and growth measurement will be retained and the quality will be improved.

The school health service will adopt a more child health promotion focus, and be managed by the Community Child Health Co-ordinator.

All schools will have a named school nurse who will provide the main link and deliver a planned programme of screening, health advice and health promotion supported by medical officers and health promotion specialists.

All parents would have the opportunity of meeting the school nurse to discuss their child's health.

The development of the educational psychology service will allow stronger links to develop with Health Board psychological services and child psychiatry services who will more appropriately be able to deal with the emotional and behavioural problems for which they have the skills.

Opportunities to support the SPHE programme in schools will be taken full advantage of.

There will be greater emphasis on listening to parents and teachers.

Problems identified by teachers or school nurses will be referred to the CCHT with early communication and discussion with the family's General Practitioner.

Schools will also be a natural base for many of the parenting programmes that have or will be established

This vision may sound well in theory, but it will be worthless if it does not make a practical difference to the health of children in Ireland.

On the following page are examples of the way services may meet children's needs in the future, if this model is adopted.

The role of parents in the school health service:

It is well recognised that parents are very good at identifying their children's needs and recognising defects at an early stage. Greater use needs to be made of this resource. This can be achieved by the following:

1. At school entry, parents should receive an information leaflet outlining the school health service, including content and timing of the programme.
2. Parents should be requested to complete a questionnaire at the three key screening ages.
3. Parents should be encouraged to attend school health screening visits, in particular the school entry visit.
4. Parents should be informed that they may request a meeting with the school nurse at any stage if they have concerns about their child.
5. Parents should be informed of any abnormality suspected or confirmed by the school health team.

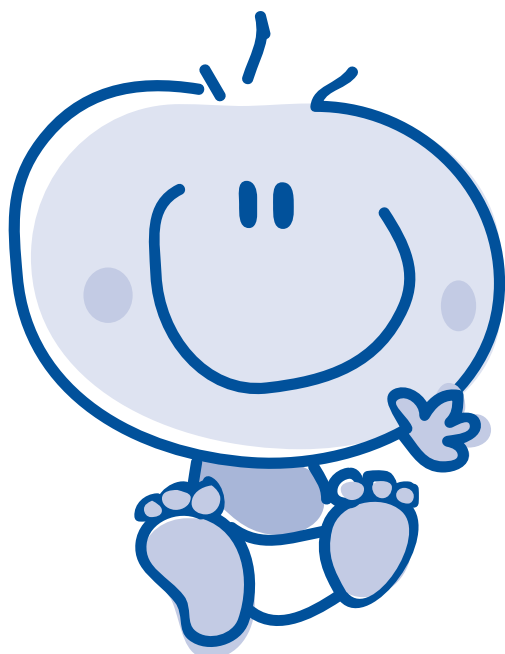
CHILDREN'S STORIES: SERVICES FOR THE FUTURE

Padraig Aged 9 Months

Padraig was taken by his mother for a 9 month check up. The check up included a check on his growth and development, an examination to detect whether there were any problems with his hips, and screening for vision and hearing. It was done at the local health centre by a doctor and nurse with skills in assessing children.

At the visit there was also discussion about accident prevention, nutrition, smoking, child car seats, developmental stimulation, and the use of sunscreens.

Padraig's mother knew what to expect because it was explained in the child health record. Padraig's mother had some concern about his hearing although at the neo-natal test, it had been normal. He was referred to the child health team for further audiological assessment. The result of the check up and reason for referral were sent to Padraig's GP that day.



Niamh Aged 1 year

Niamh's mother brought her to see her GP because she was worried about her. She didn't seem as far on as other children of her own age group. She knew from the Public Health Nurse and her child health record what was expected for a child of her age. They were new to the area and this was her first baby.

Her GP acknowledged her concerns and said he was going to make a referral to the Community Child Health Team, who he explained were a team of people who would be able to make a thorough assessment of Niamh. The GP was concerned at the mother's lack of social support, and arranged a visit from a local member of the community mothers group, through the public health nurse who also increased her visiting programme.

The Child Health Co-ordinator arranged the assessment and invited Niamh's mother to discuss the results. There was no specific health problems identified, except it was established that Niamh's mother spent very little time playing or interacting with her. A community child health nurse was assigned to help Niamh's mother stimulate and play with her.



Conor Aged 3

Conor is being seen by members of the community child health team after his parents raised concerns to their GP about his speech delay.

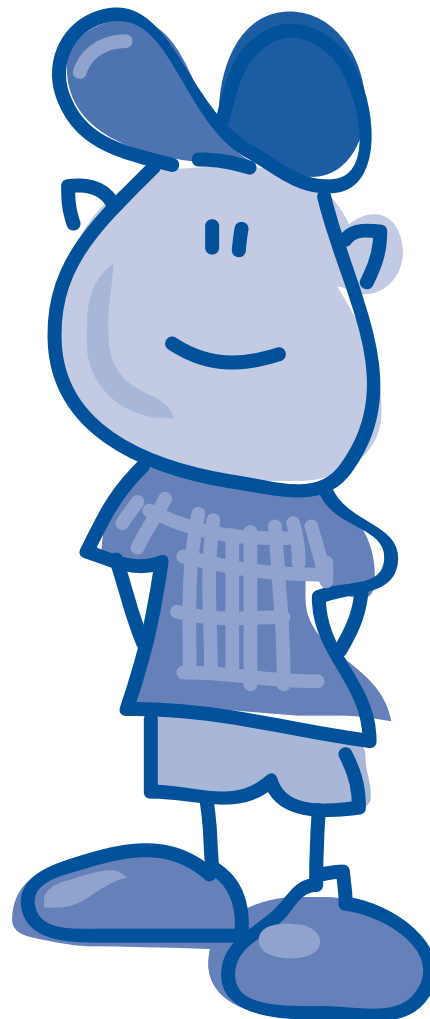
Conor was found to be partially deaf and in need of a hearing aid. The speech therapist has been working with his parents on improving his language skills.



John Aged 4

John has been seen by the community child health team since the age of six months when he was diagnosed as having a mild cerebral palsy which was causing mild developmental delay. He also has some problems with co-ordination and some hearing loss.

His key worker is a Consultant Community Paediatrician, but is also being seen by a community physiotherapist, occupational therapist and speech and language therapist. John and his family have been supported by a parents group for children with mild cerebral palsy and by the Public Health Nurse and General Practitioner. The package of services is being co-ordinated by the Child Health Co-ordinator in the team



David Aged 9

David's teacher contacted the school nurse because of worries about his behaviour and school performance. The school nurse contacted David's GP who had not seen him for some time but knew that his parents had recently separated. A previous check-up had revealed David was short sighted. However, although glasses were prescribed he never wore them. An educational psychology assessment had shown David to be of above average ability. David's mother was invited to talk to the teacher and school nurse, and after further discussion with his GP, who was referred to one of the psychologists who worked with the community child health team.

David's mother also began attending a parenting course run at the school by facilitators trained by the Health Board.

MOVING TO THE NEW MODEL

Many parts of the new model are already in place, or could be in place with a minimum of effort.

Some aspects of the new model do present significant challenges in both commitment and in implementation.

Whilst it is obviously important to have a vision for a service, it is equally important to have a clear idea of how this vision may become a reality. In doing this it is important to recognise current structures, possible barriers to change, and how these may be overcome.

Earlier in the report a list of questions were suggested that might be asked in relation to evaluating the success of a child health programme.

In this section the same headings are used to suggest the changes that will need to be made to move to the new model.

It should also be apparent that many parts of the new model are already in place, or could be in place with a minimum of effort. Some aspects of the new model do present significant challenges in both commitment and in implementation.

1. What are the professional skills needed and to what extent are needs for training and continuing education being met?

Public Health Nurses work as generic community nurses and while this has many strengths, evidence would suggest that with increased throughput in hospitals and a more dependent elderly population, the health promoting work with children inevitably loses out on priority.

Some GPs have highly developed skills and interest in children's health but for some increased input into screening would require updating of skills.

GPs are also very busy and in the present climate are unlikely to want to take on additional time-consuming work without additional remuneration.

Area Medical Officers currently perform developmental checks and school medicals. This has allowed them to develop skills in this area, and to be familiar with the various problems and the referral services.

However, consultation and feedback with other services including General Practice is variable. A parent attending a developmental assessment may be referred back to the GP if they have an unrelated health problem thus necessitating two visits.

There has hitherto been a lack of expertise available in dealing with children with complex developmental problems.

Co-ordination and liaison between professionals is variable and can often leave parents without an agreed care plan for their child.

Many other professionals such as speech and language therapists, psychologists, community ophthalmologists and audiologists spend considerable amounts of their time in assessing and treating children with developmental problems.

Moving to the New Model

The child health service at a local level should have the Community Child Health Team at its centre. There should be a team in each community care area.

The core of such a team would be the Child Health Co-ordinator with medical, epidemiology and public health skills, a Consultant Community Paediatrician where he/she exist, and a Senior Public Health Nurse. The core team would be joined by named clinical staff such as psychologists, speech and language therapists, occupational therapists, and physiotherapists.

The Community Child Health Co-ordinator should be responsible for "purchasing" developmental checks for the children in their population and ensuring that the training and quality of developmental checks is of a high standard.

They would also co-ordinate training and development in relation to this, in association with their colleagues in the community child health team.

He/she will be responsible for the child health information system, and for supplying each board with information for performance management.

Screening should be carried out in a local setting convenient to parents. The screening should be carried out by a doctor/and or a nurse depending on the particular screening or developmental check.

The doctor should either be an area medical officer or a general practitioner who has the required experience and evidence of updating of skills. Area medical officers may do checks in health centres or where appropriate in a GP setting.

The Child Health Co-ordinator would draw on the expertise of other professional groups to form the community child health team including speech and language therapists, psychologists, occupational therapists, physiotherapists and area medical officers, social workers and health promotion officers, named people within their professional functions who have dedicated time within the child health team.

The Consultant Community Paediatrician would provide consultant clinical input, links with hospital and tertiary paediatric services, training, and clinical support to General Practitioners & AMO's.

The Superintendent Public Health Nurse or her nominee would co-ordinate public health nursing input into child health services.

The team would have to develop very strong links with child mental health and child protection services, through the General

Manager in each community care area.

Each primary school should have a named school nurse and doctor. The Child Health Co-ordinator and PHN in the community child health team would ensure coverage of the school system. It is envisaged that the main body of the work of the school health service will be carried out by the school nurse, with the doctor having an advisory and referral role.

The concepts of a child and family at the centre of services is shown diagrammatically in the figure on this page.

Training of key professionals in the School Health Service

Designated school nurses and doctors should have special training in the health of children. The school nurse should be trained specifically in screening methods for vision, hearing and growth. The school doctor should ideally have training in community child health. Both professionals should have an understanding of emotional and behavioural problems, child protection issues, research, infectious disease control and health promotion.

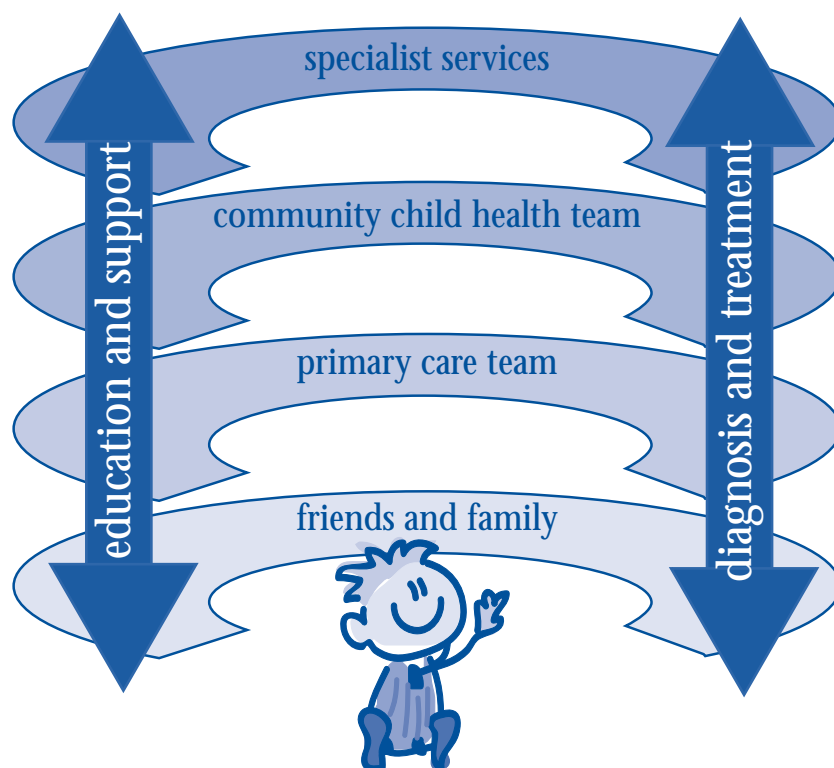
Training of key professionals

Adequate training and continuing education of these professionals is essential to ensure a quality service.

Doctors working in community child health often have a Masters in Public Health. Whilst valuable, this may not be found enough on clinical and children's issues for doctors wishing to specialise in this area.

A Masters in Community Child Health should be developed in an Irish University. It should be opened to all child health professionals, with specialist modules for particular professions.

Regular courses in screening techniques need to be held and everyone carrying out hearing and vision testing, for example needs, to have



Child Centred Services are the guiding principle of this model

their skills regularly reviewed. We would suggest that doctors and nurses carrying out surveillance and screening should be required to attend a refresher course every 3 years to keep up their skills and learn of new development techniques and that this should be a major quality consideration when the Co-ordinator purchases developmental screening.

2. *How clear are areas of responsibility and lines of accountability?*

At present these are blurred and whilst returns are currently produced by the SAMO in relating to statistics they themselves have concerns about the quality of the data. Little constructive use is made of the data at a regional or national level and there is wide variation in practice and procedure.

Moving to the New Model

Responsibility for the quality of the programme at a National level should be with the National Co-ordinator who should be supported in this role by a National Child

Health Committee which would set minimum standards for the programme and commission an annual report from each region. They would identify particular areas of the programme to be audited on a rolling basis. The National Co-ordinator would advise the CEOs and DOH on the programme. At community care level the Child Health Team Co-ordinators would report to the General Managers for Community Care. There would be strong links with hospital paediatric services.

The Child Health Co-ordinator should produce an annual quality report.

Members of the Community Child Health Team would report to service heads on professional and clinical supervision issues and to the Child Health Co-ordinator on operations and co-ordination issues.

Services such as parenting programmes or parent support programmes funded or facilitated by the board should be the subject of service agreements which state levels of service, quality standards etc.

The school nurses should be managed via the Senior Public Health Nurse in the community child health team, with overall responsibility for the school health service with the Child Health Co-ordinator.

3. *What emphasis is given to parental involvement?*

At present parents obtain support primarily from family and peers. They may get additional support from community groups. The main professional contacts are GPs and Public Health Nurses. As the child gets older the school will be an increasingly important setting.

Moving to the new model.

The new model would require much more attention to be given to parents as partners and to improving information and support.

A Parents Charter should be developed at national level which sets out what parents can expect in relation to child health services and also outlines parental responsibilities. The Community Child Health Co-ordinator should take responsibility for monitoring performance against the standards in the Charter. They are likely to want to do this as part of the development of a minimum data set for child health.

4. *What commitment is there to parent support and education?*

Parent Education has shown itself to be effective but provision is patchy.

Support programmes such as the Community Mothers Programme have not been extended to all those areas that could benefit from them or it may have been done in a half-hearted way.

Moving to the New Model

Community Child Health Teams in conjunction with Departments of Health Promotion in each Board should review the provision of parent training in their region and take responsibility for formulating the parent training strategy which involves consumer and provider of parent training. Good practice should be disseminated by the development of a parenting network for example.

The Community Child Health Co-ordinator should liaise with the social work and health promotion services and organisations such as the Leader programmes in assessing the need for and provision of support programmes for children and parents and should monitor quality standards.

The Community Child Health Teams in conjunction with Health Promotion Departments should review the information available to support parents and develop or adopt materials in consultation with them.

5. *What commitment is there to trying to achieve equality of outcomes for children?*

There is currently inequality in the system of child health services. There is also inequality of access for young children in relation to GP services, and access to specialist services. However, Public Health Nursing services are available to all children free of charge.

The area medical officers offer a free screening and development service to all children. Referrals on from this service are also free of charge. It is our view that a scaling down of the surveillance programme should be accompanied by an improvement in access to general practitioner services for young children, as any barriers to seeking help should be removed.

Some vulnerable groups such as traveller children have a poor outlook in terms of health. Some health boards have done useful and successful work to improve the health of

these groups but it has tended to be on a project basis with patchy application.

There seems to be little commitment to a systematic programme of health improvement for travellers although recent developments in funding are welcome.

There is a paucity of research into the health status of children in different social groups or income

There have been few studies of the attendance patterns of children in Ireland by income or social class, but existing evidence from GPs suggest that parents may delay seeking help for non-acute problems.

Moving to the new model

A standard child health data set should be collected. This would allow a much better understanding of outcomes and how they are affected by equity.

There should be a national system of registration with a family doctor to ensure all children have access to a GP and to allow more robust data on outcomes to be collected. The provision of a unique identifier for health purposes is also an essential adjunct to this.

All children should be given access to the services of a General Practitioner free of charge, but this is particularly important for children under 5. The cost of providing this for pre-school children is unlikely to be prohibitive.

A National Child Health Committee should be established which should hold a budget for commissioning research into aspects of children's health including issues of equity.

A named officer within the board should be given specific responsibility for travellers health, ideally with a medical and public health and should co-ordinate regional programmes ideally with a medical and public health background.

6. *To what extent do current practices in screening and surveillance programmes reflect current evidence?*

For a long period there was little systematic review of the evidence surrounding screening.

The emergence of an evidence based culture in health care has helped to address this. Consequently there are more than half a dozen major systematic reviews concurrently being carried out which have relevance to child health surveillance and screening. This has made it difficult to outline a definitive screening programme as:-

- There are likely to be significant recommendations to take on board as new evidence emerges.
- Some of the findings of reviews will be equivocal and highlight the need for further research.

Hence the ground will continue to shift. In general terms however there would seem to be a trend towards a more holistic child health promotion approach in relation to surveillance.

There are also some difficulties in reviewing the evidence as it is difficult to quantify some benefits for example the value parents place on re-assurance. Lack of evidence is not in itself a good basis for discontinuing programmes.

It is also difficult to exactly transfer situations between countries. For example in Great Britain there is a more developed community child health service.

Moving to the New Model

As stated before we have recommended an interim programme which is likely to continue to change as the evidence base becomes more robust.

The National Child Health Committee should have responsibility for the review and dissemination of new information and developments in this area and for liaising with Child Health Co-ordinators.

There is also a need to link with those services which receive referrals from screening, in order that they may appraise themselves of developments and feedback their observations on the process and outcomes of screening.

The collection of more relevant, higher quality data will allow a much better assessment of effectiveness. This data set and the systems used to collate and analyse it need to be flexible to allow for likely changes over the coming years.

7. To what extent have standards for quality and outcomes been defined and monitored?

As outlined in an earlier section, screening programmes stand or fall by the effectiveness of their quality control. This is a particular area of weakness within the current service.

This is partly because of the uncertainty as to whether particular procedures are effective, a lack of commitment to producing information of good quality, and a lack of investment in training and continuing education.

Moving to the New Model

The Child Health Co-ordinator should have a responsibility for monitoring the quality of the child health programme and reporting to the health board.

The performance of services should be monitored by the Department of Health, with technical advice from the National Child Health Committee.

The National Child Health Committee should be responsible for setting broad national minimal standards. They may be added to on a regional basis.

A report on Child Health Services should be produced on an annual or bi-annual basis by the National Child Health Committee or may form part of the Chief Medical Officers annual report.

Table of Contents

PART TWO

PAGE

Summary of Recommendations	1
1. Child Health Screening and Surveillance	9
2. Health Status of Children in Ireland	11
3. History of the Community Child Health Services in Ireland	25
4. The Strengths and Weaknesses of the Current System	27
5. Perinatal Reporting System	31
6. Behaviour Problems and Psychiatric Disorders in Childhood and Adolescence	33
7. Promoting Children's Health through Parent Education	37
8. Parent Held Child Health Records	41
9. Roles and Responsibilities of Professionals	45

Table of Contents

Continued

10. A National Child Health Surveillance Programme	51
11. Newborn Screening for Metabolic Disorders	55
12. The Six Week Examination	57
13. Seven - Nine Month “Developmental”	59
14. Screening for Hearing Defects	63
15. Screening for Vision Defects	69
16. The School Health Service	75
17. Idiopathic Adolescent Scoliosis	81
18. Referral Pathways and Information Feedback	83
19. Monitoring Child Health Surveillance. Information and Outcomes	85
Acknowledgements	91
Appendices	
Participants at Workshop on Parent Held Records 7th October 1997	92
Participants at Child Health Workshop in Westport April 23-25, 1997	93

SUMMARY OF RECOMMENDATIONS

Perinatal Reporting System (Chapter 6)

It is recommended that the notification of birth form be reviewed.

There is a need to develop a system for preliminary notification of births which will provide the necessary information in a timely fashion to allow for the PHN to carry out a domiciliary visit within 24 hours of the discharge home of a newborn baby. The content of this form should be standardised nationally. The mode of transmission of this information from the maternity unit to the relevant PHN should be via fax, electronic mail or computer link.

It is recommended that the marital status of the mother should not be a factor in delaying the release of a birth notification by a hospital.

A copy of the notification of birth form should be sent routinely from the maternity unit to the baby's general practitioner (as nominated by the parent).

Behaviour Problems and Psychiatric Disorders in Childhood and Adolescence (Chapter 7)

The prevalence of childhood behaviour problems and psychiatric disorders in Ireland needs to be quantified by national research.

The services for children with these problems need to be improved in the following areas: education of parents and teachers in identification of problems; training of primary care health professionals; and the provision of adequate specialist psychology and psychiatry services.

Promoting Children's Health through Parent Education (Chapter 8)

It is recommended that a parent education programme be developed nationally.

Regular evaluation should be undertaken of the effectiveness of any new service introduced.

Parent Held Child Health Records (Chapter 9)

Serious consideration should be given to the development of a PCHR in Ireland which would be used for all children. It is recommended that prior to its introduction it should be subjected to a pilot phase followed by a full evaluation. Parent representatives should be involved at all stages of planning and evaluation.

Roles and Responsibilities of Professionals (Chapter 10)

Child Health Team: The child health services at community care level should be managed through a child health team.

Child Health Co-ordinator: The team should be led by a child health co-ordinator. The Child Health Co-ordinator should work closely with the local Department of Public Health in relation to planning and evaluation of services, and epidemiological matters.

Delivery of services: It is envisaged that the delivery of the child health services in each community care area would be carried out by members of the multidisciplinary team, including

AMOs, PHNs, Psychologists, Physiotherapists, Occupational Therapists, Speech and Language Therapists and other professionals as appropriate. It is recommended that the Child Health Co-ordinator may contract with the GP to carry out the health examinations at 7-9 months of age and in schoolchildren - this would be dependent on the GP having the appropriate skills, training and continuing education required for the task

General Practitioners: The relationships between the GP and other professionals involved in child health surveillance should be fostered and strengthened. It is recommended that the GP should receive a report of the outcome of each examination carried out by community health staff. Where a child is referred from the community services to a specialist, the specialist should send a copy of his/her report to the GP, as well as to the referring professional. A GP carrying out child health surveillance examinations on contract to the health board should be obliged to complete and return a full report on the outcome of the examination.

Community Paediatricians: The establishment of posts of Community Paediatricians in Ireland offers an opportunity to enhance the skills available to the community child health team. These skills should be blended in the developing new services. Roles and responsibilities should be clearly defined, as should relationships with other relevant professionals; in particular, strong emphasis should be placed on the relationship with the Child Health Co-ordinator. The appointment of Community Paediatricians in the North Western Health Board should be seen as an opportunity to evaluate their role in the Irish context.

Community Child Health Nurses: We recommend that community nursing services for infants and pre-school children be delivered by community child health nurses and for schoolchildren by school nurses. PHNs, by virtue of their training, would be suitable for such positions. It is essential that the community child health nurse and the school nurse have the necessary training and ongoing education to deliver a high quality service.

A National Child Health Surveillance Programme (Chapter 11)

A core programme for child health surveillance is outlined. It is recommended that this programme be implemented in a standardised manner nationally.

The needs of the child must be the central focus of the new programme.

Newborn Screening for Metabolic Disorders (Chapter 12)

Responsibility for co-ordinating the newborn metabolic screening programme should be assigned to one body. Nationally agreed protocols for screening should be drawn up.

The target uptake rate for neonatal metabolic screening should be set at 100%. In order to ensure that this is achieved an audit should now be carried out of the screening programme, addressing in particular the completeness of cover, and the timeliness of testing and reporting.

It is recommended that the recent UK research on neonatal metabolic screening be examined by experts here to assess the relevance of the results to the Irish population and services.

The Six Week Examination (Chapter 13)

It is recommended that a standard set of data be recorded on each child at the six week examination.

It is recommended that a standard form be designed for use nationally by any doctor carrying out

a six week examination.

The reasons for the overall low uptake of the Maternity and Infant Care Scheme and the wide variation in its uptake throughout the country should be investigated.

Seven - Nine Month "Developmental" (Chapter 14)

All children should be offered an appointment for a developmental examination in the first year of life, ideally at age 7-9 months. Access to the service should not be limited by geographic location or availability of staff.

The physical environment of health centres should be improved.

Efforts should be made to facilitate the attendance of babies of working mothers by extending clinic hours or establishing evening clinics on a pilot basis.

Co-ordination: The Child Health Co-ordinator should be responsible for co-ordinating the programme.

Monitoring and evaluation: The developmental service should be monitored on an ongoing basis. Reasons for non-attendance should be determined in each area with implementation of relevant policies to improve attendance rates.

Training: It is essential that those professionals who are involved in developmental surveillance should be adequately trained in normal child development.

Screening for hearing defects (Chapter 15)

There is a need for a well-organised audiology service.

Serious consideration should be given to the introduction of universal neonatal screening on a pilot basis.

The distraction test should remain part of the developmental examination performed by the AMO and PHN at 7-9 months.

The current sweep test of hearing of school children should be retained but should be carried out in all children at age 5-6 years.

A systematic approach to increasing parental awareness about hearing loss should be encouraged.

Parental concerns about possible hearing loss must be taken seriously.

Procedural guidelines for hearing tests should be available in all localities.

All staff involved in screening need proper training in audiology and this should be the responsibility of the child health co-ordinator.

Regular evaluation of the programme should take place.

The child health co-ordinator should be responsible for co-ordinating the programme, including screening, monitoring, training, and refresher courses.

Screening for Vision Defects (Chapter 16)

Children with dysmorphic syndromes or neurodevelopmental problems should undergo a specialist eye examination as some may have serious defects of vision.

Babies with a birth-weight of less than 1500 g, or born at 31 weeks gestational age or less, should be screened for retinopathy of prematurity.

Screening for non-disabling visual defects in children under 2 years of age should be confined to history and observation.

Children of any age with suspected vision defects, a significant family history, or any neurological or disabling condition should be referred routinely for visual assessment.

In the absence of sound evidence to support such a programme, it is not recommended that a new preschool vision screening programme be implemented at this point.

It is recommended that a programme of school vision screening be retained. The programme should be standardised throughout the country in relation to the age of child (5-6 years), procedure of examination, referral guidelines and training of professionals. The programme should be monitored closely, with particular attention to quality indicators in terms of practice and outcomes. The programme should be kept under review in the context of emerging evidence.

Any child undergoing assessment for educational under-achievement or other school problems should have a visual acuity check.

Vision screening should be undertaken in schools for children with hearing impairment

The Child Health Co-ordinator should be responsible for co-ordinating the programme, including screening, monitoring, training, and refresher courses.

It is recommended that a standardised referral form be devised for use where a child is referred for further assessment.

Ophthalmologists and optometrists to whom a child is referred should provide a written report to the referring professional and to the general practitioner as soon as possible after first assessment of the child.

Parental concerns about possible visual defects must be taken seriously.

The vision screening and referral services should be monitored on an ongoing basis

It is essential that those professionals who contribute to the screening of children should be adequately trained.

The school health service (Chapter 17)

A core programme for child health surveillance is recommended for all primary schools. It should be carried out by the school nurse, in close co-operation with parents and teachers, at age 5-6 years, 7-8 years and 11-12 years, with selective medical examination of children with problems.

Children with special needs should receive particular attention.

Adequate training of key professionals, provision and maintenance of appropriate accommodation

and equipment, and provision of appropriate referral and treatment services are essential components of the school health service.

The proposed introduction of a broad-based SPHE programme in schools is welcomed.

Idiopathic Adolescent Scoliosis (Chapter 18)

It is recommended that routine screening for scoliosis in adolescents should no longer be included in the primary school screening programme. Clinicians should be encouraged to include inspection of the back in the examination of an adolescent presenting to them for other reasons.

Referral Pathways and Information Feedback (Chapter 19)

For each screening programme a clear pathway of referral must be agreed.

Criteria for review or referral of a child from a child health surveillance visit should be developed in consultation with appropriate specialists and local GPs.

The outcome of all child health surveillance examinations, even where no defect is discovered, must be reported back to the Child Health Co-ordinator.

Adequate clerical support must be provided.

It is recommended that all referrals from the community child health surveillance services should be made in the name of the Child Health Co-ordinator

A copy of the referral letter should always be sent to the GP.

The specialist should send a copy of the report to the child's GP.

Where a defect is suspected or detected, parents should be notified by the Child Health Co-ordinator.

Specialist service provision must be adequate to treat, in a timely and effective fashion, children identified by the surveillance programme as having abnormalities.

Monitoring Child Health Surveillance. Information and Outcomes (Chapter 20)

The Child Health Co-ordinator should produce an annual report on the child health surveillance services for the Director of Public Health and the Department of Health. This report should be standardised nationally and should record key performance data, including indicators of health outcome of the services.

A set of outcome indicators should be developed for Ireland.

Child health surveillance data should be held on computer.

There is a need for a national personal identification number.

KEY REPORTS

There were several key reports which were of great benefit in carrying out this review and to which we refer repeatedly in this report:

The Hall Report. This is the report of the Third Working Party on Child Health Surveillance in the UK. The first two editions of the report examined the various screening tests and procedures carried out in child health clinics and recommended a core programme of checks and reviews. The third edition gives a higher profile to child health promotion.

The Polnay Report. This report was commissioned by the British Paediatric Association with the remit to review the health needs of school age children and how they might be met.

The US and Canadian Task Force Guides. These reports are designed to serve as a practical guide to health professionals and health care planners in determining the inclusion or exclusion, content and frequency of a wide variety of preventive health interventions. They use a standardised methodology for evaluating the effectiveness of preventive health care interventions and for developing clinical practice guidelines based on the evidence from published medical research. The two groups have worked closely together.

A vital element in this review was the consultation with Professor David Hall, Professor of Community Paediatrics, University of Sheffield, and Dr Sarah Stewart-Brown, Director, Health Services Research Unit, University of Oxford. We would like to acknowledge the enormous support and advice received from them.

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CHILD HEALTH SCREENING AND SURVEILLANCE

There is general agreement throughout the western world regarding the value of monitoring the growth and development of children, particularly in the early years of life. However, it has been difficult to achieve consensus on how best to carry out this monitoring. This lack of consensus reflects the paucity of good research to guide the design of programmes.

Although the more obvious debate has revolved around programme content, there has been an equally important evolution in the philosophy which must underpin any programme. The emphasis has shifted from the narrow base of developmental screening of whole populations of children at fixed intervals in order to detect unsuspected abnormality to the broader scope of 'child health surveillance'.

There is much confusion and disagreement regarding the use of the terms child health screening and child health surveillance. Butler, in a critical review of child health surveillance in the U.K., proposes that the term surveillance be used exclusively to denote secondary prevention. Hall has proposed that child health surveillance should be regarded as synonymous with secondary prevention and as one component of child health promotion.

According to the Court Report, surveillance is synonymous with preventive health care and comprised five principal professional activities: "oversight of the health and physical growth of all children; monitoring the developmental progress of all children; providing advice and support to parents, and treatment and referral of the child; providing a programme of effective infectious disease prophylaxis; and participation in health education and training in parenthood".

A child health surveillance programme has many aims. These include the detection of defects, the formation of a relationship between the professionals involved and the family, improving immunisation uptake rates, accident prevention and health education.

So, the goals of a child health surveillance programme are twofold :

- that all children have the opportunity to realise their full potential in terms of good health, well-being and development;
- that remediable disorders are identified and acted upon as early as possible.

These may be achieved by the application of a health promotion approach, including a combination of observation by parents and professionals with a small core programme of screening tests of proven scientific validity. The Health For All 2000 (WHO) approach to health promotion rests on three cornerstones:

- Inequalities in health
- Public participation
- Intersectoral Collaboration

Parental participation in health is an important component of public participation in the context of child health. However, the concept extends wider than this. Intersectoral collaboration involves working with local organisations including the voluntary sector.

Why has this change in philosophy been necessary? Inequalities in health among children in the 1990s are due to different health problems from those seen 50 years ago. Models based on screening for abnormality are no longer as effective as they were. For example, accidents now feature more prominently as a cause of inequalities in health and accident prevention needs to encompass services targeted at the environment and at parents as well as at children.

Limited resources have forced health service providers to target these resources more effectively at those most in need, and at promoting health rather than simply treating disease. The emphasis has shifted from the one-dimensional defect-detecting model to a model for promoting healthy families in all their many dimensions, which depends significantly on efficient and effective child health surveillance.

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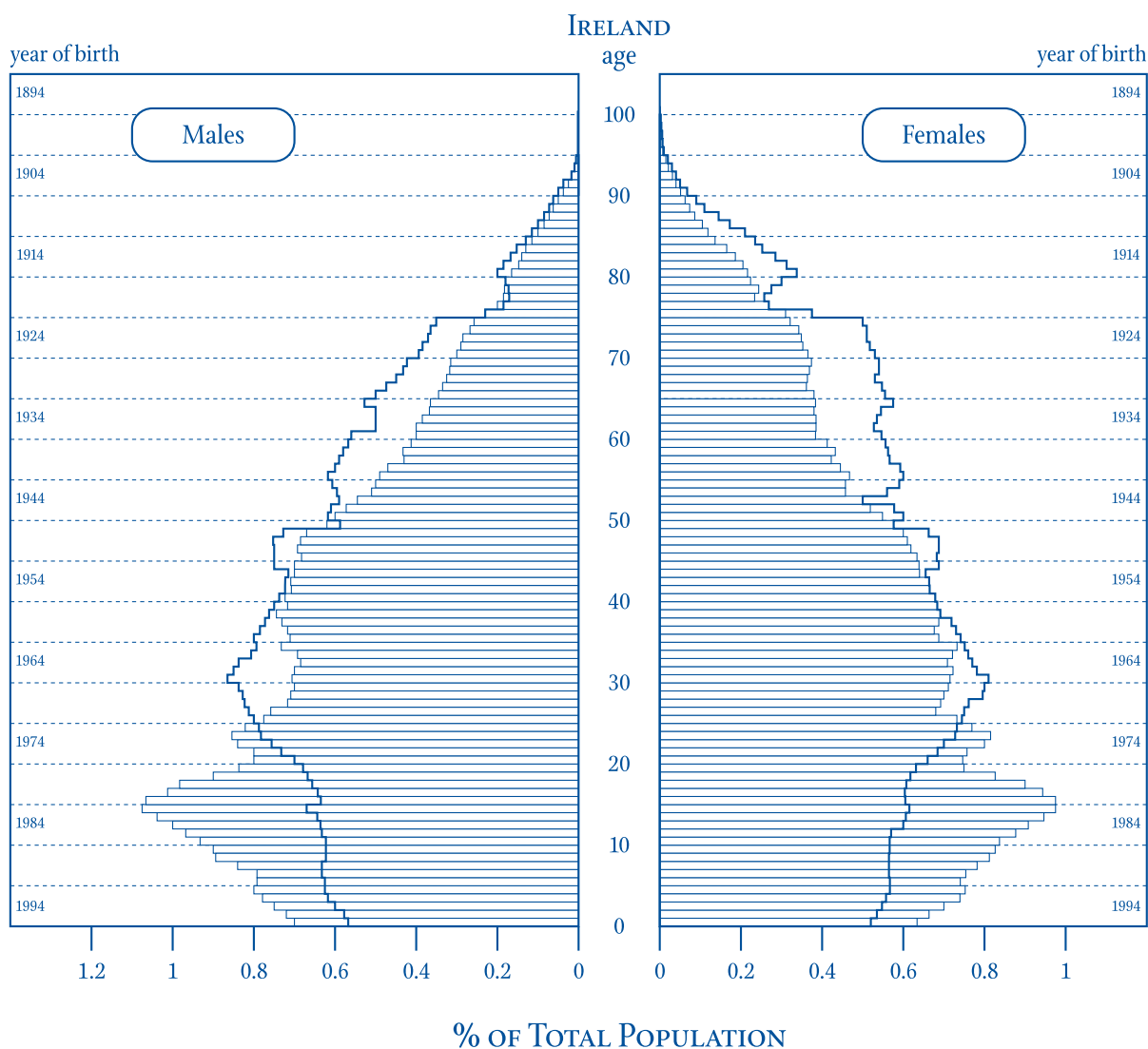
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HEALTH STATUS OF CHILDREN IN IRELAND

CHILD POPULATION

Almost one quarter (24%) of the Irish population is aged under 15 years. This is by far the highest of the 15 European Union (EUR 15) countries, where the average population 0 to 14 years is 18%. The next highest to Ireland is France, with 20% of the population in the 0 - 14 years age group. In Ireland the figure in this age group has declined steadily over the past decade, being 29% in 1986.

The attached *Age Pyramid* for Ireland, with that for the EUR 15 countries superimposed, shows the “bulge” in the child population in Ireland.

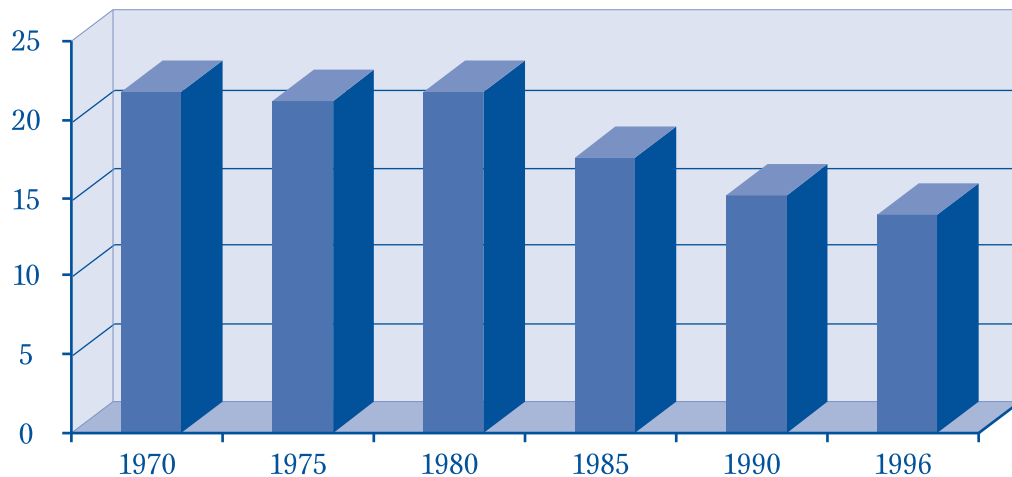


Source: Eurostat. Demographic Statistics 1996.

BIRTHS

The birth rate in Ireland had declined rapidly from the early 1980s but now seems to have reached a plateau. In 1980 there were 74,388 live births nationally, a birth rate of 21.9 per 1,000 population. In 1996 there were 50,390 births, a rate of 13.9. The birth rate in Ireland is much higher than the average for the 15 European Union countries where it was 10.9 in 1994 compared with an Irish rate of 13.4 for the same year.

Figure 31: Annual birth rate per 1,000 population, Ireland 1970-1996.



Source: Central Statistics Office. Vital Statistics. Fourth Quarter and Yearly Summary 1996.

Non-marital and teenage births

In 1996, 24.8% of births in Ireland were non-marital. In 1993, 19.5% of births in Ireland were non-marital compared with 21.8% for the 15 European Union countries (1993 is the most recent year for which EU statistics are available).

There was a downward trend since 1980 in the number of marriages registered in Ireland with an annual marriage rate per 1,000 of the population of 6.4 in 1980 falling to 4.4 in 1993. This decline appears to have levelled out, with a marriage rate of 4.5 in 1996.

Non-marital births are a poor indicator of deprivation or social/health need. They are no longer considered to be a risk factor per se as many are in the context of stable two parent families. More emphasis is now being placed on births to teenage mothers. Teen mothers, by virtue of their age, have completed a lower level of education and correspondingly are more likely to achieve lower levels of income. They are also less mature in terms of parenting skills.

In 1996, 2,560 women aged under 20 years gave birth outside marriage in Ireland, representing 21% of all unmarried mothers delivering in that year.

Prematurity and Low Birth Weight

Prematurity and low birth weight are associated with increased morbidity and mortality in newborn infants. The predominant cause of low birth weight infants in developed countries is premature birth. It is difficult to completely separate factors associated with prematurity from

those associated with low birth weight. A strong positive correlation exists between both premature birth and low birth weight and low socio-economic status. In families of low socio-economic status there are relatively high incidences of maternal undernutrition, anaemia, and illness; inadequate prenatal care; drug addiction; smoking in pregnancy; and obstetric complications. Other associated factors such as teenage pregnancies, close spacing of pregnancies and mothers who have borne more than 4 previous children are also encountered more frequently.

A study carried out in the Eastern Health Board found that the best predictor of low birth weight was the proportion of the population covered by medical cards.

In 1992 (the most recent year for which national perinatal statistics have been published) low birth weight babies (<2,500 gms) represented 4.1% of total births.

Breastfeeding

The prevalence of breastfeeding in Ireland is low at 33.9%.

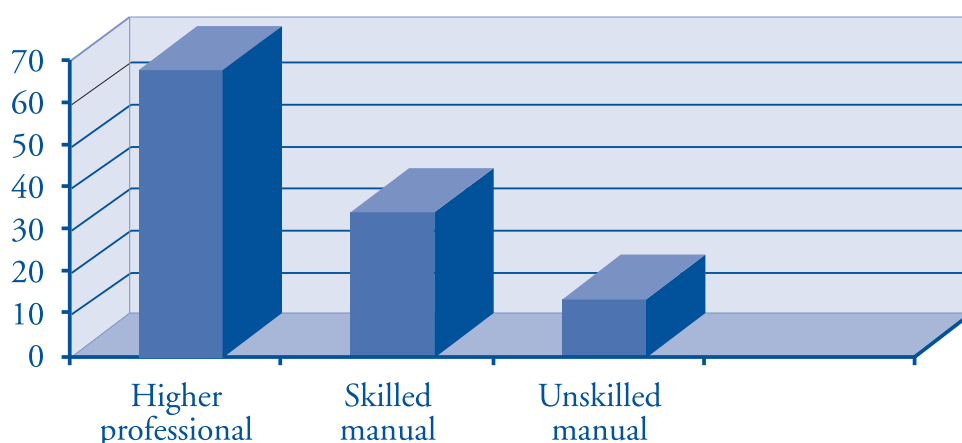
Table 3.1: Percentage of mothers breastfeeding, Ireland, 1988-1992

	1988	1989	1990	1991	1992
Ireland	32.3	32.8	31.7	31.9	33.9

Source: Department of Health. Perinatal Statistics 1992.

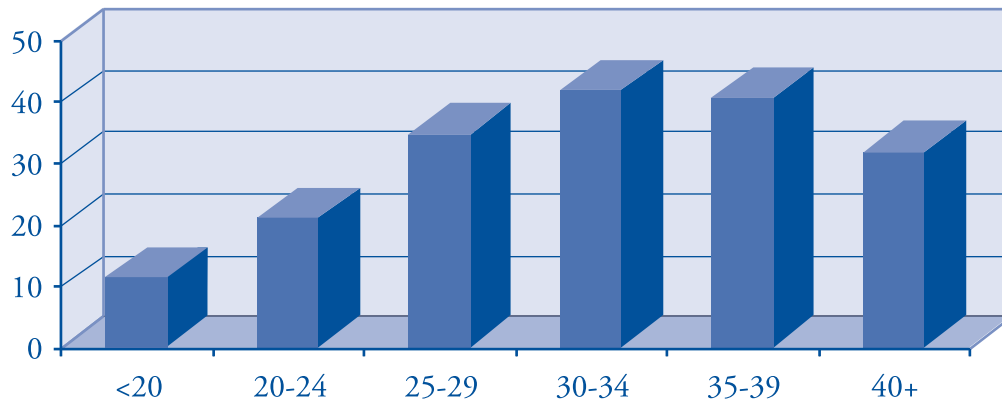
The rate of breastfeeding varies considerably with social class, as represented by father's occupation, being lowest in unskilled manual worker's families. The age of the mother is also associated with the rate of breastfeeding, the rate being lowest in younger mothers.

Figure 3.2: Percentage of mothers breastfeeding (singleton births) by selected father's occupation, 1992.



Source: Department of Health. Perinatal Statistics, 1992.

Figure 3.3: Percentage of mothers breastfeeding (singleton births) by age of mother, 1992.



Source: Department of Health. Perinatal Statistics, 1992.

The birth notification form used nationally records breastfeeding before discharge from the maternity unit. However, it is also important to determine the breastfeeding rates at later stages and a system to record these data needs to be developed.

CHILDHOOD MORTALITY

The *infant mortality rate* is often taken as an indicator of the level of medical and social standards in a community. It is defined as the number of deaths of infants under 1 year of age per 1,000 live births. The infant mortality rate in Ireland was 5.5 in 1996 and 5.9 in 1994. The EUR 15 rate for 1994 was 6.1.

The *neonatal mortality rate* is defined as the number of deaths of infants under 28 days per 1,000 live births during the same period. The neonatal mortality rate in Ireland was 3.9 in 1996. In 1991 (the most recent year for which EUR statistics are available) the neonatal mortality rate in Ireland was 5.0, compared to 4.4 for EUR 15.

The *perinatal mortality rate* is regarded as an important index of the quality of obstetric care. It is defined as the number of stillbirths, together with the number of deaths within the first 7 days of life, per 1,000 live and stillbirths. The perinatal mortality rate in Ireland was 9.3 in 1992. In 1991 (the most recent year for which EUR statistics are available) the perinatal mortality rate in Ireland was 9.4, compared to 8.1 for EUR 15.

Table 3.2: Principal causes of death of infants (<1 year) in Ireland 1996

Cause of Death	Number	% all Infant Deaths
Congenital anomalies	105	37.8
Conditions originating in the perinatal period	109	39.2
Infectious diseases including meningitis and pneumonia	15	5.4
Other causes	49	17.6
Total	278	100.0

Source: Central Statistics Office. Vital Statistics. Fourth Quarter and Yearly Summary 1996.

Note (1): This classification system does not specify Sudden Infant Death Syndrome (SIDS). See below for SIDS figures recorded by SID Register.

Note (2): Since these data are based on small numbers they should be interpreted with caution

Beyond the infant stage, injury and poisoning becomes an increasingly significant cause of death in children. In the age group 5 to 14 years injury and poisoning is the most common single cause of childhood mortality. These deaths are to a large extent avoidable.

Table 3.3: Principal causes of death of children 1-4 years of age in Ireland 1996

Cause of Death	Number	% all Deaths 1-4 years
Congenital anomalies	16	24.2
Infectious diseases including meningitis and pneumonia	11	16.7
Injury and poisoning	12	18.2
Other causes	27	40.9
Total	66	100.0

Source: Central Statistics Office. Vital Statistics. Fourth Quarter and Yearly Summary 1996.

Note: Since these data are based on small numbers they should be interpreted with caution

Table 3.4: Principal causes of death of children 5-14 yrs of age in Ireland 1996

Cause of Death	Number	% all Deaths 1-4 years
Injury and poisoning	37	40.7
Malignant neoplasms	18	19.8
Infectious diseases including meningitis and pneumonia	7	7.7
Other causes	29	31.9
Total	91	100.0

Source: Central Statistics Office. Vital Statistics. Fourth Quarter and Yearly Summary 1996.

Note: Since these data are based on small numbers they should be interpreted with caution

Sudden Infant Death Syndrome (SIDS)

SIDS is one of the leading causes of death in babies aged four weeks to one year. Over a third (37%) of all deaths in this age group in Ireland in 1994 were due to SIDS. The decline in infant mortality rate in Ireland in recent years is primarily attributed to a drop in the post-neonatal mortality rate (deaths in infants over 28 days and under one year of age).

In the late 1980s, international epidemiological research identified a number of risk factors for SIDS. In March 1992, the Department of Health launched a health education campaign entitled "Reduce the risk of cot death". The recommendations of this campaign were based on study findings which indicated an increased risk of SIDS in infants placed prone to sleep, infants of mothers who smoked and infants who are heavily wrapped. The guidelines also encouraged breastfeeding. Research has shown that over one quarter of the risk of death due to SIDS is attributable to maternal smoking.

The National Sudden Infant Death Register aims to establish the incidence of SIDS in Ireland and collects specific epidemiological data on SIDS cases. Table 3.5 outlines the SIDS rate for Ireland.

Table 3.5: SIDS numbers and rate per 1,000 live births for Ireland 1980-1996

Year	Number of SIDS	Rate per 1,000 live births
1980	144	1.9
1985	139	2.2
1990	98	1.8
1991	84	1.6
1992	59	1.1
1993	37	0.7
1994	40	0.8
1995	33	0.6
1996*	45	0.9

* *Provisional figures*

Source: Central Statistics Office. Report on Vital Statistics 1980-1988. Central Statistics Office. Yearly Summary, 1992 and 1995. National Sudden Infant Register 1992-1996.

CHILDHOOD MORBIDITY

Disability

A survey was carried out in Northern Ireland in 1989-1990 on the prevalence of disability among children. The survey estimated that 14,600 children under the age of 16 in Northern Ireland were disabled, a rate of 35 per 1,000 children. The rate of disability increased with age. The Northern Ireland rate was similar to the rate of 32 per 1,000 children reported for Great Britain. The survey used a 13 type classification of disability based on the International Classification of Impairments, Disabilities and Handicaps. The most common type of disability was maladaptive behaviour (table 3.6).

Table 3.6: Estimated rate of disability among children in Northern Ireland by type of disability and gender (rate per thousand).

Type of Disability	Boys	Boys	Girls
Locomotion	13	11	12
Reaching/stretching	4	3	3
Dexterity	5	4	4
Seeing	4	3	4
Hearing	7	6	6
Personal Care	12	10	11
Continence	14	9	12
Communication	8	8	8
Maladaptive behaviour	20	15	18
Intell. Functioning	11	6	8
Consciousness	6	4	5
Eat/drink/digestion	1	1	1
Disfigurement	3	2	3

Source: PPRU Surveys of Disability. Report 2. The Prevalence of Disability Among Children in Northern Ireland.

Intellectual Disability

The National Intellectual Disability Database was established in 1995. The overall numbers of persons identified by the database is 26,694 with a prevalence rate of 7.57/1000 total population. Table 3.7 details the age, gender and degree of intellectual disability in the child population. This figure includes children requiring an educational service but excludes those in the "normal" and borderline categories since this group is not normally provided for in the mental handicap services.

Table 3.7: Intellectual Disability: Degree of handicap by age group and gender

AGE	Unknown		Mild		Moderate		Severe		Profound		Total		Total
	M	F	M	F	M	F	M	F	M	F	M	F	
0-4	237	191	152	106	129	97	45	38	19	11	582	443	1,025
5-9	92	57	633	378	444	292	152	108	50	27	1,371	862	2,233
10-14	32	23	1,277	735	549	399	186	119	55	38	2,099	1,314	3,413
15-19	40	25	1,147	776	632	440	220	158	68	64	2,107	1,463	3,570

Adapted from: National Intellectual Disability Database. Annual Report. Health Research Board. 1996.

Physical and Sensory Disability

There is no national database on physical and sensory disability in Ireland.

Accidents

In 1993 over 40% of all childhood deaths (1-14 years) were due to injuries. A study was conducted by analysing Hospital Inpatient Enquiry (HIPE) data on accidents for 1993. HIPE is an information system in which data are gathered on all patients discharged from acute hospitals (85% coverage in 1993).

Results: The rate for admission to hospital for injury in 1993 was 16.7 per 1,000 in the age group 0-4 years, and 12.6 per 1,000 in the age group 5-14 years.

Injuries to children under 5 years of age: The main injuries were to the head (28.1%), poisoning (21.4%), open wounds (19.0%), limb fractures (15.0%), burns (6.6%) and foreign bodies (4%). Over 40% of injuries were due to falls, with 25% due to poisoning. The majority of injuries (where the source was known) occurred at home.

Injuries to children 5-14 years: The main injuries sustained were limb fractures (37.5%), head injuries (29.9%), open wounds (13%), poisoning (5.2%), burns (1.6%) and foreign body/suffocation (1.3%). Falls accounted for over 45% of injuries.

Infectious Diseases

Infectious diseases are no longer so important for children in terms of mortality but are still responsible for considerable morbidity. Their importance also lies in the fact that many of them are preventable either by immunisation or by improving hygiene or social conditions and by education.

Under the Infectious Disease Regulations 1981 there is an obligation on the attending physician to notify to the Medical Officer of Health cases of specified infectious diseases. It is well recognised in Ireland and in other countries that there is considerable under-notification of infectious diseases. However the figures are still important in indicating trends from year to year and in detecting excess cases and outbreaks. Table 3.8 lists the most frequently notified diseases in 1996. It will be noted that many of these are diseases which are preventable by vaccines which are delivered as part

of the national childhood immunisation programme - mumps, some bacterial meningitis (Hib), whooping cough and measles.

Table 3.8: Ten most commonly notified infectious diseases in Ireland 1997.

Disease	Number of Notifications
Gastroenteritis (under 2 years)	2967
Salmonellosis	958
Bacterial meningitis (including meningococcal septicaemia)	476
Whooping cough	458
Food poisoning (bacterial other than salmonella)	448
Viral hepatitis A	421
Tuberculosis	434*
Mumps	285
Infectious mononucleosis	212
Measles	185

Source: Department of Health.

* 1996 figure

Immunisation

The current uptake of primary childhood immunisation in Ireland is less than satisfactory. It is estimated that 72-88% (range through 7 health boards) of children have received the third dose of Diphtheria/Pertussis/Tetanus (DPT) by 18 months of age (Source: Department of Health). This falls far short of the recommended target uptake of 95% by 12 months of age.

THE HEALTH OF TRAVELLER CHILDREN

Demographics

There are no detailed statistics on the exact size of the traveller population today in Ireland. An annual count of traveller families is carried out by the local authorities. It should be noted that this annual count is not entirely reliable in predicting the actual size of the traveller population for projecting population increases. The last complete census on travellers was undertaken in late 1986 as part of the Travellers' Health Status study carried out by the Health Research Board and recorded a population of about 16,000 travellers, distributed among 2,800 households. Research carried out for the Task Force Report on the Travelling Community has projected an annual increase of 3.3 per cent up to 1999.

Table 3.9 outlines the annual count of traveller families from 1986 to 1994. This indicates an approximate thirty per cent increase over the period using information collected by the Local Authorities. The age-sex distribution of travellers by age group is presented in Table 3.10.

Table 3.9: Number of traveller families by year, 1986-1994

Year	Number of traveller families
1986	3,073
1987	3,069
1988	3,125
1989	3,513
1990	3,705
1991	3,850
1992	3,906
1993	3,998
1994	4,083

Source: Annual Count of Traveller Families: Annual Housing Statistics Bulletin. Department of the Environment

Table 3.10: Age-Sex distribution: Travellers Census 1986

Age Group	Male	Female
0 - 4	1,522	1,473
5 - 14	2,603	2,538
15 - 19	1,002	1,041
20 - 64	2,615	2,670
65+	141	140

Adapted from: The Travellers' Health Status Study Census of Travelling People, November 1986

Fertility

Traveller fertility is much higher than that of the general population: 5.3 versus 2.3 in 1987 {Total fertility rate(age 15-49)}. The crude birth rate for travellers in 1987 at 34.9 was much higher than the national crude birth rate of 16.6.

Mortality

Mortality rates are higher for traveller children than for the children of the settled community. Particular causes include metabolic, congenital anomalies and accidents. Standardised mortality ratios particularly relevant to traveller children for various causes of death are given in table 3.11. The standardised mortality ratio was higher for unhoused than housed travellers, for both males and females. Accidental deaths are much more likely in unhoused travellers of both sexes.

Table 3.11: Standardised Mortality Ratios (SMR) particularly relevant to traveller children, 1987 (Standard Population is Ireland)

Cause of Death (icd 9th revision)	Irish Males SMR	Traveller Males SMR	Irish Females SMR	Traveller Females SMR
All Causes (ICD 001 - 999)	100	222	100	307
Natural Causes (ICD 001 - 799)	100	192	100	280
Accidents (ICD 800 - 999)	100	397	100	612
Metabolic 0-14 years (ICD 270-9)	100	1,250	100	2,000
Congenital Anomalies 0-14 years (ICD 740-759)	100	727	100	000

Adapted from: The Travellers' Health Status Study Census of Travelling People, November 1986

Mortality in Early Life

Mortality figures in early life are much higher among travellers than the general population. These are summarised in table 3.12.

Table 3.12: Mortality in early life for Travellers and Ireland, 1987

	Ireland	Travellers (95% confidence interval)
Stillbirth rate (per 1,000 total births)	6.9	19.5 (12.6 - 26.4)
Perinatal mortality rate	9.9	28.3 (20.0 - 36.6)
Infant mortality rate	7.4	18.1 (10.9 - 25.3)

Source: The Travellers' Health Status study Census of Travelling People, November 1986

Life Expectancy

Travellers have a lower life expectancy at birth and the differentials persist in both sexes up to 65, being more marked in all ages in female travellers.

A study comparing traveller women with women whose husbands were classified in the "unskilled manual" occupational group, the most deprived group in the settled community, found that travellers had significantly more previous stillbirths, miscarriages and shorter birth intervals. Uptake of antenatal care is poorer in travellers with statistically significant differences for those having no antenatal care and late first attendance at hospital during pregnancy.

The rate of low birthweight is significantly higher in travellers. Breastfeeding levels (3%) and immunisation uptake (19%-26% for primary immunisation) in travellers are low compared with the settled population and the consanguinity rate (15%, first cousin unions) is higher than in any other group in Ireland.

The principal features of the serious difficulties being faced by travellers are well summarised in the Report of the Task Force on The Travelling Community. These include:

- insufficient accommodation with 1,085 traveller households living on the roadside and another 257 households on temporary sites many of which are without basic facilities or services which are taken for granted by the vast majority of the settled population;
- infant and adult mortality rates that are over twice those of the settled population and a general health status which is much lower than for members of the settled community;
- low participation of traveller children in education particularly at second-level. It has been estimated that 80% of traveller children in the 12-15 age group do not attend school;
- high levels of illiteracy which present a major barrier to full traveller participation in society and to traveller participation in adult education programmes;
- a very low rate of participation in the mainstream labour force with high levels of unemployment and reliance on social welfare payments.

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HISTORY OF THE COMMUNITY CHILD HEALTH SERVICES IN IRELAND

The child health services in Ireland have their origins in the early part of this century. The Local Government Act, 1925 provided for the appointment of County Medical Officers of Health who were given responsibility for the Maternity and Child Welfare Services. The Health Act, 1953 provided for Child Welfare Clinics in towns of over 3,000 population and also for the School Health examinations. The Health Act 1970 sections 63, 66 and 67 form the legislative basis for the current child health service. A study group appointed by the Minister for Health to inquire into the Child Welfare Clinic Service and the School Medical Service made its recommendations in 1967. Department of Health Circular 22/70 outlined the measures necessary to implement the main recommendations of this report.

MATERNITY AND INFANT CARE SCHEME

Under section 63 of the Health Act 1970, the health board shall make available without charge medical, surgical and nursing services for children up to the age of 6 weeks. All are now eligible for up to six GP visits during the pregnancy and one visit for the mother and baby in the postnatal period. The 6 week check may be carried out in the maternity hospital or by the GP.

The Preschool child

Under section 66 of the Health Act 1970 a health board shall make available without charge at clinics, health centres or other prescribed places a health examination and treatment service for children under the age of 6 years. In relation to services for infants and preschool children, the 1967 Study Group appointed by the Minister made the following recommendations:

- Domiciliary visiting by the district nurse (up to then it had been mostly drop-in infant welfare clinics)
- Developmental assessment clinics
- Open access clinics.

The stated objectives were:

- To ensure by regular screening that preschool children develop both physically and mentally in a healthy and normal manner.
- To discover and arrange for the further investigation or treatment of any deviation from normal in physical and mental progress. Arrangements for the assessment of handicapped children would be included.
- To promote the proper management, feeding and care of infants and preschool children and of good health practices generally.

These recommendations formed the basis of the service as it operates now.

This service is free of charge and children who are referred for further specialist out-patient attention or for admission to hospital are also treated free of charge.

School Health Service

The school health service in Ireland was put in motion by the Public Health (medical treatment of children, Ireland) Act in 1919 under which the local authorities were required to provide for the

medical inspection and treatment of children attending national schools.

The 1967 Study Group appointed by the Minister for Health made certain recommendations regarding the school health service. They concluded that the school health service should be retained in some form but that it required remodelling and that the routine examination of large numbers of healthy children should cease. They recommended a system under which there would be:

- a comprehensive medical inspection of all children between the 6th and 7th birthday
- routine annual screening by the district nurse for vision, posture and cleanliness
- audiometric screening of special groups
- selected medical examinations of 9 year olds
- the examination in any year of a child referred by the parent, teacher or district nurse or a child due for re-examination

The following were the stated objectives of the school health service:

- To ensure that schoolchildren develop both physically and mentally in a healthy manner.
- To detect at the earliest possible stage any defect or disorder which would interfere with the child's educational progress and to see that effective remedial measures were taken.
- To concentrate particularly on the assessment of handicapped children and to arrange for their further investigation and care.

Under section 66 of the Health Act 1970 a health board shall make available without charge a health examination and treatment service for pupils attending a national school (or a school not a national school at the discretion of the health board). Children who are referred for further specialist out-patient attention or for admission to hospital are treated free of charge.

The present structure of the school health service is nominally in line with the recommendations of the 1967 study group but varies considerably from area to area.

Dental, ophthalmic and aural treatment: Health boards are required under section 67 of the Health Act 1970 to make dental, ophthalmic and aural treatment available without charge to pre-school and national school children referred from child health examinations. Health boards employ ophthalmologists to provide sight testing services, examine eye defects, and prescribe glasses or refer patients to specialists. The health boards also contract to private opticians to provide similar services under the sight testing scheme.

Current Services

While we have outlined what is perceived to be the structure of the community child health services, in practice there is no standardised approach to the delivery of the services around the country. Individual aspects of current services are described in the relevant chapters.

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THE STRENGTHS AND WEAKNESSES OF THE CURRENT SYSTEM

Child health services in Ireland were first set up in the early part of this century when childhood mortality and morbidity were high and many children did not have access to medical care. These services have developed in a rather ad hoc manner as needs arose or as remedies became available and many services provided by a range of statutory and voluntary agencies have been continued without any scientific evaluation of their relevance to present health needs.

However, it must be recognised that there are many strengths to the current child health screening and surveillance services in Ireland.

Accessibility and acceptability: The pre-school and school health services operated by the Health Board community care staff have provided an opportunity for all children to receive a health service, regardless of income. For some children, particularly the most vulnerable whose parents are often reluctant to access other health services, it may be the only contact they have with health professionals in their childhood. Traditionally the services have been considered very acceptable to parents, as evidenced by the high uptake recorded and by the results of consumer surveys.

Advocacy/facilitation: There are many children who do not fit in easily to mainstream services, for medical, social, emotional or educational reasons. Traditionally the community care professionals, having identified such children through the screening services, have played a major advocacy role in facilitating these children to access appropriate services and thus to achieve their full potential. The local knowledge and contacts developed over the years by these professionals is invaluable in this regard, as is the liaison with a multidisciplinary team at local level.

Capture of entire childhood population: In the absence of a general practitioner registration system as exists in many other countries, the only opportunity to access the entire population of children is by using the birth notification registration system. This is the basis of the system used currently for screening and surveillance services in Ireland. These services thus allow unique access to the population at a critical age in life - to assess not just the physical aspects of health but also the broader social, emotional and environmental influence on health of the child, and an important opportunity for introducing the concepts of health promotion. Such a captive population base also holds the potential for valuable epidemiological analysis.

Expertise and experience: The contact with such large numbers of children through these services has allowed the health professionals involved to develop a high level of expertise in a wide range of areas of child health.

Cost: The present salaried/session-based system has been run at a relatively low cost compared to that of the alternative of a fee-per-item system.

Weaknesses identified in the current system include the following:

Equity and access: The pre-school examination service was set up to apply to areas of population of 5,000 or greater. This discriminated against children from rural areas. However, in practice the service has now been extended to cover, when staff resources allow, all children in most parts of the country. Some families in more remote rural areas may have difficulty accessing health board clinics due to lack of transport.

Orientation of the services: To date the emphasis of the services has been on the detection of defects through the examination of large numbers of mostly healthy children. It is now recognised that the main causes of morbidity and mortality in childhood and in adult life are related to

lifestyle issues and behavioural problems. It may be more appropriate to address these with a health promotion type model.

Standardisation: There is a lack of uniformity around the country in all aspects of the community based child health services: in the delivery of services, referral pathways and follow up, definition of defects and recording of outcomes, feedback of information, and information systems. The result of this is that evaluation of the service nationally is not possible and consumers are confused in their expectations of the service.

Information systems: Community based child health information systems are poorly developed in most health board areas. What is required in each health board is a computerised child health system allowing for record linkage and which records data in a fashion which is comparable nationally.

Outcome of service: Much of the content of the child health surveillance programmes is not based on evidence, rather it has continued on a historical basis. In addition, little attempt has been made to apply outcome measures by which health and social gain resulting from the programmes could be assessed - instead, process measures are used as performance indicators.

Staff training: There is little or no in-service training for all AMOs and PHNs working in the child health services. This has serious implications for the quality of services and standardisation of practices. This lack of ongoing training may be a factor in the late detection of defects and the overall low yield of the services; it may also be contributing to the perceived low morale among the health professionals involved.

Staff resources: In times of competing demands on community care staff resources, child health screening services have tended to be put on hold e.g. infectious disease issues or special immunisation programmes would generally be given priority. The importance of prevention/promotion programmes are not given due recognition.

Staff recruitment: There has been an ongoing difficulty experienced in the recruitment of AMOs in some parts of the country.

Inappropriate use of manpower: The inappropriate use of manpower through use of doctors for routine examinations which could be performed by nurses has been recognised over the years. This has occurred particularly in the school screening services. In addition to this, there are some aspects of child surveillance which could competently be undertaken by parents given adequate advice.

Conclusion

In summary, the current child health screening and surveillance programmes in Ireland have the potential to deliver a first class service but there is an urgent need to restructure some elements, as outlined above. The need for change is widely recognised and it is apparent among the professionals involved that the goodwill exists to facilitate this change.

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PERINATAL REPORTING SYSTEM

Development of the perinatal reporting system

The need to rationalise data collection systems on childbirth became increasingly evident during the 1970s. The decision was taken to devise an integrated system to provide on one form for the registration and notification of births and for the informational requirements of all those involved in perinatal care including the provision of basic perinatal statistics for research and planning purposes. A four-part form was designed and printed on self-copying paper, and pilot tests were carried out to ascertain the feasibility of the scheme. By 1982, the Perinatal Reporting System covered approximately 64% of all births; the first report of the PRS which referred to 1984 had 94% coverage; and complete national coverage has now been achieved.

Data collection

Births are registered and notified on a standard, four-part form. The top copy of the form is sent by the hospital to the Registrar of Births and serves as the official document of registration. This copy is subsequently forwarded to the Central Statistics Office for use in the production of Quarterly and Annual Reports on Vital Statistics. The second part of the form containing additional information on the health of the mother and the infant and on the care received goes to the Director of Community Care and Medical Officer of Health of the area of residence of the mother. It serves the dual purpose of notifying the local medical and nursing services which have responsibility for the postnatal care of the mother and child and of providing the basis for the health records used by the health boards. The third part of the form has all identifying information deleted and is sent to the Department of Health. The fourth and final copy is retained by the hospital. Domiciliary births are notified on a special two-part form.

Perceived problems with the perinatal notification system

The system of birth notification is pivotal to the smooth operation of a child health service. It is essential that any problems with this system are addressed and rectified.

The perceived problems come under two headings:

- (1) the **content** of the birth notification form;
- (2) the **delays** in transmission of the form.

Content of notification of birth form

The following information, not contained on the current form, may be useful for the purposes of child health surveillance:

- Telephone number of parent
- Mother's occupation
- Mother's smoking history
- Surname of infant
- Specific questions regarding fetal distress and Apgar scores
- Infant's length and head circumference
- Outcome of neonatal examination - normal or abnormal
- Guthrie test carried out - yes/no
- Feeding method **on discharge**
- Name of **infant's** GP

It is recommended that the notification of birth form be reviewed now to consider these suggestions and others that may be put forward by users of the data.

Timeliness and mode of transmission of information

The National Health Strategy document "Shaping a Healthier Future" gives a commitment to implement the recommendations of the Review Group on Maternity and Infant Care: "Every baby will have a visit from the Public Health Nurse as soon as possible after discharge from the maternity hospital/unit, ideally during the first 24 hours". The perinatal reporting system as it currently operates is unable to support this aspiration. If the form is posted from the hospital on the day of discharge of the baby, it may take several days to reach the local community care office. There may be further delays within the community care area before the form reaches the relevant PHN to trigger the first home visit.

The need for a preliminary notification form has been recognised throughout the country, as evidenced by the fact that most areas have developed some type of preliminary form (often known as the "36 hour form"). The content of this form varies from area to area, as does the method of its transmission to the PHN: regular mail, electronic mail, hand delivery, fax, computer link.

There is a need to develop a system for preliminary notification of births which will provide the necessary information in a timely fashion to allow for the PHN to carry out a domiciliary visit within 24 hours of the discharge home of a newborn baby. The content of this form should be standardised nationally. The mode of transmission of this information from the maternity unit to the relevant PHN should be via fax, electronic mail or computer link. It is envisaged that the data contained in the preliminary form would be a subset of that on the final form and that the final birth notification form would be transmitted by fax, electronic mail or computer link on the day of discharge home of the baby.

Some hospitals have a practice of delaying the release of birth notification forms on babies born to unmarried mothers until such time as they can be "cleared" by social workers. This can sometimes result in delays of up to several weeks. This practice should be discontinued. ***It is recommended that the marital status of the mother should not be a factor in delaying the release of a birth notification by a hospital.***

General practitioners are often unaware of the birth of a new baby until several weeks have elapsed. ***A copy of the notification of birth form should be sent routinely from the maternity unit to the baby's general practitioner (as nominated by the parent).***

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BEHAVIOUR PROBLEMS AND PSYCHIATRIC DISORDERS IN CHILDHOOD AND ADOLESCENCE

Behaviour problems are now the most important cause of disability in childhood and as such constitute an important public health issue.

In the last three and a half decades Ireland has undergone dramatic and rapid economic and social change. One might expect that the improved economy would benefit the mental health of the population at large. However, research has pointed to increased rates of psychiatric and behavioural disturbances, particularly among young people over the last 30 years, in most countries which have undergone a similar change. This is particularly true for conduct disorders and crime, alcohol and substance abuse, suicide and depression.

Mental health problems in children and young people may be defined as abnormalities of emotion, behaviour or social relationships sufficiently marked or prolonged to cause suffering or risk to optimal development in the child or distress or disturbance in the family or community.

Prevalence

The overall prevalence of psychological problems in the child population is estimated to be up to 20%, of whom perhaps a quarter need psychiatric specialist assessment. A survey carried out in Great Britain in 1988 found emotional or behavioural problems sufficiently severe to be disabling in 2.1% of all children (aged up to 16 years). The prevalence of such problems in children in Ireland needs to be established by national research.

Risk factors

Risk factors for child psychiatric conditions include:

- Families suffering socio-economic disadvantage or family discord.
- Parents suffering from psychiatric illness, notably maternal depression.
- Child abuse.
- Physical illness (especially chronic conditions such as diabetes and cystic fibrosis).
- Learning difficulties, especially reading problems. It has been found that 40% of children with an IQ below 50 can be expected to have severe psychiatric disturbance.
- Young offenders.

Persistence

Minor psychological problems are relatively persistent, particularly when linked with continuance of risk factors. This is true even for young children. Nearly half the psychiatric disorders in 14-15 year olds represent conditions which have persisted since childhood.

Types of disorders

The most common psychiatric and behavioural disorders of childhood are:

- Emotional disorders, e.g. depression, anxiety states, phobias and psychosomatic disorders.
- Conduct disorders, e.g. stealing, truancy, aggression, fire setting and more persistent delinquency.

- Attention deficit disorder, with or without hyperactivity.
- Major psychiatric disorders e.g. psychosis which occur from puberty onwards.
- Developmental delay and autism.
- Eating disorders e.g. anorexia nervosa.
- Elimination disorders, e.g. wetting and soiling.

Surveillance of behaviour problems and psychiatric disorders in childhood

These problems are usually first noticed by parents or, in the case of older children, by teachers. Whether parents and teachers identify the behaviour as abnormal depends on their experience and knowledge of normal child development and behaviour.

Mechanisms must be put in place to encourage parents to discuss their concerns for their child's behaviour with health professionals, both in the routine settings of developmental clinics and the school health visits, and also by special arrangement at any other times. Teachers must also be facilitated in bringing such problems to the attention of health professionals. Health professionals in primary care need to have the training and skills to recognise behaviour/psychiatric problems, to manage the less complex problems, and to recognise those problems requiring referral to specialist services. The services of psychologists and psychiatrists must be available to facilitate this.

It has been demonstrated in England that it is possible to detect autism at 18 months of age by the application of the CHAT (**Checklist for Autism in Toddlers**) by the health visitor or general practitioner. Diagnosis is not possible using the CHAT alone, but should be followed by referral for expert assessment. The potential advantage of early detection is in allowing for early support for families and early treatment of the child. However, at this point there are some limitations to the use of this as a screening tool: it is not yet clear whether outcome for the child is improved by early detection and treatment, nor is the rate of false negatives associated with this test known. Further consideration needs to be given to this and other screening tests of behaviour and development.

Current referral and treatment services

Once a problem has been identified, the likelihood of a child being referred for the necessary assessment and treatment depends on the availability of local resources and on the responsiveness of the services. In Ireland, most areas have some referral and treatment services for child psychiatric and behaviour problems, but it is recognised by professionals that these services are to a large extent inadequate in range, accessibility and quantity. It is widely reported that parents complain about these inadequacies.

Service needs

Specialist service provision must be adequate to treat, in a timely and effective fashion, children identified by the surveillance programme as having abnormalities.

There is a continuum of service needs from those less severe problems that are usually managed by paediatricians to extremely severe and complex problems that require highly specialised units for their management.

Services should be child-centred and responsive to age-related and other particular needs such as minority groups. A multidisciplinary, inter-agency approach is required for the development of effective and supportive team work.

Proper diagnostic, assessment and treatment facilities are essential. Outpatient consultation should

be available in a variety of settings to suit the needs of individuals and their families. Access to day facilities for multidisciplinary treatment, with appropriate educational and play facilities, should be provided. There is a need for appropriately sited in-patient facilities, designed, equipped and staffed to offer the specialist treatment required. An agreed protocol in accident and emergency departments needs to be developed for the referral of children and young people who need emergency psychiatric care

Child psychiatric teams having an appropriate mix of skills, experience and seniority are required. Specifically, there should be an adolescent team to assess, advise, treat and support young people between the ages of 12 to 19 who have serious emotional or behavioural problems. This team should be prepared to work in a variety of settings and act as a resource in terms of information, training and advice to other staff involved in the care of young people.

The prevalence of childhood behaviour problems and psychiatric disorders in Ireland needs to be quantified by national research. The services for children with these problems need to be improved in the following areas: education of parents and teachers in identification of problems; training of primary care health professionals; and the provision of adequate specialist psychology and psychiatry services.

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PROMOTING CHILDREN'S HEALTH THROUGH PARENT EDUCATION

Concepts of childhood and parenting have changed throughout the years with different perceptions emerging both of children's needs and parental roles. In recent times, society has undergone rapid changes in social structures, religious and ethical beliefs, employment patterns, the roles of men and women and family structures and learning processes with regard to parenting can no longer be relied on. Given the evidence which highlights the link between positive childhood experience and positive health, there is a need to fill the vacuum created by societal changes and to consciously recreate in a structured way what was previously available within extended family and community structures.

Historically, the roots of parent education are varied - they come from the fields of adult education and health education, the growing body of knowledge about child development and also the movement towards review of the individual which emphasises competency and empowerment rather than problems (Kagan, 1984). This particular view is incorporated into now widely held definitions of health education and health promotion. Pugh and De'Ath defined parent education as "a range of educational and supportive measures which help parents and prospective parents to understand themselves and their children and enhance the relationship between them".

The delivery of parent education is varied and ranges from on-going, informal support programmes such as Mother and Toddler Groups to time-limited structured parenting courses using materials and guidelines such as the STEP Programme. Other forms include home visiting schemes to new mothers (Community Mothers Programme), ante-natal and post-natal groups and education for parenthood during the school years. The goals and activities of parent education at a community level tend to cover a broad spectrum of content area, with the focus usually on one or more of the following areas: information sharing, skill building, improving self-awareness, problem sharing. Research findings to date indicate that parents enjoy parenting programmes, and many parents report that they are being helped. Garabino (1980) points to the preventive value of programmes which by their nature help build informal networks and provide positive models of parenting.

Not everyone is in favour of parenting programmes, in particular those that are run by an "expert". A number of researchers have questioned the intrusion of "parenting experts" into the family on the grounds that the self confidence of parents may be diminished rather than enhanced and a pattern of dependence on professionals created. Parent education can sometimes make the mistake of taking a prescriptive rather than a supportive approach.

An extensive study by Barnardos in 1995 highlighted the support of parents for peer-education around parenting, with support of a skilled non-professional parent rather than an expert. The methodology of parenting groups is also central, with a participative style of learning much more likely to result in the promotion of parents self-esteem and the building up of confidence. Barber has made the point that parent education in groups reduces social isolation and promotes the self-confidence of parents, increasing their ability to build more supportive social networks.

Developing programmes of parent education

From the experience of Health Boards already involved in parent education, and from the results of the Barnardos 1995 survey/review, a number of issues have emerged which need to be addressed if the health service is to promote parent education in a pro-active and comprehensive manner. These include:

- a need for quality assurance measures for programmes already available
- the importance of peer-support rather than an 'expert' approach
- the need to develop strategies to involve fathers in parent education programmes
- the need to 'normalise' parent education, so that it is seen as something for all parents and not just for parents in trouble
- the need for Irish based programme materials
- the need for training programmes for parents to act as peer tutors
- the need for some mechanism to share information about programmes and to disseminate models of good practice
- parenting programmes should be adequately funded

Community Mothers Programme – a model of good practice?

The Community Mothers Programme (Eastern Health Board) has been shown to be an effective method of offering parents support in child rearing. The Programme was launched in Dublin in 1983 and has continued to grow and develop since then. It is based on a home visiting strategy whereby experienced volunteer mothers give support and encouragement to first time parents in rearing their children. The mothers work under the guidance of a family development nurse, each mother supporting 5 to 15 first time parents. The Programme works on the principle of empowering parents to enable them to achieve their potential and develop their skills. Community mothers work on an individual basis, but in recent years the structure of the Programme has in some areas been used for group work, such as mother and toddler groups and breastfeeding support groups.

The Community Mother's Programme was evaluated by a randomised controlled trial in 1989. This study showed significant gains for children and mothers in areas such as immunisation, infant feeding and early reading. A follow-up case control study is now being undertaken to determine if these early gains have been maintained.

Review of the effectiveness of parent-training programmes

A systematic review of the effectiveness of parent-training programmes in improving behaviour problems in children aged 3-10 years was carried out in the United Kingdom in 1997. This consisted of a review of the literature on parent-training programmes and child behaviour outcome measures. The author comments on the apparent lack of interest in research on such programmes despite an increasing interest in parent training programmes, both on the part of parents and of professionals in clinical and public health settings.

The main findings of this report were as follows:

- Group-based parent training programmes have a positive impact on the behaviour of children between the ages of 3-10 years.
- Group-based parent training programmes are more successful in improving the behaviour of children compared with methods that involve working with parents on an individual basis. This finding was consistent across both parent-report outcome measures and, to a lesser extent, independent observations of children's behaviour.
- Parent-report outcome measures, in addition, showed that community-based parent training programmes produced more changes in children's behaviour than individual clinic-based programmes, and that community-based programmes may be up to six times as cost-effective and more acceptable to parents.
- There is still insufficient research to demonstrate which aspect of group parent-training programmes are the decisive factor in bringing about change.
- There is a need for further controlled studies utilising both process and outcome indicators, alongside a study of the cost-effectiveness, and public health potential of such programmes.

Conclusion

In a world where many parents feel isolated and unsupported, where the skills which children need in a changing society do not come "naturally" and where there is increased realisation of the importance of the early years in terms of the individual's health career, there is an important role for health boards to play in the development of a range of parent support. Parent education is just one element of this support, and one which should not be overlooked or relegated to meeting the needs of parents in crisis or parents at risk. All parents can benefit from access to peer led, participatory and enabling education. Parent training should be undertaken as a partnership venture with voluntary groups and with the education system - in this way it is much more likely to be sustained and to involve a broader range of participants.

Recommendations

It is recommended that a parent education programme be developed nationally. This parent support service should be based on the following principles:

- accessible to all parents free of charge
- the role of fathers should be recognised and promoted
- high quality, assured by continuous monitoring
- adequately funded
- group-based in the community and peer-led

Further work will need to be carried out before specific recommendations for the introduction of such a programme nationally can be made. This work should include research into parenting services currently operating in Ireland and abroad, and a process of consultation with key stakeholders. The services can be delivered by statutory or voluntary bodies or a combination of both, depending on local resources.

Regular evaluation should be undertaken of the effectiveness of any new service introduced.

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PARENT HELD CHILD HEALTH RECORDS

There has been much change in recent years in the perceived role of parents in relation to the health of their children. Parents and professionals are increasingly being viewed as partners in overseeing the health of children. Professionals in general recognise that parents are effective in determining the health needs of their children and in detecting problems at an earlier stage than professionals. Parents increasingly demand information from professionals and expect to be involved in decision making in relation to their children's health. It is against this background that the concept of parent held child health records has been under active discussion in recent years.

The use of parent held child health records is widespread in other countries: France, New Zealand, parts of Africa, America and Australia. In the United Kingdom a report in 1990 of the Joint Working Party on Professional and Parent Held Records used in Child Health Surveillance recommended the introduction of a national Personal Child Health Record (PCHR) held by parents. Research and development on the concept of the PCHR had been ongoing for 10 years before its introduction in 1991. The PCHR is now in use in most of England and Wales and in Northern Ireland.

The main theoretical advantages of a PCHR are:

1. The record should be available wherever the child is seen - at home, child health clinic, doctor's surgery, A&E department, hospital outpatients or inpatients.
2. The record should be immediately available when the parents/child move from one place to another.
3. Confidentiality rests with the parents, so that they can show it to whoever is looking after their child.
4. The parents are more involved in the surveillance programme.
5. The record can contain useful health promotion and education material which is immediately available to the whole population of children and parents.
6. The record can help to disseminate information to a wide range of professionals in health, education and social services.

Research in the United Kingdom prior to the introduction of the PCHR had shown that:

- the majority of parents would like to hold the record of their child's health and development;
- parents are extremely good at looking after them and rarely lose them;
- where parents do hold the main record of their child's health and development, nine out of ten GPs and Health Visitors consider it a better system than clinic held records.

The PCHR in the UK

The use of the PCHR in the United Kingdom is being reviewed on an ongoing basis and many modifications have been made to the original record. The contents of the record are directly in line with the national child health surveillance programme. The health education content focuses particularly on accident prevention, feeding, dental health, immunisation, and prevention of cot death. Standard growth charts are included. The record covers the child only for the preschool years. It takes the form of an A5 size loose leaf booklet, contained in a plastic wallet. A standard prototype has been developed, with a recommended "core", but individual districts may vary the contents according to local needs.

Should parent held records be introduced in Ireland?

The concept of parent held child held records is not new to this country. A record booklet was developed in 1994 by a working group representing the Faculties of Paediatrics and Public Health Medicine (Royal College of Physicians of Ireland), Irish College of General Practitioners and the Health Promotion Unit, Department of Health. This record took the form of a 30 page pocket sized booklet which allowed for the recording of demographic and key milestone information including immunisation, and contained some health education material and advice. It was circulated to maternity hospitals, and GPs were notified of its introduction. Although the record is still in use it has not attained a high acceptance rate. The reasons for its underusage are considered to be the following:

- there was little publicity attached to its introduction, many parents and professionals never having heard of it;
- it has not been actively promoted on an ongoing basis;
- no one person or body was responsible for ensuring its success;
- there was no incentive for already busy professionals to use it;
- in general, it was used by the better educated parents, with parents in more deprived circumstances not availing of it.

These reports are anecdotal as there has not been a formal evaluation of the record.

Although the idea of introducing parent held child health records on a nationwide basis in Ireland appears to have widespread support from those consulted to date by the authors of this report, there are many issues to be addressed before recommending this route:

1. What are the aims? It is important to decide what benefits we would hope to get from the introduction of PCHRs. We can learn much from the experience of their use in the UK.
2. Do parents want them? Do professionals want them? The answers to these questions may require qualitative research to be carried out. The fact that such records are acceptable to parents and professionals in other countries is not sufficient to indicate their likely acceptability in Ireland, given the many differences in health care systems, culture, geography, ethnic factors and others. It may be helpful to carry out an evaluation of the parent held records previously introduced here.
3. Is there an agreed nationwide programme of child health surveillance? It would be important that the PCHR would record the outcome of a nationally agreed child health surveillance programme.
4. The planned use of data recorded in the PCHR should be agreed in advance. The experience from the UK has been that most of data collected is never extracted and analysed.
5. It would be essential that the health education content of the PCHR would reflect nationally agreed health education/promotion priorities. The use of a loose leaf format would facilitate change of materials when appropriate and the addition of extra materials to reflect local priorities.
6. Would PCHRs replace some existing record systems? The experience from the UK has been that it was not possible to replace any existing system. There would therefore be concerns about the duplication of record keeping and the extra time involved for the professionals.
7. Would the absence of a personal identifying number be an obstacle to the introduction of PCHRs?

8. A suitable means of evaluating the PCHR, if introduced, would have to be worked out.
9. The agreement, followed by appropriate training, of all relevant professionals would be essential to its effective introduction.
10. Issues of confidentiality and data protection would need to be addressed, bearing in mind the relevant legislation.
11. Legal issues of ownership of the record and of the information contained within it would need to be addressed.

The costs involved in introducing PCHRs on a nationwide basis would be considerable. The potential added value should be weighed against that of other competing demands on the child health services budget.

Serious consideration should be given to the development of a PCHR in Ireland which would be used for all children. It is recommended that prior to its introduction it should be subjected to a pilot phase followed by a full evaluation. Parent representatives should be involved at all stages of planning and evaluation. A working group has been set up to explore these issues further.

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ROLES AND RESPONSIBILITIES OF PROFESSIONALS

The Child Health Team

The child health services at community care level should be managed through a child health team. The team should be led by a Child Health Co-ordinator who should have medical, epidemiological and public health skills and expertise. The membership of the team would include: AMO/s, PHN/s, Psychologist, Physiotherapist, Occupational Therapist, Speech and Language Therapist and other professionals as appropriate. It is envisaged that this team would have a defined working relationship with non-community care professionals working in child health such as General Practitioners and Paediatricians, both hospital-based and community-based. It is vital that all members of the team recognise the importance of the role of parents as partners in overseeing the health of their children.

Role of the Area Medical Officer in Community Child Health

The role of the area medical officer (AMO) has been evolving rapidly in recent years. Traditionally, AMOs had responsibility for a wide range of services delivered in a specified geographic area. Nowadays, many AMOs have developed expertise in specified functional areas such as infectious diseases, child health, disability, the elderly, child protection.

It is envisaged that this process of evolution in the role of the AMO will continue to develop. In particular, it is envisaged that the delivery of the child health services in each community care area would be carried out by a number of dedicated AMOs who have developed specific expertise in child health. Such AMOs would work closely with the Child Health Co-ordinator in the planning and evaluation of the services, and in ensuring that targets are met and standards maintained. The Child Health Co-ordinator should work closely with the local Department of Public Health in relation to planning and evaluation of services, and epidemiological matters.

Training for the role of AMO in community child health: AMOs will continue to require at least 6 months hospital paediatric training before taking up an AMO post. It is desirable that an AMO would rotate through all the core functional areas of AMO work, as specified above, before committing him/herself to a specific area/s. An AMO wishing to work in community child health should be encouraged to obtain an MSc in Community Child Health. Such a course is not currently available in Ireland. There would also be a requirement for ongoing training in child health for the AMO. An AMO with such expertise would be better placed to work in partnership with Paediatricians, perhaps running joint child health clinics in the community.

The role of the AMO in the school health service has changed in recent years. Traditionally, the AMO played a key role through the annual physical examination of large numbers of children. Nowadays, most child health screening in schools is carried out by PHNs working in conjunction with AMOs. This report recommends further streamlining of this school service. However, it is recognised that teachers would welcome regular and formalised contact with a designated medical officer. It is therefore recommended that for each primary school there would be a designated medical officer who would liaise with the school principal each year and be available for ongoing support.

The important role that the AMO has played over the years in advocacy and facilitation, particularly in relation to children with special needs, would be enhanced by this proposed new structure. It is envisaged that the AMO in child health would play a particular role in promoting the health of children of traveller families and other disadvantaged groups.

The need for change in the role of the AMO has been recognised by the majority of AMOs and there is a willingness to cooperate in the changes necessary to provide an up to date, quality service.

The child health services at community care level should be managed through a multidisciplinary Child Health Team. The team should be led by a Child Health Co-ordinator.

It is envisaged that the delivery of the child health services in each community care area would be carried out by members of the multidisciplinary team, including AMOs, PHNs, Psychologists, Physiotherapists, Occupational Therapists, Speech and Language Therapists and other professionals as appropriate.

The Child Health Co-ordinator should work closely with the local Department of Public Health in relation to planning and evaluation of services, and epidemiological matters.

The Role of the General Practitioner in Community Child Health

The GP plays a pivotal role in overseeing the health of children and in delivering child health services in the community. He/she is familiar to parents, is accessible and flexible, and has a unique insight into the family and personal background of the child. The recent development of employing practice nurses has the potential to enhance the role of the GP in child health surveillance.

The Core Programme outlined in this report specifies the GP's role in relation to the examination at 6-8 weeks of age. However, the role of the GP in child health surveillance should be much broader than this:

- under the Mother and Infant Care Scheme a mother is entitled to 6 visits to her GP, free of charge, during pregnancy - these visits allow a valuable opportunity to discuss important health topics such as breastfeeding, immunisation and parental smoking
- if the recommendation made in this report to extend the GMS scheme to cover all children from birth to five years is implemented, this will strengthen the role of the GP in the health surveillance of young children and facilitate opportunistic health promotion
- the GP should have a defined working relationship with the local community child health team and may play an important role in the management of the child with complex needs - the GP should receive adequate remuneration for this work

It is recommended that the Child Health Co-ordinator may contract with the GP to carry out the health examinations at 7-9 months of age and in schoolchildren - this would be dependent on the GP having the appropriate skills, training and continuing education required for the task.

The relationships between the GP and other professionals involved in child health surveillance should be fostered and strengthened.

It is recommended that the GP should receive a report of the outcome of each examination carried out by community health staff. This could be in the form of a duplicate copy of the child health system input record.

Where a child is referred from the community services to a specialist, the specialist should send a copy of his/her report to the GP, as well as to the referring professional.

A GP carrying out child health surveillance examinations on contract to the health board should be

obliged to complete and return a full report on the outcome of the examination. The transmission of information about child health surveillance would be facilitated by the use of parent held records.

Community Paediatricians in Ireland

There has been widespread interest in the concept of introducing Community Paediatricians (CPs) in Ireland in recent years. To date, no CP or Consultant Paediatrician with a Special Interest in Community Child Health has been appointed in Ireland. One of the factors influencing this debate has been the fact that the United Kingdom has a well-developed CP service. The British Paediatric Association has recommended a ratio of 1 CP per 100,000 population.

It is envisaged that the introduction of CPs in Ireland would be advantageous to the child health services in many ways:

- strengthen the existing links between hospital and community services
- improve the continuity of care for individual children and their parents
- provide a more accessible clinical service at consultant level to rural children
- reduce waiting times for specialist services by clarifying referral pathways and by improving the appropriateness of referrals to specialist services
- reduce admission rates for some children with chronic illnesses by providing a higher level of care in the community.

In general there is a good working relationship between community care medical teams and the hospital based paediatricians in providing a paediatric service in most areas. However, in some parts of the country there are gaps in some aspects of the child health services - these gaps would most noticeably be in the areas of service development for children with disabilities, developmental paediatric training for AMOs, and child abuse medical assessments.

While there is undoubtedly a role for CPs in certain settings in Ireland, arrangements to introduce this new post must take account of existing and developing structures, and the introduction of any new structures should be based on local needs. It would not be appropriate to directly replicate the Community Paediatric service that exists in the UK - apart from the many differences in the healthcare systems between the two countries there are also cultural, historic and geographic differences to be considered. The need for a CP service may vary in different parts of the country. In particular, urban and rural needs may be quite different.

The job description for a CP should be clearly defined and tailored to local need. There would not be one job description that would serve all areas. The BPA has developed different models for CP from one which is entirely community based, mainly non-clinical, to one which is part hospital and part community based.

Some broad elements of the role of the CP are outlined here:

Immunisation and infectious diseases. CPs, Public Health Departments and primary care providers could usefully work together on the planning and delivery of immunisation programmes, and on the surveillance of infectious diseases. In addition, CPs would have a role in providing guidance and training of practitioners in relation to infectious diseases.

Child Protection. While the statutory responsibility lies with the health boards, CPs would have a role in clinical assessment and management, in improving communication between hospital and community, in working with the community care team to develop local guidelines on child protection, and in the training of staff in the clinical aspects of child abuse.

Health Promotion. CPs could work in liaison with Departments of Public Health and the Health Promotion Unit of the Department of Health in the development of health promotion

programmes, particularly in relation to such issues as accidents, smoking and drug and alcohol misuse.

Children with special needs, disability, chronic illness. CPs might play a role in the co-ordination of multidisciplinary early intervention teams for children with disability, where such a service does not already exist. CPs would have an important role in identifying and assessing children with disabilities, in service planning, in training, in liaison with other agencies, in liaison between hospital and community. By improving the care in the community of children with chronic illness e.g. diabetes, asthma, it may be possible to reduce the referral of such children to hospital.

Pre-school and school referrals. CPs would have a role in the clinical assessment and management of children referred from the existing community care pre-school and school health services, by acting as a secondary referral agency. They might work with community care staff to agree referral pathways to other specialities. Community based paediatric clinics run by CPs, with the involvement of AMOs would improve communication, provide an accessible service for children and allow training opportunities for staff.

Hospital. The CP would share in the hospital on-call rota and possibly the OPD commitment.

Training. The CP could play an important role in providing paediatric training for AMOs and PHNs.

Research. Joint research initiatives between the hospital and community.

The establishment of posts of Community Paediatricians in Ireland offers an opportunity to enhance the skills available to the community child health team. Roles and responsibilities should be clearly defined, as should relationships with other relevant professionals; in particular, strong emphasis should be placed on the relationship with the Child Health Co-ordinator. The appointment of Community Paediatricians in the North Western Health Board should be seen as an opportunity to evaluate their role in the Irish context.

The Role of the Public Health Nurse in Community Child Health

Traditionally PHNs have had responsibility for delivering a wide range of services in a specified geographic area. However, a minority of PHNs in some localities are dedicated to working with children in areas such as school health, child protection and developmental examinations.

There are clear advantages in having community based nurses who have training and experience in child health issues and who work exclusively with children. ***We recommend that community nursing services for infants and pre-school children be delivered by community child health nurses, and for schoolchildren by school nurses. PHNs, by virtue of their training would be suitable for such positions.***

Community child health nurse

In addition to carrying out the activities as outlined in the Core Programme, the **community child health nurse** would work in the following areas:

- antenatal visiting to meet prospective parents and introduce the range of services - this would be an important opportunity to promote healthy practices such as breastfeeding
- as a member of the local child health team, particularly in the multidisciplinary management of the child with complex needs, including child abuse
- follow up of immunisation status on children identified by the child health co-ordinator

- provision of additional support for first time and vulnerable parents (mothers and fathers).

It would be helpful if community child health nurses operated flexible working hours to facilitate the needs of parents working outside the home. Where possible, an appointment system should be operated to reduce time wasted through unsuccessful visits.

School nurse

In addition to carrying out the activities as outlined in the Core Programme, the school nurse would work in the following areas:

- as a member of the local child health team, particularly in the multidisciplinary management of the child with complex needs, including child abuse
- immunisation of schoolchildren
- support for the teachers in delivering the SPHE Programme and in promoting a healthy school environment.

It is essential that the community child health nurse and the school nurse have the necessary training and ongoing education to deliver a high quality service. In particular, attention must be paid to their skills in: examination of hearing, vision and hips; measurement and plotting of growth parameters; and health promotion.

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A NATIONAL CHILD HEALTH SURVEILLANCE PROGRAMME

The terms of reference of this review were to define a programme for child health surveillance the content of which would be based on best available evidence.

Evidence-Based Medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. Evidence-based health care extends the application of the principles of evidence-based medicine to all professions associated with health care, including purchasing and management. The Health (Amendment) Act, 1996 imposes on Health Boards the obligation “.... to secure(ing) the most beneficial, effective and efficient use of resources.”

The application of evidence-based principles to child health surveillance has inherent difficulties:

- In relation to many child health surveillance activities, there is no evidence on which to make a recommendation for or against the activity. In some cases this absence of evidence is due to the fact that there is simply no published research, but for many aspects of child health surveillance it is not possible to measure or record the effect of the activity. Absence of evidence is not sufficient grounds alone on which to base decisions.
- It would be easy to dismiss a given screening test on the basis that the yield was low and the test not cost-effective. But this might be to ignore the possible hidden or unmeasurable benefits to the family of the contact between the parent and health professional.
- While considerable research has been carried out in other countries in reviewing the available evidence, the conclusions reached have sometimes been conflicting from one centre to the next.

In Ireland it is widely recognised by professionals that there is a need to adapt the child health surveillance service in line with the current needs of children. In drawing up proposals for a revised child health surveillance service the following points were taken into consideration:

- the child health surveillance service is still the only free primary health examination service for all children;
- the service has enormous potential for health promotion;
- for many vulnerable families, the service has been an acceptable means of contact with the health services;
- many parents use the visits as an opportunity for informal discussion and support;
- contact with professionals can have negative outcomes for some parents, e.g. the anxiety attached to false positive diagnoses;
- evidence exists to support some aspects of surveillance programmes, to not support other aspects, and for many components of child health surveillance programmes there is no available evidence;
- where evidence exists its interpretation is often difficult, particularly where conflicting evidence is reported.

A core programme for child health surveillance is outlined. It is recommended that this programme be implemented in a standardised manner nationally.

We have attempted to achieve a balance between the use of an evidence based approach and the need to bring about a gradual change that will have the support of the parents and professionals, and not endanger the health and safety of any child.

The needs of the child must be the central focus of the new programme.

Content and Timing of Core Child Health Surveillance Programme

Age at examination	Content		Topics for health education	Professional involved
	History	Examination		
Birth	Family history. Pregnancy. Birth. Parental concerns.	Full physical examination. Note particularly colour, respirations, birth marks, heart murmur, congenital dislocation of hip (CDH)*, testicular descent. Inspect eyes, view red reflex. Guthrie test on day 5. <i>Universal hearing screening</i> [†] .	Cot death. Feeding and nutrition. Vitamin K. Baby care. Sibling management. Crying and sleep problems. Transport in cars.	Doctor - usually hospital doctor. Guthrie test usually carried out by hospital midwife or public health nurse (PHN).
Within 48 hours of discharge	Parental concerns.	External appearance. Note particularly colour, respirations, chest movements. Check for CDH.	Nutrition and breast-feeding. Parental smoking. Accident prevention. Immunisation. Post-natal depression. Recognition of illness and what to do.	PHN
6-8 weeks	Check history. Parental concerns, particularly relating to hearing and vision. Refer as appropriate.	Physical examination. Weight and head circumference. Check for CDH, testicular descent.	As at 10-14 days, particularly immunisation, weaning.	Doctor - usually GP.
3 months	Parental concerns, particularly relating to hearing and vision. Refer as appropriate.	External appearance. Weight and head circumference if indicated by parental concern or appearance. Check for CDH.	As at 6-8 weeks	PHN

* Congenital dislocation of the hip is now known as developmental dysplasia of the hip

[†] see chapter on screening for hearing defects

**Content and Timing of Core Child Health Surveillance Programme
(Continued)**

Age at examination	Content		Topics for health education	Professional involved
	History	Examination		
7-9 months	Parental concerns Ask specifically about general health and development, vision and hearing.	Weight and length as indicated or requested by parent. Check for CDH, and testicular descent. Observe visual behaviour and look for squint. Distraction test of hearing. Where there are concerns, a full developmental examination should be carried out.	Accident prevention, nutrition, iron deficiency, parental smoking, transport in cars, dental prophylaxis, developmental stimulation, sunburn.	Doctor, usually AMO, and PHN
18-24 months	Parental concern. Ask specifically about vision, hearing, comprehension, behaviour. Refer as appropriate.	Height and gait.	As at 7-9 months. Also, avoidance and management of behaviour problems.	PHN
3.25 - 3.5 years	Ask about vision, squint, hearing, behaviour, language acquisition and development. Refer as appropriate.	Measure height and weight if indicated. Check for testicular descent only if not previously recorded. Refer to doctor for physical examination where indicated.	Accidents, preparation for school, nutrition and dental care.	PHN
5-6 years (senior infants)	Parental and teacher concerns. Review pre-school records.	Measure height and weight, and plot on chart. Check visual acuity using Snellen chart. Check hearing by "sweep" test. Opportunity for general health check.	As per SPHE Programme	School nurse School doctor-advisory and secondary referral role Teacher-SPHE
7-8 years (2nd class)	Parental and teacher concerns. Review school health records.	Check visual acuity. Measure growth if concern about child's health or growth. Opportunity for general health check.	As per SPHE Programme	School nurse School doctor-advisory and secondary referral role Teacher-SPHE
11-12 years (6th class)	Parental and teacher concerns. Review school health records.	Check visual acuity. Check colour vision. Opportunity for general health check.	As per SPHE Programme	School nurse School doctor-advisory and secondary referral role Teacher-SPHE

NEWBORN SCREENING FOR METABOLIC DISORDERS

The national programme

A national programme for screening for metabolic disorders in newborns was established in 1966 with screening for phenylketonuria. Since 1966 other conditions have been added to the screening programme: galactosaemia (1972), maple syrup urine disease (1972), homocystinuria (1971), hypothyroidism (1979).

The National Neonatal Screening Laboratory in Temple Street Hospital is responsible for carrying out the tests and for notifying test results. However, there is no body having overall responsibility for co-ordinating the Programme nationally. There are no nationally agreed protocols for screening - in particular there are no nationally agreed protocols for screening of high risk children.

In 1990 a Working Group was appointed by the Minister for Health to review the screening programme. The Group reported in 1993 making recommendations regarding responsibility, and practices and procedures to ensure that all infants would be screened for metabolic disorders.

Responsibility for co-ordinating the newborn metabolic screening programme should be assigned to one body. Nationally agreed protocols for screening should be drawn up.

The target uptake rate for neonatal metabolic screening should be set at 100%. In order to ensure that this is achieved an audit should now be carried out of the screening programme, addressing in particular the completeness of cover, and the timeliness of testing and reporting. In order to fully evaluate the programme it will be necessary to look at the outcomes of treatment in children having metabolic defects discovered through screening. The audit should investigate the extent to which the recommendations of the Working Group have been implemented. It may be appropriate to reconvene the Working Group.

Research on neonatal metabolic screening was recently carried out in the UK. This consisted of: (1) a systematic review of the literature on inborn errors of metabolism, neonatal screening programmes, new technologies for screening and economic factors; (2) a questionnaire sent to all newborn screening laboratories in the UK; (3) site visits carried out to assess new methodologies for newborn screening.

The authors conclusions included the following:

- Universal neonatal screening for PKU is worthwhile and should be continued.
- There is no evidence to support a newborn screening programme for galactosaemia and any current newborn screening should be discontinued.
- The accepted criteria for a neonatal screening programme are not currently met by non-PKU amino acidopathies (including homocystinuria and maple syrup urine disease).

The findings of this research may or may not be applicable in the Irish context. *It is recommended that the recent UK research on neonatal metabolic screening be examined by experts here to assess the relevance of the results to the Irish population and services.*

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THE SIX WEEK EXAMINATION

There is a lack of standardisation in the six week infant examination service. Currently there are four alternative ways in which this service may be delivered:

- GPs contracted under the Maternity and Infant Care Scheme
- GPs contracted privately
- Paediatrician contracted privately
- Maternity hospital

Apart from the examination carried out under The Maternity and Infant Care Scheme there is no obligation on the examining doctor to submit any records of the examination to either the health board or the Department of Health. Under the Maternity and Infant Care Scheme the doctor is requested to provide only the following few items of information: birth weight, current weight, outcome of delivery and type of feeding. Payment is not dependent on providing even this information. The uptake of the Maternity and Infant Care Scheme varies throughout the country, the overall uptake rate being 54%.

The lack of standardisation in the delivery of this service makes it impossible to gather any useful information on the six week examination. *It is recommended that a standard set of data be recorded on each child at the six week examination.* The examination should comprise a full physical examination including hips, testicular descent, vision, behaviour.

It is recommended that a standard form be designed for use nationally by any doctor carrying out a six week examination. On completion of this form, the examining doctor should return it to the Child Health Co-ordinator so that the data can be collated locally. There should be an appropriate fee paid to the examining doctor for the completion of this form. Where the examination is carried out under the Maternity and Infant Care Scheme, the fee for this examination should be dependent on completion of this form. However, it is recommended that the current fee be increased to reflect the additional time required.

The reasons for the overall low uptake of the Maternity and Infant Care Scheme and the wide variation in its uptake throughout the country should be investigated. In addition, mothers who do not choose to avail of the Scheme for antenatal care should be facilitated in availing of it for the care of the infant if they so wish.

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SEVEN – NINE MONTH “DEVELOPMENTAL”

In discussing the developmental surveillance of small children, we have attempted to define what is meant by some of the terminology in current use.

Hall defines **developmental examination** as a clinical procedure which evaluates the level of development reached by a child at a particular age and detects any significant deviations from the normal. It may include an interview with parents, structured observations, physical and neurological examination, and the administration of specific tasks. Interpretation of a developmental examination relies on a comparison of the abilities of the child being examined with those of other children of the same age. The data about normal development which are needed to make this comparison are available in various developmental tests, charts, and scales.

Developmental screening - refers to the process of testing whole populations of children at specified ages in infancy and early childhood to identify those who may have some undetected abnormality. The goal of screening is to detect children who are at high risk for developmental delay who would not otherwise be identified. It is generally recognised that the majority of severe developmental impairments are identified by means other than screening such as parents or professionals voicing concerns for the child. Screening is most often concerned with the identification of children at risk for more subtle developmental problems that would otherwise elude early detection such as mild mental handicap, speech and language delays, and clumsiness.

The Denver Developmental Screening Test (DDST), as the most widely used developmental screening test in the world, has been subjected to considerable analysis and has been shown to have low test sensitivity. Many proposed alternative tests have received limited critical evaluation but their use remains controversial.

Assessment involves the detailed, expert, and often multidisciplinary investigation of manifest or suspected developmental delay or abnormality. Here assessment is a diagnostic or problem-solving exercise.

The emergence of concerns regarding the effectiveness of routinely administered developmental screening tests has led to an increasing emphasis on the process of *development surveillance*. Development surveillance is a flexible, continuous process, that is broader in scope than screening, whereby knowledgeable professionals perform skilled observations of children throughout all encounters during childhood.

It includes obtaining a relevant developmental history, making accurate and informative observations of children, and eliciting and attending to parental concerns.

Emphasis is placed on monitoring development within the context of the child's overall well-being, rather than viewing development in isolation during a testing session. Parents are generally in the best position to play this role.

Surveillance also includes activities designed to promote development, such as the sharing of information with parents. Development surveillance does not necessarily exclude the use of developmental screening tests. Such tests may serve as a valuable aid to memory, contribute to the examiners acquisition of knowledge, focus attention on the child's developmental status during a visit, encourage parents to raise concerns or questions, and help validate the examiners concerns for a child or assist in reassuring parents that a child is normal. "Screening tests are but one strategy whereby the health professionals may perform skilled observations of children" (Dworkin, 1989).

The recommendations made below are intended to embrace the broader concept of developmental surveillance.

Current services

A national study of the child health services in 1993 showed that there was a relatively uniform child developmental programme for children in their first year of life with the majority of community care areas offering an appointment to all babies. This study, and another regional study, found a mean uptake rate for developmental examination of 71% and 75%.

A consumer survey carried out as part of a regional review of the child health services found that there was a high level of satisfaction with the developmental examination service except in relation to physical surroundings.

Recommendations

All children should be offered an appointment for a developmental examination in the first year of life, ideally at age 7-9 months. Access to the service should not be limited by geographic location or availability of staff.

Developmental examinations should be carried out in health centres by a doctor and public health nurse.

The physical environment of health centres should be improved.

Efforts should be made to facilitate the attendance of babies of working mothers by extending clinic hours or establishing evening clinics on a pilot basis.

A full history of the child's general health and development, including vision and hearing should be obtained. Parents should be encouraged to discuss any concerns they might have and these concerns must always be taken seriously.

Physical examination should include measurement of weight and length if indicated or at parents request. Look for evidence of congenital dislocation of the hip. Observe visual behaviour and look for squint. Carry out distraction test of hearing. Where there are concerns, a full developmental examination should be carried out.

Topics for health promotion: accident prevention, nutrition including iron deficiency, parental smoking, review transport in cars, dental hygiene, developmental stimulation, sunburn.

Co-ordination: The Child Health Co-ordinator should be responsible for co-ordinating the programme.

Monitoring and evaluation: The developmental service should be monitored on an ongoing basis. Reasons for non-attendance should be determined in each area with implementation of relevant policies to improve attendance rates.

Training: It is essential that those professionals who are involved in developmental surveillance should be adequately trained in normal child development.

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SCREENING FOR HEARING DEFECTS

The ultimate aim of screening for hearing impairment is to detect early in the first year of life all sensorineural hearing deficiencies ranging from moderate to severe deafness, as well as long-standing conductive hearing loss in childhood.

Sensorineural hearing loss (SNHL)

SNHL is caused by a lesion in the cochlea or the auditory nerve and its central connections. It may be unilateral or bilateral. In the absence of appropriate intervention children with SNHL suffer impairment of language acquisition.

Conductive hearing loss

Conductive hearing loss is related to middle ear pathology. This is most commonly due to secretory otitis media, now most commonly known as otitis media with effusion/"Glue Ear"(OME).

The extent of the disability caused by OME is still controversial. Few research studies differentiated between those children with transient OME and minor impairment, and those with more permanent hearing loss. In addition, it is highly likely that hearing loss interacts with other factors, such as environmental deprivation, temperament, and genetic influences on the rate of language acquisition. Parental smoking is a risk factor for OME. Breast-feeding may be protective.

The long-term benefits of surgery for conductive hearing loss are unclear. Conservative management is advocated for the majority of children who are not severely affected. An alternative approach for the most severely affected is the provision of a low-power hearing aid. Continued audiology, tympanometry and educational supervision are essential.

Prevalence

- The estimated birth prevalence of congenital sensorineural hearing loss (SNHL) or mixed hearing impairment (>40 dBHL in the better ear averaged over the frequencies 0.5, 1, 2 and 4kHz) is 1.16 per 1,000.
- 1.3 per 1,000 children have this degree of hearing loss and require a hearing aid; the difference is accounted for by acquired and conductive hearing loss.
- Meningitis is the most important cause of acquired hearing loss, though the figure may have fallen since the introduction of Haemophilus influenzae vaccine and the consequent fall in the incidence of meningitis from this cause
- The incidence of SNHL is at least 10 times higher in babies admitted to neonatal intensive care units compared with the 'normal' population
- If all high-risk factors are considered, between 40% and 70% of all cases could be identified by testing between 5% and 10% of all babies. This yield can only be obtained by a systematic and well-organised approach to the identification and testing of at-risk babies.
- Conductive hearing loss is extremely common. At least 50% of all pre-school children have one or more episodes of OME. A smaller number of children, perhaps 7%, have OME for at least half of the time between 2 and 4 years.
- Ascertainment of less severe hearing loss in pre-school children is incomplete, but at least 0.3 per 1,000 have a hearing loss which, though less than 40dB, is clinically significant and requires a hearing aid

Early diagnosis and intervention

There are several reasons for the current commitment to early diagnosis of congenital SNHL (CSNHL). The reason most commonly quoted is that very early diagnosis might improve outcome in terms of speech and language quality and communication skill. Since age of diagnosis and intervention depend on so many factors, confirmation of this is very difficult to obtain and the results of published surveys are contradictory.

The evidence that early intervention improves outcome is still equivocal. However, there are several reasons why screening may be useful:

- It is easier to achieve good coverage for screening and early detection services for babies in the first year of life than at any time subsequently until school entry.
- Most parents welcome early diagnosis of disabling conditions and have a low opinion of services which fail to identify serious long-term problems in their children.
- It is easier to establish the cause of congenital SNHL if it is diagnosed early. In particular, intrauterine infections become increasingly difficult or impossible to diagnose after the first few months of life.
- Social development

Arguments in favour of screening for hearing impairment after the neonatal period.

Parents sometimes recognise hearing loss themselves, but hearing loss of moderate degree, or predominantly affecting high frequencies, is easily missed, sometimes for years.

Since most cases of SNHL are congenital and the process of language acquisition begins at birth, the obvious time to screen is in the neonatal period. However, even universal screening would not detect all children with hearing loss for the following reasons:

1. SNHL due to rubella or cytomegalovirus may deteriorate during the first two years of life, but may not be readily detectable during the neonatal period.
2. Some types of genetically determined SNHL are progressive and may present at any time in childhood.

APPROACHES TO SCREENING

1. Neonatal screening

Universal neonatal screening appears to offer a "captive population" and it should be possible to achieve high uptake rates, but the rapid turnover and early discharge policy in most maternity units make this difficult in practice. Hall says the most promising technique for universal screening is evoked otoacoustic emissions (EOAE) but there are still many problems with this method. There is a high failure rate in the first two days of life and the follow-up needed for babies who do not pass the screen increases both the cost and the amount of anxiety caused. Another method which can be used is brain-stem evoked response audiometry (BSERA). This involves the computer analysis of EEG signals evoked in response to a series of clicks. A full BSERA study is a skilled undertaking. Screening devices can be operated by unqualified staff after appropriate training and have been used for neonatal screening of high-risk babies, but this method is too time consuming for universal screening. The tasks of providing training for screeners, ensuring that all infants are tested, and maintaining standards present challenges which should not be underestimated. The auditory response cradle (ARC) is an automated behavioural method which detects changes in the infant's head turns and bodily movements in response to a sound stimulus. This device is not suitable for testing hearing of premature babies.

Selective neonatal screening of high risk groups is increasingly popular and, as parents and professionals become more familiar with the concept of 'high risk', it is likely that demand for the service will increase.

High risk includes the following:

1. Family history of hearing loss
2. Congenital infections (e.g. Rubella, cytomegalovirus, syphilis)
3. Anatomical malformations involving the head and neck (e.g. cleft palate, aural atresia, dysmorphic syndromes)
4. Birth weight less than 1,500g
5. Severe neonatal asphyxia
6. Neonatal hyperbilirubinaemia >20mg/100ml (less in the preterm)
7. Bacterial Meningitis
8. Ototoxic drugs administration (particularly if prolonged)

Currently in Ireland, there is no nationally agreed screening programme for neonates although there is a policy in some hospitals to screen high risk groups.

Recently *a critical review of the role neonatal hearing screening in the detection of congenital hearing impairment* was carried out in Britain. This review was commissioned because of increasing doubts about the ability of the existing screening programmes (mainly health visitor distraction test (HVDT) at 7-8 months) to identify children with congenital hearing impairment, and technological advances which have made neonatal hearing screening an alternative option.

An important finding of this review is that the current infant hearing screening programme is poor. Current services of ad hoc programmes are missing a half of the hearing impaired children by 11/2 years of age, and a third by 31/2 years of age. The HVDT appears to be at its most effective in identifying children with severe hearing impairment. It is not very effective at identifying moderate losses. In the absence of neonatal screening most children with moderate losses are identified as a result of parental or professional concerns over speech and language development later in the pre-school period. Such late identification of hearing impairment greatly reduces the responsiveness of the services for individual children. Hearing impaired children (both SNHL and CHL) identified late are at risk of substantial delay in their acquisition of language and communication skills, with consequent longer-term risk to educational achievement, mental health and quality of life. No controlled trials have been carried out on the benefits of early aiding (fitting the baby with hearing aids) but observational studies support the clinical belief that language acquisition is improved by early "aiding".

The survey of current practice in Britain identified a major problem with poor information systems. Intervention and habilitation for the majority of those screened neonatally is routinely undertaken within 6 months of birth. In comparison, those screened only by the health visitor were identified at an average age of 26 months with intervention at an average age of 32 months.

Controlled trials show that universal neonatal screening reduces the age at which babies are identified from a mean of 12-18 months with the distraction test, to 2 months. The limited number of universal screening programmes in operation give yields of the expected order (1-1.3 per 1,000), with a median identification age for those screened of about 2 months. Universal neonatal screening appeared to have lower associated initial costs than the HVDT on a cost per child screened. The health economic arguments in favour of a universal neonatal hearing screen and the abandonment of other pre-school population screening programmes is persuasive. Neonatal screening will fail to identify progressive congenital or acquired hearing loss. The authors recommend a targeted HVDT to identify these babies.

The authors conclude that universal screening has a lower running cost and much lower cost per

child detected than HVDT. Coverage can be over 90%, and specificity 95%. Sensitivity has not yet been assessed but may be greater than 90% as indicated by the yield from the universal screening trial.

It was recommended that a programme comprising universal neonatal screening, followed at 7 months by a targeted screen using an infant distraction test (mainly for those children not screened in the neonatal period) would be the most equitable and responsive, and would give the best value for money.

Behavioural testing during the first year of life, (the distraction test) requires two people working in collaboration. A developmental maturity of around 7 months is optimum for this test. Beyond 10 months of age, the development of object permanence and increasing sociability make the test more difficult. Quiet conditions, proper equipment, adequate sound level monitoring, and careful technique are essential. Good results can be obtained if initial and regular refresher training courses are provided to ensure that technique is meticulous and standard guidelines are observed. Ideally the test should be done in protected time rather than during a busy clinic. Inadequately performed, the distraction test is not merely valueless it can be positively harmful because the child's apparent responses to sound may persuade parents that their worries were unfounded. This can lead to delays in identification. Hall considers this test inappropriate to 'screen' babies with high risk factors such as a positive family history or a long stay in NICU. These babies should be referred for definitive diagnosis if this was not done in the neonatal period.

In Ireland, 'distraction testing' is performed by the AMO and PHN as part of the developmental paediatric examination for children at 7-9 months. Often a sound- proofed room is not available for testing these infants.

Pre-school testing after the age of 7-9 months has been called an 'intermediate' screen. The argument in favour is that a few children with acquired or progressive SNHL and those with severe OME may otherwise elude diagnosis until they start school, with possible serious consequences for their learning and education. The disadvantages of such a policy are as follows:

- The low yield of significant new cases
- The high incidence of transient OME
- The difficulty determining which cases of OME are transient and which are persistent.

The school entry 'sweep' test of hearing.

This test consists of a modified pure tone audiogram performed at fixed intensity level. Criteria for failure on this test vary from 20 through 25 to 30 dB at one or more frequencies and after one or more tests. Many variables can affect the results of this procedure, including ambient noise, the skill of the screener and the maturity of the child.

Very few cases of severe SNHL remain undiagnosed at this age, but occasionally a child is found to have a progressive hearing loss. A significant number of milder cases are detected and unilateral losses are usually identified for the first time. OME is very common and may have educational implications, even though few children require treatment.

- The current sweep test of hearing on school entry at age five years be retained.
- Further screening tests of hearing after school entry should be performed on new pupils into a school where previous results are unknown, as well as for children for whom there are parental or professional concerns.
- The service should also have the resources to provide hearing tests for children with special needs who may require a specialist audiology service.
- The target should be to test all five years olds. Those who fail a sweep test should be retested 4-6 weeks later. Only a small percentage fail a second test. These children should be referred to the school doctor. This doctor should have training in hearing screening and should decide the appropriate referral pathway.
- The criteria for failure are 30dB at 500Hz and 25dB at 1-4kHz.

- The child health services, in collaboration with the educational authorities, need to provide adequate conditions for hearing testing in schools and annual calibration of audiometers.

Current practice:

Currently in Ireland, all areas undertake routine audiometric screening in schools but there is variation in the age at which children are tested and in the frequency of testing. There is also variation in the method of audiometric testing with some areas screening at 20dB only while others undertake full diagnostic audiometry. The test is most commonly carried out in senior infants but in some areas it is carried out on junior infants or children in first class. There is also wide variation in the policy for repeat testing and for referral.

Various surveys carried out in Ireland indicate existing screening programmes are not standardised. This applies to all facets of audiological screening: (a) the examination, interpretation, registration and evaluation; (b) there is concern with the level of expertise of those carrying out the tests; (c) lack of evaluation of effectiveness of existing programmes; and (d) the apparent lack of co-ordination between the various services especially the preventive and curative health care workers.

Acquired hearing loss - meningitis. Profound hearing loss following meningitis in a young child is an educational emergency, since the benefits to the child of having the previous experience of sound will be squandered if amplification and teaching are not provided promptly.

An audiology screening survey carried out in the Eastern Health Board in 1989 included an economic appraisal of programme options. The authors considered it was not clear that employing audiologists would confer additional benefits to the screening programme and the economic analysis militated against this option. They considered it would be more cost effective to improve AMO training with this AMO supervising audiology services within each community care area.

Recommendations

- *There is a need for a well-organised audiology service.* The first step to considering changes to the screening programme must be to examine the whole paediatric audiology service and to review present and future staffing needs. There is no point in creating an excellent screening network if the facilities for behavioural testing, definitive BSERA studies, ENT assessment, diagnosis, or education and rehabilitation are inadequate.
- *Serious consideration should be given to the introduction of universal neonatal screening on a pilot basis.* The systematic review carried out in the UK should guide us but bearing in mind that there are differences in the two services.
- *The distraction test should remain part of the developmental examination performed by the AMO and PHN at 7-9 months.* A targeted screen programme should be agreed if universal neonatal screening is introduced on a wider scale.
- 'Intermediate' screening is not routinely recommended
- Children with delayed speech should have an audiological assessment
- *The current sweep test of hearing of school children should be retained but should be carried out in all children at age 5-6 years.* The target should be to test all children. This should be performed by the schools nurse with appropriate training.
- Further screening tests of hearing after school entry should be performed on new pupils into a school where previous results are unknown, as well as for children for whom there are parental or professional concerns.
- The service should also have the resources to provide hearing tests for children with special needs who may require a specialist audiology service.
- Children who fail a sweep test should be retested 4-6 weeks later. Only a small percentage fail a second test. These children should be referred to the school doctor. This doctor should have audiological training and should decide the appropriate referral pathway.

- The criteria for failure are 30dB at 500Hz and 25dB at 1-4kHz.
- A systematic approach to increasing parental awareness about hearing loss should be encouraged. A developmental hearing card has been used successfully in other countries and has reduced the age at which hearing loss is first detected. This card is simple to use and contains a 'hearing checklist' at various childhood ages up to 12 months. This card should be evaluated by a pilot study in one region.
- *Parental concerns about possible hearing loss must be taken seriously*, and a rapid efficient referral route to an audiological service must be available in all parts of the country. Parents are more likely to detect severe and profound loss, and may easily overlook less severe or high frequency impairments.
- Acquired hearing loss should be followed-up before or soon after discharge from hospital
- Consideration should be given to developing an at Risk Register in each community care area which should be managed by the child health co-ordinator.
- *Procedural guidelines for hearing tests should be available in all localities.*
- Districts should have a protocol for management of screening failures with clear referral pathways to the GP, community audiology clinic or ENT clinic.
- *All staff involved in screening need proper training in audiology and this should be the responsibility of the child health co-ordinator.*
- *Regular evaluation of the programme should take place* and the data should be collected in such a way as to reflect outcome measures rather than just activities.
- *The child health co-ordinator should be responsible for co-ordinating the programme, including screening, monitoring, training, and refresher courses.* Information should be collected on the coverage of the programme, the number of referrals, delays experienced between referral and diagnosis and between diagnosis and treatment, and the age at which each child with SNHL is diagnosed. Liaison between other disciplines and agencies is vital to ensure that nationally agreed standards of service are achieved.
- Organisation and equipment. All staff involved with screening tests of hearing should have access to the necessary equipment and proper training in their use. Equipment should be checked and calibrated regularly. Staff involved should have their own hearing tested every 2 years.
- The child health services, in collaboration with the educational authorities, need to provide adequate conditions for hearing testing in schools.
- Hearing aids should be easily obtainable for those in need. The child health co-ordinator should be informed when a child receives a hearing aid.

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SCREENING FOR VISION DEFECTS

The purpose of screening and surveillance for visual defects throughout childhood is the early detection and treatment of relevant ophthalmic disorders to minimise their impact on a developing child.

Vision defects

According to Hall, disorders of vision can be subdivided into the following categories:

(a) serious defects likely to cause a disabling impairment of vision ranging from partial sight to complete blindness - these are uncommon.

(b) the common and usually less incapacitating defects, including refractive errors, squints, amblyopia, and defects of colour discrimination. The most important of these is amblyopia.

Amblyopia has been defined as a unilateral or bilateral decrease of vision, for which no cause can be found on physical examination of the eye. It can be present at varying levels of severity and usually affects one eye only.

Refractive errors describe the situation in which light rays cannot be focused on the retina and a blurred image is formed. These include myopia (short sight), hypermetropia (long sight), astigmatism (degree of refractive error is different between the two axes of the eye, and anisometropia (the degree of refractive error is significantly different between the two eyes). The image can almost always be focused with the help of spectacles.

Squint (strabismus) is a condition in which the two eyes are not aligned. In cosmetically obvious squint one eye is obviously looking in a different direction from the other. In small angle or micro-squint the deviation is not obvious and is revealed with the cover test. Latent and intermittent squints are only present under certain circumstances and can be revealed with the uncover test.

Refractive errors may cause squints. Squints may also arise independently of refractive errors. Both are thought to predispose to childhood amblyopia because vision in one eye may be suppressed to prevent double vision. Experimental evidence from animal studies and clinical experience in humans suggests that there is a sensitive period in the human child up to the age of about eight years when this process may occur and may be reversible.

Amblyopia may be suspected in infants who present with other eye problems such as squint, but it is difficult to diagnose with confidence before the child can co-operate with visual acuity testing. Prompt referral of infants with squint or other obvious vision problems may help to avoid the development of amblyopia or reduce its severity. However, in many cases amblyopia presents for the first time after the age of 3 years without any other obvious signs of eye problems.

It is generally thought that untreated amblyopia results in permanent vision impairment, but some studies suggest that mild degrees of amblyopia may resolve spontaneously. The natural history of the condition is largely unknown.

The management of amblyopia often involves correction of refractive error and patching, but is not entirely satisfactory. Some authorities question whether treatment is effective at all.

Prevalence

Up to 6% of pre-school children will have an ocular or vision defect requiring treatment or follow up. Amblyopia affects 1-3% of the general population and up to 5% of the pre-school age group.

The measurement of visual acuity in young children

There is currently no satisfactory way of assessing visual acuity suitable for the universal screening of children too young to co-operate with acuity tests.

Vital components of the identification of vision defects in children include:

- asking about a family history (of vision defects),
- asking about past medical history (e.g. low birth weight or prematurity)
- asking parents about the child's visual behaviour.

The majority of manifest squints are first recognised by parents or relatives. Many other cases of visual defect are also detected by parents. A family history of high refractive error or squint in a first degree relative may be significant.

Children with dysmorphic syndromes or neurodevelopmental problems should undergo a specialist eye examination as some may have serious defects of vision.

Babies with a birth-weight of less than 1500 g, or born at 31 weeks gestational age or less, should be screened for retinopathy of prematurity.

Screening for non-disabling visual defects in children under 2 years of age should be confined to history and observation.

Children of any age with suspected vision defects, a significant family history, or any neurological or disabling condition should be referred routinely for visual assessment.

Current services

Some aspects of the current childhood vision screening and referral services in Ireland have been criticised by both professionals and members of the public. These concerns include:

- absence of a nationally agreed programme of screening;
- lack of uniform policy regarding referral criteria and lack of locally agreed pathways of referral;
- long waiting lists for assessment and treatment services;
- inappropriate referrals from screening programmes;
- late diagnosis of certain conditions;
- poor feedback to parents, general practitioners and professionals involved in screening;
- inadequate training of professionals involved in screening.

These issues must be addressed in any recommendations for the future of the services.

Preschool vision screening

Screening in the preschool age group has been the subject of reviews of evidence in Britain and North America recently.

Systematic review: In Britain a systematic review was carried out of research on the effectiveness of preschool vision screening. The three target conditions chosen were: amblyopia, refractive errors, and squints which are not cosmetically obvious. It identified serious deficiencies in the research evidence on the natural history of the target conditions, the disabilities associated with them, and the efficacy of available treatments. Although there is a strongly held clinical belief that treatment works, there is a lack of methodologically sound trials of the effect on visual function of

treatment of any of the conditions. The authors also discussed the lack of research on the potential psychological impact of treatment on the child or the family, such as patching and spectacle wearing. The authors recommended that providers currently offering screening programmes should consider discontinuing them and that from an ethical point of view it is appropriate to continue screening only in the context of a controlled trial of treatment.

Review of essentially the same data by the US Preventive Services Task Force and the Canadian Task Force on the Periodic Health Examination resulted in a different conclusion being reached. They concluded that preschool vision screening should continue.

Hall discusses the arguments in favour of and against preschool screening and concludes that the question is not yet finally resolved. Community-based secondary screening or outreach services by an orthoptist in the preschool age group are probably worth-while and cost effective, but the value of vision screening by other staff is more limited.

Pre-school screening in Ireland: There is currently no formal programme of preschool vision screening in Ireland. The key issue to address now is whether a programme of preschool vision screening would offer benefits over the existing vision screening in infant classes in school. Vision screening at school entry is currently the subject of a systematic review in Britain. However, if the available literature is of the same quality as that relating to preschool screening, such a review may not provide the information required to change policy. It is clear that further research will be required.

In the absence of sound evidence to support such a programme, it is not recommended that a new preschool vision screening programme be implemented at this point.

School Vision Screening

School entrant screening: The detection of vision defects in school entrants is easier than in the preschool years as school children are a "captive population" and children at this age can cooperate more easily with the vision test. The standard Snellen chart can be used for most children in this age group. The UK report of the Joint Working Party of the Royal College of Ophthalmologists and the British Paediatric Association states that the aim of the school entry screen is to identify children with amblyopia or significant unilateral or bilateral refractive errors.

Amblyopia: The aim of identifying children with amblyopia at this age may be disputed. The natural history of the condition is unknown. Where amblyopia is detected by screening, compliance with treatment is often poor, the effectiveness of treatment is unknown and there have been no studies comparing those treated with those not treated. Overall, the value of screening programmes has not been properly evaluated in terms of comparing the final outcome in children who have been screened with that in those who have not. In other words, we do not know that screening for amblyopia is worthwhile.

Consequently, recommendations for school vision screening cannot be solely influenced by the aim of detecting amblyopia, an aim which may not be realistic.

Current practice: The current practice in relation to the age of "school entrant" vision screening varies throughout the country, with some areas screening in junior infants, some in first class, but the greatest number of areas screening in senior infants. It is essential that this practice be standardised nationally. Senior infants (age 5-6 years) would be the most practical year in which to screen for vision for the following reasons: (1) most children at this age are old enough to cooperate with the Snellen test, a test which is easy to carry out and with which most staff are familiar, (2) senior infants is the optimal year for carrying out the "school entrant" visit in terms of hearing screening and the consultation between the school nurse and the child's parents and

teachers. It would be impractical to have the vision screening carried out as an additional visit.

We recognise that the choice of this age group may be criticised by those who feel that screening in junior infants would allow for the earlier detection and treatment of amblyopia. Therefore it is essential that: (1) the screening programme recommended here would be evaluated on an annual basis and that (2) the service should be reviewed in the light of any new evidence appearing regarding the value of screening and the optimal age for screening. In the meantime, it would be useful to investigate the feasibility of vision screening in junior infant children. This would involve (1) the use of a new screening test, for example the Sonksen-Silver test (with the necessity to train staff in its use), and (2) an additional visit to the school by the school nurse, thus incurring extra costs. This could be carried out as a pilot project in one area.

Referral criteria: Children whose vision is 6/12 or worse in either eye should be referred for further assessment. Children with unequal vision in their two eyes less severe than 6/12 (e.g. 6/6, 6/9) should be retested in 3-6 months by the PHN; if on the second testing the vision has deteriorated to 6/12 they should be referred for further assessment. Children whose vision is 6/9, 6/9 or 6/6, 6/9 on repeat Snellen testing do not need further assessment.

Colour vision: Children found to have a colour vision defect should be told that they have a difficulty in discriminating colours which might be important with regard to certain career choices.

Referral services: Currently, the majority of children referred for further assessment are referred to either community ophthalmologists or consultant ophthalmologists in hospital out-patient departments. It is recommended that community ophthalmology services, with appropriate accommodation and equipment, be available in all areas. The potential role of *optometrists* in the assessment of children referred from the school health services should be explored, particularly in relation to children in the older age groups and children who have a first assessment carried out by an ophthalmologist.

Referral services should be monitored locally to ensure that children are seen in a timely manner. It is recommended that every child should be seen within 3 months of referral, with urgent referrals being seen at the earliest opportunity.

Parents should be given written information on any abnormal results of vision screening carried out in school. *Parents should be informed that a screening test is not diagnostic.*

It is recommended that a programme of school vision screening be retained. The programme should be standardised throughout the country in relation to the age of child, procedure of examination, referral guidelines and training of professionals. The programme should be monitored closely, with particular attention to quality indicators in terms of practice and outcomes. The programme should be kept under review in the context of emerging evidence.

Any child undergoing assessment for educational under-achievement or other school problems should have a visual acuity check.

Vision screening should be undertaken in schools for children with hearing impairment.

Recommended programme of vision screening

Birth: Inspection of the eyes, including viewing of a red reflex, should be carried out by a hospital doctor, or general practitioner for those born at home. Parents should be asked if there is a family history of vision disorders.

6-8 weeks: Parents should be asked if they have any concerns about the baby's vision, and the eyes

should be inspected, including viewing of a red reflex, by a doctor, usually the general practitioner.
6-9 months: At the routine surveillance visit carried out by the AMO and PHN parents should be asked if they have any concerns about the baby's vision, and visual behaviour should be observed, including search for a squint.

5-6 years (senior infants): Visual acuity screening should be carried out by the school nurse using an *illuminated Snellen chart* at 6 metres with both eyes being tested together and separately. Children whose developmental age prevents them from using a Snellen chart should be examined using the Sonksen-Silver test (a linear test of visual acuity which is suitable for younger children).

7-8 years (2nd class): A test of visual acuity should be carried out by the school nurse.

11-12 years (6th class): A test of visual acuity should be carried out by the school nurse. A colour vision test should be carried out using the Ishihara plates.

Co-ordination

The Child Health Co-ordinator should be responsible for co-ordinating the programme, including screening, monitoring, training, and refresher courses. Liaison between the Child Health Co-ordinator and ophthalmologists is essential.

Referral and feedback

It is recommended that a standardised referral form be devised for use where a child is referred for further assessment, and that this form should specify the reason for referral. This information is essential to allow for priority to be determined.

Ophthalmologists and optometrists to whom a child is referred should provide a written report to the referring professional and to the general practitioner as soon as possible after first assessment of the child.

Parental concerns about possible visual defects must be taken seriously.

Monitoring and evaluation

The vision screening and referral services should be monitored on an ongoing basis to ensure that the services are meeting local needs, in both quality and quantity, in an efficient manner. Information should be collected on the coverage of the programme, the number of referrals, delays experienced between referral and diagnosis and between diagnosis and treatment, and the age at which each child is diagnosed.

Training

It is essential that those professionals who contribute to the screening of children should be adequately trained in the development of normal vision and have training in simple techniques of visual assessment, through paediatric and ophthalmological input into their training.

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THE SCHOOL HEALTH SERVICE

The school environment offers a number of unique characteristics and also many challenges and opportunities for health gain to which health services for school age children can respond:

- The population is “captive”;
- The environment is educational;
- The focus is child-centred;
- Health and lifestyle are open to influence through curriculum and example;
- Health may be promoted in partnership with teachers and the wider community;
- The effects of ill-health and disability may be minimised in co-operation with teachers;
- Services for children in need may be initiated;
- Health monitoring may be offered;
- Ill health, including infectious disease, in the individual and the child population as a whole may be prevented.

(adapted from the "Polnay Report" - Report of a Joint Working Party on Health Needs of School Age Children, British Paediatric Association).

The aims of a school health service are: (a) to achieve the best possible level of health (mental and physical) and social well being, current and future, for all children of school age; and (b) working in partnership with children, parents and teachers, to enable children to benefit fully from education.

There is currently wide variation throughout the country in the content, delivery and staffing of the school health service. However, the service has been shown to be widely acceptable and is generally considered to be equitable. The service should be retained but a more streamlined service is recommended which would be operated in a standardised fashion in all areas. The recommendations are as follows:

Management of the school health service: The Child Health Co-ordinator should have overall responsibility for the management of the service, including planning and evaluation. The Child Health Co-ordinator should produce an annual report on the service for the Director of Public Health and the Department of Health. The format of this report should be standardised nationally and should record key performance data, including indicators of health outcome of the service. The data contained in this report should give information on the health of the school population, point out local problems and put forward plans to address unmet needs.

Key professionals: In each area there should be designated nurses and doctors for the school health service. Each primary school should have a named school nurse and doctor. It is envisaged that the main body of the work of the school health service will be carried out by the school nurse, with the doctor having an advisory and referral role. We recommend that staffing should be based on the health needs of individual school populations rather than pupil numbers. In the UK, recommendations for school nurses have ranged from 1 in 1,500 to 1 in 2,500 school children. However, workload is more important than caseload as health needs can vary widely from school to school. In delivering the school health service, the school doctor and nurse will work closely with many other professionals, including speech and language therapists, community physiotherapists, community occupational therapists, general practitioners, ophthalmologists, clinical psychologists, child psychiatrists, paediatricians, audiologists, social workers, dentists. The school health team should work in partnership with parents and teachers.

Training of key professionals: School nurses and doctors should have special training in the health of children. The school nurse should be trained specifically in screening methods for vision, hearing and growth. The school doctor should ideally have training in community child health.

Both professionals should have training in the identification of emotional and behavioural problems, in the identification and management of child protection issues, and expertise in health promotion. Adequate training and continuing education of these professionals is essential to ensure a quality service.

The role of the key professionals in the school health service: It is envisaged that the school nurse and doctor would work in the following areas:

1. carrying out a limited programme of child health screening
2. supporting the development and implementation of health education and health promotion programmes in schools
3. advising teachers, parents and children about current health issues that arise
4. playing a facilitatory, advocacy and monitoring role in relation to children with special needs.

These areas are expanded on below.

Operation of the school health team: The school nurse should have a formal meeting with the school principal towards the end of the school year to plan the child health surveillance programme for the coming year - this discussion should address the content and timing of screening examinations, facilities required for examinations, the programme for immunisation, consent forms and questionnaires, ways in which the nurse and doctor might facilitate and support the school in developing a health promoting ethos and in dealing with health issues arising during the year, and procedures for dealing with child protection issues. This meeting should also provide an opportunity to plan for new entrants and individual children with special needs.

The role of parents in the school health service: It is well recognised that parents are very good at identifying their children's needs and at recognising defects at an early stage. Greater use needs to be made of this resource. This can be achieved by the following:

1. at school entry, parents should receive an information leaflet outlining the school health service, including content and timing of the programme
2. parents should be requested to complete a questionnaire at the three key screening ages
3. parents should be encouraged to attend school health screening visits, in particular the school entry visit
4. parents should be informed that they may request a meeting with the school nurse at any stage if they have concerns about their child
5. parents should be informed of any abnormality suspected or confirmed by the school health team

The role of teachers in the school health service:

1. teachers are well placed to identify children who may be at risk of neglect, and those with educational, emotional or behavioural problems
2. teachers should be the key individuals in the delivery of health education/promotion programmes in schools - in this role they should have access to any required support from health professionals in the school health team
3. the co-operation of teachers is vital in facilitating the work of the school health team.

Confidentiality: Clinical information obtained by the school nurse or doctor in the course of school health visits cannot be revealed to school staff without the consent of the parents. However, parents should be made aware of the need for teachers to have certain medical information.

Child health screening programme in schools: The objective of child health screening in school is the identification of ill-health, disability and problems of behaviour or development. The

school health service should complement the primary care services in the early detection and management of ill-health in this age group. The child health screening programme in schools should focus in particular on the following:

- the identification of problems of vision, hearing, growth and dental health (the latter not addressed in this report), with further referral as appropriate
- the identification (in conjunction with parents and teachers) of children needing physical examination by the school doctor, with further referral as appropriate
- the identification (in conjunction with parents and teachers) of children with psychological/behavioural problems requiring referral to psychiatric or psychology services
- the identification (in conjunction with parents and teachers) of children with speech or language problems requiring referral to speech and language services

Content and timing of screening programme: There seems to be little justification for continuing the practice of full physical examination of essentially healthy school children. It must be acknowledged that this has ceased to be routine practice in many areas over the past decade. There are key areas in which screening is recommended and these form the basis of the core programme now outlined:

Senior infants (5-6 years): All children should be seen at this stage, with their parents if possible. The visit should be carried out by the school nurse, who should allow sufficient time for discussion with parents. It is desirable that the nurse would have access to each child's pre-school record at this time. Sufficient clerical support should be available to facilitate this process. Parent held records, if in use, might be a valuable and additional source of information.

Topics for discussion should include: immunisation; completion and outcomes of pre-school surveillance; past medical history; family history; current health problems; concerns about behaviour.

The examination should include growth measurement (height and weight), testing of visual acuity and of hearing (sweep test), and general observation.

Second class (7-8 years): The visit should be carried out by the school nurse. The examination should include:

- testing of visual acuity
- measurement of growth, where there is concern about the child's health or growth.

Sixth class (11-12 years): This visit should be carried out by the school nurse. The examination should include:

- testing of visual acuity
- testing of colour vision.

It is recommended that routine screening for scoliosis in adolescents should no longer be included in the primary school screening programme.

Each of these three screening visits should be seen as an opportunity for a general health check where this is deemed appropriate by the school nurse. Where the school nurse has concerns about a child based on the outcome of screening, on issues raised by parents or teachers, or on previously identified problems, these concerns should be discussed with the school doctor and a decision may be made to offer the child an appointment to be examined by the school doctor.

The core programme described here does not preclude a more detailed assessment (by the school nurse or doctor) at any age of a child where concerns are expressed by the parents, teacher or the child him/herself. At all stages, relevant positive findings should be discussed with the parents.

Vision screening should be carried out at ages 5-6, 7-8 and 11-12 by the school nurse using an illuminated Snellen chart at 6 metres with both eyes being tested together and separately. Vision of 6/12 or worse in either eye should be referred. Children whose visual acuity is 6/9 or whose vision is causing concern will warrant referral if there are other concerns about the child's vision. At age 11-12, a colour vision test should be carried out using the Ishihara plates.

Hearing screening should be carried out at 5-6 years by the "sweep" test. Approximately 20-25% of children aged five may fail a sweep test and this should be repeated 4-6 weeks later. Only a small proportion will fail a second test. Procedural guidelines for hearing tests should be available. The criteria for failure are 30 dB at 500 Hz and 25 dB at 1-4 kHz. Each area should have a protocol for management of screening failures with clear referral pathways to the general practitioner, community audiology clinic or ENT clinic.

Role of school health team in relation to health education and health promotion programmes: It is expected that social, personal and health education (SPHE) will shortly be included in the primary (and post-primary) school curriculum. Already some health boards, supported by the Health Promotion Unit of the Department of Health, have developed resource materials and trained teachers in aspects of health education. It is envisaged that teachers will be the key people involved in the delivery of SPHE programmes. The school nurse and doctor should play a support and advisory role in the development and implementation of health education and health promotion programmes. Health promotion should be an integral part of every consultation between the school nurse or doctor and the schoolchild and parents.

Advisory role of school health team in relation to current health issues: The school nurse and doctor should be available to advise teachers, parents and children about health issues that arise, such as: infectious diseases (meningitis, gastroenteritis, headlice, scabies, hepatitis), immunisation queries, child abuse/child protection. In relation to infectious disease problems, such as an outbreak of disease, the school doctor and nurse will work closely with the Medical Officer of Health. (A very useful manual for teachers on infection in school has been produced by Dr K Butler, on behalf of the Health Promotion Unit of the Department of Health. It provides information and guidance in the prevention and management of infectious disease in the school setting.)

Role of school health team in relation to children with special needs: The term "children with special needs" is used here to include: children with disability, chronic illness, or emotional or behavioural problems; children who are marginalised socially, for example traveller children; children considered at risk of child abuse or neglect. While these children may need extra support at all ages, it is likely that particular attention to planning for the needs of these children at school entry age may minimise difficulties at a later stage.

The school nurse and doctor should aim to minimise the effects of childhood disabilities and social and health disadvantage by playing a facilitatory, advocacy and monitoring role. Examples of ways in which the team may function here would be: the co-ordination of different elements of a multi-disciplinary group; advising the school or parents of services available to them; arrangement for the provision of facilities/equipment for children with special needs; targeting of resources to those with greatest need. More children with special needs are now being educated in mainstream schools and the school nurse and doctor should facilitate this integration wherever possible.

Emotional and behavioural problems are the most common cause of disability in childhood. Close co-operation is required between all services having a role in the identification and management of emotional and behavioural problems: these include the school health service, child psychiatry, education services, social services, primary health care teams, clinical and educational psychologists and hospital paediatric services. Where emotional or behavioural problems are identified through the school health service, generally on the basis of reports from teachers or

parents, there should be adequate provision of specific assessment and treatment services in the form of child guidance clinics, child psychiatry and clinical psychology services.

Co-operation also needs to take place in the development of strategies for primary prevention and for the promotion of mental health. The school health service should play a key role in developing such strategies.

Children with specific learning difficulties require the provision of remedial teachers and educational psychologists. These services should be the responsibility of the Department of Education. There should be a close working relationship between the educational psychology service and the health board services for children.

Coverage of school health service: The school health service, including the booster immunisation programme, should cover all primary schools, including private schools and special schools, to ensure equitable service provision.

Questionnaires and consent: It is recommended that a short questionnaire be completed by the parents of each child at the three stages specified in the core programme. Emphasis should be placed on questions about vision and hearing, but the questionnaire should also contain simple questions about general growth and development, physical health, and behaviour. There should be an open response question to allow parents to voice any concerns they might have about the child's health. This form should also record the parents' consent to examination of the child, where appropriate, by the school health team. It would be helpful if these questionnaires were standardised nationally. Where possible, these questionnaires should incorporate questions required by other services such as psychology and dental services. Consent to immunisation should be requested on a separate form.

Referral and treatment services: The general issues are addressed in the chapter on referrals. In particular, there should be clearly defined and locally agreed referral pathways, secondary examination and treatment services must be available and appropriate, and there should be timely feedback to the referrer and to the GP. Standards should be set in relation to acceptable waiting times for specialist appointments and adherence to these should be audited regularly. Results of referrals should be monitored on an ongoing basis. Children referred from the school health service to specialist services are treated free of charge (Health Act 1970).

Accommodation and facilities: Rooms used for school health visits should be suitable for the purpose. They should provide privacy, be warm and appropriately equipped. The room should be sufficiently quiet to allow for hearing testing and should be of large enough dimensions (diagonally if necessary) to allow for vision testing. Routine child health screening (vision, hearing and growth) and discussion with parents should take place in the school if possible. Where a child is deemed to require referral to the doctor, this visit should take place in the local health centre, by appointment.

Equipment: An illuminated Snellen box should be used for vision screening, with Ishihara plates for colour vision testing. Hearing testing should be carried out by the "sweep" test. Audiometers should be calibrated annually. Growth monitoring should be carried out using regularly calibrated and maintained measuring instruments. Every child's health record should contain an appropriate centile chart on which measurements should be plotted.

Evaluation: The school health service should be evaluated regularly to ensure that it is meeting the evolving needs of schoolchildren. This evaluation will be dependent on good data collection (see chapter on Information and Outcomes). In particular, the following should be carried out:

- Regular monitoring of coverage of the service
- Recording numbers of treatable conditions identified through the core programme
- Collecting information on late diagnosis of health problems
- Regular audit of referrals, including measurement of waiting times, outcome of referral, identification of inappropriate referrals, provision of appropriate treatment
- Regular audit of the quality of measurements in the core screening programme
- Surveys of parental, pupil and teacher satisfaction with the service

The information obtained from the above should be used to make recommendations where necessary for changes in practice. Much of this information should be contained in the annual report of the Child Health Co-ordinator.

A core programme for child health surveillance is recommended for all primary schools. It should be carried out by the school nurse, in close co-operation with parents and teachers, at age 5-6 years, 7-8 years and 11-12 years, with selective medical examination of children with problems. Children with special needs should receive particular attention. Adequate training of key professionals, provision and maintenance of appropriate accommodation and equipment, and provision of appropriate referral and treatment services are essential components of the school health service.

The proposed introduction of a broad-based SPHE programme in schools is welcomed.

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IDIOPATHIC ADOLESCENT SCOLIOSIS

Scoliosis is a lateral curve of the spine. Idiopathic scoliosis generally occurs in healthy, neurologically normal children and the most common age of onset is in adolescence.

Prevalence

The estimated prevalence of idiopathic adolescent scoliosis (IAS) among adolescents at the end of their growth period is 2-3% for curves of greater than 100 and 0.2% for curves of greater than 40-500. It is more common in girls than in boys. IAS has an insidious and asymptomatic onset. The response to detection of a case of IAS will depend on the degree of scoliosis and the local treatment policies. The range of treatment options include ongoing review, conservative treatment with bracing or lateral electrical surface stimulation, and surgery in a small number of cases. The etiology of the condition is unknown and the natural history is poorly understood. There is no easy means of distinguishing curves that will become progressive from those that will remain static or resolve.

School screening

School screening for IAS by the forward bend test has been in place for many years in Europe and the United States. This test has been considered to be simple, cheap and sensitive. The stated motivation for a scoliosis screening programme is to achieve early diagnosis of spinal deformity at a time when conservative treatment will be effective and surgery can be avoided.

Scoliosis screening in Ireland

Internationally, one of the largest longitudinal scoliosis screening surveys has been carried out by the National Scoliosis Screening Programme based in Our Lady's Hospital, Crumlin, Dublin. It has concentrated on girls in the age group 10-14 years. An analysis was carried out by Goldberg et al of scoliosis screening in this Dublin unit for the years 1979-1990. The analysis focused on: (1) the validity of the screening test used (the forward bend test), and (2) improved health outcome resulting from early detection of curves with application of effective treatment.

The authors found that, in the detection or prediction of 400 curves, the test had a sensitivity of 0.83, a specificity of 0.99, and a predictive value of only 0.08. This would be considered an unacceptably low predictive value. There was little evidence of improved health outcome - a maximum potential benefit of 33 saved from surgery over 11 years, 0.06% of the screened population. This would be considered a low health outcome for the population. The authors concluded: *"Although the experience of scoliosis screening since 1979 has contributed greatly to our perception and understanding of adolescent idiopathic scoliosis, the prime objective of the program has not been achieved. Early diagnosis and treatment have not contributed to a decline in the numbers with serious deformity or needing surgery."*

The issue of screening for IAS has been addressed by the Canadian Task Force on the Periodic Health Examination. This report states that there have been no controlled trials to demonstrate that adolescents who are screened routinely for scoliosis have better outcomes than those who are not screened. The adverse effects of screening and treatment are discussed including the generation of anxiety, effects on future health insurance and work eligibility, adverse psycho-social effects of conservative treatment, the general risk of surgery and financial costs. The Task Force concludes: *"There is insufficient evidence from published clinical research to indicate that screening for idiopathic scoliosis in adolescents is either effective or ineffective in improving the outcome. It is reasonable for*

clinicians to include periodic visual inspection of the back in their examination of adolescents seen for other reasons. Clinicians and public health personnel should bear in mind the limited current evidence regarding the effectiveness of scoliosis screening and treatment and the uncertainties about the natural history of the condition.”

The U.S. Preventive Services Task Force has come to a similar conclusion: *“There is insufficient evidence to recommend for or against routine screening of asymptomatic adolescents for idiopathic scoliosis. The evidence does not support routine visits to clinicians for the specific purpose of scoliosis screening or for performing the examination at specific ages during adolescence. It is prudent for clinicians to include visual inspection of the back of adolescents when it is examined for other reasons. Additional specific inspection maneuvers to screen for scoliosis, such as the forward-bending test, are of unproven benefit.”*

It is recommended that routine screening for scoliosis in adolescents should no longer be included in the primary school screening programme. Clinicians should be encouraged to include inspection of the back in the examination of an adolescent presenting to them for other reasons.

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REFERRAL PATHWAYS AND INFORMATION FEEDBACK

It is essential that staff know when, where and how to refer a child who fails a screening test. If this information is not easily available, there is a danger that the child may be subjected to repeated tests which fail to produce a definitive diagnosis, or else is lost to follow-up and never receives appropriate treatment. The route of referral will depend on local resources.

Responsibility for the management of the community child health surveillance service lies with the Child Health Co-ordinator. He/she should develop clear written guidelines for referral and should monitor the quality of service and the waiting time experienced. These guidelines should be developed in conjunction with the colleagues who will receive referrals when abnormalities are suspected.

For each screening programme a clear pathway of referral must be agreed to allow for timely and appropriate management of children who are positive on screening examinations.

Studies have shown that most area medical officers do not use guidelines or criteria for making decisions on referrals, many preferring to rely on experience. *Criteria for review or referral of a child from a child health surveillance visit should be developed in consultation with appropriate specialists and local GPs.*

The outcome of all child health surveillance examinations, even where no defect is discovered, must be reported back to the Child Health Co-ordinator by the professional carrying out the examination. This procedure should apply also in cases where a GP is contracted to supply the child health surveillance examinations. Where a defect is discovered or suspected, it is the responsibility of the professional carrying out the examination to arrange for further referral or review, according to the locally agreed protocol, and to inform the parents of both the outcome of the examination and of the fact that a referral is being made. Adequate clerical support must be provided.

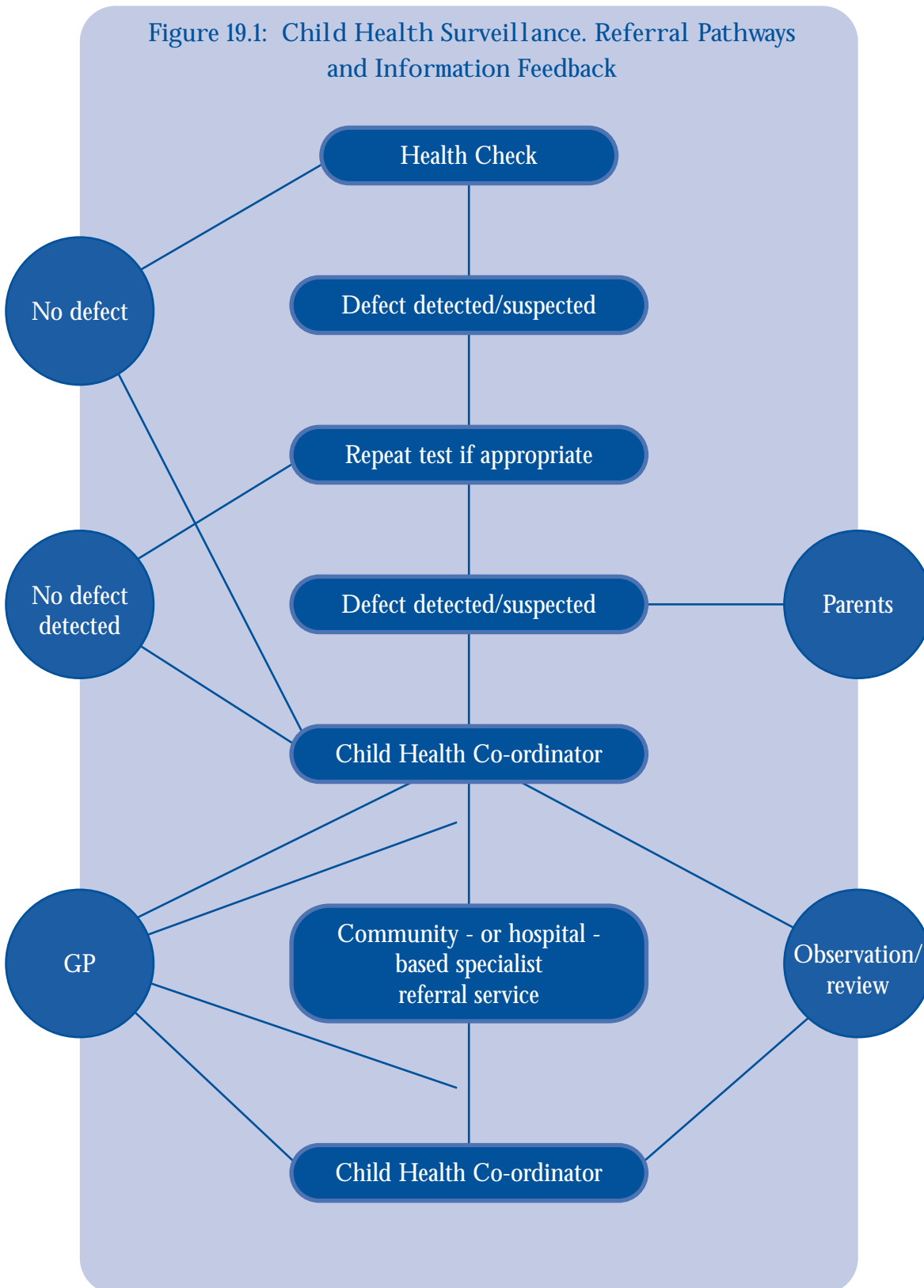
It is recommended that all referrals from the community child health surveillance services should be made in the name of the Child Health Co-ordinator, but should clearly state the name and title of the professional who has carried out the examination. Where a referral is made to a specialist, the referral letter should also specify the name and address of the child's GP. A copy of the referral letter should always be sent to the GP.

When a child is referred from child health surveillance examinations to a GP or specialist, or for ongoing review, the outcome of this visit should be notified in writing to the Child Health Co-ordinator. *The specialist should send a copy of the report to the child's GP.*

Where a defect is suspected or detected, parents should be notified by the Child Health Co-ordinator. Specialist service provision must be adequate to treat, in a timely and effective fashion, children identified by the surveillance programme as having abnormalities.

The diagram below is a schematic representation of referral procedures and flow of information. (The unbroken lines indicate action to be taken or outcome of examination; the broken lines indicate transfer/feedback of information).

Figure 19.1: Child Health Surveillance. Referral Pathways and Information Feedback



Monitoring Child Health Surveillance. Information and Outcomes

Introduction

The success of child health surveillance programmes is dependent on rigorous monitoring of their effectiveness and efficiency. The standardisation of the programmes as proposed in this report, and the advent of computerised child health systems, makes routine service monitoring a realistic goal, both nationally and regionally.

The national health strategy document "Shaping a Healthier Future" challenges the health services to achieve measurable improvements in health and social gain and emphasised the necessity for comprehensive and good quality information.

Current monitoring

Monitoring of child health surveillance services in Ireland to date has not had a high profile. Routine data collection has been carried out annually by the Department of Health and has consisted of recording of activities and of simple results of examinations, such as number of defects discovered, number of children referred to a specialist. These data have provided little information about the effect of these services on the health of children. In addition, it is commonly held that the method of recording of data varied widely, resulting in little confidence being placed in the interpretation of these data nationally.

There is increasing recognition of the need to concentrate on the outcomes of services. However, it is important to remember that measurement of activities is still essential in service planning and in the interpretation of outcomes. Measurement of activities should be purposeful, reliable, accessible and standardised nationally. It is necessary to collect data in a standardised fashion in order to plan an equitable national service and to allow for valid comparisons between regions and over time.

Why collect data?

Data on child health are collected for the purposes of: assessment of health status of children; needs assessment, particularly in relation to special needs groups; planning of services for children both in the short and long-term; and evaluation of the effectiveness and efficiency of services, including preventive, screening and treatment services.

Data are required to inform three key groups

- decision makers both at national and local level
- professionals
- consumers, specifically parents

The data gathered through evaluation of the services should be used to bring about continuous improvement, both in terms of quality and equity of service. Informed consumer views are essential components in the decision making process.

Categories of data

The broad categories of data which are required for planning and evaluation of child health surveillance services are as follows:

Health status indicators. These data will provide an overview of the health of the child population and indicate target areas or groups requiring specific services.

Performance indicators - quantitative and qualitative measures of the activities carried out in the delivery of the services.

Indicators of the outcome of interventions - measures of the effectiveness of the services in improving the health of children.

Health Service Outcome Measurement

Measuring the outcome of health care has been the subject of increasing interest. According to the Oxford Textbook of Public Health: "Outcomes are the changes, favourable or unfavourable, in the health status of individuals or populations". "Changes in health status may arise from factors unrelated to health service activities. Convincing evidence that health status changes are, in fact, due to health service interventions is an essential objective of outcome analysis".

Although measurement of outcome is an important part of the process of validating health care effectiveness and funding, the measures developed to date have, to a large extent, been subject to difficulties in their determination and interpretation.

Measuring the outcome of health care is not a straightforward undertaking. In order to measure the outcome of health care it is first necessary to define the objective of health care intervention and to select a measure of outcome which is relevant to this objective. An indicator chosen to measure outcome may only represent a single aspect of an outcome of a particular service but can be of practical use, for example if the measure is found to be unsatisfactory it can highlight the need for further examination of other aspects of the services. A health effect of health services may take a long time to manifest itself and it may be necessary to use interim points as proxies for ultimate health outcome.

In the context of screening, it may not be appropriate to regard disease incidence rates as a proxy outcome measure, because an effective screening programme may well show an apparent increase in incidence as undetected cases are located. The appropriate outcome may be the age at which necessary treatment is implemented. The appropriate outcome measure for a health promotion programme may be an intermediate measure such as a change in risk factors, for example smoking behaviour.

Outcome indicators

A Department of Health working group on health service outcome indicators in England and Wales suggested a list of potential indicators. These included some indicators which are relevant to child health surveillance services:

- mental retardation following missed congenital hypothyroidism
- learning difficulties following missed permanent hearing loss
- childhood immunisation (proxy for favourable outcome)
- early surgery for undescended testes (proxy for favourable outcome)

A feasibility study was carried out in England and Wales to investigate the use of some of these outcome indicators. The framework chosen for each indicator was as follows:

- definition of the baseline health problem
- expectation of change
- definition of outcome objective
- definition of service/intervention required
- definition of indicator(s)
- definition of data
- constraints in using the indicator(s)
- extent to which an indicator reflects local health service provision.

Each of the indicators was based on routinely collected data. Some of the indicators such as immunisation rates, early orchidopexy rates, were process measurements but were used as proxies for favourable outcome.

In relation to children the authors' recommendations included the following:

"It is recommended that the number of notifications of pertussis and measles and the immunisation uptake of their vaccines be used as local health service outcome indicators for the immunisation services and the reporting of infectious diseases".

"It is suggested that the cumulative orchidopexy rate as a percentage of male births before their fifth birthday, the annual orchidopexy rate in boys between the ages of 5 and 14 years inclusive, and the annual proportion of boys undergoing orchidopexy who are over the age of 5 years be used as outcome indicators of one aspect of child health surveillance".

The British Paediatric Association (Outcome Measures Working Group of the Health Services Committee) recommended a set of outcome measurements, including the following:

- age at fitting hearing aid for congenital deafness
- number of children with congenital dislocation of the hip identified after 6 months of age
- number of resident children tested for congenital hypothyroidism by the age of one week
- number of resident children starting treatment for congenital hypothyroidism after age 3 weeks, as a proportion of all children starting treatment

Outcome measures suggested by the Faculty of Community Medicine (UK) include:

- age at operation for congenital dislocation of the hip
- age at diagnosis of sensorineural hearing loss
- prevalence of amblyopia at school entry

Outcome indicators for child health in Ireland

It is necessary to develop a set of outcome indicators by which the effectiveness of the child health surveillance services in Ireland can be measured. The selection of indicators would best be carried out as a collaborative exercise between public health doctors and clinicians. It may be appropriate to use some indicators which have been developed in other countries, but their applicability and the feasibility of their use in Ireland would need to be established. Where possible, indicators chosen should be based on routinely available data although in some cases there may be a necessity to put in place new data sources or special surveys. In general, the approach should be to choose measures which are:

- appropriate to the service
- important
- feasible

Annual report of the Child Health Co-ordinator

The Child Health Co-ordinator should produce an annual report on the child health surveillance services for the Director of Public Health and the Department of Health. This report should also be made available to the general practitioners in the area. The format of this report should be standardised nationally and should record key performance data, including indicators of health outcome of the services. The appropriate level at which to gather data is the community care area. There should be a core minimum dataset to be recorded nationally, with each area recording additional data to reflect local priorities. The data contained in this report should give information on the health status of children, point out local problems and put forward plans to address unmet need. Specifically the report should address the following:

- Demography and vital statistics
- Staff numbers, level of training and arrangements for ongoing education
- Consumer satisfaction with services - some aspect to be measured annually
- Activities, e.g. number of clinics held, number and percentage of children examined, average age at specified visits,
- Population cover for each component of each stage of the programme
- Referrals, specifying reason for referral, outcome of referral, inappropriate referrals
- Waiting times for relevant services
- Outcomes of services, as measured by a set of nationally agreed indicators
- Arrangements in place for management of children with special needs
- Parenting programmes

Computerisation of child health surveillance data

Compatibility and comparability: It is desirable that child health surveillance data would be held on computer and that systems used in different regions would be compatible to allow for comparison between areas and to allow for collation of data nationally.

Accessibility and confidentiality: Computerised systems should be accessible to those who need to know the information, and the need to observe absolute confidentiality in relation to personal data should be supported by appropriate training and security.

Person-based: Information should be person-based, rather than event-based. There is a need for a national personal identification number. This would greatly facilitate record linkage and outcome evaluation.

Quality of data: Information should be accurate, up-to-date and complete.

Small area analysis: Information should be recorded in such a way as to allow for small area analysis. This is particularly important to allow for special attention to be paid to geographic areas where indicators of health status are below average.

The Child Health Co-ordinator should produce an annual report on the child health surveillance services for the Director of Public Health and the Department of Health. This report should be standardised nationally and should record key performance data, including indicators of health outcome of the services. A set of outcome indicators should be developed for Ireland.

Child health surveillance data should be held on computer.

There is a need for a national personal identification number.

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O'Connor Ray, Irish College of General Practitioners.
O'Connor Theresa, Public Health Nurse, Mobile Clinic, Eastern Health Board.
O'Donoghue Emer, Irish Society of Public Health Medicine.
O'Donovan Cecily, Senior Medical Officer, NRB Audiology Services.
O'Donovan Margaret, Family Development Nurse, Eastern Health Board.
O'Dowd Tom, Professor of General Practice, Department of Community Health and General Practice, Trinity College, Dublin.
O'Leary Finbar, Consultant Child and Adolescent Psychiatrist, Cork.
O'Mahony Tom, Department of Health.
O'Neill Dolores, Superintendent Public Health Nurse, Western Health Board, Roscommon.
O'Reilly Orlaith, Director of Public Health, South-Eastern Health Board.
Prenderville Patricia, Senior Area Medical Officer, South-Eastern Health Board, Cashel.
Quirke Bridget, Pavee Point, Dublin.
Scrivener Ross, Royal College of Paediatrics, London.
Sheehy Liz, Community Mothers Programme, Eastern Health Board.
Sheen Mary, Chairperson of Educational Committee, Irish College of General Practitioners.
Shiels Sally, Principal Teacher, North Dublin Project School.
Stakelum Anne, Research Officer, Dept of Public Health, North Eastern Health Board.
Stewart-Brown Sarah, Director Health Services Research Unit, Department of Public Health, University of Oxford.

Participants at Workshop on Parent Held Records

7th October 1997

Prof David Hall, Professor of Community Paediatrics, University of Sheffield.
Ms Debbie , Health Visitor, Department of Community Paediatrics, Sheffield.
Ms. Marian Lyon, National Parents Council.
Dr. Lelia Thornton, Specialist in Public Health Medicine, Eastern Health Board.
Ms. Una Doherty, Superintendent Public Health Nurse, South-Eastern Health Board.
Dr. Paul McCormack, General Practitioner, Dublin.
Dr. Margaret Fitzgerald, Senior Registrar in Public Health Medicine, Eastern Health Board.
Ms Paula Campbell, Health Education Officer, North Eastern Health Board.
Dr. Mary McKay, Consultant Paediatrician, National Children's Hospital, Dublin.
Prof. Denis Gill, Professor of Paediatrics, Royal College of Surgeons in Ireland.
Mr. Owen Metcalfe, Health Promotion Unit, Department of Health.
Ms. Hilary Kenny, Irish Pre-school Playgroups Association.
Dr. Heidi Pelly, Director of Community Care, Western Health Board, Roscommon.
Dr. Emer O'Donoghue, Irish Society of Public Health Medicine.
Dr. Ray O'Connor, Irish College of General Practitioners.
Ms. Mary Liston, Superintendent Public Health Nurse, Mid-Western Health Board, Nenagh.
Prof. Tom O'Dowd, Professor of General Practice, Department of Community Health and

General Practice, Trinity College, Dublin.
Mr. Tommy Hourigan, Management Services Officer, Mid-Western Health Board.
Ms. Dora Hennessy, Principal Officer, Community Health, Department of Health.
Ms. Deirdre Kavanagh, Pavee Point, Dublin.
Ms. Liz Duff, Baby Unit Sister, National Maternity Hospital, Holles Street, Dublin.
Dr. Stephen McDermott, Principal Dental Surgeon, Eastern Health Board, Wicklow.
Ms. Theresa O'Connor, Public Health Nurse, Mobile Clinic, Eastern Health Board.

Participants at Child Health Workshop in Westport

April 23-25, 1997

Caulfield Eileen, General Practitioner, Co Sligo.
Denyer Sean, Director of Public Health, North Western Health Board.
Doherty Una, Superintendent Public Health Nurse, South Eastern Health Board.
Fitzgerald Margaret, Senior Registrar in Public Health Medicine, Eastern Health Board.
Fitzsimons Deirdre, Nursing Advisor, Department of Health.
Foley-Nolan Aisling, Community Ophthalmologist, North Eastern Health Board.
Greally Tessa, Specialist in Public Health Medicine, Mid Western Health Board, Limerick.
Hennessy Dora, Principal Officer, Community Health, Department of Health.
Jennings Phil, Specialist in Public Health Medicine, Midland Health Board, Tullamore.
Kiely Jim, Chief Medical Officer, Department of Health.
Kilgallon Ann, Senior Registrar in Public Health Medicine, North Western Health Board.
Lyon Marian, National Parents Council.
Mannion Seamus, Programme Manager Community Care, Western Health Board.
McKay Mary, Consultant Paediatrician, National Children's Hospital, Dublin.
McNally Maura, Health Promotion Officer, North-Western Health Board.
Morrow Ruby, Psychology Unit, Department of Education.
O'Connor Anne, Director of Community Care, Eastern Health Board.
O'Donovan Cecily, Senior Medical Officer, NRB Audiology Services.
O'Leary Finbar, Consultant Child and Adolescent Psychiatrist, Cork.
O'Neill Dolores, Superintendent Public Health Nurse, Western Health Board Roscommon.
Pelly Heidi, Director of Community Care, Western Health Board, Roscommon.
Prenderville Patricia, Senior Area Medical Officer, South-Eastern Health Board Cashel.
Shiels Sally, Principal Teacher, North Dublin Project School.
Stewart-Brown Sarah, Director Health Services Research Unit, Department of Public Health, University of Oxford.
Thornton Lelia, Specialist in Public Health Medicine, Eastern Health Board.