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Evidence Review of the Child Health Model

prepared by the

Child Public Health Group,
Strategy & Planning Division

for

The National Steering Group for
Implementation of the
Revised Child Health Model.

October 2018

The National Healthy Childhood Programme

Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service

Version Management		
Version 1	Chapter 1 – 11	October 2014
Version 2	Chapter 1 – 11	March 2015
Version 3	Chapter 1 – 11 plus Infant Mental Health	October 2016
Version 4	Chapter 1 – 11 Updated Chapter 1 Demography Updated Chapter 3 Health Outcomes section Updated Chapter 4 Legislative & Strategic context	October 2018

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Foreword

As Director of Public Health Lead for Child Health in the Strategy & Planning , I am pleased to present the next version of evidence review of the Child Health Model. The first version was prepared by the Child Public Health Group and circulated to the Steering Group for the Implementation of the Revised Child Health model at the end of October 2014.

The current version contains the additions and changes that were received from the Steering Group and the Child Public Health Group. As this is a working document, there may be further changes and additions to sections 1 and 2 .

In Section 1 a new chapter on Health Inequalities has been added. It contains current population statistics and related reports set out relevant child demographic trends. A new section on Infant Mental Health has been included. The health status of children in terms of health outcomes and lifestyle factors is also provided. An outline of the legislative framework that governs the provision of child health services is given. A brief critique of the implementation of Best Health for Children is presented. Current national strategies are referenced and the relevant departments/organisations are also outlined.

In Section 2 the report contains a desktop review of the seven of the eight key areas of Best Health for Children 2005. Within the timeframe available to the Child Public Health Group, it seemed reasonable to draw on available research/audit and interviews with key informants to review the current status of child health screening and surveillance services. Current evidence on best practice was reviewed and is presented under the eight key areas. Recommendations are provided only as back drop to inform the work of the Steering Group for the Implementation of Revised Child Health Model.

I wish to thank the members of the Child Public Health Group & the Steering Group for their individual contributions to this review and their enthusiasm and commitment to overall work of the group.

Signed

Phil Jennings

Dr. Phil Jennings
National Lead HI Healthy Childhood Programme

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Framework for The National Healthy Childhood Programme, October 2018 also available.

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Please cite as: *HSE Evidence Review for Child Health Model, October 2018, Version 4, HSE Strategy & Planning*

Section One

Demography
Health Inequalities
Healthy Childhood
Legislative and Strategic Context

Chapter 1: Demography

Key Points

The consequences for the delivery of child health services are self-evident when the data regarding children are analysed:

- Of the total population of 4,761,865 people in 2016, 25% (1,190,502) were aged less than 18 years old[1].
- The child population of Ireland increased by 14.8% between 2006 and 2016[1].
- In 2015, Ireland had the highest percentage of children in the European Union (at that time estimated to be 26%). The EU-28 average was 19%.[2]
- The number of foreign national children increased by 27.8% between 2006 and 2016; approximately 6.7% of the total child population[1].
- Of all the family units with children aged 18 and younger, 21.3% were one parent families and 17.3% of children aged 18 and younger in the State were living in families with one parent[1].
- In 2015, 1.0% of all deaths were in the 0-14 year age group, 76% of deaths in this age group were in infants under one year[3].
- The infant mortality rate dropped to 2.8 per 1,000 live births in 2017 from 3.5 in 2011 and remains in the mid-range of EU values[4].

Population figures provide key context for the development of any health service. The Irish population is undergoing significant change with significant population growth since 2002 (22%) and in the last twenty years the population has grown by 31%[1]. Between 2006 and 2016, high births and falling deaths are the main reasons for the population growth in Ireland. The median age is the age about which half of the population is younger and half is older. In 2017, the median age of the population of Ireland was 36.8 - the lowest of any EU Member State and considerably lower than the EU average of 42.8[4].

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[1] Census 2016 for Ireland Statbank. Accessed at www.cso.ie

[2] State of the Nation's Children: Ireland 2016 Department of Children and Youth Affairs Dublin: Government Publications Available at: www.dcya.ie

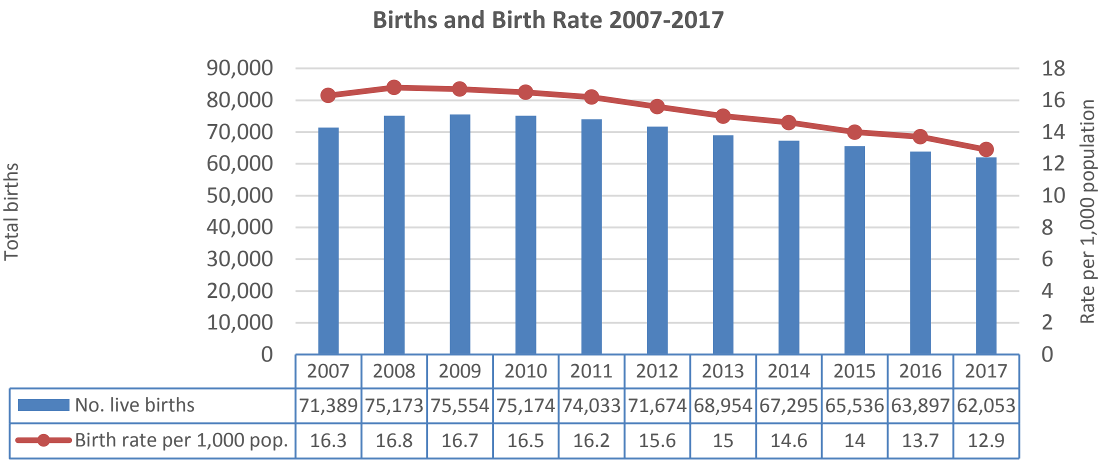
[3] Vital Statistics Yearly Summary 2017 CSO May 2018 Available at: www.cso.ie

[4] Eurostat. Accessed at http://ec.europa.eu/eurostat/

1.1 *Births and Birth Rates*

Irish birth numbers and rates peaked between 2008-2010 reaching 75,554 in 2009 (birth rate of 16.7 per 1000) and a reducing trend has been evident since then which is confirmed by 62,053 births in 2017[3, 5].

Figure A: Births and birth rates in Ireland 2007 to 2017



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
No. live births	71,389	75,173	75,554	75,174	74,033	71,674	68,954	67,295	65,536	63,897	62,053
Birth rate per 1,000 pop.	16.3	16.8	16.7	16.5	16.2	15.6	15	14.6	14	13.7	12.9

Over the last ten years Ireland's total fertility rate has been higher than the average for the EU-28 countries. The most recent comparable figures are from 2015, when Ireland's total fertility rate was 1.86 compared to 1.58 for the EU-28 countries[5]. See Table 1.

Table 1: Total fertility rate, Ireland and EU-28 2007 to 2016

	Total Fertility Rate	
Year	**Ireland**	**EU-28**
2007	2.03	1.56
2008	2.07	1.61
2009	2.06	1.61
2010	2.06	1.62
2011	2.02	1.59
2012	1.99	1.59
2013	1.96	1.55
2014	1.94	1.58
2015	1.86	1.58
2016	1.82	n/a

The average age of all mothers with babies born in 2017 was 32.8 years[3]. The trend in the decreasing number and rate of teenage mothers continued in 2017, with 1.7% of all births to teenage mothers. Over the 6 year period 2011-2017, the number of births to mothers aged 10-17 has decreased by 38.1%. In 2017, there were 211 births to mothers aged 10-17, a rate of 340 per 100,000. Of these births, 91% were to mothers aged 16-17.

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[5] Health in Ireland Key Trends 2017 Department of Health 2017 Available at: www.doh.gov.ie

Table 2: Births to mothers under 20 years 2011-2017

	2011	2012	2013	2014	2015	2016	2017
Under 20 years	1,690	1,616	1,380	1,226	1,187	1,098	1,041
All ages	74,033	71,674	68,954	67,295	65,909	63,897	62,053
	2.3%	2.3%	2.0%	1.8%	1.8%	1.7%	1.7%

1.2 Changing Family Profiles

Data from Census 2016 show a 3.3% growth in number of families since 2011 and a 51% increase since 1996[1]. In this case family is defined as a family is defined as a couple with one or more children, a couple without children or a lone parent with one or more children. Among families with children, the numbers of married couples, cohabiting couples and one parent families have all increased. Family size has declined from an average of 1.8 children in 1996 to 1.4 children in 2016, with rural families on average larger (1.5) than urban families (1.3)[1].

The following data also highlight changing family profiles in Ireland[1]:

- Over ten-fold increase in divorce between 1996-2016.
- 6,034 same sex couples living together, of which 591 couples with children (2016), 2.6 times more than in 2011 (230 couples).
- 25.4% increase in cohabiting families with children since 1996.
- 17% of population of Ireland born outside Ireland.

Just over 17% of children aged 18 and younger lived in a one parent household in 2016 (216,991 of those aged 0-18). The table below shows that 21.3% of families with children 18 and younger were one parent families – the majority of which were one parent families with mothers (19.4%).

Table 3. Family households of children 18 and younger 2011 and 2016

Family Type	2011		2016	
	No. of families	**%**	**No. of families**	**%**
Married couple with children aged 18 and under	416,629	68.4	421,885	67.4
Cohabiting couple with children aged 18 and under	57,180	9.4	71,050	11.4
One parent mother with children aged 18 and under	123,491	20.3	121,196	19.4
One parent father with children aged 18 and under	12,004	2.0	11,737	1.9
Total families with children aged 18 and under	**609,304**		**625,868**	

1.3 Pre-school children

The number of 0-4 year olds increased from 302,252 to 331,515 between 2006 and 2016, an increase of 9.7%[1]. Of those preschool children who spoke a foreign language at home, 35% or 7,699 could not speak English well or at all[66]. These figures have significant implications for the delivery of the school child health programme now and over the coming years when these children enter the school system. There has been a fall of 24,814 persons in the 0-4 age group between 2011 and 2016, primarily due to a fall in births since 2009[1]. Table 4 shows that in 2016 Cork County had the highest number of 0-4s (31,337), followed by Dublin City (30,683).

Table 4: Number of 0-4s by County and City in Census 2011 and Census 2016

County and City	Number of 0-4s by County and City 2006		County and City	Number of 0-4s by County and City 2006	
	2011	2016		2011	2016
Carlow	4,345	4,056	**Limerick City and County**	14,194	13,135
Cavan	6,177	5,725	**Longford**	3,241	3,051
Clare	8,905	7,901	**Louth**	10,411	9,473
Cork City	6,042	6,305	**Mayo**	9,199	8,393
Cork County	34,146	31,337	**Meath**	17,502	15,736
Donegal	12,727	10,776	**Monaghan**	4,929	4,672
Dublin City	30,250	30,683	**Offaly**	6,239	5,631
Dún Laoghaire-Rathdown	13,155	13,810	**Roscommon**	4,642	4,360
Fingal	26,708	24,899	**Sligo**	4,594	4,310
Galway City	4,869	4,772	**South Dublin**	23,043	21,733
Galway County	14,091	13,027	**Tipperary**	11,947	10,874
Kerry	10,025	9,020	**Waterford City and County**	8,644	7,614
Kildare	18,914	17,314	**Westmeath**	6,882	6,464
Kilkenny	7,501	7,112	**Wexford**	11,539	10,327
Laois	7,538	6,644	**Wicklow**	11,474	10,173
Leitrim	2,456	2,188			

Figure B shows that the highest proportions of 0-4 years out of the total population in 2016 were in Fingal and Meath.

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[6] Census 2016 Summary Results Part 1 CSO Available at: https://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart1/Presentation_Census_Summary_Results_Part_1.pdf

Figure B: Proportion of 0-4% in City and Counties 2016

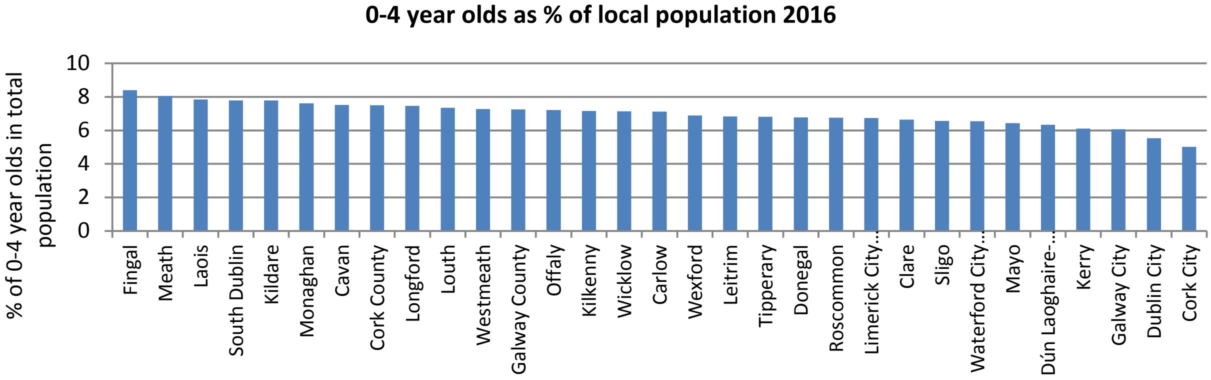


Figure C: Composition of households where pre-school children lived 2011-2016

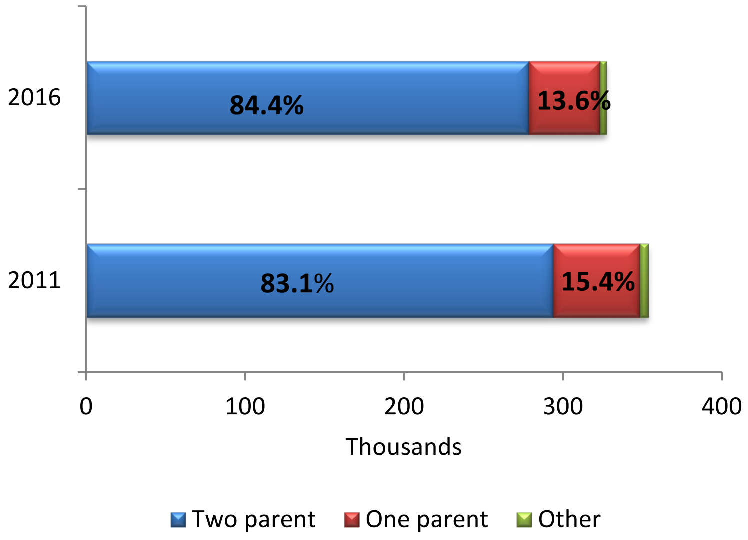


Figure C shows the categories of household in which preschool children lived[1], showing that 84.4% of this age group lived in family units with both parents, with 13.6% in one parent families. There was a decrease in the number of pre-school children living with one parent, and this type of family unit has decreased as a proportion of all household types from 15.4% in 2011 to 13.6% in 2016.

1.4 Ethnicity

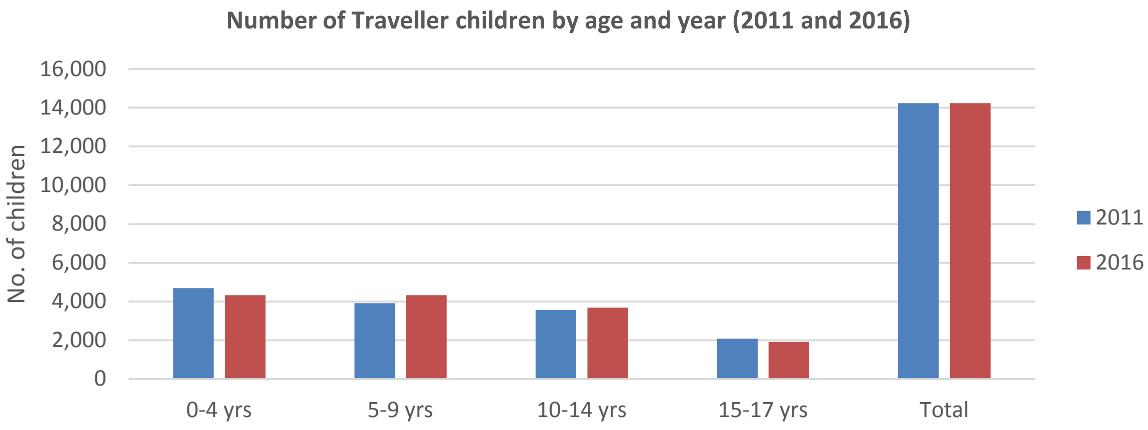
In 2016, approximately 1 in 14 children (6.7%) living in Ireland were of a nationality other than Irish[1] (Table 5). Close to 3 in 10 of these children were born in Poland, while the UK was the second most popular nationality at 11%.

Table 5: Number and percentage of foreign national children, by nationality 2016

Number and percentage of foreign national children, by nationality (2016)		
Nationality	No.	%
Polish	23,254	29.2
UK	9,043	11.4
Lithuanian	7,210	9.1
Other EU28	6,691	8.4
Other Asian	6,316	7.9
Romanian	5,113	6.4
African	4,246	5.3
Latvian	4,185	5.3
Other nationalities	2,214	2.8
American (US)	2,004	2.5
Indian	1,907	2.4
Other European	1,448	1.8
Spanish	1,348	1.7
French	1,070	1.3
German	1,067	1.3
Italian	1,025	1.3
Brazilian	817	1.0
Other American	578	0.7
Total	79,536	100%

While the number of Traveller children has increased by 30.3% between 2006 and 2016[1], it remained almost identical between 2011 (14,245) and 2016 (14,246). There were slightly fewer Traveller children in the 0-4 and 15-17 age groups, and slightly more between the ages of 5 and 14 (Figure D).

Figure D: Number of Traveller children by age and year 2011-2016



1.5 Deaths

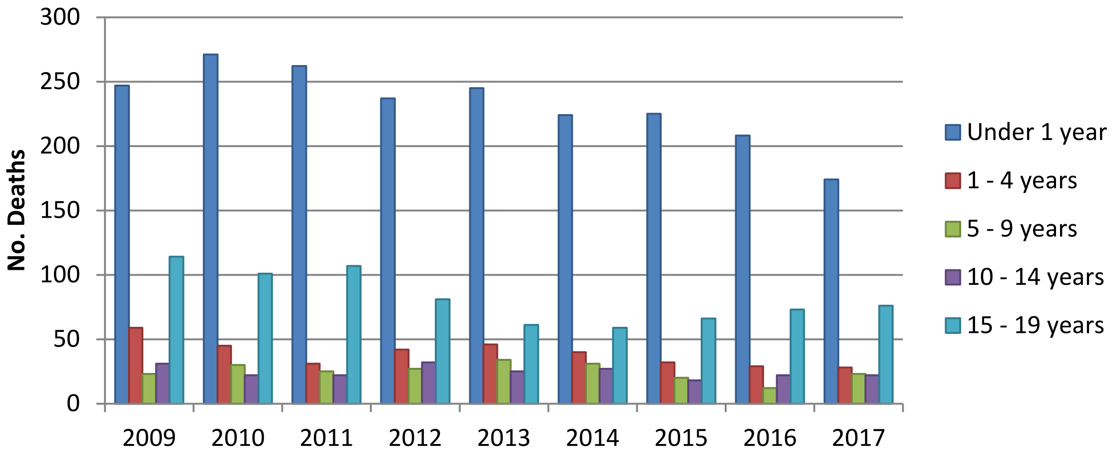
Life expectancy for males at birth in 2015 was 79.6 years, and for females was 83.4 years[4]. The total number of deaths in Ireland in 2017 was 30,484 – 0.8% of all deaths were in the 0 to 14 year age group[3]. Just over 70% of all deaths in the 0-14 age group were in infants under one year.

Table 6: Deaths in the 0 to 14 year age group in 2017

Age Group	Number of Deaths	% of total
Under 1	174	70.4%
1 to 4 years	28	11.3%
5 to 14 years	45	18.2%
Total	247	100%

Figure E shows the number of deaths in children 0-19 years by age group and year from 2009 until 2017 and further illustrates the impact on the under 1s[5].

Figure E: Number of deaths in children (0-19 years) by age group and year 2009-2017



1.5.1 Infant Mortality Rate

The infant mortality rate is the number of deaths of children under one year of age in a given year, expressed per 1,000 live births. It is used as an indicator of the '*effect of economic and social conditions on the health of mothers and newborns, as well as the effectiveness of health systems.*'[7] The infant mortality rate in Ireland has dropped from 4/1,000 live births in 2008 to 2.8/1,000 live births in 2017 [3]. In 2016, Ireland, together with Denmark, was approximately midway in the EU-28 league of countries at 3.0/1,000 live births. The infant mortality rate for the EU-28 was 3.6/1,000 in 2016[4].
See Appendix 2.

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[7] Health At a Glance Europe 2012 Accessed at: http://www.oecd.org/eu/health-at-a-glance-europe.htm

Chapter 2: Health Inequalities and Chronic Disease – Foundations laid in Early Childhood

Key Points:

There is a gradient in health all the way up the social ladder. Those who are poorest have the worst health, while those at the highest social level have the best health.
This unequal distribution of health is not inevitable, but is associated with an unequal distribution of income and education, living and working conditions and of supportive family and community networks.

Changes in economic arrangements and in social policies and programmes have been shown to reduce the health gap. These changes can save both lives and money.

While changes are needed across different groups and settings, early childhood is a special case. '*The foundations for virtually every aspect of human development – physical, intellectual and emotional – are laid in early childhood. What happens during these early years (starting in the womb) has lifelong effects on many aspects of health and well-being – from obesity, heart disease and mental health to educational achievement and economic status.'* Marmot, 2010.[8]

To have an impact on health inequalities and on chronic disease in later life, it is vital to address the social gradient in children's access to positive early experiences.
Later interventions, though important, are considerably less effective, and are more costly, where good early foundations are lacking.

Investment in early childhood development, starting from conception, provides one of the most cost effective interventions available to reduce health inequalities and chronic illness in later life. This is because its impact is seen not just on the health of the child but because it also provides the foundation for health, or predisposition to illness, over a person's lifetime.

There is, therefore, an economic as well as a social argument to invest in early childhood. At present, however, most developed countries spend proportionately more on children as they get older. A disproportionate proportion of income disadvantage is borne by children and young people.

Within the health and social sphere, there are a number of interventions in early childhood which have been shown to work on improving child and adult health and social outcomes and which have been shown to be cost effective. These include: home-visiting programmes, promotion of parenting skills; smoking cessation; support for mothers with mental health problems. Such interventions can have a greater impact on the development of those children who are more disadvantaged. In order to really impact on health inequalities and chronic disease, some interventions should be universally available while additional programmes should be provided based on need – progressive or proportionate universalism.

In the broader policy frame, policies to address childhood poverty, parental leave and early childhood education have also been shown to be effective.

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[8] Marmot M. (2010). Fair Society, Healthy Lives. The Marmot Review. Strategic Review of Health Inequalities in England post-2010. London.

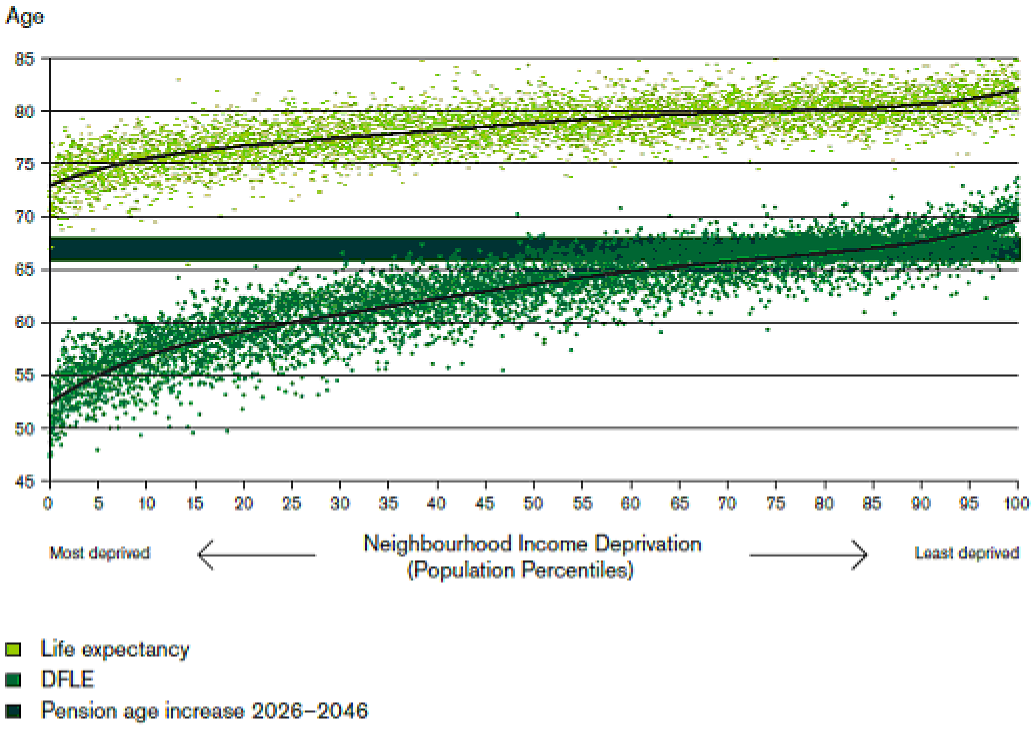
If we are serious about impacting on adult health and well-being, and reducing health inequalities, current models of resource allocation and of service delivery will need to be re-assessed, and additional resources identified, to order to invest in early childhood.

2.1 Health Inequalities

In Ireland, life expectancy at birth for males living in the fifth quintile of most deprived areas is 4.3 years less than that for males living in least deprived quintile (i.e. most affluent areas) (73.7 years vs. 78 years) [9]. For females, life expectancy for those living in the most deprived areas is 2.7 years less than that for females living in the least deprived areas (80 years vs. 82.7 years).
There is a gradient in health status across all social strata, from the lowest to the highest.

In his review of health inequalities in England, Marmot showed that people living in the poorest 5% of neighbourhoods will, on average, die 7 years earlier than people in the richest neighbourhoods.8 See Figure F.
Marmot also showed that the gap in disability free life expectancy (DFLE) between high and low income neighbourhoods is 17 years.

Figure F Life expectance and disability-free life expectancy (DFLE) at birth, persons by neighbourhood income level, England, 1999-2003



*Source: Marmot M. (2010)*8.

The All Ireland Traveller Health Study reports that life expectancy at birth for Traveller males is 15.1 years lower than the general male population and for Traveller females is

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[9] Central Statistics Office ,Mortality Differentials in Ireland, (2010), Dublin: CSO.

11.5 years lower than the general female population.[10] Infant mortality is 3.5 times higher among Travellers, while the suicide rate among male Travellers is 6.6 times higher than among the general male population.

Peri-natal mortality and low birth weight are significantly higher among lower income groups.[11] Babies born to parents who are unemployed or whose socio-economic status was unknown were twice as likely to be of low birth weight when compared with those whose parents were recorded as higher professionals.

The Growing Up in Ireland data show that one in ten 9-year-olds (11%) have a chronic illness or disability.[12] Chronic illness or disability is more heavily concentrated among children from lower socio-economic backgrounds.

A 2011 report from the Growing up in Ireland group found children from less socio-economically advantaged households (29% of boys and 38% of girls) have higher levels of overweight compared to children from professional households (19% of boys and 18% of girls).[13]

2.2 Early Childhood – Foundation of Health and Ill-Health

Health inequality is caused by an unequal distribution of resources across families, not only in terms of wealth, but also in living conditions, levels of education, supportive family and community networks, social capital and parenting skills.8,[14] These influences are evident at the individual and at the societal level and are cumulative over a person's lifetime.

While changes are needed across different groups and settings in order to impact on health inequalities, childhood a special case. '*The foundations for virtually every aspect of human development – physical, intellectual and emotional – are laid in early childhood. What happens during these early years (starting in the womb) has lifelong effects on many aspects of health and well-being – from obesity, heart disease and mental health to educational achievement and economic status'.* 8

The Adverse Childhood Experiences (ACE) studies show that the more adverse childhood experiences an individual has endured, the greater the later incidence of [15]:

- ischaemic health disease,
- stroke,
- chest diseases,
- cancer,
- diabetes,
- hepatitis,

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[10] All Ireland Traveller Health Study Team. (2010). All Ireland Traveller Health Study: Our Geels. School of Public Health, Physiotherapy and Population Science. Dublin: University College Dublin. 2010.

[11] McAvoy H., Sturley J., Burke S. and Balanda K.P. (2006). Unequal at birth - Inequalities in the occurrence of low birthweight babies in Ireland. Dublin: Institute of Public Health in Ireland.

[12] Williams J et al. (2009) Growing Up in Ireland: National Longitudinal study of children – The Lives of 9-year-ols. Report 1. Dublin: OMCYA. Accessed at: http://www.growingup.ie/fileadmin/user_upload/documents/1st_Report/Barcode_Growing_Up_in_Ireland_-_The_Lives_of_9-Year-Olds_Main_Report.pdf

[13] Layte, R., McCrory, C. (2011). Growing Up in Ireland: National Longitudinal Study of Children: Overweight and Obesity Among 9-year-olds. Dublin: DCYA. Accessed at: http://www.growingup.ie/fileadmin/user_upload/documents/Second_Child_Cohort_Reports/Growing_Up_in_Ireland_-_Overweight_and_Obesity_Among_9-Year-Olds.pdf

[14] Wilkinson R, Pickett K (2009) The Spirit Level - Why equality is better for everyone.

[15] Felitti VJ et al (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. American Journal of Preventive Medicine, 14(4); 245-58.

- severe obesity,
- depression and attempted suicide
- smoking,
- fractures,
- alcohol and drug use,
- STIs.

To have an impact on health inequalities and on chronic disease in later life, it is vital to address the social gradient in children's access to positive early experiences.[16, 17] Later interventions, though important, are considerably less effective where good early foundations are lacking.

Child development begins before birth, when the health of a baby is affected by the health and well-being of their mother. [18, 19] Brain architecture is established early in life through dynamic interactions between genetic and environmental influences. [20]

Maternal health during pregnancy, including stress, diet, drug and tobacco use, has a significant influence on foetal and early brain development.8 Barker has shown that when human foetuses have to adapt to a limited supply of nutrients, they permanently change their structures and metabolism. [19] Maternal stress in pregnancy can have lifelong effects on health through alterations to gene expression.[21] [15] These changes may be the origin of a number of diseases in later life, including coronary heart disease, stroke, diabetes and hypertension. Low birth weight is particularly associated with poorer long-term health and educational outcomes .[19]
The first year of life is vital for neuro-development to provide the foundations for children's cognitive capacities. [22, 23] It is also important for non-cognitive skills, such as application, self-regulation and empathy.

Traumatic experiences during childhood, such as physical abuse or the adversities that accumulate for children reared in deep and persistent poverty, are capable of disturbing the neurobiological systems that guide physiological and behavioural responses to stress, potentially for the remainder of an individual's life. [24] [21]Altering these regulatory mechanisms (e.g. setting the stress response system on a "short fuse") can permanently increase the risks of acute and chronic disease, and can be the cause of a shortened life span.

While brain development continues well into adulthood, interaction with the primary caregiver in the first few months of life can set the journey towards healthy social and

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[16] Commission on the social determinants of health, WHO (2008). Closing the gap in a generation: Health equity through action on the social determinants of health

[17] Waldfogel J (2004) Social mobility, life chances and the early years, CASE Paper 88, London: London School of Economics.

[18] Jefferis B J M H, Power C and Hertzman C (2002) Birth weight, childhood socioeconomic environment and cognitive development in the 1958 birth cohort study. BMJ 325:305.

[19] Barker DJP (1998) In Utero programming of chronic disease. Clinical Science 95: 115-128.

[20] Jenson B B, Currie C, Dyson A, Eisenstadt N, Melhuish E (2013) Early years, family and education task force report. WHO, Europe. Accessed at: http://www.euro.who.int/__data/assets/pdf_file/0006/236193/Early-years,-family-and-education-task-group-report.pdf

[21] Shonkoff J, Boce W and McEwn B (2009). Neuroscience, Molecular Biology, and the Childhood Roots of Health Disparities – Building a New Framework for Health Promotion and Disease Prevention. JAMA 2009;301(21):2252-2259. Accessed at: http://www.brooklyn.cuny.edu/pub/departments/childrensstudies/conference/pdf/Shonkoff-Boyce-McEwen_JAMA.pdf

[22] Perry BD (2002) Childhood experience and the expression of genetic potential: what childhood neglect tells us about nature and nurture. Brian and Mind 3: 79100

[23] Lexmond J and Reeves R (2009) Building character. London: Demos

[24] National Scientific Council on the Developing Child (2010) The foundations of lifelong health are built in early childhood. Centre on the Developing Child, Harvard University. Accessed at: http://developingchild.harvard.edu/resources/reports_and_working_papers/foundations-of-lifelong-health/

emotional development throughout life. [20] On the other hand, children with an insecure attachment are more likely to have social and emotional difficulties, such as increased domestic violence, higher alcohol and substance use and multiple sexual partners.

Having a more sensitive parent was associated with a higher development score in infants. [12, 25] Parenting styles and the quality of mother-child and father-child relationships were associated with better social and emotional development.

Mental health problems in the mother have health consequences for the child over the short and long term. [26, 32] Of the estimated costs associated with peri-natal mental health problems, nearly three quarters (72%) relate to adverse impacts on the child rather than on the mother.

Disadvantages in early childhood have implications for how prepared children are when they enter school. School readiness includes not only cognitive skills but also those associated with socialisation, self regulatory behaviour and learning approaches.
School readiness is associated with a number of factors, including maternal education and with household income.[27] Cognitive, language and social development are influenced in the longer term by the quality of the early years' home learning environment. [20] Higher cognitive scores are associated with healthier lifestyles and better health outcomes, as well as better educational attainment, leading to higher future income. 8

While these readiness measures indicate that children from more enriched environments enter school better prepared, longitudinal data demonstrate that these early gaps persist and even widen as children progress through school. 8[, 28] Children from disadvantaged backgrounds also experience higher rates of special education use, grade repetition and dropping out of high school.

There is some evidence that income, especially maternal income, has a direct impact on parenting and on children's health and well-being.8[, 12] However, the evidence for the impact of income, on its own, is difficult to separate from other influences on child health.

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[25] Nixon E, Swords L, Murray A (2013). Growing Up in Ireland: National Longitudinal Study of Children: Parenting and Infant Development. Dublin: DCYA. Accessed at: http://www.growingup.ie/fileadmin/user_upload/documents/Second_Infant_Cohort_Reports/Parenting_and_Infant.pdf

[26] Jenkins H, Meltzer P B, Jones T, Brugha P, Bebbington M, Farrell D, Crepaz-Keay and Knapp M (2008) Foresight Mental Capital Wellbeing Project. Mental health: Future Challenges. London: The Government Office for Science.

[27] Doyle O and Timmins L (2010) School Readiness Matters: Socioeconomic Inequalities in Early Childhood Skills. Policy Briefing No. 2. UCD Geary Institute. Accessed at: http://www.ucd.ie/geary/static/publications/policybriefings/UCD_Geary_policy_no2.pdf

[28] Karoly L, Kilburn M and Cannon J (2005) Early childhood interventions – Proven Results, Future Promise. Rand Corporation.

2.3 *Early Childhood Influences on Health – Irish Data*

2.3.1 Social influences

Low birth weight impacts on subsequent health. [29] The most important determinant of low birth weight in children is maternal smoking during pregnancy.[30] Nearly 1 in 5 mothers (17.6%) of children in the infant cohort of the Growing Up in Ireland study reported smoking at some stage during their pregnancy. Women from lower income and social-class households and those with lower levels of education were significantly more likely to smoke during pregnancy.

Ireland has one of the lowest national levels of breastfeeding in the world. [30] Overall, the Growing Up in Ireland data show that 56% of women breastfed their child to some extent. However, women of lower income, education and social class were much less likely to breastfeed, and tended to breastfeed for a shorter time.

There is evidence that mental health problems in pregnancy and the post-natal period are associated with adverse outcomes for the child, both in the short term and long term.[31] Up to 20% of women have mental health problems (including depression anxiety, psychosis, post-traumatic stress disorder) in the antenatal and postnatal periods.[32] A high proportion of such cases go undetected. (See Infant Mental Health section in Chapter 3 – to be added).

Parenting styles are shown to be linked with infant development. Three quarters of mothers (77%) and 68% of fathers of 9-year-olds used an authoritative style of parenting, which is considered the optimal style. Children whose parents used an authoritarian style of parenting (4% mothers and 7% fathers) or an indulgent or permissive style (16% mothers and 20% of fathers) had more social and emotional problems. [12]

Along with poverty, the next most prevalent risk factors for children at risk of experiencing social and emotional problems and of poorer cognitive development are living in social housing and having a lone parent. [33] In 2011, there were 43,578 households with children in Ireland in need of social housing. [34] Nearly 1 in 5 children (18.3%) lived in a lone parent household. This proportion increased to 27.3% for children with a disability.

Parental education, particularly the mother's, is a central factor in a child's early development. [12, 35] Nearly a third of mothers (31%) of 9-year-old children had achieved an educational level of lower secondary school or less; a further 37% had reached Leaving Certificate level while the remaining 32% had achieved a third level qualification. [12]

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[29] Barker DJP (1995) Fetal origins of coronary heart disease. BMJ 311: 171-174.

[30] Layte R and McCrory C (2014). Maternal health behaviours and child growth in infancy. Analyses of the Infant cohort of the Growing Up in Ireland study. Dublin: DCYA. Accessed at: http://www.growingup.ie/fileadmin/user_upload/documents/Maternal_Health_Report/GUI_Infant_Maternal_Health_4_web.pdf

[31] National Collaborating Centre for Mental Health (2014) Antenatal and Postnatal Mental Health – the NICE guideline on clinical management and service guideline. London. Accessed at: http://www.ncbi.nlm.nih.gov/books/NBK54487/pdf/TOC.pdf

[32] Bauer A, Parsonage M, Knapp M, lemmi V, Adelaja B (2014) Costs of perinatal mental health problems. London School of Economics and Political Science, London, UK.

[33] Blank L, Baxter S, Messina J, Fairbrother H, Goyder L, Chilott J Summary review of the factors relating to risk of children experiencing social and emotional difficulties and cognitive dofficulties. Accessed at: http://www.nice.org.uk/resource/7ybbnvfqj4xju6y3a6ibfsw3q4

[34] State of the Nations Children (2012). Dublin: DCYA. Accessed at: http://www.dcya.gov.ie/documents/research/StateoftheNationsChildren2012.pdf

[35] Doyle O and Timmins L (2010) School Readiness Matters: Socioeconomic Inequalities in Early Childhood Skills. Policy Briefing No. 2. UCD Geary Institute. Accessed at: http://www.ucd.ie/geary/static/publications/policybriefings/UCD_Geary_policy_no2.pdf

2.3.2 Local Area

In 2010, 90.8% of all children aged 10-17 reported feeling safe in the area where they live. Traveller children (77.9%), immigrant children (87.5%) and children with a disability and/or chronic illness (87.9%) were less likely to report feeling safe in the area where they live.**Error! Bookmark not defined.** The percentage of children who report that there are ood places in their area to spend their free time has increased from approximately 42% in 2006 to 51% in 2010.**Error! Bookmark not defined.**

2.3.3 Education

Variations in levels of early school leavers were evident from the 2011 census also, with higher proportions in the Border area and in the South East in the under 18age group. See Appendix 3.

Average class sizes in primary school were lowest in the West (22.6) and highest in the Mid-East (Kildare, Wicklow, Meath) (26.1)- secondary school sizes were also highest in the Mid-East indicating pressure on the expanding conurbation of these counties.

2.3.4 Crime and Disorder

A 2013 study on recidivism by the CSO and Probation Service examined the re-offending rates of those placed on Probation Orders and Community Service Orders in the year 2007 and 2008.[36] This analysis excluded most sex offences and in terms of reoffending certain traffic offences were excluded. While the report does not explicitly define recidivism it has been defined as '*a person's relapse into criminal behaviour, often after the person receives sanctions or undergoes intervention for a previous crime….is measured by criminal acts that resulted in rearrest, reconviction or return to prison with or without a new sentence during a three-year period following the prisoner's release.*'[37]

The Irish Probation Service report compares the two and three-year recidivism rates for two cohorts from 2007 and 2008. The report states that the two-year rate is the most reliable for comparison of the two cohorts due to incompleteness of the data for year three of the 2008 cohort.

In the 2007 cohort there were 181 children (5%) aged under 18 years. The majority were male (86%). Over 53% (115) reoffended within two years, compared to 37% for the overall cohort. There where 277 (7%) children aged under 18 years in the 2008 cohort and again the majority were male (86%). While the reoffending rate at two years was slightly lower at 48% (109) it was still higher than the overall rate of 33% in that cohort. The rates of reoffending tended to decrease by age, with older age groups having lower rates. While the report does urge caution in interpreting these data due to small numbers it does state *'the population of young people subject to Probation supervision nevertheless, comprises the more difficult and challenging offenders as the majority of young offenders coming to An Garda Síochána attention are diverted at an earlier point out of the criminal justice system and engaged with other services.'*

2.3.5 Looked after Children

As at October 2013, the HSE reported that there were 6,486 children in care with just over 90% placed in foster care. Of the 5,997 children living in foster care approximately 30% were living with relative foster carers.[38] The number of children in the care of the HSE increased from 5,307 in 2007 to 6,486 in 2013, an increase of 22.2%.

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[36] Probation Service Recidivism Study 2008-2013 Probation Service Research Report 4 December 2013 Accessed at: www.probation.ie

[37] National Institute of Justice Accessed at: http://www.nij.gov/topics/corrections/recidivism/Pages/welcome.aspx

[38] Foster Care Department of Children and Youth Affair 2013 Accessed at: http://www.dcya.gov.ie/docs/Foster_Care/2591.htm

Table 7: Birth and Domestic Adoption Trends in Ireland 2008-2012

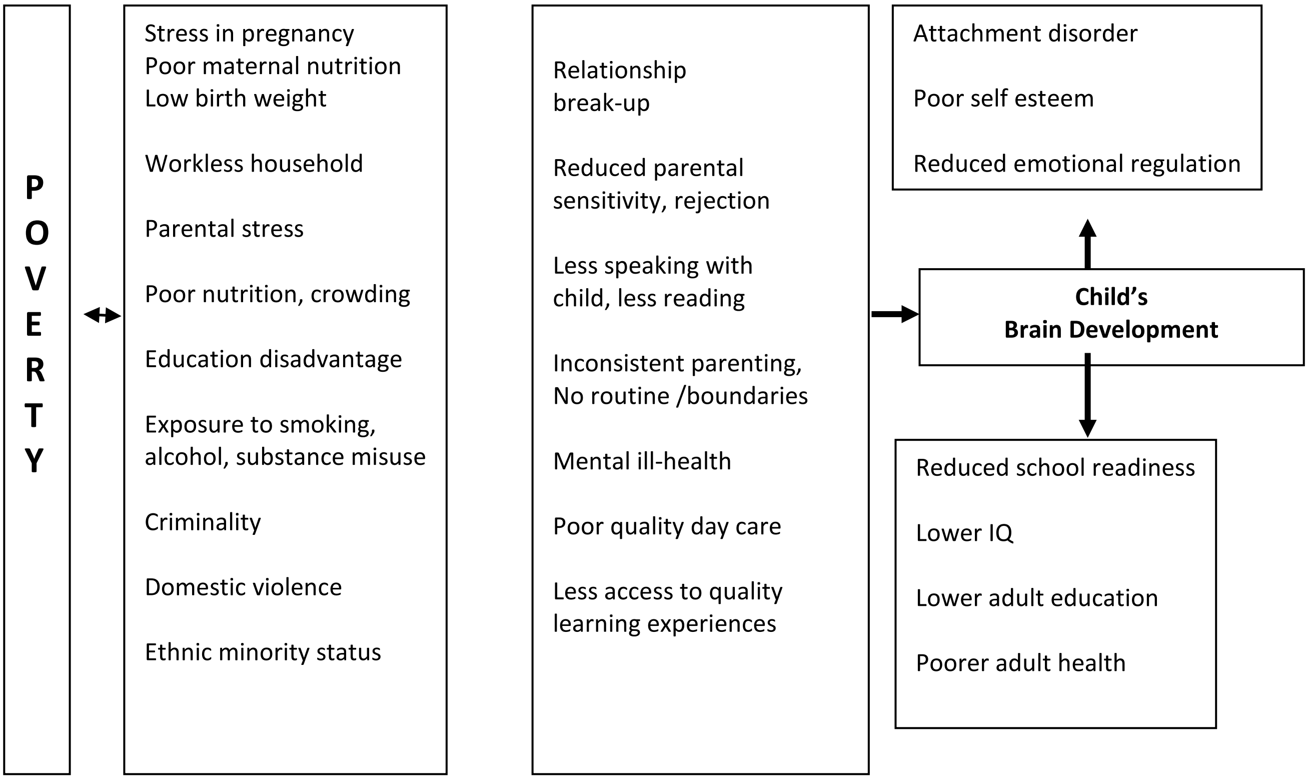
Year	Total births	No. of adoptions	% of total Births
2008	75,065	200	0.27%
2009	74,728	190	0.25%
2010	73,724	189	0.26%
2011	74,650	39	0.05%
2012	72,225	49	0.07%

Source: Adapted from the Annual Report of the Adoption Authority of Ireland 2012[39]
In 2012 there were 117 intercountry adoptions with most of the children coming from Russia (49), Ethiopia (32) and the USA (19)

2.3.6 Economic Influences

There is a complex interplay between the influence of poverty on health and other influences on health.8 See Figure G. In addition, some of the effects of poverty are also the causes of poverty in the next generation. This is reflected in the intergenerational element of income deprivation.

Figure G Influences of poverty on child development and subsequent adult health.



While children who do not live in poverty experience adverse childhood events, and there are more such children overall, [15] [40] children living in poorer families are more likely to

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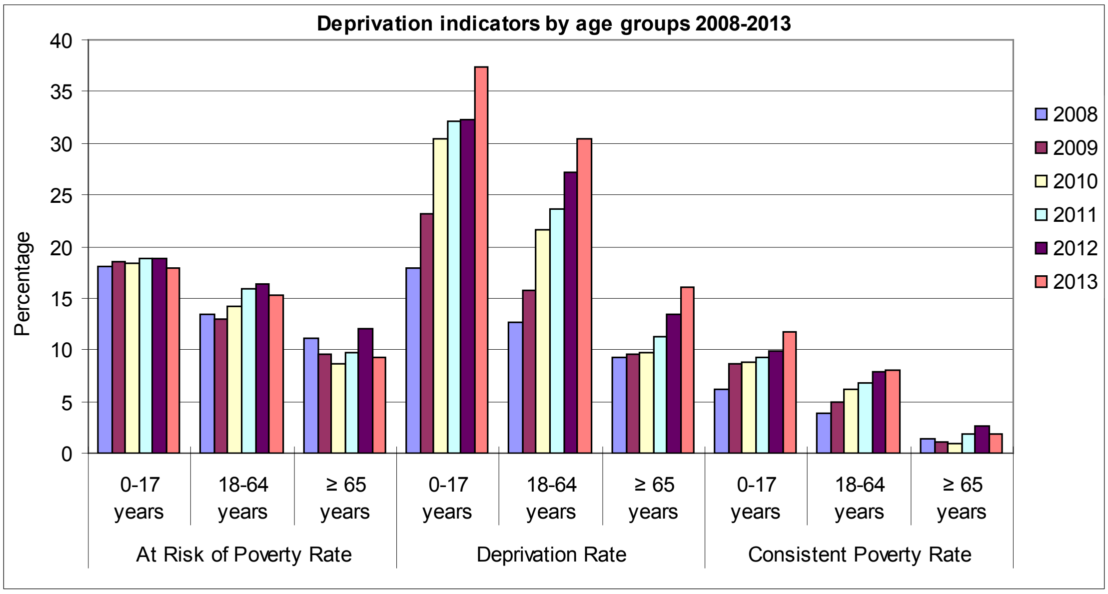
[39] The Adoption Authority of Ireland Annual report 2012 Accessed at: http://www.aai.gov.ie/index.php/publications.html

suffer from adverse childhood experiences and are more likely to experience multiple adverse events.8

Trends from the Surveys on Income and Living Conditions show that children aged 0-17 years were the population group most likely to be at risk of poverty, of being deprived and to live in consistent poverty, between 2008 and 2013. [41] See Figure H.

All age groups experienced an increase in income deprivation in the years between 2008 and 2013. However children bear the burden of income deprivation. In 2013, over 1 in 10 children aged 0-17 years (11.7%) lived in consistent poverty, an 89% increase from 2008.

Figure H Deprivation indicators by age group 2008-2013



Source: Central Statistics Office (2009-2014)

A recent UNICEF report looking at the impact of the recession on children in developed countries showed that Ireland's increase in child poverty in the 4 years from 2008 to 2012 ranked fifth highest among a group of 41 developed countries. [42] Children living in persistent poverty are also more likely to be poor as adults.[43]

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[40] Fives A, Purcell L, Heary C, Nic Gabhainn S and Canavan J. (2014) Parenting support for every parent: A population-level evaluation of Triple P in Longford Westmeath. Final report. Athlone: Longford Westmeath Parenting Partnership (LWPP). Accessed at: http://www.nehb.ie/eng/services/news/media/pressrel/Triple%20P/finalreport.html

[41] Central Statistics Office (2009-2014). 2008-2013 Surveys on Income and Living Conditions (SILC). Dublin: CSO. www.cso.ie

[42] UNICEF Office of Research (2014). 'Children of the Recession: The impact of the economic crisis on child well-being in rich countries', Innocenti Report Card 12, UNICEF Office of Research, Florence

[43] Moore K.A. Redd Z. Burkhauser M. Mbwana K. and Collins A. (2009). Children in Poverty: Trends, Consequences and Policy Options. Child Trends Research Brief.

2.4 Cost of Health Inequalities - Benefits of Reducing Inequalities

In England the costs of health inequality, in human terms, has been estimated at between 1.3 and 2.5 million years of life lost and a further loss of 2.8 million years free of limiting illness or disability per year.8 In economic terms (lost work productivity and taxes, excess welfare payments and additional health costs), the costs have been estimated at between £56 to £70 billion per year.
If the same studies could be extrapolated directly to Ireland's population, the costs could be estimated to be at least 113,000 years of life lost, a loss of 243,600 years free of limiting illness or disability and economic costs of €6.5 - €8 billion per year.

Health inequalities are not inevitable and can be addressed by tackling the social determinants of health. While it would be difficult to eliminate the social gradient in health completely, a shallower gradient can be achieved. 8 There is a shallower socioeconomic gradient in health in some regions than in others.

Marmot argues that focusing solely on the most disadvantaged will not reduce health inequalities sufficiently.8 See Figure F. Actions are required across all strata. Only a small proportion of adverse health problems are found in the most income-disadvantaged families.[15 40] However, in order not to increase inequality, actions should be proportionate to the level of need – proportionate or progressive universalism. The universal delivery of a service to the whole population has additional benefits – it both normalises and de-stigmatises such service - improving acceptability, and it can form the foundation of a needs assessment framework – allowing the identification of additional needs, so that families can be signposted or referred to additional services. The OECD also recommends such a system (termed a 'cascading model' in their paper). [44]

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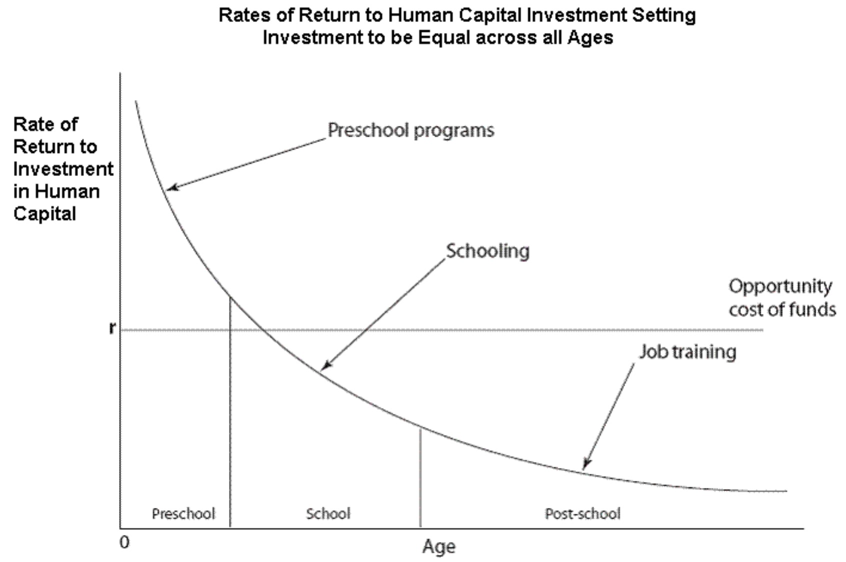
[44] OECD (2009) Doing Better for Children. Accessed at: http://www.oecd.org/els/family/doingbetterforchildren.htm

2.5 *Investment in Early Childhood Services*

It is now known that investment in early intervention initiatives aimed at child development, educational disadvantage and parenting has been shown to provide a greater rate of return than later interventions, with the most effective time for intervention being before birth and in early childhood. 8[24, 45, 46, 47] See Figure I.

Figure I Rates of Return to Human Capital Investment



Rates of return to human capital investment setting investment to be equal across all ages

Source: Carneiro and Heckman – Human Capital Policy [45]

Conversely, most developed countries spend proportionately more on children as they get older.[44] This is particularly the case in Ireland. See Figure J.

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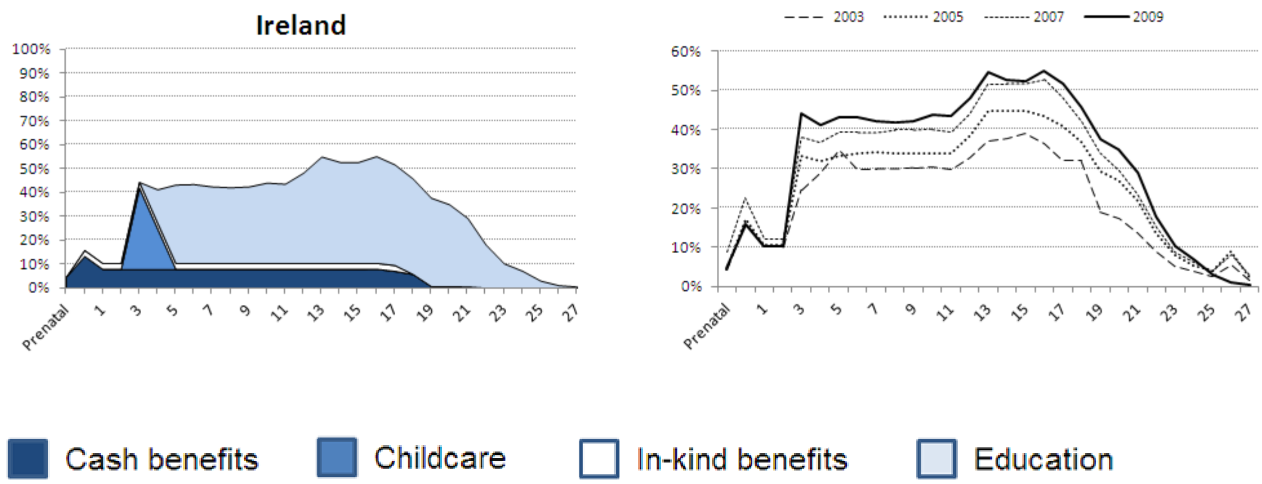
[45] Heckman J and Masterov D (2007) The productivity argument for investing in young children. NBER Working Paper No. 13016. Accessed at: http://jenni.uchicago.edu/human-inequality/papers/Heckman_final_all_wp_2007-03-22c_jsb.pdf

[46] Carneiro P and Heckman J (2003) Human Capital Policy. National Bureau of Economic Research Working Paper 9495. Accessed at: http://www.nber.org/papers/w9495.pdf

[47] Wave Trust (2013) The economics of early years' investment, Appendix 4 in Conception to age 2 – the age of opportunity report. Accessed at: http://www.wavetrust.org/sites/default/files/reports/conception-to-age-2-full-report_0.pdf

Figure J Average and Yearly Expenditure on Children and Young People by Benefit type, 2003-2009. Ireland, UK and OECD average.



Source OECD: Doing Better for Children (2009)

The largest cost benefit ratios were found in programmes with longer-term follow-up because they allowed measurement of outcomes at older ages.[47] As most programmes measure outcomes in the shorter-term, the cost-benefit for most programmes are, therefore, likely to be conservative. Even from such conservative analyses, the rates of return on investment significantly exceed both their costs and stock market returns.

There is some suggestion that spending on support services more consistently reduces income poverty in young families compared to cash benefits.[48] It seems that countries such as Sweden and Norway, which adopted whole country approaches to investment in early years' service provision, have achieved better health and financial returns for the whole population across the lifespan. [49]

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[48] Richardson D. (2014) Social spending across the child's life cycle: International variation and its consequences. Presentation to conference: The long shadow of childhood adversity. ESRI, Dublin.

[49] WAVE Trust. (2013). Conception to age 2 – the age of opportunity. Accessed at: http://www.wavetrust.org/sites/default/files/reports/conception-to-age-2-full-report_0.pdf

2.6 Early Childhood Interventions – What works?

Within the health and social sphere, there are a number of interventions in childhood which have been shown to work on improving child and adult health and social outcomes and have been shown to be cost effective. [28, 44, 50 ,51, 52, 53, 54, 55] Such interventions can have a greater impact on the development of those children who are more disadvantaged[8]. Investment in early childhood services can break the inter-generational cycle of disadvantage.[49]

Table 8 provides a synopsis of the type of early childhood interventions which have been shown to be effective. Other sources or reviews should be sought to identify the details of specific programmes or on their effectiveness when implemented in different settings.

Table 8 Types of effective early childhood intervention programmes

Antenatal	Home-visiting programmes, especially for those most disadvantaged; Promotion of smoking cessation; Improvement of maternal nutrition; Promotion of breastfeeding; Identification and support of mothers with mental health issues; Promotion of parenting skills Immunisation
Post-natal and Early years	Home-visiting programmes, particularly for disadvantaged families For those with universal home-visiting programmes, needs assessment to identify those requiring more intensive interventions. Promotion of, or continuation of, smoking cessation; Promotion of breastfeeding and infant nutrition, parent-child relationships, positive parenting, regular sleep patterns, injury prevention, oral health, SIDS, early literacy and reading. Identification of, and support, for mothers with mental health issues Immunisation
Pre-school	Parent education programmes Quality early education interventions

Features of effective programmes include: [24, 44]

- care-givers are better trained;
- smaller staff-to-child ratios;
- appropriately intensive programmes;
- sufficient fidelity to base programme;

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[50] Public Health England (2015). Rapid Review to Update Evidence for the Healthy Child Programme 0-5. Accessed at: https://www.gov.uk/government/publications/healthy-child-programme-rapid-review-to-update-evidence

[51] Devaney C, Canavan J, Landy F and Gillen A. (2013) What works in Family Support? Dublin: Child and Family Support Agency

[52] Rochford S, Doherty N, Owens S (2014) Prevention and Early Intervention in Children and Young People's Services: Ten years of Learning. Dublin: Centre for Effective Services. Accessed at: http://www.effectiveservices.org/images/uploads/PEII_10_Years_of_Learning_Report.pdf

[53] Siegenthaler E, Munder T, Egger M (2012) Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. J Am Acad Child Adolesc Psychiatry. 51(1):8-17.

[54] Aos S, Lieb R, Mayfield J, Miller M and Pennucci A (2004) Benefits and costs of prevention and early intervention programs for youth. Olympia: Washington State Institute for Public Policy. Accessed at: http://www.wsipp.wa.gov/ReportFile/881/Wsipp_Benefits-and-Costs-of-Prevention-and-Early-Intervention-Programs-for-Youth_Summary-Report.pdf

[55] Allens Consulting Group (2008) The (draft) national framework for universal child and family health services.

- support provided during times of transition – e.g. first-time parents, transition to pre- or primary-school.

Interventions can be provided universally, can be targeted to those with greater needs or can provide elements of both. Of those that are targeted, they can be area-based (e.g. in disadvantaged areas), child- or family-based (e.g. child or parent with disability) or targeted at a specific group (e.g. travellers).

When cost effectiveness studies have been carried out, most such interventions have been found to be cost effective. In general, greater returns have been found for those interventions targeted at families which experience greater adversity. However, there is some evidence that programmes which provide elements of both universal and targeted interventions can have greater returns on investment than more targeted programmes. [47, 56]

Marmot recommends that the proportion of social expenditure allocated to the early years be increased and that it is focused progressively across the social gradient. 8However, unequal access, poor quality or inappropriate programmes can actually increase health inequality.
Looking at the broader policy framework, policies on parental leave and on early year's education can impact on children's health. [24]

Finally, a reversal of the trend for a higher rate of income deprivation and poverty in childhood compared to other age bands may have an impact on children's health, especially where this investment is concentrated on the early years.8[,44]

2.7 Conclusion

There is good evidence that investment in early childhood is cost effective. It can deliver both a social and an economic return.
Evidence-based interventions can reduce health inequalities and chronic disease in later life. Such interventions need to be proportionate to the level of need.

Further work is needed, in this country, to develop and integrate such services. Our current resource allocation and service delivery models should be re-assessed.

If we are to really impact on adult health and well-being, current resources will need to be re-assigned, and additional resources identified, to invest in early childhood.

More detailed research on alternative policy options for early childhood interventions within this country is required.

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[56] Washington State Institute for Public Policy (WSIPP) (2012). Return on Investment Evidence-Based Options to Improve Statewide Outcomes: April 2012 Update.

Chapter 3: Healthy Children

3.1 Infant Mental Health

Key Messages

Brain development, attachment & emotional regulation, supported by healthy parent – child interaction, is the cornerstone of infant mental health.

The developmental period of infancy and early childhood provides a unique opportunity to lay the foundation for healthy psychological, social and emotional development and for the creation of healthy mental health and wellbeing in later childhood, adolescence, adulthood and across the life span.

Without timely intervention, there will be repeated intergenerational transmission and patterns of adversity and disadvantage, inequality and child maltreatment. The consequences of these patterns will add to the burden of mental health problems and will be costly for the health services, the state and Irish society.

There is a large body of evidence on the effectiveness of interventions in both mental health promotion and adverse outcome prevention.

Human relationships are the building blocks of health development. The primary attachment relationship with the caregiver, usually the mother, sets the condition for the development of systems of emotional control and stress regulation.

Emotional regulation is recognised as a core component of social emotional competence, self regulation and is functional in almost all of a child's transactions with the world.
Children start life completely incapable of modulating the expression of overwhelming feelings and need the support of an attuned sensitive care giving relationship to initially co-regulate their emotional states.[57]

The economics of intervening early with targeted interventions show high returns for money invested through a reduction in a wide range of government costs, including the spend on health service.
There is a powerful economic argument for developing increased investment in services that target parents and pre-school children.

In comparison to other countries, Ireland has significant gaps in services for infants, toddlers and their caregivers who are at risk of social and emotional difficulties.

Early childhood policy and strategy in Ireland advocate for prevention and early intervention at all levels of child service provision. The message regarding infant and toddler development and early care giving relationships has not been translated at practice level.

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[57] Early Childhood Education and Care Oireachtas Library & Research Service No 4 2012 Accessed at: http://www.oireachtas.ie/parliament/media/housesoftheoireachtas/libraryresearch/spotlights/spotEarlyEd180412.pdf

3.1 Background

The purpose of this review is to introduce and review Infant Mental Health (IMH) principles and practices, not previously addressed in Best Health for Children Revisited 2005. Infant Mental Health is a relatively new term within the Irish health services. The evidence presented in this chapter will show that the period from conception to three years is a foundational development period in a child's development that encompasses significant opportunity as well as risk. Good mental health or infant mental health should be a central component of any child health service. It will show that inclusion of infant mental health in universal and targeted child health services will have dividends for generations to come.

The framework addresses promotion, prevention intervention and treatment services and includes attention to child development, child health, and parental and early childhood mental health. In comparison to our international colleagues, significant service gaps exist in services for infants and toddlers and their caregivers in Ireland at risk for social and emotional difficulties or presenting with relationship disturbances or disorders of infancy. Evidence based interventions and public health approaches that screen and assess for conditions that place the infant or family at risk have shown the benefits that can be gained by early services for the individual, the family and society.

3.1.2 What is Infant Mental Health

The term Infant Mental Health (IMH) was first used by Selma Fraiberg and her colleagues in the late 1960's. They defined the meaning of the term as the *"social, emotional and cognitive wellbeing of a baby within the context of care giving relationship".* [58]

The following definition has received widespread acceptance

> *Infant Mental Health is the developing capacity of the child from birth to three years to experience, regulate (manage), and express emotions, form close and secure interpersonal relationships; and explore and master the environment and learn- all in the context of family, community, and cultural expectations for young children.*[59]
>
> - ***Developing capacity** is a reminder of the extraordinary rapid pace of growth and change in the first three years of life.*
> - *Infant and toddlers depend heavily on adults to help them to experience, **regulate (manage), and express emotions**.*
> - *Through **close secure interpersonal relationships** with parents and other caregivers, infants and toddlers learn what people expect of them and what they can expect of other people.*
> - *The drive to **explore and master one's environment** is inborn in humans. Infants and toddlers' active participants in their own learning and development is an important aspect of their mental health.*
> - *The contexts of **family and community** are where infants and toddlers learn to share and communicate their feelings and experiences with significant caregivers and other children. A developing sense of themselves as competent, effective, and valued individuals is an important part of infant mental health.*
> - ***Culture** influences every aspect of human development, including how IMH is understood, adults' goals and expectations for young children's development, and the child rearing practices used by parents and caregivers.*

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[58] Fraiberg, S. (1980). *Clinical studies in infant mental health*. New York: Basic Books.

[59] Infant Mental Health Task Force (2001) : Definition of Infant Mental Health Accessed at: http://www.zerotothree.org/imh

> *These caregivers include the child's birth parents, adoptive/foster parent's grandparents, child care and educational providers as well as other significant adults who share the primary care and nurturance of infants and toddlers.* [60]

3.1.3 Why is Infant Mental Health Important

Early experiences matters. When infants and toddlers are provided with predictable, consistent care giving environments where they are supported and nurtured, they are afforded the best possible opportunity for their health and wellbeing. This enables their capacity to make healthy transitions into education and their capacity to sustain this health and wellbeing across later developmental stages in childhood, adolescence and throughout adult life.[61]

The developmental period of infancy and early childhood provides a unique opportunity to lay the foundation for healthy psychological, social and emotional development and a further opportunity for the creation of healthy mental health and wellbeing in later childhood, adolescence, adulthood and across the life span. [62]

Evidence based research in genetics, neuroscience, child development studies, and developmental psychopathology, in combination with half a century of programme evaluations on studies documenting clinical disorders, their treatment and outcomes have provided the empirical foundation for this critical developmental period contributing to infant mental health.[63]

Data on the prevalence and incidence of mental health disturbances or disorders in infants and toddlers is very limited. [64] [65] In 2000, the Copenhagen Child Cohort (CCC) Study was established to investigate developmental psychopathology from birth in the general population. [66] [67] A random sample of 211 children from the CCC were reviewed when the toddlers were 1.5 years old. Mental health problems were detected in 16-18% of children. Regulatory disorders and infant-parent relationship disturbances were reported as both frequent and frequently co-occurring. [67]

A follow up epidemiological study concluded that for the first time, it is shown in the general population that children as young as 1.5 years may suffer from mental health disturbances at the same rate that older children do. Risk factors and predictors of mental health illness can be identified in the first 10 months of life and the association of risks found in studies of older children seems to already operate from birth.[66]

The results point to the potential of mental health screening and intervention in existing child health surveillance services.

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[60] Weatherston, D. & Tableman, B. (2002). Infant mental health services: Supporting competencies/reducing risks (2nd ed.). Southgate: Michigan Association for Infant Mental Health.

[61] Shonkoff, JP. Phillips, DA.(2000). From Neurons to Neighbourhoods: the science of early development National Research Council Institute of Medicine Washington DC

[62] Mares, S., Newman, L. & Warren, B. (2011). Clinical Skills in Infant Mental Health: *The first three years.* Acer Press

[63] Zeanah C.H. & Zeanah, P.D. (2009). The scope of infant mental health. In Charles J. Zeanah Jr. (Ed.), Handbook of infant Mental Health (3rd ed., pp. 5-21). New York: Guilford Press.

[64] Carter, A.S., Briggs-Gowan, M.J., & Davies, N.O. (2004). Assessment of young children's social and emotional development and psychopathology: Recent advances and recommendations for practice. *Journal of Child Psychology and Psychiatry,* 45:
1; 109-34.

[65] Egger, H.L. & Angold, A. (2006) Common emotional and behavioural disorders in preschool children : presentation, nosology and epidemiology. *Journal of Child Psychology and Psychiatry,* Vol. 47, Issue 3-4, 13-337.

[66] Skovgarrd, A.M. (2010). Mental health problems and psychopathology in infancy and early childhood: An epidemiological study. *Danish Medical Bulletin*, 57; B4 193

[67] Skovgarrd, A.M., ,Houmann, T., Christensen, E., Olsen,E.M., Landorph, S.L., Lichtenberg, A.& Jørgensen, T. (2007). The Prevalence of Mental Health Problems in Children 1½ of Age - The Copenhagen County Child Cohort CCC 2000. Journal Child Psychiatry & Psychology 48: 1; 62-70

3.1.4 What influences Infant Mental Health?

Healthy infant mental health does not exist or develop in isolation. An infant's early development is the product of the infant's characteristics (including genetic), infant-caregiver relationships and the environment within which these relationships unfold. These collective factors influence an infant's mental health.[68]

The clinical practice of IMH includes a number of key tenets which consider the strengths in infants and families, a relationship assessment framework and intervention and a prevention orientation. [63] It advocates for early childhood strategies when the actions of families or caregivers are not effective in promoting positive behaviour and reducing challenging or other distressing behaviours. These strategies include:

- Promote the emotional and behavioural wellbeing of all young children, particularly those compromised by virtue of poverty or other environmental or biological risks.
- Help families of young children to overcome whatever barriers they face to ensure that their children's emotional development is not compromised.
- Expand the competencies of non familial caregivers, health professionals and allied social and health care service providers and others to promote the emotional wellbeing of young children and families, particularly those at risk of biological risks or exposed to less optimal environments.
- Ensure that young children who experience clearly atypical behavioural and emotional development and their families have access to services and supports.

Consequently, services and policies are required to address the adverse influences that can occur between the infant and his or her primary caregiver and the broader systems of relationships that influence the infant's healthy development. [69] [70]

Table 9: Main Types of Infant Mental Health Problems

• Exposure to parental mental health disorders ○ Exposure to maternal mental health disorders or previous maternal mental disorders such as depression, anxiety, major mental health disorders, drug abuse ○ Infants and toddlers who have experienced being on the receiving end of chronic abuse, neglect and violence[71]	• Adverse Childhood Experiences (ACEs) ○ The impact of exposure to teratogens , alcohol abuse, domestic violence, maltreatment, abuse, neglect, chronic and enduring stress[72]
• Regulatory behaviour disorders	• Feeding, sleeping, problems
• Sleeping disturbances	• Excessive crying/inability to be soothed
• Developmental disabilities • Problem behaviours	

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[68] The Centre for the Social and Development Foundations of Early Learning Infant Mental Health and Early Care and Education Providers Accessed at: www.csefel.vanderbilt.edu

[69] Knitzer, J. (2007) Putting knowledge into policy: Towards an infant-toddler policy agenda. Infant Mental Health Journal, Vol. 28(2), 237-245

[70] Ministry of Health. (2011) *Healthy Beginning: Developing perinatal and infant mental health services in New Zealand.* Wellington: Ministry of Health

[71] Wave Trust Report (2005) Accessed at: http://www.wavetrust.org/key-publications/reports/all

[72] Feletti, VJ. Anda, RF. Nordenberg, D. *et al.(* 1988) Relationship of childhood abuse and household dysfunction to many leading causes of death in adults: the Adverse Childhood Experiences (ACE) Study American Journal of Preventative Medicine; 14(4): 245-258

The causes and factors that affect an infant's mental health are further explored under the following main headings:

Antenatal and Neonatal Period
Brain Development
Attachment
Emotional Regulation

3.1.5 Antenatal and Neonatal Period

The Marmot Report (2010) on health inequalities cited evidence that the health of a baby is crucially affected by the health and well-being of the mother from the time of conception.[73] Evidence suggests that the best outcomes for both mother and baby, in the period after birth, are most probable in circumstances where mothers:

- enjoy a well-balanced diet;
- are not experiencing stress or anxiety;
- are in a supportive relationship – partner violence is increasingly recognised as an important risk factor for perinatal mental disorders across the diagnostic spectrum; and not experiencing domestic violence;
- are not smoking, consuming alcohol or misusing illegal substances;
- are in good physical, mental or emotional health;
- are not socio-economically disadvantaged;
- are at least 20 years old; and, have a supportive person at the birth itself.
- It is not possible to discuss all of these issues here but as a major public health issue that often goes unrecognized, it is important to highlight the issue of perinatal mental illness.

Examples of perinatal mental illnesses include antenatal and postnatal depression, obsessive-compulsive disorder, post-traumatic stress disorder (PTSD) and postpartum psychosis. These conditions often develop suddenly and range from mild to extremely severe, requiring different kinds of care or treatment.[74] Perinatal mental illnesses are one of the leading causes of death for mothers during pregnancy and in the year after birth.

Paternal mental health should also be considered as a factor in child development. In their review article Ramchandani and Psychogiou (2009) conclude that, "most psychiatric disorders that affect fathers are associated with an increased risk of behavioral and emotional difficulties in their children, similar in magnitude to that due to maternal psychiatric disorders" [75] It is also true that social support, particularly that of the partner, is critical for the mother and the family.

The post-partum period is a time of particularly high risk. In many cases, perhaps 10-30%, according to some estimates, depressive episodes are recurrences of earlier illness, and up to 60% of women with perinatal depression may have recurrences later on.[74] Environmental and psychological risk factors along with hormonal and biological changes play a large role in perinatal depression. Most studies show a deleterious effect of maternal stress and distress on foetal and infant wellbeing.[76,77,78]

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[73] Marmot, M. (2010).Fair Society, Healthy Lives, Strategic Review of Health Inequalities in England Post Department of Health

[74] Bauer, A. Parsonage, M. Knapp, M. Iemmi, V. Adelaja , B. (2014).(The Costs of Perinatal Mental Health Problems London School of Economics and Political Science, London Available at http://www.centreformentalhealth.org.uk/pdfs/Costs_of_perinatal_mh.pdf

[75] Ramchandani PG, Psychogiou L. Paternal psychiatric disorders and children's psychosocial development. The Lancet, Early Online Publication, 5 May 2009

[76] Diego, M. A. Field, T. Hernandez-Reif, M. (2005)Prepartum, postpartum, and chronic depression effects on neonatal behavior. Infant Behavior and Development; 28: 155-164

[77] Monk, C. (2001)Stress and mood disorders during pregnancy: Implications for child development. Psychiatric Quarterly; 72(4): 347-357

Given the potentially serious impact of maternal psychopathology on both foetal health and maternal caretaking abilities, obtaining appropriate treatment is of critical importance. With supportive mental health treatment and psychotherapeutic interventions, women can recover from these illnesses and reduce the risk of poor outcomes for the infant.

In most cases, psychotherapy is the preferred treatment if the disturbance is mild. Psychotherapy can both help the mother deal with her current difficulties and prepare her for transition to motherhood. In more severe cases medication may be necessary. Pregnancy is a time ripe for intervention but it is also a time when difficulties can result in a troubled pregnancy and a disturbed mother-child relationship. Thus, signs of trouble in a woman's adaptation to pregnancy should be taken seriously. When anger, ambivalence, depression, unrelenting anxiety, excessive somatisation, or emotional disengagement define the woman's experience during this period, intervention can be critical and should be initiated as soon as possible.[79]

There is a clear consensus that the *focus* of support that is provided to both mothers and fathers during the perinatal period should be the *parent-infant relationship*. Even during pregnancy, health care professionals should have as a central focus of their care, the parents' feelings about the pregnancy, and the developing baby. During the postnatal period, health care professionals should again focus their attention on the relationship between the parent and infant.[80] This should be done by staff 'working in partnership with parents' and that staff should have the necessary skills to do this, including the ability to listen effectively, motivate families to change and plan problem-solving strategies. Of additional importance, understanding of past traumatic experiences as they affect present social and emotional wellbeing of the infant and parent needs to be taken into consideration. These approaches also highlight the importance of staff being provided with appropriate knowledge and skills through the delivery of infant mental health training, as well as, ongoing supervisory support.

Antenatal and parenting programmes need to address the emotional needs of parents and babies and the likely impact on child development and infant mental health, maternal mental health family life and to help parents develop coping skills.[81] They also need to target mothers and fathers who face the greatest difficulties in raising infants and young children.

3.1.6 Brain Development

There is no other period of brain development that is as critical to setting the stage for human growth, development and positive or negative mental health as the first six years of a child's life.[82] The infant's brain is approximately 25-30% developed at birth and at its most adaptable during the first two years after birth. During this period, it will grow and develop to reach its potential through the interactions and influences it has with its primary caregiver who will also act as an external psychobiological regulator of the "experience dependent" growth of the infant's nervous system. [83]

Consequently, the shape, structure and functioning of the infant and toddlers developing brain is shaped by the parent's more mature brain and occurs within an environment of

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[78] Monk, C. Sloan, RP. Myers, MM. Ellman, L. Wener, E. Jeon, J. *et al*. (2004).Fetal heart rate reactivity differs by women's psychiatric status: An early marker for developmental risk? Journal of the American Academy of Child and Adolescent Psychiatry; 43: 283-288

[79] Slade, A. Cohen, LJ. Sadler, LS. Miller, M. (2009)The Psychology and Psychopathology of Pregnancy: Reorganization and Transformation in Zeanah, CH. (Ed.) Handbook of Infant Mental Health. New York:; 22-39 The Guilford Press

[80] Barlow, J. Schrader MacMillan, A. Kirkpatrick, S. (2008). Health-led Parenting Interventions in Pregnancy and Early Years: Department for Children. London: University of Warwick

[81] Combes, G. Schonveld, A. Life Will Never Be the Same Again. (1992)London: Health Education Authority

[82] Young Children Develop in an Environment of Relationships. (2009) Centre on the Developing Child at Harvard University http://developingchild.harvard.edu/resources/reports_and_working_papers

[83] Malekpour, M. (2007). Effects of attachment on early and later development. *The British Journal of Developmental Disabilities*, Vol. 53, Part 2, No. 105, pp. 81-95.

emotional communication. [84] These early social events are imprinted into the neurobiological structures that are maturing during the spurts in brain growth which are taking place during the first two years of life and have far reaching effects. [85]
International Institutes of Health designated the last decade of the 20th century as the "Decade of the Brain" in recognition of the significant scientific progress made during this period. Advances in research demonstrate the robust interactions among genes, early experiences and environmental influences that shape the architecture and function of the developing brain, in addition to the challenges of toxic stress on early brain development. Untreated, toxic stress during the early childhood period increases the risk of physical and mental illness as well as cognitive impairment across the lifespan. [86] [87] [88]

The potential long-term impacts of these physiological disruptions to infant and toddlers, however, are unknown to most policymakers. The scientific rationale is clear, when nurtured by sensitive, attentive caring parents, the infants and toddler brain network system is activated and strengthened and neuronal firing spreads to associated brain networks facilitating the full potential for healthy growth and development; Conversely, investment in vulnerable young children is critical, otherwise society will likely have to pay the costs in remedial education, clinical treatment, public assistance and incarceration when opportunities for preventative intervention are ignored. [83] [87] [89]

3.1.7 Attachment

Human relationships are the building blocks of healthy development. From the moment of our conception to the finality of death, intimate and caring relationships are the fundamental mediators of successful adaption.[61] It has been said that *'for the developing infant, the mother is the environment.'*[90]
Attachment behaviour is the sensitive, nurturing and predictable caregiving behaviour that enables infants and toddlers develop a secure attachment with their caregiver/s. Whilst especially evident during early childhood, attachment behaviour is held to characterize human beings from cradle to the grave.[91] [92]

Current research has advanced the understanding of the role and function of the primary attachment relationship between an infant and its caregiver into a more complex and clinically relevant model.[93,94,95]

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[84] Siegal, D. (1999). The developing mind: Towards a neurobiology of interpersonal experience. New York: The Guilford Press.

[85] Schore, A. N. (2001). The effects of early relational trauma on right brain development, affect regulation, and infant mental health. *Infant Mental Health,* 22,: 1-2, 201- 269.

[86] Fox, S.E., Levitt, P. & Nelson, C.A. (2010). How the timing and quality of early experiences influence the development of brain architecture. *Child Development,* Jan-Feb; 81 (1) 28-40.

[87] Shonkoff, J. P. & Levitt, P. (2010). Neuroscience and the future of early childhood policy: Moving from why to what and how. Neuron, 67, September 9, pp. 689-691

[88] Murray, D.W., Rosanbalm, K., Christopoulos, C. & Hamoudi, A. (2014). Self Regulation and Toxic Stress: Foundations for Understanding Self Regulation from an Applied Developmental Perspective.
OPRE Report # 2015-21, Washington, DC. Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

[89] Shonkoff, J. P. (2012). Leveraging the biology of adversity to address the roots of disparities in health and development. Center on the Developing Child at Harvard University, Cambridge, MA.
www.pnas.org/cgi/doi/10.1073/pnas.1121259109

[90] Schore, A.N. (1994)Affect Regulation and the Development of the Self in The Neurobiology of Emotional Development New Jersey Erlbaum

[91] Bowlby, J. (1969). Attachment and Loss Volume 1: Attachment London: Hogarth Press New York: Basic Books. Harmonds-worth: Penguin Books (1971)

[92] Bowlby, J. (1979.).The Making & Breaking of Affectionate Bonds Routledge. London.

[93] Schore, AN (2001).The effects of a secure attachment relationship on right brain development, affect regulation and infant mental health. Infant Mental Health Journal; 22 (7): 201-269.

[94] Schore, AN (2001). The effects of early relational trauma on right brain development, affect regulation and infant mental health. Infant Mental Health Journal; 22 (7): 7- 66.

[95] Schore, JR. Schore, AN. (2008). Modern attachment Theory: The Central role of Affect Regulation I Development and Treatment. Clinical Social Work Journal,;36: 9-20.

In this model, attachment forms the basis of an individual's capacity to regulate his or her emotional states.

When this relationship is *'good enough'* (Winnicott, 1987) and the infant has developed a primary attachment relationship with an attentive and responsive caregiver, usually its mother, it is this relationship more than any other, that sets the conditions for the development of systems of emotional control and stress regulation.[96] Regulation of emotional states is a fundamental quality of early social and emotional development. [97] [90]

A window of opportunity occurs during the pregnancy and the postnatal period to prepare and obtain support for the transition to becoming a parent/s. Secure attachment provides a significant protective factor; children who are securely attached show greater enthusiasm, compliance and positive affect and less aggression (during shared tasks with their mother). Approximately two thirds of infants are securely attached. Securely attached infants tend to maintain more harmonious relations with their parents in the second year of life.[98]

Insecure attachment patterns - (described as anxious or ambivalent) make the young child increasingly vulnerable to life's events. However, insecure attachment in itself is not considered a disorder but rather a risk factor when other risk factors or adverse life experiences are also present in the child's emotional or physical environment. [99] The term disorganised attachment is a high indicator that maltreatment, abuse and neglect has occurred. It has also been described as "fear without solution", as the caregiver's source of comfort and secure base is also a source of fear and fright, with no predictable pattern of behaviour in responding or soothing the infant or toddlers distress. To the infant, their caregiver is thus perceived as frightening, unsafe and neglectful and a source of terror. Disorganised attachment is frequently characterised by internalising and externalising problems, poor self esteem, poor self regulation and ultimately poor school performance. Infants who have experienced violence, chaotic caregiving and adverse early child hood experiences that remain untreated, have been shown to experience significant consequences in their physical social and emotional health across the lifespan.[72,73]

3.1.8 Emotional Regulation

Emotional regulation has been defined as the individuals attempt to monitor, evaluate and modify his or her emotional reactions, particularly in pursuit of a goal. [98] It is considered to be the cornerstone of social and emotional development during infancy and toddlerhood. [100] [90] Increasingly, it is recognized as a core component of social emotional competence, self regulation and is functional in almost all of a child's transactions with the world. [101]

Emotional regulation can also be seen at the centre of self regulation of the mind, and has also been considered to be the most challenging aspect of emotional development. [102] [103]

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[96] Winnicott, DW .(1987) .Babies and Their Mothers London: Free Association Books.

[97] Fonagy, P. & Target, M. (2002). Early intervention, the development of self regulation. *Psychoanalytic Inquiry*, 22, 307- 335.

[98] Thompson, R.A. (1994). Emotional regulation: a theme in search of a definition. *Monographs for the Society of Research in Child Development*, 59 (2-3, Serial No. 240), 250-283.

[99] Goldberg, S. (2000). Attachment and Development. International Texts in Developmental Psychology Series. London: Arnold.

[100] Crockenberg, S & Leerkes, E. (2000). Infant social and emotional development in family context.
In C. H. Zeanah, Jr. (Ed.), *Handbook of Infant Mental Health*, Second Edition, (pp 60-90). New York:
Guilford Press:

[101] Calkins, S.D. & Hill, A. (2007***)***. Caregiving influences on emerging emotional regulation. Biological and environmental transaction in early development. In J.J. Gross (Ed.), Handbook of emotional regulation, (pp.229-248). New York: Guilford Press.

[102] Siegel, D. (1999). The Developing Mind: How relationships and the brain interact to share who we are. New York: Guilford Press.

[103] Shonkoff, JP. Phillips, DA. (2000). Frome Neurons to Neighbourhoods: the science of early development. National Research Council Institute of Medicine Washington DC

At the heart of emotional regulation is the ability to recognise and reflect (reflective capacity) on an individual's own and others' emotions and to make a decision about how one will respond. Emotional Regulation is a core component in the healthy functioning across the lifespan.

Development of Emotional Regulation.

Children start life completely incapable of modulating the expression of overwhelming feelings and need the support of an attuned sensitive caregiving relationship to initially co-regulate their emotional states.
From an early age, infants begin develop rudimentary skills for managing their own emotional experiences by learning to enlist others who can help comfort them).[103]
In the toddler stage of development- during the middle to end of second year, toddlers can be observed to begin to make active efforts to avoid or ignore emotionally arousing situations. By school age, children's regulatory capacity has become more proficient and flexible as they learn that their interpretation of events can affect how they react and that they can camouflage their emotions if they need to.[104] [103]
Children who have developed the capacity to self regulate and manage their emotions constructively not only have an easier time with disappointments, frustrations and hurt feeling that are so prevalent when they are young, but are also considered happier as a result. In addition, they also tend to relate easier at home.
This capacity to foster positive social relationship also supports their transition to childcare, their capacity to play and develop peer relationships, their entry into education and later into society. Acquiring the capacity to regulate emotions or self regulate helps children believe that emotions are manageable, controllable and can be appropriately organized and expressed.[103]
Children who do not feel in control of their emotions are more prone to outbursts, inattention and rapid retreat from stressful situations, thereby creating a self -fulfilling prophecy.[105]

Parental care giving contribution to co-regulation

Research suggested that mothers who are successful at calming their temperamentally difficult infants may develop high degrees of sensitivity than either mothers with temperamentally "easy" infants or mothers who have difficult infants but are unsuccessful at soothing. When parents view their temperamentally challenging infants as soothable, they display higher levels of sensitive caregiving .[106] [107]
From an infant mental health perspective, it is critical to assess the parent-infant emotional "dance", and to observe both the process of the emotional synchrony as well as the process of repair following disruptions .[108] [109] [110]
Infant and toddlers experience a wide range of emotional states. Without the timely responses of their caregiver who have the capacity to interpret and respond to these emotional states, infants or toddlers will experience these emotional states as distressing

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[104] Harris, P.L. (1993) Understanding emotions. In M. Lewis & J.M. Haviland (Eds.) Handbook of Emotions pp. (237-246). New York: Guilford.

[105] Garber, J., Braafladt, N. & Zeman, J. (1991). The regulation of sad affect: information processing –perspective. In J. Garber and K.A. Dodge (Eds*.), The Development of Emotional Regulation and Dysregulation* (pp. 208-240). New York: Cambridge University Press.

[106] (Leerkes, E. & Crockenberg, S. B. (2003). The impact of maternal characteristics and sensitivity on the concordance between maternal reports and laboratory observations of infant negative emotionality. *Infancy, 4, 517- 539.*

[107] Ghera, M.M., Hane, A.A., & Malesa, E. (2006). The role of infant soothability in the relationship between negativity and maternal sensitivity. *Infant Behaviour and Development,* 29. (2), 289- 293.

[108] Stern, D.N. (1985). The Interpersonal world of the infant: A view from psychoanalysis & developmental psychology, (pp. 101-102). Basic Books.

[109] Rosenblum, K. L., Dayton, C. J. & Mc Donough, S. (2006). *Communicating feelings: Links between mothers' representation of their infants, parenting and infant emotional development.* New York: Cambridge University Press

[110] Tronick, E. Z. (2006). The inherent stress of normal daily life and social interaction leads to the development of coping and resilience and variation in resilience in infants and young children. *Annals of the New York Academy of Sciences.* 1094, 83-104

and overwhelming. Failure to respond to these states can also disrupt an infant's or toddler's sense of self. [111]

Mentalisation-based programmes which include interventions such as *Minding the Baby* have shown effectiveness in improving the reflective functioning of women exhibiting a range of problems in the perinatal period.[112,113]

3.1.9 Policy

Current legislation and early childhood strategies and policies in Ireland all advocate the importance of prevention and early intervention services to improve child health, social and emotional development and wellbeing, physical health and improved pro-social behaviour.[114,115,116,117]

However, their specificity regarding infant and toddler development and early care giving relationships have not translated to a practice level regarding what is required to effectively promote and support care givers in their vital roles. Integration into clinical practice within the Irish health services has been a slow and difficult process.[118,119]

A clearer understanding of the principles underpinning IMH is required along with a response to the deficits present in the relevant sections of the health services dealing with this young population.

IMH services which include timely intervention will reduce the high costs of health care, education and social services across the lifespan, thereby presenting the Government with a unique opportunity to make sound economic investment in its youngest citizens while at the same time delivering on best practice approaches to infant and toddlers, their caregivers and families. [120] [121]

A window of opportunity occurs between conception and the first 3 years. Parental support, early identification and early intervention strategies are essential to reduce the risks of developmental delays or disorders of infancy and early parenthood. Priority for this critical period of early development should be elevated to the same realm as the security of the state. [122]

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[111] Joyce, A. (2005). The parent-infant relationship and infant mental health. In T. Baradon, C. Broughton, I. Gibbs, J. James, A. Joyce & J. Woodhead of the Parent-Infant Project at the Anna Freud Centre: The Practice of Psychoanalytic Parent-Infant Psychotherapy: Claiming the Baby. Routledge.

[112] Suchman, NE. DeCoste, C. Castiglioni, N. McMahon, TJ. Roundsaville, B. Mayers, L.. (2010);.The Mothers and Toddlers Program, an attachment based parenting intervention for substance using women. Results at 6 weeks follow up in a randomized clinical pilot. Attachment and Human Development 12(5): 483-504.

[113] Suchman, NE. DeCoste, C. McMahon, TJ. Roundsaville, B. Mayers, L. (2011)The mothers and toddlers Program, an attachment based parenting intervention for substance using women Post treatment results from a randomized clinical pilot. Infant Mental Health Journal,; Vol. 32 (4): 427-449.

[114] The Agenda for Children's Services : A Policy Handbook Office of the Minister for Children Department of Health and Children December 2007

[115] Department of Health & Children A Vision for Change: Report of the Expert Group on Mental Health Policy 2006 Dublin The Stationary Office

[116] Report of the Task Force on the Child and Family Agency 2012 Accessed at: http://www.dcya.gov.ie/documents/childfamilysupportagency/TaskForceReport.pdf

[117] Prevention and Early Intervention in Childrn and Young People's Services Child Health and Development CES Report 2013 Accessed at: http://www.effectiveservices.org

[118] Burke, K. Owens, S. Ghate, D. (2010). Learning from experience to inform the future: Findings emerging from the initial phase of the Children's Services Committees in Ireland Centre for Effective Services 2010 Accessed at: http://www.effectiveservices.org

[119] Maguire, C. (2012): Advocating for a National Infant Mental Health Strategy for Ireland: Progress to Date: The Signal, Vol. 20 No. 2 (April-June 2012)

[120] Weatherston, D.J. (2000) Introduction to the infant mental health program. In Shirilla, J.J. & Weatherston, D.J.(Eds), *Case Studies in Infant Mental Health: Risks, Resiliency, and Relationships (pp 1-14)* . Washington D.C. ZERO TO THREE

[121] Schweinhart, LJ. Montie, J. Xiang, Z. Barnett, WS. Belfield, CR. Nores, M. The High/Scope Perry Preschool Study Through Age 40 Summary, Conclusions, and Frequently Asked Questions www.highscope.org

[122] All Party Parlimentary Group for Conception to Age 2- The First 1001 Days (2015). Building Great Britons. ***www.1001criticaldays.co.uk***

3.1.10 Interventions - Providing a Spectrum of Services across Prevention, Intervention and Treatment Frameworks

Optimal infant and toddler development occurs in the context of a nurturing caregiver relationship. It is this relationship that provides the central focus for infant mental health interventions and treatment services.
However, with increasing emphasis on evidence based practice (EBP), a number of promising approaches to practice have been documented, showing improvements in parent-infant/toddlers relations and advances in social and emotional development. [123] [124]

The development of a mental health promotion model was initially conceptualised by Mrazek & Haggerty. Further adaptations of this model were made to this model to advance an infant mental health continuum of services.[125] [126] [119].
This continuum is conceptualised on three broad levels of intervention: universal prevention approaches to focussed interventions for high risk groups to tertiary interventions which require direct infant- parent mental health assessment and intervention service provision for parent and child. [127]
Other adaptations of this model have been described providing a continuum which includes Promotion, Prevention, Intervention and Treatment. [128] Updated reviews from 2008-to mid 2014 in The Healthy Child Programme (HCP) included in its systematic review level evidence which focus on promotion, universal selective and indicated interventions. [129]

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[123] Shonkoff , J.P. & Phillips,D.A. (2000). From Neurons to Neighbourshoods: The Science of Early Childhood Development. pp. 1-15. Washington DC: National Academy Press.

[124] Zeanah, P.D., Stafford, B. & Zeanah, C.H., Jr. (2005). Clinical intervention in infant mental health: A selective review. In *Building state early childhood comprehensive system series* (Vol. 13). Los Angeles: National Center for Infant and Early Childhood Policy.

[125] Zeanah, P.D. Gleason, M. M., & Zeanah, C.H. Jr. (2008). Infant Mental Health. In M.M. Haith & J. B. Benson (Eds.) Encyclopaedia of infant and early child development (pp. 301-311). New York: Elsevier.

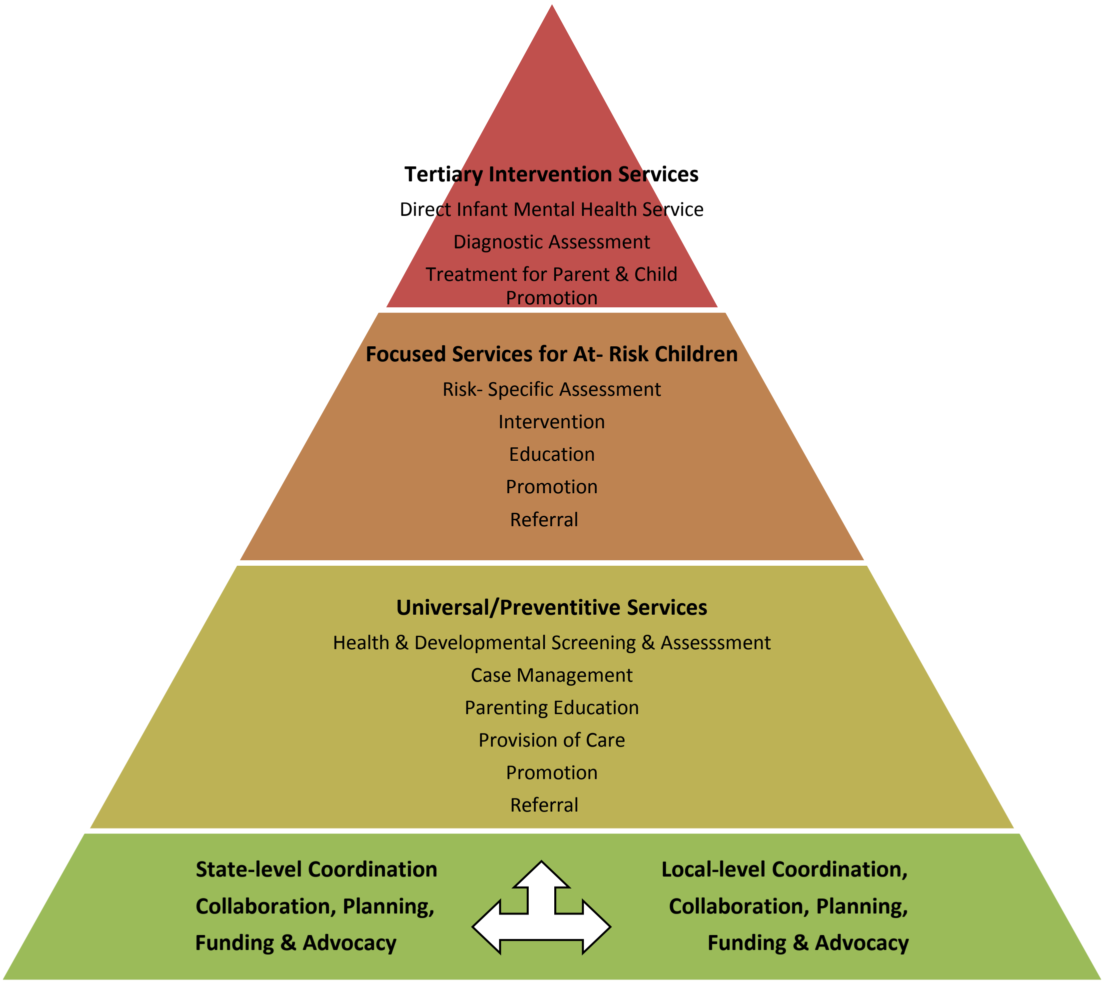
[126] Mrazek, P. J., & Haggerty, R. J. (Eds.). (1994). *Reducing risks for mental disorders: Frontiers for preventive intervention research*. Washington, DC, US: National Academy Press.

[127] Rosenblum, K. L., Dayton, C. J. & Mc Donough, S. (2006). *Communicating feelings: Links between mothers' representation of their infants, parenting and infant emotional development.* New York: Cambridge University Press

[128] Weatherston, D. (2012). The gift of love: A birthright. Child Links Infant Mental Health: the Journal of Barnardos' T raining and Resources Services, 2 pp.2-7.

[129] Public Health England (2015).Protecting and improving the nation's health. Rapid Review to Update Evidence for the Healthy Child Programmes 0-5.

Figure K Levels of Infant Mental Health Services:



Source Zeanah, Stafford Nagle & Rice, 2005

Preventative interventions have been divided into three distinct levels - [126]

- Universal preventions
- Selective interventions
- Indicated preventions

3.1.11 Cost Effectiveness - Economic Rationale for Early Intervention

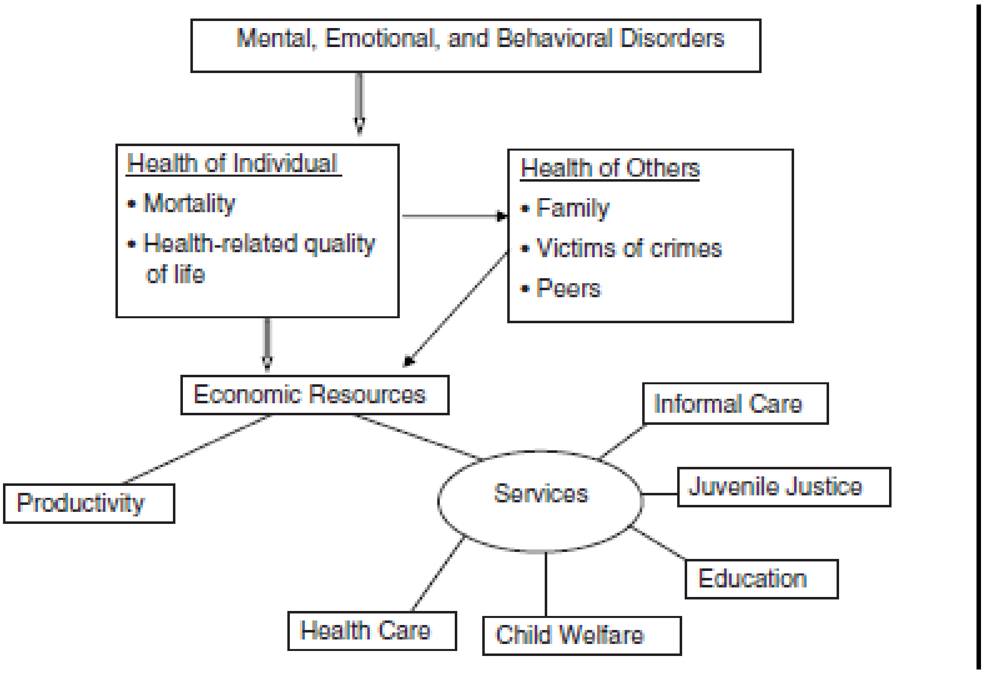
As shown in Chapter 1-Health Inequalities, investment in early childhood services show a greater rate of return than later interventions.

The economic rationale presents a powerful argument for investment in services in infant mental health strategies and service models.

It is known that mental health problems experienced by infants during the perinatal and early childhood period can potentially have serious, long-lasting consequences on the health and development of the infant well into adulthood.

The costs of mental, emotional and behavioural disorders among young people are shown in Figure L.

Figure L: Costs of mental, emotional and behavioural disorders among young people



Source: Eisenborg and Neighbor (2007)[130]

The value of early timed infant mental health interventions to reduce the risk of social and emotional disorders in infancy and early parenthood is said to be two-fold – *'they can prevent infant problems and treat existing parental problems.*[120] The following basic beliefs are said to support and sustain infant mental health interventions

1. Optimal growth and development occur within nurturing relationships
2. The birth and care of a baby offers a family the possibility of new relationships, growth and change
3. What happens in the early years affects the course of development across the entire lifespan.[121]

There is a large body of evidence on the effectiveness of interventions in both mental health promotion and adverse outcome prevention. The evidence on cost-effectiveness is more limited; however interventions targeting parents and pre-school children show a high level of effectiveness and cost-effectiveness.
Intervention delivered with these two groups have been shown to more than pay for their costs by reducing governmental costs. The Perry Preschool Project[131] followed low-income children receiving and not receiving services into adulthood (age 40 years). The intervention included an intensive preschool, home visiting and group meetings for parents over one to two years. The economic evaluation found that there was a gain of $17 for every $1 spent-the government gained €12.90 in reduced expenditures for special education, welfare and crime and increased taxes, while the individual gained $4.17 in

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[130] Eisenberg, D., & Neighbors, K. (2007). Economics of Preventing Mental Disorders and Substance Abuse Among Young People. Paper commissioned by the Committee on Prevention of Mental Disorders and Substance Abuse Among Children, Youth, and Young Adults. Washington, DC: Research Advances and Promising Interventions, Board on Children, Youth, and Families, National Research Council and Institute of Medicine.

[131] Schweinhart, LJ. Montie, J. Xiang, Z. Barnett, WS. Belfield, CR. Nores, M. The High/Scope Perry Preschool Study Through Age 40 Summary, Conclusions, and Frequently Asked Questions www.highscope.org

increased income. The primary benefits were reduced crime, positive academic outcomes and reduced smoking,

many of which were observed into adulthood. Heckman based his arguments for investment in early childhood services on the outcomes of this study.[132]

The Chicago Child Parent Centres programme showed similar results. This was a centre-based preschool education programme for disadvantaged children, which showed a gain of $7 for every $1 spent.[133]

Home visiting in the 0-3 age group has also been shown to be a cost effective intervention providing immediate and long term payoffs. The long term pay off for government shows that for every $1 invested there was a $4 return in terms of cost reductions for delinquency, welfare and tax increase. The results show gains in the high and low risk groups.[134]

While the evidence is available to support the cost effectiveness of interventions with high-risk families (targeted interventions), there is a dearth of evidence on the cost effectiveness for the delivery of infant mental health interventions on a universal basis.

3.1.12 Recommendations

The inclusion of IMH promotion, prevention, intervention and treatment services in the revised child health programme promises improved child, family and public health outcomes. Benefits include promotion of the psychological health and wellbeing of young children, the capacity to sustain good mental health across the lifespan and reduction in the prevalence of mental illness across childhood, adolescence and adulthood.[61,90 ,135]

There is overwhelming evidence for the inclusion of infant mental health in the revised child health programme.

- In line with international best practice, the content of the revised child health programme should include explicit reference to infant mental health.
- The most effective interventions for both infant mental health promotion and adverse outcome prevention should be identified for inclusion in the Irish child health setting.
- The service/interventions should be in line with the universal service delivery model and include targeted interventions when required.
- A programme of up skilling, staff training and accreditation is required to build a skilled workforce and to ensure a quality service.
- The economic rationale for investment in services in infant mental health presents a powerful argument that should be made across a number of health service settings at senior management level.
- Workforce capacity, especially in local community settings and primary care area, needs to be reviewed and resourced if the potential for good infant mental health services are to be realised.
- Modules on the principles and practice of infant mental health should be integrated into all undergraduate, post-graduate education and professional development courses on early childhood programme for professionals/ practitioners at every level, where the clinician has a remit for the conception - three year period of development.

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[132] Heckman, JJ. (2000)Working Paper-Invest in the very young Chicago: Harris Graduate School of Public Policy Studies

[133] Chicago Child Parent Centre http://centerforeducation.rice.edu/slc/LS/CCPC.html

[134] Top Tier Evidence Initiative: Evidence Summary for the Nurse-Family Partnership www.toptierevidence.org, Updated June 2014.

[135] Dube, SR. Felitti, VJ. Dong, M. Giles, WH. Anda, RF. (2003)The Impact of Adverse Childhood Experiences on Health Problems: Evidence from four birth cohorts dating back to 1900 Preventative Medicine; 37: 268-277

- The development of a national training programme on infant mental health for the early year's workforce has the potential to impact up to 94% of children in the State (the estimate percentage taking up the free preschool year).[136]
- Research has proven that the inclusion of reflective practice supervision is a key component of effective infant –family work.
- Policy makers and researchers should have the specialised infant mental health knowledge and skill to enable them to devise policies and partake in research regarding this critical stage of early development.
- Health service programmes should have a remit to ensure that the most vulnerable children and families have access to highly trained specialists in infant and early childhood mental health.

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[136] Early Childhood Education and Care Oireachtas Library & Research Service No 4 2012 Accessed at: http://www.oireachtas.ie/parliament/media/housesoftheoireachtas/libraryresearch/spotlights/spotEarlyEd180412.pdf

3.2 Health Outcomes

3.2.1 Birth Weight

In 2015, 5.9% of all babies born were in the low birth weight category (weighing less than 2,500 grams).[137] Girls were more likely than boys to be born in this category (6.5% and 5.3% respectively). There were also social class differences. The percentage of babies born in the low birth weight category was highest among mothers who reported having 'home duties' (7.7%) and who were 'unemployed' (7.2%). The percentage of low birth weight babies has increased slightly over the 5-year period 2011-2015.

3.2.2 Breastfeeding

In 2015, the percentage of babies that were breastfeed on discharge from hospital was 58%; 47.7% exclusively breastfed and a further 10.3% fed using a combination of bottle and breastfeeding.[137] The percentage of infants who were breastfed (either exclusive or combined) is higher among older mothers and also higher among mothers in 'higher professional' and 'skilled manual' groups (77.3% and 75.4% respectively) compared to mothers who reported to be 'unemployed' (36.4%). The percentage of infants who were breastfed, either exclusive or combined, on discharge from hospital has continued to increase over the 5-year period 2011-2015.

3.2.3 Hospitalisations

Almost half of the 2015 hospital discharges of children (birth-17 years) were of infants (20.7%) and children aged 1-4 years (27.2%).[138] The most commonly reported principal diagnosis was 'diseases of the respiratory system' (19,071 discharges: 12.4%), followed by 'injury, poisoning and certain other consequences of external causes' (14,264 discharges: 9.2%). Twenty-eight percent of the hospital discharges with a diagnosis of 'external causes of injury or poisoning' were of children aged 1-4 and 59.8% were of boys. Over the 5-year period 2011-2015, the total number of hospital discharges of children with a diagnosis of 'external causes of injury or poisoning' has remained quite stable between 14,000 and 14,300. Over this period, the number of discharges of children due to 'transport accidents' has fallen 13.4%.

3.2.4 Disability

Based on the 2016 population census, there were 75,963 children (birth-17 years) with a disability, accounting for 6.4% of the total child population of Ireland.[139] The disability rate was 63.8 per 1,000 children. Almost two-thirds of children with a disability (62%) were boys.

Data from the 2015 National Intellectual Disability Database showed that 9,066 children were registered as having an intellectual disability.[140] Of children registered, 11.9% were aged 0-4 years (rate of 3.0/1,000); 32.4% were aged 5-9 (rate of 8.3/1,000); 33.6% were aged 10-14 (rate of 9.6/1,000); and 22.1% were aged 15-17 (rate of 11.2/1,000). Just over two thirds of children registered were boys (66.6%) and 32.4% were girls. This equates to a rate of 9.8 per 1,000 boys and 5.1 per 1,000 girls. The majority of children were registered as having a mild (32.3%) or moderate (31.2%) disability. The number of

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[137] National Perinatal Reporting System, 2015; taken from Department of Children and Youth Affairs (2017). State of the Nation's Children: Ireland 2016, Dublin: Government Publications. Available at www.dcya.ie

[138] Hospital In-Patient Enquiry, 2015; taken from Department of Children and Youth Affairs (2017). State of the Nation's Children: Ireland 2016, Dublin: Government Publications. Available at www.dcya.ie

[139] Census 2016 for Ireland Statbank. Accesses at www.cso.ie

[140] National Intellectual Disability Database, 2015; taken from Department of Children and Youth Affairs (2017). State of the Nation's Children: Ireland 2016, Dublin: Government Publications. Available at www.dcya.ie

children registered as having an intellectual disability has increased over the 5-year period 2011-2015.

In 2015, the National Physical and Sensory Disability Database had 6,230 children registered as having a physical and/or sensory disability[141]. Of the children registered, 6.5% were aged 0-4 years (rate of 1.1/1,000); 27.5% were aged 5-9 (rate of 4.9/1,000); 38.5% were aged 10-14 (rate of 7.6/1,000); and 27.5% were aged 15-17 (rate of 9.5/1,000). Over 62.4% of children registered were boys and 37.6% were girls.
See Appendix 5 for further figures. This equates to a rate of 6.3 per 1,000 boys and 4 per 1,000 girls. Children were mostly registered as having a physical disability (37.4%), multiple disabilities (36.0%), or a speech and language disability (21.7%).

3.2.5 Mental Health

It is reported that more Irish young people die by suicide than in other countries.[142] Over the period 2011-2015, the number and rate per 100,000 of suicides was consistently higher among boys aged 15-17 years compared to girls of the same age.[143] Suicide accounted for 21.9% of all deaths of children aged 10-17 in 2015.

In 2015, there were 503 admissions of children (5-17 years) to psychiatric hospitals, of which 80.9% admitted were aged 15-17 years.[144] Almost 39.8% were boys and 60.2% were girls, equating to a rate of 32.4 per 100,000 boys and 51.2 per 100,000 girls respectively. The most common reason for children to be admitted was for '*depressive disorders'* (32.4%), followed by '*neuroses*' (25%). Other reasons included ''*psychoses'* (8.8%) and '*personality disorders* (7%).

3.2.6 Injury

Injury has previously been reported as the leading cause of death in children and adolescents aged 0-19yrs in Ireland.[145] In 2015, while conditions originating in the prenatal period and congenital abnormalities accounted for the leading cause of death in children under 1, external causes of injury and poisoning accounted for the leading cause of death in children aged 1 to 19 (37.5% of deaths in this age group). In 2015, 52 children aged 0-19 died as a result of injury, 14.4% of all deaths in this age group.[146] In young males aged 0-24, injury accounted for 64% of all deaths, whereas injuries accounted for 25% in all female deaths in this age group.[147] This supports previous data indicating differences between males and females.[148] Analysis of the number of deaths by injury for children aged 0-18 between 2010-2015 found suicide/self inflicted injury to be the leading cause of death by injury over this period (116 deaths), with the most common unintentional injury being road traffic accidents (83 deaths), followed by drowning (22 deaths)[149].

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[141] National Physical and Sensory Disability Database, 2015; taken from Department of Children and Youth Affairs (2017). State of the Nation's Children: Ireland 2016, Dublin: Government Publications. Available at www.dcya.ie

[142] Scoliers G, Portzky G, Madge N, Hewitt A, Hawton K, Wilde EJD, et al. (2009). Reasons for adolescent deliberate self-harm: a cry of pain and/or a cry for help? Findings from the child and adolescent self-harm in Europe (CASE) study. Social Psychiatry and Psychiatric Epidemiology; 44(8):601-607.

[143] CSO Vital Statistics; taken from Department of Children and Youth Affairs (2012). State of the Nation's Children: Ireland 2012, Dublin: Government Publications. Available at www.dcya.ie

[144] National Psychiatric In-Patient Reporting System, 2011; taken from Department of Children and Youth Affairs (2012). State of the Nation's Children: Ireland 2012, Dublin: Government Publications. Available at www.dcya.ie

[145] Accessed at: http://www.childsafetyeurope.org/reportcards/info/ireland-country-profile.pdf

[146] CSO mortality data

[147] CSO mortality data

[148] Accessed at: http://www.childsafetyeurope.org/reportcards/info/ireland-country-profile.pdf

[149] O'Sullivan, G. (2017). Data from Knowledge Review for a Child Injury Prevention Action Plan for the Republic of Ireland. Childhood injury in Ireland and the risk factors. Available at https://www.hse.ie/eng/health/child/childsafety/publications/inj-risk.pdf.

In 2015, of the 14, 264 hospital discharges of children with a principal diagnosis of 'injury, poisoning and certain other consequences of external causes', the most common reasons for attendance were accidental falls (42.6%), followed by accidents caused by objects (20.8%)[150].

Injury surveillance data are not currently captured in emergency departments, or at community level. Other studies that yield useful information at the population level on injury are the HBSC[151] and GUI.[152]
The relationship between injury and socioeconomic status in Ireland is unclear. There are indications that Irish children from poorer social groups seem to be less disadvantaged in terms of injury morbidity than is the experience in other countries.[151, 152]

3.3 Lifestyle Factors

3.3.1 Physical Activity

Children in Ireland have one of the highest levels of physical activity among 40 WHO countries and regions. In 2010, 50.5% of children aged 10-17 reported being physically active for at least 60 minutes per day on more than 4 days per week.[153] Immigrant children were significantly less likely to report being physically active for at least 60 minutes per day on more than 4 days per week. There was no significant difference between Traveller and other children, and children with and children without a disability and/or chronic disease. Statistically significant differences were observed across age and gender, with a lower percentage of older children (41.4%) and girls (40.4%) reporting being physically active for at least 60 minutes per day on more than four days per week. There was no major difference in physical activity levels when assessed by social class.

3.3.2 Nutrition

In 2010, 76.6% of children aged 10-17 reported eating breakfast on five or more days per week.[153] Traveller children and immigrant children were statistically less likely to report eating breakfast. There were no significant differences in breakfast consumption between children with and without disability and/or chronic illness. A higher percentage of boys (79.9%), younger children (83.8%) and children in higher social classes (81.1%) reported that they eat breakfast on five days or more per week. Internationally across 39 countries and regions, the average percentage of children who reported eating breakfast on five or more days per week was 69.3%. The corresponding figure for Ireland was 76.0% (based on data from children aged 11, 13 and 15 only).

In 2010, 20.8% of children aged 10-17 reported drinking soft drinks that contain sugar at least once a day.[153] Traveller children and children with a disability and/or chronic illness were significantly more likely to report drinking soft drinks. There were no significant differences between immigrant and other children. A lower percentage of girls (18.5%) and a higher percentage of older children (22.9%) and children in lower social classes (26.8%) reported drinking soft drinks that contain sugar daily or more frequently. Across

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[150] Hospital In-Patient Enquiry, 2015; taken from Department of Children and Youth Affairs (2017). State of the Nation's Children: Ireland 2016, Dublin: Government Publications. Available at www.dcya.ie

[151] Molcho, M., Barry, M., Van Lente, E., McGee, H., Morgan, K., Conroy, R., Watson, D., Perry, I. and Harrington, J. (2009). *SLÁN 2007: Survey of Lifestyle, Attitudes and Nutrition in Ireland. Injuries in Ireland: Findings from national population surveys*, Department of Health and Children. Dublin: The Stationery Office.

[152] Williams, J., Greene, S., McNally, S., Murray, A. and Quail, A. (2010). *Growing up in Ireland Infant –National Longitudinal Study of Children. GUI Infant cohort: The Infants and Their Families*. Dublin: The Office of the Minister for Children and Youth Affairs.

[153] HSBC Survey, 2010; taken from Department of Children and Youth Affairs (2012). State of the Nation's Children: Ireland 2012, Dublin: Government Publications. Available at www.dcya.ie

40 countries and regions, an average of 20.9% of children reported drinking soft drinks containing sugar at least once a day.

3.3.3 Overweight and Obesity

Twenty-five percent of 3 year olds are overweight (19%) and obese (6%), i.e. a quarter of all 3 year olds had a body mass index (BMI) beyond the range that is considered healthy for this age group according to the International Obesity Task Force thresholds[154]. One in every four 3 year olds in Ireland had a raised BMI, which exposed them to increased risk of disease now and into the future. The child's weight was also related to household social class, with 9% of 3 year olds in lower socio-economic groups classified as obese compared to 5 % in higher socio-economic groups. At least one fifth of children in all social classes are overweight.

Twenty-six percent of 9 year old children are overweight (19%) and obese (7%).[155] Girls were more likely than boys to be classified as overweight (22% compared to 16%) and obese (8% compared to 6%). Twenty-two percent of children from semi-skilled/unskilled backgrounds were classified as overweight compared with 18% of children from professional/managerial backgrounds. For obesity, the prevalence was 11% and 4% among those from semi-skilled/unskilled and professional/managerial occupations respectively.

3.3.4 Smoking

In 2010, 7.9% of children aged 10-17 reported smoking cigarettes every week.[153] Traveller children, immigrant children and children with a disability and/or chronic illness were statistically more likely to report smoking every week. A higher percentage of older children and children from lower social classes report smoking. The percentage of children who report smoking has decreased from 13.2% in 2002 to 7.9% in 2010. Across 39 countries and regions, the average percentage of children who reported smoking every week was 7.7%. The corresponding figure for Ireland was 6.0% (based on children aged 11, 13 and 15 only).

In 2010, 73.5% of children aged 10-17 reported never smoking.[153] This figure was 50.8% in 1998. Traveller children and children with a disability and/or chronic illness were significantly less likely to report never smoking but there were no significant differences between immigrant and other children. A lower percentage of older children, boys and children from lower social classes reported never smoking. Across 39 countries and regions, the average percentage of children who reported never smoking was 71.8%. The corresponding figure for Ireland was 78.2% (based on children aged 11, 13 and 15 only).

3.3.5 Alcohol Use

In 2010, 18.3% of children aged between 10 and 17 reported that they had been drunk at least once in the last 30 days.[153] Traveller children and children with a disability and/or chronic illness were more likely to report being drunk at least once in the last 30 days, while immigrant children were less likely to report same. A lower percentage of young children and girls (17.4%) reported being drunk at least once in the last 30 days. 19.1% of boys reported being drunk. There was no statistically significant difference regarding being drunk between each social class category.

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[154] ESRI, TCD, DCYA (2011). Growing Up in Ireland: Key Findings: Infant Cohort (at 3 years), No.1 The Health of 3 year olds. Available at www.growingup.ie

[155] ESRI, TCD, DCYA (2009). Growing Up in Ireland: Key Findings: 9 Year Olds, No.4 The Health of 9 year olds. Available at www.growingup.ie

Across 37 countries and regions, an average of 24.1% children reported that they had been drunk at least once in the last 30 days. The corresponding figure for Ireland was 26.4% (based on data for children aged 15 only).

In 2010, 54.1% of children aged 10-17 reported never having had an alcoholic drink.[153] Traveller children and children with a disability and/or chronic illness were statistically less likely to report never having had an alcoholic drink, while there were no significant differences between immigrant children and other children. A lower percentage of older children aged 15 to 17 years (30.6%) and boys (51.7%) reported never having had an alcoholic drink. 56.7% of girls reported never having had an alcoholic drink. The percentage of children who report never having had an alcoholic drink has increased from 40% in 2002 to 54.1% in 2010. Across 37 countries and regions, an average of 25.2% of children reported never having had an alcoholic drink. The corresponding figure for Ireland was 37.2% (based on data for children aged 15 only).

3.3.6 Drug Use

In 2010, 10.5% of children aged 10-17 reported that they had taken cannabis at least once in their lifetime.[153] Traveller children, immigrant children and children with a disability and/or chronic illness were statistically more likely to report that they had taken cannabis at least once. A higher percentage of older children, boys and children from lower social classes were more likely to report taking cannabis. The percentage of children who reported taking cannabis at least once in their lifetime has decreased from 15.7% in 2006 to 10.5% in 2010. Across 38 countries and regions, an average of 17.8% of children reported having ever used cannabis. The corresponding figure for Ireland was 15.1% (based on data from children aged 15 only).

3.3.7 Sexual Activity

In 2010, 27.3% of children aged 15-17 reported that they have had sex.[153] Children with a disability and/or chronic illness were statistically more likely to report that they have had sex. There was no significant difference between immigrant and other children. A higher percentage of boys (30.9%) and children in the lower social class categories (29.2%) reported that they have had sex. Across 38 countries and regions, an average of 25.6% of children who reported that they have had sex. The corresponding figure for Ireland was 22.3% (based on data from children aged 15 only).

Chapter 4: Legislative and Strategic Context

Introduction

It is impossible to review child health services without also exploring the legislative and strategic context for the delivery of those services. These areas have intertwined for almost ninety years to produce the child health service we have today.

4.1 Child Health Legislation

The following key pieces of legislation form the basis of the provision of the child health service:

1. The Notification of Births Act 1907 and 1915 (Extension)
   - Section (1) Subsections (1) and (2) of the Notification of Births Act, 1907 and Notification of Births (Extension) Act, 1915 provides that it is the duty of the parent and any person in attendance on the mother at the birth, or within six hours of the birth, whether the child is born alive or dead, to notify, within thirty-six hours, the medical officer of health of the district of the birth.[156]

     Practice Standard 1 of the Practice Standards for Midwives also states that '*a Birth Notification Form (Form BNF/01) should be completed for each live birth.*[157]

     The Civil Registration Act, 2004 requires the parent(s) of a new-born child to register the birth, not later than 3 months from the date of the *birth.*[158]

2. The Local Government Act 1925 provided for the appointment of County Medical Officers of Health (MOH) who were given responsibility for environmental and personal health services, including maternity and child welfare services and school health services.[159]

3. Twenty-two years later the Health Act of 1947[160] enacted the establishment of the Department of Health, which took over responsibility for personal health services from the Department of Local Government and Public Health. It also provided for the establishment of County or City Medical Officer (CMO) posts including the transfer of MOH post holders into this role.

4. The Health Act 1970[161] provided for the establishment of eight health boards and the responsibility for the provision of health services transferred from the 27 health authorities. The post of Director of Community Care was established – post holders had the wider brief of the CMO role and responsibility for the provision of all community care services.

   Sections 63, 66 and 67 form the legislative basis for the current child health service. It placed an obligation on health boards to provide without charge medical, surgical and nursing services for children up to the age of six weeks including choice of GP; a health examination without charge at clinics, health centres and national schools including follow up treatment for any conditions identified for children up to 6 years of

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[156] The Notification of Births Act 1907 and 1915 Accessed at: http://www.irishstatutebook.ie/1915/en/act/pub/0064/print.html

[157] The Practice Standards for Midwives An Bord Altranais 2010 July Accessed at: www.nursingboard.ie

[158] The Civil Registration Act 2004 Accessed at: http://www.irishstatutebook.ie/2004/en/act/pub/0003/

[159] Local Government Act 1925 Accessed at: http://www.irishstatutebook.ie/1925/en/act/pub/0005/

[160] Health Act 1947 Accessed at: http://www.irishstatutebook.ie/1947/en/act/pub/0028/

[161] Health Act 1970 Accessed at: Accessed at: http://www.irishstatutebook.ie/1970/en/act/pub/0001/

age. The Minister for Health subsequently set up a Working Group to survey the workload of public health nurses and to make recommendations regarding the PHN service. Their recommendations in relation to child health were:

- *'PHNs on district duties should be available to the maximum degree possible for child health clinics including developmental paediatric clinics.*
- *In areas where a developmental paediatric service is not yet available, the PHN should visit children at the age of six to eight months and should report on their development on the basis of a standard checklist.*
- *The Department's policy of having nurses on district duties involved in school health services should be implemented in areas where it is not now operating.'*[162]

5. The Health Act 2004[163] provides the legislative basis for the Health Service Executive. Health boards were abolished and the national executive established with a governing board to *'to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public.'*[163]

6. The Disability Act, 2005, children under 5 years old are entitled to an independent assessment of health and educational needs. Following the assessment, the HSE is obliged to provide a statement of the services that will be provided. Children with disabilities need a wide range of services that extend across the board from specific health interventions to community and hospital-based therapies to preschool and school education.[164]

7. The Children First Act, 2015 puts elements of the *Children First: National Guidance for the Protection and Welfare of Children (2011)* on a statutory footing and forms part of a suite of child protection legislation which already includes the National Vetting Bureau (Children and Vulnerable Persons) Act, 2012 and the Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Persons) Act 2012. The Act obliges certain professionals and others working with children to report child protection concerns to the Child and Family Agency and to assist the Agency, if requested to do so, in its assessment of a child protection risk. The Children First Act 2015 also provides for an amendment to the Non-Fatal Offences Against the Person Act 1997 to abolish the common law defence of reasonable chastisement.[165]. The new legislation will operate in tandem with the existing *Children First: National Guidance for the Protection and Welfare of Children [2011].*[166] The Children's First oversight group is mandated to offer strategic direction and monitoring of HSE Implementation plan for Children's First Guidelines.

Other key developments that influenced the delivery of child health and child protection services include:

- The Child Care Act 1991, which focused on the child and the promotion of the child's welfare and placed a duty on Health Boards to identify children who were not receiving adequate care and protection and to provide child care and family support services.

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[162] Department of Health Survey of Workload of Public Health Nurses Report of Working Group appointed by Minister for Health Government Publications Dublin Stationary Office 1972

[163] Health Act 2004 Accessed at: http://www.irishstatutebook.ie/2004/en/act/pub/0042/sec0007.html#sec7

[164] http://www.justice.ie/en/JELR/DisabilityAct05Guide.pdf/Files/DisabilityAct05Guide.pdf

[165] http://www.oireachtas.ie/documents/bills28/acts/2015/a3615.pdf

[166] Children First National Guidance for the Protection and Welfare of Children 2011 Accessed at: http://www.dcya.gov.ie/documents/Publications/ChildrenFirst.pdf

4.2 Other Relevant Legislation

4.2.1 Child and Family Agency Act 2013

The Child and Family Agency Act 2013[167] led to the establishment of the Child and Family Agency, Tusla, in January 2014. Tusla brings together a number of children and family services in the one agency for the first time, including child welfare and protection services previously operated by the HSE , the Family Support Agency, the National Educational Welfare Board and a range of other services.

4.2.2 Children and Family Relationship Act 2015

The Children and Family Relationships Act 2015[168] is intended to create a legal structure to underpin diverse parenting situations and provide legal clarity on parental rights and duties in diverse family forms. The Children and Family Relationships Act 2015 provides for a contemporary legal architecture on guardianship, custody, access and the upbringing of children in diverse family forms. This includes married families, families that rely on the care of children by members of the extended family, families based on cohabiting couples and civil partnerships. This Act also addresses issues that have arisen in the context of Assisted Human Reproduction and Surrogacy. The Act also reflects the new constitutional provision relating to children arising from the 2012 Children Referendum.

4.3 Child Health Strategy

While the legislative framework for the delivery of child health services stretches back to the beginning of the 20th century, more recent strategies have been implemented and proposed that have had and will have an impact on child health in Ireland.
It is useful in the context of this review to look at those key strategies and their impact.

4.3.1 Best Health for Children 2000-2005

In 1999, *Best Health for Children-Developing a Partnership with Families*[169] (BHFC) was published following a review of child health screening and surveillance (0-12 years), which was commissioned by the CEOs of the eight health boards. This report contained recommendations for best practice and Dr. Sean Denyer, national lead for child health led a project team that drove the implementation of the recommendations.
While the initial focus of the strategy was on screening and surveillance in the 0-12 age group, the remit was enlarged (under HeBE)[170] to include other services for children and young people and became known as the Programme of Action for Children (PAC).
The screening and surveillance aspect is generally referred to as the *core programme*.
In 2000, a report on training in child health surveillance was published and funded for implementation. [171] Over the following five years training posts, training programmes and supporting materials were developed and implemented. The evidence base was regularly updated with the most recent published in 2005 - BHFC Revisited.[172] See Section 4 of this report for a review of the eight areas of BHFC Revisited and an update on evidence base for each area.

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[167] http://www.irishstatutebook.ie/eli/2013/act/40/enacted/en/html

[168] http://www.irishstatutebook.ie/eli/2015/act/9/enacted/en/html

[169] Best Health for Children Developing a partnership with families Report of the national conjoint child health committee 1999 Accessed at: http://www.lenus.ie/hse/bitstream/10147/45180/1/6871.pdf

[170] The Health Boards Executive HeBE Accessed at: http://lenus.ie/hse/bitstream/10147/42853/1/2333.pdf

[171] Training of doctors and public health nurses in child health surveillance 2000 Link to follow

[172] Best Health for Children Revisited Report from the National Core Child Health Programme Review Group to HSE 2005 Accessed at: www.lenus.ie

In 2002 PAC produced its second major report *Best Health for Adolescents, Get Connected, Developing an Adolescent Friendly Health Service.*[173] It was intended that the document be used *'in service planning, alongside processes of consultation with adolescents, parents and service providers (voluntary and statutory) to ensure the agenda for adolescent health is as full and as vibrant as adolescence itself.'* The review included general recommendations along with recommendations on the specific areas of mental health; chronic physical illness and disability; accidents and injuries; educational disadvantage; homelessness and minority groups; health related behaviours. The majority of the recommendations had lead agencies identified and some also had target dates for implementation. They were in line with the National Children's Strategy *Our Children Their Lives* which had been published in 2000.[174]

However, a review of the implementation of that strategy in 2011 found that the recommendations in the 2002 report regarding the development of an adolescent friendly health service were not acted upon.[175]

The third major PAC report, also published in 2002, was the *Supporting Parents Strategy*.[176] The purpose of this strategy was *'to support, reinforce, and act as a vehicle for the implementation of relevant aspects of existing national strategies that pertain to supporting parents.'* No review of this strategy could be found. While the 2005 review of BHFC[172] recognises *'the need to work in partnership with parents to achieve positive health outcomes'* no specific recommendations are made regarding parenting support.

PAC had five other sub-groups whose work focused on designing a child health indicator dataset,[177] developing training modules for staff involved in child health screening and surveillance[178] and reviewing three priority areas (Universal Neonatal Hearing Screening (UNHS), Cystic Fibrosis Screening and Newborn screening for inherited metabolic disorders[179]) which provided the basis for developments in childhood screening implemented in intervening years.

4.3.2 Best Health for Children 2005 to date

It would appear that the impetus for the implementation of the PAC waned after 2005. This may be due in some part to the significant organisational restructuring that ensued in the health service with the setting up of the HSE. Some of the work of PAC came under the HSE Population Health Directorate with the remainder under the Primary Care Directorate. The focus of child health service development appears to have narrowed to the imperative of meeting the screening and surveillance key performance indicators.

It is worth noting that around 2006/2007 the then HSE CEO, Brendan Drumm established a panel of Expert Advisory Groups (EAG) *'to allow the clinical/health community and patients to drive reform and development in specific service areas; such as diabetes, old*

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[173] Best Health for Adolescents, Get Connected, Developing an Adolescent Friendly Health Service 2002 Accessed at: http://lenus.ie/hse/handle/10147/44900

[174] The National Children's Strategy *Our Children Their Lives* 2000 Government Publications Dublin

[175] Ten Years On, Did the National Children's Strategy Deliver on its Promises? Alliance Review 2000-2010 Children's Rights Alliance, February 2011 Accessed at: http://www.childrensrights.ie

[176] Investing in Parenthood to achieve Best Health for Children, The Supporting Parents Strategy 2002 Accessed at: http://lenus.ie/hse/handle/10147/44898

[177] Towards the development of health indicators for Irish children The National Conjoint Child Health Committee April 2001 Copy on file

[178] Training Programme for Public Health Nurses and Doctors in Child Health Screening, Surveillance and Health Promotion Units One to Nine developed between 2004 and 2008 Accessed at: http://www.hse.ie/eng/services/Publications/Children

[179] Programme of Action for Children Review of the national newborn screening programme for inherited metabolic disorder October 2004

age, children etc. They act as important sources of operational policy/strategic advice and propose changes and implementation plans, cognoscente of the wider transformation agenda towards service integration and seamless patient journeys'[180]. In 2007, the EAG for Children's Services made a submission to the Strategic Planning and Reform Implementation (SPRI) division for funding to support the national rollout of a Parent Held Record (PHR), the Child Health Information Service Project (CHISP) and Cystic Fibrosis Screening. In March 2013 a Position Paper by the Child Health Training and Development Officers reported that the PHR is implemented in seven local health areas (out of a possible 32).[181]The CHISP was implemented and the information booklets are currently being updated and will be re-issued in 2014. Cystic Fibrosis Screening was added to the newborn bloodspot screening programme in 2011 when the HSE also agreed a national governance structure for procedures and standards.[182]

Other work completed by PAC included:

- The development a Child Health Research Forum which was a *'network of people and agencies with an interest and expertise in the area of child health research.'*[183] The current status of that group could not be established.
- An ICGP/PAC project aimed at developing a *new model for the six week baby check under the statutory Maternity and Infant Care scheme (MIS) as part of the national core child health programme* was implemented in HSE West (Donegal, Sligo, Leitrim & West Cavan). One of the subsequent recommendations was to include new model for six week baby check in national GP contract renegotiations.[184]
- Co-operation and Working Together (CAWT) also funded a series of children's projects in the North West and border counties to ensure participation of young people, who use health and social care services, in the informing, designing, evaluating and planning of these services. Conferences were held and reports and reference documents were produced.

4.3.3 Best Health for Children Relevant Reviews

A number of published reviews and reports, directly related to child health services, have been published since 2005. While some of these focus on a specific profession (community medical services and public health nursing services), they provide an important backdrop to information required when developing a model of care for child health development and surveillance services.

- ***2009 Audit of child health screening and surveillance programme***
  The report on the audit of child health screening and surveillance (CHSS) programme[185] was identified as a HSE service plan deliverable in 2008. An audit of the child health screening and surveillance programme was carried out using a questionnaire issued to all Local Health Offices (LHO). While a literature review is mentioned it is not contained in the report. The pre-school health check data are taken from 2007 and school health check data refers to year 2006/2007. It is clear from the report that many LHO struggled to provide the data required, illustrating the lack of uniformity in data collection systems. The report made specific

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[180] Diabetes Expert Advisory Group First Report HSE April 2008 Accessed at: www.hse.ie

[181] Child Health Training & Development Officers Position Paper March 2013 Copy on file

[182] Report of the Evaluation Subgroup of the Newborn Bloodspot Screening Programme Version 2 June 2014 Copy on file

[183] A study of the quality of life took KIDSCREEN for children and adolescents in Ireland Department of Health & Children February 2008 Stationary Office Dublin

[184] McBride L., McMaster C. Six week baby check in general practice project ICGP HSE PAC March 2006 Accessed at: http://www.lenus.ie/hse/bitstream/10147/65234/1/SixwkBabycheck.pdf

[185] Report of the Audit of the Child Health Screening and Surveillance Programme HSE 2009 May Accessed at: http://lenus.ie

recommendations regarding service delivery, standards, training and child health information systems. See Appendix 2.

- ***2009 Current public health nursing practice regarding visits to newborn babies***
  The current public health nursing practice regarding visits to newborn babies and their mothers within 48 hours of hospital discharge[186] was contained in a report produced by a Primary Community Continuing Care (PCCC) review group to explore the issues impacting compliance rates and to make recommendations based on the findings. An examination of the data at the time had shown considerable variation in compliance with the national target of PHN visit within 48-hours of hospital discharge. Data for this report were gathered as part of the review of child health screening and surveillance outlined above.[185]
  One of the main recommendations of the review group was to redefine the Performance Indicator (PI) and change the time from 48 hours to 72 hours in order to ensure consistent interpretation of the PI and to bring it in line with international norms. A literature review is included in the report.
  The report notes that the purpose of the postnatal consultation within 72 hours of hospital discharge is *'to engage in primary health care activities such as providing anticipatory guidance and allaying parental concerns, initiating necessary referrals and promoting links with community based services….to assess the growth and development of the newborn infant within the home environment.'*

- ***2011 National review of community medical services***
  The report of the national review of community medical services provides a comprehensive overview of the community medical services following a review process that included a survey, interviews with key stakeholders and a focus group with Principal Medical Officers (PMO). In providing a comprehensive historical background to the development of child health services the report highlights the development of community medical services. Roles within the child health screening and surveillance services and the childhood immunisation programme are explored. One of the key recommendations of the report is the implementation of a revised model for child health services operating at Health & Social Care Network (HSCN) and Primary Care Team (PCT) level. This is a very important report in the context of this review.

- ***2012 National and regional reviews of public health nursing services***
  A review of public health nursing services was carried out by an expert advisory group under the auspices of the Nursing and Midwifery Services Director. One national and four regional reports are available. [187] The review consisted of three parts – 1) a questionnaire completed by directors of public health nursing on current PHN services (84% response) along with 2) another questionnaire on their respective roles (71% response) and 3) regional consultations with all nursing staff working in the PHN service (300 attendees in total). It is interesting that the national report sets out the findings and puts them into context but it does not make recommendations or provide pointers as to how the issues identified could be addressed. The four regional reports have similar concluding comments that point to the '*strengths and weaknesses in the generalist nature of the PHN service'*, it notes universal access for clients, across the life span and open ended referral system for clients as key strengths but which '*are now one of its greatest*

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[186] Current public health nursing practice regarding visits to newborn babies and their mothers within 48 hours of hospital discharge HSE Office of the Director of Nursing Services January 2009 Copy on file

[187] Office of the Nursing and Midwifery Services Director (2012) Report on Current Public Health Nursing Services; Report prepared by Patricia O'Dwyer, Project Officer to the Expert Advisory Group on Public Health Nursing Services

limiting factors.' It notes that *'advantages for the clients must be enormous albeit infrequently measured'* and universal access to the PHN Service is '*under threat from the epidemiological and demographic transitions in the location of care*.' Despite this the regional reports note that *'it is possible to propose a path for the future in the context of the pressures on the service….PHN services in other jurisdictions have been at a similar cross road in their development and have been innovative in response to demands on their service.'*
The soon to be available Public Health Nursing Strategy on Quality Integration and Collaboration 2014 may provide the necessary roadmap.[188]

- ***March 2013 Position paper from Child Health Training and Development Officers***
  The Child Health Training and Development Officers presented a position paper to Dr. Kevin Kelleher, Assistant National Director for Public Health and Child Health in March 2013. The paper highlights a range of issues that require attention including review of the BHFC 2005 standards, implementation of the new growth charts, training and overall governance for child health screening and surveillance nationally.

- ***September 2013 Discussion paper on Child Health Institute of Community Health Nursing[189]***
  The discussion paper on child health 'Best option for Children' aimed to *'stimulate discussion regarding providing an equitable effective health service by PHNs for all children and to consider the implications for the changes required in both the education and delivery of PHN services'*. The paper notes the generalist role of the PHN, delivered through an area based approach, but states that *'the capacity of the service to deliver is greatly challenged by competing priorities.'* The paper states that *'the commitment to child health is squeezed by the demands of early hospital discharges and an ageing population'*, the increase in the number of babies born and the increasing demand for clinical nursing services for children with long term conditions are key factors. The development of a dedicated child and family health nursing service along with the development of advanced nurse practitioner posts, improved resources for professional development and better information systems are just some of the recommendations.

4.3.4 Related Strategy - Better Outcomes Brighter Futures 2014-2020

Better Outcomes, Brighter Futures: National Policy Framework for Children and Young People 2014-2020[190] is the successor to the 2000-2010 national Children's Strategy *Our Children Their Lives*.
The purpose of the framework is to '*move policy development and service delivery beyond the present scenario – where children and young people* (from birth to 24 years) *are viewed primarily within narrow organisational responsibilities – to a whole of Government response and a clear picture of overall need and the progress required to achieve improved outcomes.'* The policy framework has one vision, five national outcomes and four aims under each outcome. There are six transformational goals (cross-cutting themes) to help achieve the five outcomes. (See Appendix 7).

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[188] Status Report to Dr. Áine Carroll on the draft Public Health Nursing Strategy on Quality Integration and Collaboration 2014 from Michael Shannon June 2014 Copy on file

[189] Institute of Community Health Nursing Best Option for Children Discussion paper on child health September 2013 Copy on file

[190] Department of Children and Youth Affairs (2014). Better Outcomes Brighter Futures The national policy framework for children and young people 2014-2020

The Department of Children and Youth Affairs has overall responsibility for its implementation, reporting to the Cabinet Committee on Social Policy (chaired by the Taoiseach). Under the Children's & Young People's Policy Consortium the Department of Health is sponsor of Outcome 1 – Active and healthy, physical and mental wellbeing. The aims are that all children and young people are physically healthy and able to make positive health choices, have good mental health, have a positive and respectful approach to relationships and sexual health, and that their lives are enriched through the enjoyment of play, recreation, sports, arts, culture and nature.

The commitments under the transformational goal of earlier intervention and prevention, central to the delivery of Outcome 1 are:

- Bring a focus to healthy early development, prioritising the under-two year-olds, strengthening pre-natal and ante-natal supports around the mother, addressing maternal health and wellbeing, and raising breastfeeding and vaccination rates in line with international norms. (DH, HSE, DCYA, Tusla).
- The HSE, in collaboration with Tusla, The Child and Family Agency, will explore the provision of an integrated maternal ante-natal and early childhood development service, building on the review of the Community Nursing Services. (HSE, Tusla, DH, DCYA)

4.3.5 Related Strategy - Healthy Ireland A Framework for Improved Health & Wellbeing 2013-2025

Healthy Ireland A framework for Improved Health & Wellbeing 2013-2025 [191]sets out the government's commitment to improving the health and wellbeing of the population. The Health & Wellbeing Programme in the Department of Health is responsible for strategic planning and coordination of the implementation framework. All implementation plans and progress reports will be overseen by the Cabinet Committee on Social Policy. The Healthy Ireland Council, which was established earlier this year, will provide *a national advisory forum to support the implementation of the framework across sectors.*
(See Appendix 8)
The Health and Wellbeing Division in the HSE will play a significant role in contributing to implementation plans and leading and directing implementation of many of the actions. The actions relevant to child health are laid out below

- ***Theme 2: Partnership & Cross-Sectoral Work***
  2.8 Implement evidence-based prevention and early intervention initiatives aimed at children and families, initially focusing on areas of disadvantage, drawing evidence emerging from the Prevention and Early Intervention Programme.
  Partners: DCYA, C&FSA, DH, DSP, HSE Directorates and others.

- ***Theme 3: Empowering People and Communities***
  3.4 Support, link with and further improve existing partnerships, strategies and initiatives that aim to improve the capacity of parents, carers and families to support healthier choices for their children and themselves
  Partners: DH, DES, DCYA, other departments, local authorities, HSE Directorates, statutory agencies, C&V Bodies and private sector.

- ***Theme 4: Health and Health Reform***
  4.7 Further support the roles of local health and social care staff who work in community settings, such as public health nurses; devise ways to leverage their expertise in improving the health of local communities and develop supports for this.

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[191] Healthy Ireland - A Framework for Improved Health and Wellbeing Department of Health 2013 Accessed at: http://www.dohc.ie/issues/healthy_ireland/

Partners: DH and HSE Directorates.
4.8 Ensure that community-based programmes and projects are oriented to promote healthy behaviours and disease prevention to populations and communities at greatest risk.
Partners: DH and HSE Directorates.
4.9 Promote a skilled, diverse, cross-trained prevention workforce through training and continual professional development for primary care workers, health improvement and promotion staff, public health, educationalists (including those working in the early years sector), environmental health, health protection and staff in other sectors.
Partners: Relevant Government Departments, statutory agencies, HSE Directorates, regulators, training bodies.

- ***Theme 6: Monitoring, Reporting and Evaluation***
  6.7 Develop a basic child health dataset.
  Partners: DH, DCYA, DES, DSP, HSE Directorates and others as appropriate

An outcomes framework will be designed that will identify and specify a *'comprehensive set of indicators relevant to each goal that will allow progress to be measured on improving the health and wellbeing of the population across the life course.'* Some preliminary key performance indicators (KPI) and targets are given in the framework. The KPIs which could be considered relevant to child health are:

- Decrease infant mortality per 1,000 live births, no target is provided
- Increase the number of adults and children with a healthy weight, with a target of increasing by 6% the number of children with a healthy weight by 2019

4.3.6 Future Health – A Strategic Framework for Reform of the Health Services 2012 – 2015

The Government's health reform programme is set out in *Future Health – A Strategic Reform of the Health Services 2012-2015*.[192] The core of the reform is a single-tier health service, supported by Universal Health Insurance (UHI) which will mean that:

- the population will have equal access to healthcare based on need, not income
- everyone will be insured for a standard package of curative health services
- there will be no distinction between "public" and "private" patients
- there will be universal primary care, with GP care free at the point of use for all
- universal hospital care will include independent, not-for-profit trusts and private hospitals
- social care services will be outside the UHI system but integrated around the user
- the health system will be based on a multi-payer insurer model, with competing insurers
- the service will remain, fundamentally, public provided

Its delivery is dependent on four inter-dependent pillars of reform –

- health & wellbeing focus concentrating on keeping people healthy
- service reform- the current hospital-centric model of care cannot deliver the quality of care required at a price which the country can afford.
- structural reform of the HSE
- financial reform – introduction of Money Follows the Patient (MFTP) model

The reforms are being delivered in three phases:

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[192] Department of health and Children Future Health A Strategic Framework for reform of the Health Services 2012-2015, Department of Health November 2012 Accessed at: http://health.gov.ie/future-health/delivering-the-reform-programme/

Phase 1: saw the abolition of the HSE Board and the establishment of Directorates and a new management structure within in the HSE. Hospital Groups have been established on an administrative basis with Group CEOs having budget and staff responsibilities for both statutory and voluntary hospitals in the group.
Phase 2: this phase will progress the development of a formal purchaser/provider split with a Commissioning Unit and the effective dissolution of the HSE.
Phase 3: this phase will result in a move from a tax funded system to a combination of UHI and tax funding.

Bedrocks for the reform approach includes:

- Introduction of programme based budgeting
- Roll out of a comprehensive financial management system
- Introduction of a new (MFTP) model that creates incentives that encourages treatment at the lowest level of complexity that is safe, timely, efficient and delivered as close to home as possible for each patient. The model will see money used as a lever to achieve quality and safety objectives rather than simply being a means of paying for activity.

Money Follows the Patient

The recently published *Money Follows the Patient – Policy Paper on Hospital Financing*[193] translates the approach to insurance based funding, purchaser-provider split through the Pricing Office and Healthcare Commissioning Agency and Diagnosis Related Groups (DRG) based funding and "*recommends that the existing approach of indirect price-setting using relative weights should be maintained. This is efficient and enables the relative resource consumption of different Diagnosis Related Groups (DRGs) to be compared. However, the approach will have to take account of the move towards best practice pricing*".

4.3.7 Relevant National Clinical Programmes

The Clinical Strategy and Programmes Division was established in 2010 to oversee the implementation of a range of clinical care programmes, the aim of which are to *improve and standardise patient care throughout the organisation by bringing together clinical disciplines and enabling them to share innovative solutions to deliver greater benefits to every user of HSE services.*[194]

- ***The National Paediatrics and Neonatology Clinical Programme***
  The National Paediatrics and Neonatology Clinical Programme was set up in 2011 as a joint clinical initiative between the HSE and the Faculty of Paediatrics, RCPI. Two clinical leads were appointed; Professor Alf Nicholson for Paediatrics and Professor John Murphy for Neonatology.
  The overall aim of the programme is to provide high quality care to the children of Ireland at first point of contact. The programme works closely with the Paediatric Patient Reference Group through the HSE Advocacy Unit so that the views of children and parents can be incorporated into developments. The Programme also works with other clinical programmes to ensure that aims are aligned; e.g. clinical programmes in Obstetrics and Gynaecology, Emergency Medicine, Radiology and Asthma.
  Outputs

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[193] Department of Health and Children. Money Follows the Patient – Policy Paper on Hospital Financing Department of Health http://www.dohc.ie/publications/MoneyFollowsthePatient_HFPP.html

[194] Accessed at: http://www.hse.ie/eng/about/clinicalprogrammes/

  - Review of Paediatric and Neonatology Services and Framework for Future Development completed
  - Twenty-five algorithms have been developed for medical, nursing and allied health professionals working in both primary and emergency care setting
  - The Programme is developing a national model of care for paediatric and neonatalogy
  - A patient charter is being developed - the Charter will describe ten key principles in relation to the provision of healthcare for children and young people in Ireland.

- ***Diabetes Clinical Programme***

  In 2011 a subgroup of the Paediatrics and Neonatology Clinical Programme and the Diabetes Clinical Programme was established to examine the delivery of Type 1 diabetes care to all children in Ireland. The subgroup (Paediatric Diabetes Working Group) is chaired by Dr Stephen O'Riordan, Clinical Lead for Paediatric Diabetes, Consultant Paediatrician, Cork University Hospital.

  The initial focus of the Paediatric Diabetes Working Group was on children under five years with Type 1 diabetes. Evidence has shown that the best way to treat children with Type 1 diabetes is by using an insulin pump. It is important that children and their families are assessed for suitability for an insulin pump.

  The key objectives in this model of care are to:
  - Provide CSII therapy to children under five, where appropriate.
  - Ensure that diabetes services and staffing levels are equitable in the five centres nationwide (Cork, Crumlin, Limerick / Galway, Tallaght, Temple St)
  - Reduce acute and chronic complications of Type 1 diabetes
  - Improve the quality of life of children living with diabetes and their families

- ***Rare Diseases Clinical Programme***

  This programme was established December 2013 with Dr. Eileen Tracey as clinical lead.

  Programme objectives
  - Access - Patients with rare diseases and their families should have access to quality information and support, to enable accurate and timely diagnosis and access to appropriate specialist care.
  - Quality - Clinical expertise for rare diseases should be provided through a network of national Centres of Excellence/Health Care Providers or at designated centres abroad.
  - Value - Timely access to appropriate diagnosis and care should result in decreased mortality, morbidity and disability and be cost-effective.

- ***Obstetrics and Gynaecology Clinical Programme***

  The programme was established in 2010 with Professor Michael Turner as clinical lead. The objectives of the programme are based on the access, quality and cost domains for all clinical programme:
  - Quality - To maintain the low national maternal and perinatal mortality rates. Stop the rate of increase of caesarean sections in first time mothers. To develop and disseminate national guidelines.
  - Access - Increase the number of patients attending for antenatal care for early pregnancy. To improve choice by developing and delivering new models of maternity care.
  - Cost - To reduce the number and cost of medical negligence cases in obstetrics. To reduce the medication costs in obstetrics and gynaecology.

  The programme has developed a range of guidelines including the Irish Maternity Early Warning System (IMEWS).

4.3.8 The Child and Family Agency

The Child and Family Agency was established, under the Child and Family Act, 2013, on January 1st 2014. As an independent legal entity it comprises HSE Children & Family Services, Family Support Agency and the National Educational Welfare Board as well as incorporating some psychological services and a range of services responding to domestic, sexual and gender based violence.[195]

The Child and Family Agency's services include a range of universal and targeted services:

- Child protection and welfare services
- Educational Welfare Services
- Psychological Services
- Alternative care
- Family and Locally-based Community Supports
- Early Years Services
- Domestic, Sexual and Gender-based Violence Services

4.3.9 Department of Children and Youth Affairs[196]

The aim of the Department of Children and Youth Affairs is to lead the effort to improve the outcomes for children and young people in Ireland.

High-level Objectives of Department of Children and Youth Affairs

- Develop, strengthen and align policies, legislation and resources in order to achieve better outcomes for children and young people and provide support for parents and families.
- Monitor and evaluate performance through strong governance and accountability systems in respect of the responsibilities of the Department and its agencies.
- Support the Department and key stakeholders in accessing better evidence and facilitating the active participation of children and young people in decisions that affect their individual and collective lives.
- Improve systems for supporting families, safeguarding and protecting children, providing alternative care and assisting those young people whose behaviour poses a risk to themselves or others.
- Support children and young people so that they can fully engage in active learning, including through the provision of high-quality early childhood care and education, youth services and addressing issues of school attendance and participation.
- Collaborate with stakeholders, including across Government, in monitoring and promoting the physical, emotional and economic well-being of children and young people and reducing inequalities.
- Be recognised as an organisation where, on an ongoing basis, high performance is achieved and personal development is supported.

The Expert Advisory Group (EAG) on the Early Years Strategy published its report in 2013.[197] The report states that *'a comprehensive Early Years Strategy, backed up by national commitment, could shape a stronger and healthier society, and strengthen families. It could break cycles of poverty and disadvantage, and remove barriers of inequality. It could significantly reduce anti-social behaviour, dependency and alienation. It could help to build a stronger economy.'* The *Right from the Start* report is the EAG's contribution to the process of the development of an early years strategy.

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[195] Accessed at: http://www.tusla.ie/about

[196] Accessed at: http://www.dcya.gov.ie/

[197] Right from the Start Report of the Expert Report of the Expert Advisory Group on the Early Years Strategy September 2013 Department of Children and Youth Affairs Accessed at: http://www.dcya.gov.ie/

4.3.10 Other Organisations

- **The Centre for Effective Services** (CES)[198] was established in 2008 in the Republic of Ireland, and in 2010 in Northern Ireland. The overall remit of the Centre was to provide technical and organisational 'expertise' to promote and support the application of an evidence-informed approach to policy making and service provision across the island of Ireland. CES is part of an emerging body of intermediary organisations across the world. The Centre is funded jointly by The Atlantic Philanthropies, the Department of Children and Youth Affairs and the Department of the Environment, Community and Local Government for an initial period of five years up to 2013. The staff complement of CES is now eighteen people, which includes a number of part-time and shared posts across both jurisdictions. CES has also hosted three full-time graduate interns and five secondees from a number of Government Departments and Agencies.
  Work to date has largely been focused over four key areas:
    - Policy Advice and Implementation Support
    - Programme Design, Implementation and Practice Development
    - Evaluation, Quality and Outcomes
    - Knowledge and Communications

- **Katherine Howard Foundation**[199] has operated as an independent all-Ireland grant making foundation since the early 1990's. The Foundation has a particular emphasis on supporting community projects and initiatives in areas that are socially disadvantaged, particularly those with a focus on families and young children. The work of the Foundation includes:
    - Advocacy and development work;
    - Providing funding through small grants;
    - Supporting and co-funding social administration and policy research

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[198] Accessed at: http://www.effectiveservices.org/

[199] Accessed at: http://www.khf.ie/

Section Two

Desktop Review of Best Health for Children 2005

Chapter 5: Developmental Assessment

5.1 Recommendations from Best Health for Children 2005

a. Staff training in the recognition of childhood developmental delay and disorders needs to be provided to facilitate early referral and intervention.

b. Instruments by whose use one can elicit parental concern in relation to any area of child development need to be evaluated in the Irish context and introduced if found valid.

c. The role of specific tools to guide practitioners in the assessment of childhood development needs to be explored in the Irish context, as the use of individualised checklists is no longer in line with available evidence.

5.2 Update on the Implementation of the Recommendations

There has been wide variation in the implementation of Best Health for Children between different health boards and subsequently across different HSE areas; this includes allocation of resources, staff training, roles and responsibilities. The HSE developed a training programme for Public Health Nurses and doctors but the duration and coverage of this programme is unclear.[200] Although a parent health child health record was developed and piloted, this was not implemented at a national level and a national child health information system has not been developed. The role of child health surveillance tools has not been evaluated or agreed nationally in the Irish context.

5.3 Update on the Evidence to Support the Recommendations

Major reviews of child health surveillance were published in the UK (Hall 4) and Australia (NHMRC Review) in 2002.[201,202] These reviews led to the review and reform of models of child health services in a number of countries. Internationally, while developmental surveillance occurs in most countries, the opportunity presented by child health visits to promote positive behaviours has also been recognised.

Health promotion is now a major component of universal child health services in most countries, including areas such as breastfeeding, quality parenting, child management, injury prevention, and pro-literacy activities and linking children and their families to local community resources. In general, formal developmental screening tests are no longer recommended. Where concerns arise, developmental assessment tools can support professional decision making. The ASQ (Ages & Stages Questionnaire) and PEDS (Parents' Evaluation of Developmental Status) are the tools most commonly used for parental input. In general, the number of scheduled universal child health visits has been reduced, with an enhanced service provided to those identified through a process of family needs assessment (progressive universalism).

A number of countries (the United Kingdom, Scotland, the Netherlands, Australia, New Zealand), use parent-held child health records to allow families to play a larger role in child development monitoring.[203,204,205,206 207] In the UK, ages two to three years has been identified as the key time for comprehensive assessment of child development.[208,209]

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[200] http://www.hse.ie/eng/services/Publications/Children/Unit_5_Developmental_Assessment.pdf

[201] Hall DMB, Ellman, D. Health for All Children.Revised 4th edn. Oxford: Oxford University Press 2006.

[202] Child Health Screening and Surveillance: A Critical Review of the Evidence. Report prepared by Centre for Community Child Health, Royal Children's Hospital Melbourne for the National Health and Medical Research Council, Australia.

203 Department of Health Healthy Child Programme: Pregnancy and the First Five Years of Life (2009).

Common features of child health surveillance and promotion programmes include:

- a core universal programme which may be supplemented with additional visits and services for those with greater identified needs
- a nurse-led service
- a highly trained workforce
- a clear framework for delivery with referral pathways and protocols etc.
- links to local services including pre-school services and education
- the use of validated tools
- clear roles and responsibilities for each health professional
- child health record
- child health dataset
- link with school health services / school readiness check
- clinical governance structures and processes
- suitable premises and equipment
- clear information for parents in various formats including the use of new technologies.

5.4 Way Forward/Recommendations

1. The timing and content of the current schedule of child surveillance visits should be reviewed in light of international practice.
2. Child health promotion should include breastfeeding, immunisation, obesity prevention, parenting skills, information on child development etc.
3. A universal plus enhanced service should be considered.
4. Since the introduction of the universal neonatal screening programme, the timing and purpose of the current seven to nine month visit is unclear and should be reviewed.
5. Standards and a programme of staff training and accreditation are required to ensure a quality service.
6. Clinical governance structures and processes are required.
7. The universal service should be nurse-delivered, with a second tier service for further assessment.
8. Clear referral pathways are required for children where there are developmental concerns
9. Referral pathways are required for access to Allied Health professional input.
10. Children who require additional services should be able to access early intervention; standards should be developed and access should be measured.
11. A national child health information system is required.
12. The role of GPs in developmental assessment and referral pathways from primary care require clarification.
13. A comprehensive developmental assessment at age 24 – 30 months should be considered, as this has been identified as a key time period for developmental assessment.

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204 The Scottish Government. A New Look at Hall 4 – the Early Years – Good Health for Every Child.2011.

205 Australian Government, Department of Health and Ageing. National Framework for Universal Child Health and Family Health Services, 2011 Accessed at http://www.health.gov.au/

206 Ministry of Health. New Zealand. The Well Child / Tamariki Ora (WCTO) National Schedule, 2013.

207 Department of Health, Social Services and Public Safety. Healthy Child, Healthy Future, 2010.

208 Department of Health. Healthy Child Programme: the two year review (2009).

209 The Scottish Government. The Scottish Child Health Programme: Guidance on the 27-30 month child health review, 2012.

14. Further evaluation of the use of the PEDs and ADQ questionnaires is required in the Irish setting, including the capacity of services to offer further assessment to the 10% or so of children who will require further assessment based on these measures.
15. In light of the introduction of the pre-school year, consideration should be given to linking the schedule of child surveillance visits to this; e.g. a school readiness check could replace one of the visits on the current schedule.

Chapter 6 Hearing Assessment

6.1 Recommendations from Best Health for Children 2005

a. Early implementation of Universal Neonatal Hearing Screening (UNHS) programmes
b. Retention of and staff training in Universal Distraction Hearing Test (UDHT) and School Sweep Test as an interim measure
c. Implementation of clear referral criteria as agreed by National Core Child Health
d. Programme Review Group
e. Education of parents and professionals in using 'Can Your Baby Hear You' surveillance tool

6.2 Update on the Implementation of the Recommendations

A National Audiology Review Group (NARG) was established in 2010. The NARG examined audiology services currently provided to children and adults nationwide and undertook an extensive public consultation and assessed the needs of the population.

6.2.1 Newborn Hearing Screening

The review recommended that a Universal National programme of Newborn Hearing Screening (UNHS) be introduced as a priority, such that all babies have their hearing screened shortly after birth. Once UNHS has been implemented it recommended that the eight-month distraction test be discontinued.

UNHS is now rolled-out across the country and the eight-month distraction test has been discontinued.

6.2.2 School Hearing Screening

The NARG report recommended that school entry hearing screening should continue to be implemented nationally. A national group should be tasked to draw up guidance on protocols and training and initiate mechanisms for performance monitoring of the screen.

A National Technical Group for Children's Hearing Screening was established on foot of the NARG report. The group recently (August 2014) signed off on a new school hearing screening protocol based on best practice.

6.3 Update on the Evidence to Support the Recommendations

6.3.1 Newborn Hearing Screening *UK National Screening Committee*

Newborn hearing screening recommended

Internationally

Newborn hearing screening is accepted internationally as best practice.

6.3.2 School Hearing Screening

UK National Screening Committee

The Child Health Sub-Group of the UK NSC made recommendations that screening for hearing loss in school age children should continue while further research was being undertaken. The update of hearing in children has been delayed until the publication of an HTA trial, which will evaluate cost-effectiveness of screening for permanent hearing loss in children at school entry. This is expected to be published in 2015 and the UK NSC review will commence shortly after, with the expected policy decision date being revised accordingly.

6.3.3 Ongoing Hearing Surveillance

Parents are given “checklists” regarding appropriate language and auditory behaviour development on completion of the newborn screen and at the various developmental assessments.

6.4 Way Forward/Recommendations

The National Technical Group for Children's Hearing Screening (NTGCHS) aim to provide national review, governance and support for the UNHS and the SES programmes. The NTGCHS reports to the HSE Assistant Director of Health Protection and the National Childhood Screening Committee.

6.5 Roles and Responsibilities/Implementation

The NTGCHS has overall responsibility for and coordination of all childhood hearing screening programmes; this is chaired by the National Clinical Lead for Audiology. It assumes overall governance responsibility, and monitors the effectiveness and compliance of individual screening programmes.

Chapter 7 Vision Assessment

Introduction

This chapter is presented in a different format to the previous chapters. As the BHFC Revisited recommendations[172] related to specific age groups the update on the evidence and best practice is presented in this format also. The full list of BHFC recommendations can be seen in Appendix 9.

7.1 Population – Birth to Junior Infants

7.1.1 Current BHFC Revisited Recommendations

There is insufficient evidence to make a recommendation for preschool visual acuity screening beyond observation of visual behaviour.

7.1.2 Update on the Evidence and recommendations for Best Practice

UK National Screening Committee[210]	***UK Healthy Child Programme Schedule***[211]	***Northern Ireland***
Screening for congenital cataract, other media opacities and anatomical abnormalities are part of the physical examination of newborn babies and again at 6-8 weeks. Although visual disorders in the newborn are not common the various conditions can have severe impact on vision and a delay in detection could have detrimental consequences.	Eye exam at birth Eye exam at 6/52 2-21/12 check – review any concerns expressed by parents regarding vision and hearing …	Eye exam at birth - hosp Eye exam at 8/52 – GP 2 years – monitor vision

US Preventive Services Task Force (USPSTF)[212]

The USPSTF concludes that the benefits of vision screening for children <3 years of age are uncertain and that the balance of benefits and harms cannot be determined for this age group.

Most studies show that screening and treatment later in the preschool years seem to be as effective at preventing amblyopia as screening and treatment earlier in life.

The USPSTF did not find adequate evidence to determine the optimal screening interval.

Australia[213]

In 2009, the National Children's Vision Screening Project undertook a systematic review of the effectiveness of vision screening programme.

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[210] http://www.screening.nhs.uk/congenitalcataracts

[211] Department of Health Health Child Programme – Pregnancy and the first five years of life, 2009 Accessed at: https://www.gov.uk/government/publications/healthy-child-programme-pregnancy-and-the-first-5-years-of-life

[212] Screening for Visual Impairment in Children Ages 1 to 5 Years Topic Page January 2011. U.S. Preventive Services Task Force. http://www.uspreventiveservicestaskforce.org/uspstf/uspsvsch.htm

[213] Morcos A, Wright M. National Children's Vision Screening Project, Final Report: Murdoch Childrens Research Institute, 2009

Newborn Screening - The report concluded that there was little guidance from the evidence to determine whether vision screening should be carried out during the neonatal period. However, the consensus of the CCCH Project Team and the Project Advisory Group was that a vision check during the neonatal period was crucial, as this enabled the detection of rare, treatable diseases that, if left untreated, could have severe consequences for the child's future health and wellbeing. Once again, there was also a lack of evidence to support the removal of a neonatal check.

Other Screening Age/s - The consensus of the Project Advisory Group was that a further vision check should be conducted with children between the ages of three to six months, and that a screen should be conducted at four years (with an allowable range from three and half to five years). Although there was no evidence from the literature to support a check in children aged three to six months, the expert group felt this component of a screening program was necessary to ensure that any conditions missed at the newborn check were detected (as they would still be treatable), and to allow for an early assessment of visual behaviour (e.g. fixing and following), providing further scope to detect visual concerns.

New Zealand[214]

Comprehensive eye exam at birth and the 6 week check. Vision assessment at each core visit using the *Can Your Child See* questionnaire in the parent-held child record.

7.1.3 Way Forward/Recommendations

Consensus from various reviews of the literature supports screening for eye abnormalities at birth and again at six to eight weeks by a health professional. There is little evidence for screening at any other age until the preschool/school vision check at four to five years of age. However most national policies and guidelines recommend that vision is reviewed at each child health check. This is usually in the format of questions to parents regarding their child's vision and any concerns they may have. This in affect means dropping the corneal light reflex from the core surveillance visits conducted by the PHNs.

7.2 Population -Primary School Children

7.2.1 Current BHFC Revisited Recommendations[172]

School entry and exit screening- omit second class screening
Evidence for or against colour vision screening equivocal

7.2.2 Update on the Evidence and recommendations for Best Practice

UK National Screening Committee Nov 2013[215]	***Royal College of Ophthalmologists, UK***[216]	***Healthy Child Programme Schedule 5-19 years, UK***[217]	***Northern Ireland***
Screening for visual impairment between 4 and 5	The UK Royal College of Ophthalmologists supports the recommendation of the National Screening Committee that screening	Recommends that all children between the ages of four and five years of age are	Recommends vision screening in Primary One only.

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[214] Ministry of Health 2014 Well Child/Tamariki Ora Programme Practitioner Handbook: Supporting families and whānau to promote their child's health and development Revised 2014 Wellington: Ministry of Health

[215] http://www.screening.nhs.uk/vision-child

[216] http://www.rcophth.ac.uk/news.asp?section=24&itemid=1583&search

[217] Department of Health Healthy Child Programme –5-19 years old 2009 www.dh.gov.uk/publications

years of age should be offered by an orthopic-led service. Screening at older ages not recommended.	for visual impairment in children between the ages of four and five years, should be offered by an orthopic-led service.	screened for visual impairment in line with the national screening committee guidelines.	

US Preventative Services Task Force (USPSTF)[212]
USPSTF recommends vision screening of all children at least once between the ages of three and five years. There is no recommendation for screening beyond this age

American Association for Paediatric Ophthalmology and Strabismus[218]
Recommends screening between three and five years of age and every two years after that.

New Zealand
National vision screening protocol in NZ recommends vision screening at four yrs (called the B4 School check) and also recommends vision screening at 11 years of age and colour vision screening for boys.[214]

Australia
The National Children's Vision Screening Project[213] concluded that the optimal age for vision screening was between 18 months and 5 years, in addition to a standard neonatal check. The review also found that screening from ages eight to ten years and from 13 to 15 years was shown to detect very few or no new cases of eye pathology and was therefore not recommended.

The National Framework for Universal Child and Family Health Services, 2013, recommends vision screening is offered to all children in the year prior to commencing formal school. The most appropriate age for visual acuity testing is when a child is four years old.

7.2.3 Recent research on colour vision screening

A paper published in May 2014, reviewed the evidence for colour vision screening and concluded that the evidence supported either not adopting or else disinvesting routine colour vision screening of school students.[219]

7.2.4 Way Forward/Recommendations

International guidelines and recommendations support screening for visual impairment between the ages of four and five years. For many countries this coincides with a formal pre-school year. However, in Ireland this is best conducted in junior infants in primary school.

There is little support/evidence for visual screening at older age-groups. Resources from screening cohorts other than junior infants should be redirected into ophthalmology services to ensure timely referral and intervention if appropriate.

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[218] American Association for Pediatric Ophthalmology and Strabismus Vision screening recommendations May 2014.

[219] Ramachandran, N. Wilson, G. Wilson, N. Is screening for congenital colour vision deficiency in school students worthwhile? A review Clinical and Experimental Optometry 2014

7.3 Screening Test

7.3.1 Current BHFC Revisited Recommendations[172]

LogMar crowded acuity test

7.3.2 Update on the Evidence and recommendations for Best Practice

- UK NSC recommends LogMar crowded acuity test. This is also endorsed by the UK Royal College of Ophthalmologists
- New Zealand and Australia recommend Parr letter-matching or Sheridan Gardner charts

7.3.3 Way Forward/Recommendations

LogMar crowded acuity test should be used.

7.4 Personnel

7.4.1 Current BHFC Revisited Recommendations[172]

- Ideally, screening should be carried out by orthoptists.
- Designated school nurses are required for school vision screening.
- Children with special needs should be screened by orthoptists

7.4.2 Update on the Evidence and recommendations for Best Practice

UK National Screening Committee Nov 2013	***Healthy Child Programme Schedule 5-19 years, UK***	***Northern Ireland***
Screening for visual impairment between 4 and 5 years of age should be offered by an orthopic-led service.	Undertaken by school nurse	Undertaken by school nurse

New Zealand

Should be undertaken by vision and hearing technician or other competent health professional.

Australia

In 2009, the National Children’s Vision Screening Project undertook a systematic review of the effectiveness of vision screening programme. Child and family nurses with appropriate training can be employed as primary screeners.

7.4.3 Way Forward/Recommendations

In practice there is not a sufficient number of orthopists to carry out this service in Ireland. Therefore dedicated school public health nurses should continue to provide the service with specialised training led by an orthopist where possible.

7.5 Referral Criteria

Clear referral criteria

- Visual acuity of less than 6/9 in one or both eyes
  OR
- Difference of more than one line between both eyes

7.5.1 Update on the Evidence and recommendations for Best Practice

Need to amend criteria in line with LogMar test – under review as part of the Primary Care Eye Service Review

Chapter 8 Medical Examination – UDT & DDH

8.1 Current Irish Recommendations - Undescended Testes

BHFC recommended assessment for Undescended Testes (UDT) at four contacts - Birth; Six – eight week check; 7-9 month check; 3.25-3.5 years (check only if descent not previously recorded).[169]

These recommendations were superseded by BHFC Revisited,[172] which recommended assessment for UDT at Birth; Post-natal visit; Six – eight week check; Three months, with referral at three months if appropriate.

BHFC Revisited also underlined the importance of checking for descent at any age if descent has not previously been documented. The nine-month check was a nodal point to ensure that UDT was documented and appropriate referral action had been taken but was not a key assessment point.

The Faculty of Paediatrics (RCPI) and HSE algorithm (drafted by the National Paediatric and Neonatology clinical programme) recommends examination of the newborn with referral to OPD or GP review if testicle is undescended but palpable. If it is not descended at 6 weeks then the GP should either refer to a surgeon or to a paediatric clinic for review by six months. Any child with an undescended testicle at six months should be referred for surgical assessment.

Of note, the current UK National Screening Committee (NSC) policy is that there should be a systematic population screening programme for UDT. The examinations are done at birth and at 6-8 weeks as part of the routine physical examination.

8.2 Review of Evidence - Undescended Testes

8.2.1 Natural History

UDT is a common congenital condition in boys (3-5% at birth; 15% of them bilateral) but 80% of the testes descend by the age of one year, giving a one-year rate of 1%.[220] It is more common in premature babies at birth (30%) and there is a familial association. Testes do not descend after one year[221].

Boys with undescended testes are at increased risk of malignancy, infertility, torsion and self-esteem issues related to appearance. It is debate whether orchidopexy reduces the risk of complications but overall international opinion is that there is benefit in operating on UDTs and there is no reason to delay operation beyond one year, as spontaneous descent does not occur after that age. To maximise any reduction in risk, all surgical procedures should be complete by 18 months.

Boys with retractile testes have an increased risk of ascending testes, usually around aged 8-10 years. Research shows no advantage to early surgery with these boys so, generally, if the testes have previously been documented as descended then a 'watch and wait' protocol is followed until puberty.

8.2.2 Assessment and Treatment

Assessment for UDT is by physical examination. There is no role for imaging or ultrasound in establishing whether a testicle is palpable or non-palpable. Several publications describe the appropriate technique for examining boys to establish whether they have UDT.[222,223]

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[220] European Society for Paediatric Urology (2011) Guidelines on Paediatric Urology. Accessed at www.uroweb.org/gls/pdf/22%20Paediatric20%Urology_LR.pdf on 15 07 2014

[221] Perez-Brayfield M, Cendron M et al (2013) Pediatric Cryptorchidism Surgery Accessed at http://emedicine.medscape.com/article/1017420-overview on 15 07 2014

[222] European Society for Paediatric Urology (2011) Guidelines on Paediatric Urology.

The clinical examination should assess whether the testicle is palpable or non-palpable. Palpable testes should be examined to establish if they are retractile (able to be manipulated back into the scrotum) or truly undescended.

Because a testicle does not descend spontaneously after one year of age, there is little benefit in delaying a definitive procedure much beyond that age. Boys who have not got documented descended testes bilaterally should not have referral for assessment and treatment delayed beyond one year of age. Boys with retractile testes should be followed up until puberty as there is an increased risk that they will have an ascending or acquired UDT (32% risk). Treatment is by surgery.

8.3 Conclusions and Recommendations - Undescended Testes

The evidence for the benefits of screening for UDT remains the same as it was for BHFC and BHFC Revisited.

The method of examination (physical examination by a trained operator) remains the same.

However, the BHFC Revisited schedule should be updated to ensure that the resources are used to focus on early detection, appropriate second tier review and earlier and appropriate surgical intervention.

The screening programme is not currently achieving satisfactory outcomes. This may relate to issues with the screening programme itself or with the clinical care services that are needed to respond to the screening programme findings.

The following amendments to the BHFC revisited schedule are recommended:

1. The examination at birth should continue with a clear algorithm on actions to take if both testes are not descended
2. The schedule should be amended to ensure that a definitive decision re testes is made on all boys at or before the 6-8 week check. Either descent is recorded or a referral is made to the appropriate services for further assessment and management. That management may include watchful waiting until 6 months with a decision re surgical intervention if appropriate at 6 months.
3. The three month physical examination is not needed but PHNs should use any contacts during the first six months to ensure that the testes status is recorded and appropriate action has been taken.
4. Children who move into an area should have the testes status checked. Protocols should be in place for appropriately trained staff to examine the testes if it is not recorded.
5. Surveillance protocols should be developed to ensure boys with retractile testes are kept under review until puberty

The following recommendations relate to improving the overall outcomes from the screening programme and include recommendations about the whole pathway:

1. The whole pathway from birth to operation should be redefined with standards, competencies and an appropriate monitoring framework to ensure that outcomes are achieved.
2. The existing services/pathway needs to be audited and ‘deconstructed’ to establish what the barriers are to quality. Full implementation will require an understanding of acute services capacity, maternity capacity and child health

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[223] Undescended and Maldescended Testes (2012) Accessed at www.patient.co.uk/doctor/undescended-and-maldescended-testes on 15 07 2014

capacity. This should include assessment of out-patient/in-patient/theatre/paediatric surgical operative capacity/maternity ward capacity and the skills capacity to deliver the programme. The delivery of the GP 6-8 week check should also be included. A review group, to include the key stakeholders, should undertake this pathway/capacity review.

3. Training and audit will be required for all parts of the pathway.
4. Health care professionals who support parents and children in the first year of life should be aware of the importance of referral by 1 year of age.
5. The delivery agent for the examination should be considered in the context of other decisions about the neonatal and infant physical examination to ensure that the screening is holistic for the child and parents
6. Surgical treatment of all boys by 2 years of age should remain a core standard/KPI. A developmental standard of surgical treatment of all boys by 18 months should be considered.
7. A pathway should be designed for boys with retractile testes to ensure they are reviewed appropriately until puberty.
8. A protocol to deal with boys who move within or into Ireland after 1 year of age needs to be developed.
9. The National Clinical Care Programme for Paediatrics and Neonatology drafted their algorithm in 2012. This is due for revision in Dec 2014. This revision should be done in the context of the child health review and with input from public health to ensure the implementation of a screening programme with a clear pathway and a monitoring framework

8.4 Current Irish Recommendations - Developmental Dysplasia of the Hips

BHFC recommended assessment for Developmental Dysplasia of the Hips (DDH) at Birth; Within 48 hours of discharge; Six week check; Three month check; and Seven to Nine month check.[169]

BHFC Revisited[172] recommended the same schedule and outlined the following tools/signs for detection:

1. Ortolani Barlow manoeuvre from birth until six to eight weeks of age
2. Symmetry of skin folds and range of movements/abduction and Galeazzi sign (Short thigh) from birth until walking
3. Recognition of risk factors (family history; breech presentation) and appropriate referral for DDH until walking age
4. Delayed walking beyond 2 years of age
5. Waddling gait

Neither report specified who should carry out the assessments.

In 2013 the National Paediatric and Neonatology programme, in conjunction with the Faculty of Paediatrics, Royal College of Physicians of Ireland (RCPI), developed an algorithm for DDH. It recommends Barlow and Ortolani tests within 48-72 hours of birth by an appropriately trained examiner. For the six-week check it says that Barlow and Ortolani are unreliable and recommends that examination is for limited abduction of the lower limb on the affected side. It says babies with a parent or sibling with DDH and babies who were breech presentation should have a hip ultrasound at 6-8 weeks or hip X-ray at 4 months. It recommends that all professionals who examine hips must receive formal training in the technique.

8.5 Review of Evidence - Developmental Dysplasia of the Hips

In 2013, the Cochrane Collaboration undertook a review of screening programmes for DDH in newborn infants[224]. This review found that the evidence in general was poor. However, with that caveat, it concluded that if ultrasound was performed on all infants in addition to clinical examination, then the rate of treatment increased with no significant difference in the rate of late detected DDH or surgery. Targeted ultrasound screening to high risk infants did not increase the rate of treatment but also did not reduce the rate of late detected[225] DDH or surgery. For infants with clinically unstable but not dislocatable hips or for babies with mild dysplasia on ultrasound, then delaying treatment by two to six weeks reduces the need for treatment without a significant increase in the late diagnosed DDH.

Maxwell et al[226] report on the outcomes of a quality improvement initiative to reduce the incidence of late-diagnosed DDH. They found that improvements to the screening processes can reduce late incidence. They improved staff training, increased the use of ultrasound, provided quicker access to paediatric orthopaedic surgeons. They also noted that some affected children had risk factors that weren’t acted on and attention to this could reduce incidence further.

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[224] Shorter, D. Hong, T. Osborn, DA. Screening Programmes for developmental dysplasia of the hip in newborn infants (Review) Evidence-Based Child Health 2013; 8:1: 11-54

[225] Late detected = after eight weeks of age

[226] Maxwell, SL. et al Clinical screening for developmental dysplasia of the hip in Northern Ireland BMJ 2002; 324: 1031-3

8.5.1 Natural History

DDH (previously known as congenital dislocation of the hips) is a term used to describe a spectrum of pathology, ranging from mild acetabular dysplasia with a stable hip through to more severe forms of dysplasia, which can be associated with subluxation or dislocation[227]. It is estimated that approximately 1-3% of babies are affected by some form of the disorder, with one to two in 1,000 babies born with a hip that is dislocated at birth. The use of ultrasound to assess hips has increased the prevalence of the abnormality, although this may not reflect clinically significant dysplasia. The natural history of the disorder is not fully understood.

The major risk factors for DDH include family history, breech presentation (17-fold increase for vaginal delivery; sevenfold for elective caesarean section), birth weight over 5 kgs and congenital calcaneovalgus foot deformities.

Early detection is important to prevent soft tissue contractures, which increase the likelihood of surgery being required. However, neonatal tissues are lax and an unstable or even dislocatable hip may stabilise as the soft tissues tighten. Most unstable hips stabilise spontaneously by two to six weeks of age[228]. There is uncertainty about late-presentations and whether, in a country with a screening programme for DDH, they represent screening failures or true late disease.

8.5.2 Assessment

Current practice in the UK is to use an assessment of risk factors, clinical examination and targeted ultrasound examination. The main risk factors used are family history and breech presentation.

Neither Australia nor New Zealand has a countrywide policy. The policies vary from decision-making based on clinical examination alone to ones based on clinical examination and risk factor assessment. The protocols also vary between whether early ultrasound is used or later X-ray is the assessment of choice.

The first examination is usually within 72 hours and usually prior to discharge for hospital births. The timing of the second examination is variable but is usually between 6-8 weeks. NSW includes an extra examination between one to four weeks but it is not clear whether in practice this is actually to pick up babies that left hospital without the examination or were born at home. Only Northern Ireland and Ireland have an additional hip screening contact beyond six to eight weeks (NI at 14-16 weeks and Ireland at the seven to nine month check).

The clinical examination in all countries is based on the same tests as outlined in BHFC revisited although other countries consider that the Ortolani test (which aims to relocate a dislocated femoral head) and the Barlow test (which attempts to dislocate an articulated femoral head) become unreliable after 3 months (rather than at six to eight weeks). After three months they are more difficult to do and interpret because of the development of muscle tone and soft tissue contractures. Assessment in older infants relies more on other signs such as limited hip abduction (considered the most reliable sign), unilateral femoral shortening and asymmetrical thigh skin folds (considered unreliable on its own). In children of walking age limping and waddling gait may be pointers to a late diagnosis of DDH.

Ultrasound and X-rays are used for further investigation of hips if required. Ultrasound is most useful in the first four to five months. After that X-ray is preferred. In general, babies with a positive clinical examination (+/- risk factors) are referred for an opinion and an imaging investigation. If they are a newborn (or less than 6 weeks old) then the

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[227] Sewell, MD. Rosendahl, K. and Eastwood DM Developmental dysplasia of the hips BMJ 2009; 339:b4454

[228] Sewell MD, Rosendahl K, Eastwood DM (2009) Developmental dysplasia of the hips. BMJ 339:b4454

ultrasound is usually delayed until they are 6 weeks old (although England recommends that they have an ultrasound at two weeks old). If they are over six weeks but not yet 4 months they will usually have an ultrasound. If they are over four months they will usually get an X-ray. England specifies that the baby should have a specialist opinion by four weeks. The other countries recommend referral but do not have specific time frames (although some imply that the opinion may be immediate and before the imaging). In general, babies with risk factors alone will be referred for ultrasound and surveillance. The ultrasound is usually at six to eight weeks.

8.5.3 Treatment

The main early treatment is a Pavlik harness ('splinting'). This allows loose capsular soft tissue to tighten and tight adductor muscles to stretch and therefore stabilises the hip. There is one study of 332 babies that found when splinting is started before 90 days of age only a small percentage of children (5.7%) require further treatment[229]. The harness is not so effective if it is started after six to eight weeks. Bracing may then be required. There is some evidence that stable hips with mild dysplasia on ultrasonography can be observed safely for six weeks before a decision to treat is made.

If splinting fails then surgery may be required. Also, children who present at a later age will require surgery. The older the child, the more extensive the surgery is likely to be. The most common operation is a closed reduction. Older children will require an open reduction. Over 18-24 months then the child will also require pelvic or femoral osteotomy (or both)[230].

8.6 Conclusions and Recommendations - Developmental Dysplasia of the Hips

8.6.1 Conclusions

Early detection of DDH is key to ensuring good outcomes for children. However, the evidence is poor on how achieve this. Universal ultrasound increases treatment rates and is not recommended. Decision making based on assessment of risk factors and clinical examination and targeted ultrasound assessment is the favoured schedule. Improvements to the quality of the screening programme can improve the outcomes. This includes acting appropriately and in a timely manner on findings.

The hip screening programme in Ireland is broadly in line with international practice, although it has two examination points after six – eight weeks, which are not recommended in other countries. However, the pathway is not well-described, there are no standards and there is no national audit programme to measure performance.

8.6.2 Recommendations

There is evidence that the hip screening programme in Ireland is not achieving acceptable outcomes for children. There are opportunities to improve the quality of the Irish screening programme and the following recommendations are suggested for consideration:

1. Ireland continues with a screening programme based on risk factor assessment and clinical examination with targeted ultrasound of babies and infants with positive clinical findings and/or positive risk factors. Risk factor identification should start in the antenatal period and mothers with a family history should be informed that some follow up will be required. The schedule should be revised, in line with international practice, and concentrate the screening examinations at

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[229] Cashman JP et al (2002) The natural history of developmental dysplasia of the hip after early supervised treatment in the Pavlik harness. A Prospective longitudinal follow-up. J bone Joint Surg Br 84:418-25

[230] Sewell MD, Rosendahl K and Eastwood DM (2009) Developmental dysplasia of the hips. BMJ 339:b4454

birth and six weeks, with a clearer pathway to ensure appropriate actions are taken on foot of these examinations.

2. The Irish DDH screening programme should aim to detect DDH at the earliest possible point for all children. The evidence supports that children who require splinting should be in treatment by 90 days of age to get the best outcomes. The pathways and the standards should be developed to ensure that this is achieved.
3. A clearly defined pathway for screening should be developed, modelled on the English process mapping.
4. There should be standards for the programme with appropriate data collection to monitor the quality of the programme.
5. Anyone delivering the programme should be trained and competent. The training and the competency framework should be defined. Training should be accredited.
6. Organisations delivering the programme should audit the programme and be accountable for meeting the standards.
7. There needs to be a clear monitoring framework with clear responsibility and accountability for delivering to the standards and achieving the desired outcomes. All contributors to the programme need to be engaged. This includes midwives, obstetricians, paediatricians, orthopaedic surgeons, radiology (including ultrasonographers), GPs, PHNs, SMOs, managers.
8. Indicators should be meaningful and adequately reflect both process and outcome measures (including harness rates, surgery rates and late-detection rates)
9. There should be local accountability /monitoring committees (these may not need to be single-issue committees – they could take in other aspects of the child health screening and surveillance if appropriate). The PMOs would be well placed to lead these committees as part of a wider role on assurance of child health services.
10. The standards for ultrasound and x-ray delivery should also be defined. The capacity to deliver the volumes to the standards in a timely manner should be assessed and addressed
11. The capacity for timely paediatric orthopaedic assessment should be assessed and services aligned to deliver to the standards of the programme, bearing in mind that an enhanced programme may reduce the need for some of the resources currently being used to ‘back-up’ the programme
12. The treatment pathway should be nationally agreed by the appropriate stakeholders and rolled out with appropriate standards to reflect timeliness, investigation, treatment and competence. This should include the requirements for Allied Health Professional (AHP) input.

8.7 Enuresis Review

8.7.1 Background

At its inaugural meeting, the Child Health Model Review Steering Group asked that the management of enuresis be included in the scope of the group. This review has been prepared in response to that request.

This paper presents information on the current evidence-based guidance on treating nocturnal enuresis and makes suggestions for how the child health services can support parents and children in managing this condition.

8.7.2 Introduction

Gaining control of both urinary and faecal continence is a process that all children are expected to go through. There are accepted developmental norms for daytime and night-time continence but parental (and societal) expectation may differ from developmental norms. The prevalence of bedwetting less than twice a week at four and a half years of age is approximately 21% and decreases to about 8% at nine and a half years old. More frequent bedwetting is less common (approximately 8% at four and a half and 1.5% at nine and a half[231]). Therefore, nearly a quarter of all children in Junior infants, who are overall developing normally, will still be wetting the bed. In addition, up to 15.5% of children aged 4 and a half years old have daytime wetting and up to 29% have daytime faecal incontinence[232].

Bedtime urinary continence (nocturnal enuresis or 'bedwetting') is a common and stressful condition for both parents and children. Reflecting the spectrum of 'normality', its prevalence decreases with age.

Parents and children can be supported in the process of gaining continence with advice, support and more specialist assessment and management techniques.

Continence may take longer to achieve in children with learning difficulties, for example, Down's Syndrome and autism. Continence problems are also more prevalent in children with physical disabilities such as cerebral palsy and spina bifida. Looked after children have a higher prevalence and children with emotional distress may also present with continence problems.

8.7.3 Review of guidance

In 2010, the National Institute for Health and Care Excellence (NICE) in England produced comprehensive evidence-based clinical guidance for the management of bedwetting in children and young people. The guidance covers the principles of care, the information recommended for children, young people and their families; assessment and investigation; planning management; and appropriate strategies and treatments to use, in a stepped approach, to treating bedwetting. The main management strategies are advice on fluid intake, diet and toileting patterns; reward systems; treatment with alarms; and treatment with desmopressin. The guidance discusses management of children and young people who experience recurrence of bedwetting and management where there is a lack of response to the initial treatments. These include consideration of anticholinergics and tricyclics. It also offers guidance on supporting and advising parents of children under-five who are bedwetting.

The NICE Guidance is supported by other guides such as a costing statement, which gives prevalence of bedwetting by age group, and by a commissioning guide for a paediatric continence service. Because urinary incontinence can be associated with constipation and other faecal continence issues, the guidance on bedwetting refers readers to the NICE guidance on constipation as a key reference document when

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[231] NICE Clinical Guideline 111 (Oct 2010). Nocturnal Enuresis: The management of bedwetting in children and young people

[232] NICE Commissioning guide (2010) Paediatric continence service

considering how to manage children with enuresis and how to deliver a service to this cohort[233].

There is also European guidance on evaluation and treatment for monosymptomatic enuresis[234]. This has been developed by urologists and nephrologists and is based on a combination of literature review and experience of the authors. One of the authors was the chair of the NICE CG 111 Guideline Development group. As a European document , the discussion on what settings the child should be assessed and treated in is not entirely applicable to the Irish Health service structures. It differs from the NICE guidance in several areas – the approach to investigation, some elements of the advice given and it does not refer to reward systems. Otherwise the hierarchy of treatment is the same as the NICE guidance.

8.7.4 Modelling Prevalence in Ireland

NICE clinical guidance (CG111) costing template provides estimates of prevalence by age group for children aged 5-18 years in England. Assuming that the prevalence by age group is the same in Ireland as it is in England, Table 10 estimates the number (and rate per 100,000 total population) of children by age group in Ireland with enuresis. This gives an estimate of the total number of children between 5 and 17 years of 63,496 with bedwetting. The NICE guidance states that children under 7 years (the traditional minimum age for referral into secondary services) should not be excluded from the management of bedwetting on age alone. However, for a lot of these children the bedwetting will have resolved spontaneously by 7-years of age (the prevalence drops from 25.3% of five year olds to 16.4% of 7-year olds). If the 5- and 6-year olds are excluded, then the prevalence of enuresis in for 7-17 year olds is 793 per 100,000 total population.

Table 10 Estimates number of children by age group in Ireland with Enuresis.

	Population of Ireland*		**Prevalence of bedwetting****		
	Total	**Per 100,000**	**(%)**	**Total population**	**Per 100,000**
All ages	4,588,252	100,000	N/A	N/A	
5yrs	64,937	1415	25.3%	16,429	358
6yrs	64,976	1416	16.4%	10,656	232
5-6yrs	**129,913**			**27,085**	**590**
7yrs	64,441	1404	16.4%	10,568	230
8-10 yrs	187,845	4094	9.2%	17,281	376
11-14 yrs	241,062	5254	2.5%	6026	131
15-17 yrs	169,097	3685	1.5%	2536	55
5-17 years	**792,358**	**17,269**		**63,496**	**1382**

*2011 figures taken from P10 State of the Nation's Children 2012;

**Applying NICE estimates

Table 11 presents the estimates of the number of children who will require advice and management for enuresis by Community Healthcare Organisation (CHO) area[235]. It

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[233] NICE Clinical guideline CG99. 'Constipation in children and young people: diagnosis and management of idiopathic childhood constipation in primary and secondary care.'

[234] Neveus et al (2010) Evaluation and Treatment for Monosymptomatic Enuresis: A standardised document from the International Children's Continence Society. The Journal of Urology. DOI:10.1016/j.juro.2009.10.043

[235] Community Healthcare Organisations report (2104) HSE. Accessed on www.hse.ie

includes the traditional cohort of children aged 7 years and over and the expanded NICE cohort that includes 5 and 6 year olds. The document laying out the plan for the CHO areas describes a primary care network as having a population of 50,000. Therefore, there will be 396 children aged 7-17 years per primary care network requiring enuresis care and 691 in the expanded 5-17 year old cohort.

Table 11: Estimates of number of children with enuresis by CHO areas

CHO area	**Population***	**Estimate of Number of enuresis cases (Excluding 5 & 6 year olds)**	**Estimate of Number of enuresis cases (aged 5-17 years)**
Area 1	389,048	3,081	5,376
Area 2	445,356	3,527	6,154
Area 3	379,327	3,004	5,242
Area 4	664,533	5,263	9,183
Area 5	497,578	3,940	6,876
Area 6	364,464	2,886	5,036
Area 7	674,071	5,338	9,315
Area 8	592,388	4,691	8,186
Area 9	581,486	4,605	8,036

*Source: Community Healthcare Organisations report (2014)

8.7.5 Delivery models

The NICE commissioning guide for paediatric continence services recommends providing integrated paediatric continence services. This includes both integration of professionals in a multi-disciplinary services and integration of management of urinary and faecal incontinence conditions. Constipation is an acknowledge cause of enuresis and so there are benefits to integrating the services and providing a child-centred approach. Also, children with disabilities are more prone to constipation and delayed attainment of, and ongoing issues with, both urinary and faecal continence. In particular, children on the autism spectrum often present difficulties with constipation. An integrated service that caters for children with disabilities has the potential to reduce in-patient admissions and improve quality of life for these children and their families. Children in care have a higher prevalence of continence problems. Enuresis may be a response to emotional difficulties and professionals should be alert to the possibility of child maltreatment.

Using a ‘progressive universalism’ model, then the majority of 4-7 year olds and their families will only require support, information and basic guidance on how to deal with enuresis. Those who do not respond to the universal approach or have co-morbidities will require further targeted interventions, which include assessment, reiteration of advice and strategies for first line management and the options of alarms and desmopressin. A smaller number will require more complex interventions and/or more specialist investigations. The NICE commissioning guide suggests an indicative benchmark for a paediatric continence service (i.e. a service to manage both urinary and faecal continence issues) of 0.8% or 800 per 100,000. This would mean providing a service for approximately 400 children per primary care network area in Ireland.

The NICE commissioning guide on paediatric continence services provides examples of different approaches in the UK. The guide details the following benefits of an effective paediatric continence service:

1. Greater awareness of continence problems resulting in improved identification, early intervention and faster referral-to-treatment times

2. Reducing costs resulting from inappropriate referrals to paediatricians and preventing unplanned hospital admissions for children and young people with abdominal pain caused by chronic constipation
3. Improved clinical outcomes and quality of life for children and young people and their families
4. Increased clinical and cost effectiveness by basing the commissioned service on NICE guidance so using resources more effectively

They identify the key clinical issues as:

1. Increasing awareness of continence problems
2. Improving assessment and reducing unnecessary invasive examinations and procedures
3. Providing a 'whole-child' approach so that complex and co-morbid problems can be treated appropriately
4. Providing a quality assured service

The basic components of the management of enuresis are:

1. Basic advice on toilet training and associated factors (such as weaning, diet, physical activity)(universal) – tailored to the child and family during the ongoing child health contacts
2. Support for first line training in younger children – advice, tips for reducing impact, basic reward training
3. Referral to a continence service for further assessment and next line of management
4. Assessment, classification (e.g. monosymptomatic) and reiteration of first line approaches – reward systems, fluid management
5. Treatment with alarms
6. Medication – Desmopressin then other pharmacological agents
7. Management of children with non-monosymptomatic enuresis
8. Management of constipation
9. Combined assessment of soiling

The majority of the services can be delivered within primary care. Currently stages 1 and 2 above are provided through the universal PHN provision. The arrangements for the other stages vary around the country. There is a 'Consultant Paediatrician-led, Public Health Nurse delivered' model operating in Cavan and Monaghan[236] since 2004.

There is evidence that early assessment and treatment combined with a co-ordinated service has the potential to reduce the resources required and improve patient outcomes.

8.7.6 Conclusion

Enuresis is a common and stressful problem in children and young adults. Its prevalence decreases with age. It can be associated with constipation and other continence problems. Using NICE estimates of prevalence, there will be between 400 and 700 children and families per 100,000 population requiring some input from services to support them in achieving continence at night.

The main treatment options, after appropriate assessment, are support and advice, reward schemes, alarm systems and desmopressin. NICE recommends that treatment of

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[236] A Consultant Paediatrician Led and Public Health Nurse (PHN provided Community Enuresis Clinic as a Model of Care. Noone D, Van der Spek N, Waldron M. Ir Med J 2011 Feb; 104(2):44-5

continence problems is integrated, with an estimate of an overall prevalence of 0.8% (800 children per 100,000 population requiring a service).
There is no documented description of current services in Ireland. The majority is provided by PHNs through their universal child health provision. This is supplemented in some areas by other services, for example a paediatrician led service in Cavan/Monaghan.

8.7.7 Recommendations

The Public Health Nursing service currently provides the universal provision aspect of enuresis management. There is scope to build on this expertise and to use the medical skills of the Senior Medical Officers in Community Medical Services to deliver a community (now primary care)-based paediatric continence service. This service would provide a holistic assessment and management of children with continence problems who have not had their needs met by the universal approach. Depending on the resources available in each area, it could include the management of a spectrum of children from those with isolated enuresis to the children with complex continence problems related to disability. The developmental aim of each service should be that it will eventually cater for the whole spectrum. In addition to the on-going working relationships with the other primary care-based services for children, there should be links with the Paediatric services, the early intervention teams, CAMHS and TUSLA.
Based on this paper, it is recommended that:

1. Any development of enuresis services should be based on the NICE clinical guidance (CG111)
2. A mapping of current enuresis provision should be undertaken to assess the current resources being used, what elements could be used in a redesigned service and what element of resource will be freed up to support the case for an enuresis service.
3. The NICE audit tool, which relates to the clinical interaction, be used in existing services to identify the areas for improvement
4. Based on the NICE guidance (CG111), there should be national standards developed as part of the Child Health review, to guide any future developments
5. Each LHO (soon to be Community Healthcare Organisations) should consider their current provision for enuresis services and how they will deliver a paediatric continence service, using the national standards. NICE recommend that the following be considered in doing this:
    - Required competencies of and training for staff providing the service
    - Expected number of children and young people in the area
    - Ease of access and service location
    - Care and referral pathways
    - Measuring outcomes
    - Information and audit requirements
    - Planned service development
    - Address safeguarding concerns
    - Other service remits such as awareness raising
    - Service monitoring criteria

6. The model should be, as described above, a multi-disciplinary service with the core members being PHNs and SMOs, where human resources allow. The service should be linked to the paediatric service for clinical governance. There should be a clear pathway for children and their families

7. There should be a training programme for health care professionals dealing with continence
8. There should be a training programme for other non-health workers who work with young children (child care workers, teachers) to improve the awareness and understanding of continence issues

Chapter 9 Health Promotion/Health Education

9.1 *Background to the review:*

The objective of this review is to carry out a desktop exercise of the evidence on the effectiveness of the health promotion activities, as recommended by Best Health for Children (BHFC) Revisited, to be carried out as part of the Child Health Screening and Surveillance (CHSS) service delivered by health professionals during core visits.[172] The CHSS service does not currently include care provided antenatally.

A national framework for Child Health, within which the CHSS service would sit, is not currently in place. Such a framework would be based on the concept of progressive universalism, i.e. all children/families need some services while some need more, and would outline a common needs assessment framework, the pathways to services and the matrix of services and supports which would be available for families as their needs ebb and flow.

This review takes place against a backdrop of a review of community nursing services and of the possible expansion of free GP services to all children under 6 year of age. While any possible changes in service configuration as a result will need to be taken into account as part of this review of the CHSS, the evidence about effectiveness of interventions should concentrate on the skill base of service providers rather than on their professional backgrounds or on service configurations.

9.1.1 Limitations to the review

This review is not inclusive of the views of stakeholders or area specialists. It does not constitute a systematic review of all the evidence for all the topics suggested to be addressed in the CHSS service. It does, however, point to available evidence sources. It is understood as a preliminary exercise to inform the future work on child health. A review of what CHSS training has taken place, how the CHSS services are currently being delivered and the views of current service providers would be helpful in understanding how best to move forward.

9.2 Current Health Promotion and Education Programme

BHFC Revisited outlines what health education and promotion topics are to be addressed in the course of all core child health visits (See Table 12). These visits range from Birth to School exit, but are mainly concentrated on the early years. It is unclear if some or all topics are to be addressed at each visit or if the health professional will decide how best to address these issues with each individual parent.

The Training Programme for Public Health Nurses and Doctors for Health Promotion (Unit 1) is supported by a draft review of the evidence base for child health promotion and the outline of a one-day training course on health promotion and education [237]. The training programme covers ‘how to’ engage in partnership with parents*, the determinants of child health and the evidence and good use of health promotion resources.

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[237] HSE (2004) Training programme for Public Health Nurses and Doctors – Unit 1 Health Promotion.

* The term ‘parent’ in this document is used to include all parent/s, carer/s and/or guardian/s involved in major caring role/s with a child

Other BHFC Training Manuals address some of these Health Promotion topics in separate and more fully described sections, such as ‘Oral/dental health’, ‘Food and Nutrition’, ‘Growth monitoring’ and ‘Infant and Child Emotional and Mental Health’. The ‘Food and Nutrition’ and ‘Infant and Child Emotional and Mental Health’ training modules were added to the training syllabus subsequent to the publication of BHFC Revisited and, therefore, there are not specific sections in this document on these topics.

Table 12: Health Promotion activities as described in BHFC Revisited

Timing	History	Equipment	Health Promotion
Birth	Parental concerns	Skills to work in partnership with parents on all issues related to their baby's health and well being Mechanisms to support multidisciplinary and interagency working	Parental health and well-being Prevention of SIDS Transport in cars Feeding practice Sibling management Parent-infant interactions Child development Accident prevention Information about local support networks and contacts for additional advice and support when needed Identification of parents who may be in need of additional supports
Postnatal visit	As above	As above PHR – MWHB *Caring for your child* – Health Promotion Unit, DoHC *Child Safety Awareness Manual* – MHB *Caring for your baby* (CHISP) – SEHB *Breastfed is bestfed* - NWHB	As above
6 to 8 weeks	As above	As above	As above Family planning
3 months	As above	As above	As above Oral health promotion Age appropriate play Return to work Child care
7 to 9 months	As above	As above	As above
18 to 24 months	As above	As above Mother and toddler groups	As above Management of challenging behaviour Toilet training
3 to 4 years	As above	As above Access to information on local playschools/pre-schools/schools	As above
School entry (Junior infants)	Parental and teacher concerns	Skills to work in partnership with parents on all issues related to their child's health and well being Mechanisms to support multidisciplinary and interagency working	As per SPHE programme Advisory and supporting role to teacher in SPHE
School exit (5th or 6th class)	As per school entry	As per school entry	As per school entry

Source: Best Health for Children Revisited 2005[172]

9.3 Definitions

A definition of health promotion which is often used is from the World Health Organization Ottowa Charter for Health Promotion and is as follows: *'The process of enabling people to increase control over and improve their health. It involves the population as a whole in the context of their everyday lives, rather than focusing on people at risk for specific disease, and is directed towards action on the determinants of health.'*[238]
A health promotion intervention is *'any planned and informed intervention which is designed to improve physical or mental health or prevent disease, disability and premature death.'*[201] Health promotion interventions can be applied at a number of the levels, including at public policy, community and individual levels.

Child Health Promotion is a concept that focuses health promotion on the child and his or her parents, family, community and society.

In England's 'Child Health Promotion Programme'[239]and the subsequent Healthy Child Programme,[203] the concept of Child Health Promotion includes:

- Disease prevention (primary, secondary, including screening and surveillance, and tertiary);
- Health protection (including immunisation) and
- Health education.

The Australian National Framework for Universal Child and Family Health Services[205] also sees Health Promotion activities as including primary prevention (immunisation), health education (SIDS prevention), anticipatory guidance (infant tired signs), parenting skill development (toddler behaviour) and providing support for parents (reassurance).

Hall defines Health Education as *'any activity which promotes health through learning, i.e. some permanent change in an individual's capabilities or dispositions.'*[201] This definition could include information sharing, opportunistic health promotion and/or brief intervention, role modelling and skill development.

It would seem that concepts outlined in the Health Promotion section of BHFC Revisited are more in keeping with the concept of Health Education, as defined by Hall, than of the broader concepts of Health Promotion, as outlined in England's 'Healthy Child Programme' framework and Australia's Framework, and it is interventions based on this concept which will be reviewed in this paper.

The term 'anticipatory guidance' is often used in describing information exchange in the child health setting. A definition of anticipatory guidance is 'guidance provided by an expert or knowledgeable group to those with a particular interest (e.g., parents), anticipating likely upcoming concerns, parents of newborns—informing them about physical changes in their infant (e.g., teething)'.

9.4 Policy Background

In recent years there have been a number of national policy documents which are relevant to the promotion of children's health and well-being. However, given the evidence base now available which shows that the foundations of lifelong health are built in early childhood, it is clear that the health of adults, including age-related chronic disease and

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[238] Accessed at: http://www.who.int/healthpromotion/conferences/previous/ottawa/en/

[239] http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/DH-286448.pdf

health inequalities, are also impacted by what happens in childhood. See Chapter 2 Health Inequalities and Chronic Diseases.

In addition, it is now known that investment in early intervention initiatives aimed at child development, educational disadvantage and parenting has been shown to provide a greater rate of return than later intervention with the most effective time for intervention being before birth and in early childhood. [240]

It is not surprising, therefore, that '*Healthy Ireland*', the national framework for action to improve the health and wellbeing of the people of Ireland , states that every child should have the best start in life.[191] One of its key action points recommends *'improving the capacity of parents, carers and families to support healthier choices for children and themselves.'*

The national policy framework for children and young people, '*Better Outcomes, Brighter Futures*', aims to support parents to parent confidently and positively.[190]
The Health Promotion Strategic Framework emphasises the importance of a settings based approach to promoting health [241].

The report of the National Taskforce on Obesity states that antenatal, post-natal, immunisation and other visits by and to healthcare professionals provide opportunities to support parents towards healthier choices in nutrition, including breastfeeding.[242] The 2005 action plan on breastfeeding similarly recommends that all families have the knowledge, skills and support to carry out informed infant feeding decisions. [243] The Food Safety Authority of Ireland provides recommendations for a national feeding policy.[244]

'*A Vision for Change*', the report of the expert group on mental health policy, advocates increasing emotional resilience through interventions designed to promote self-esteem, life and coping skills, such as communicating, negotiating, relationship and parenting skills.[245]

TUSLA, the Child and Family Agency, has developed a National Service Delivery Framework for the Agency, which will entail the development of a continuum of support from universal support to targeted and specialist services. [246] This is based on the different levels of parenting support and Hardiker's levels of need, with Level 1 providing preventive support to all parents at a universal level (See Figure M). Subsequently, TUSLA developed a policy document on investing in families which provided for further development of this strategy.[247] In it, it calls for the re-orientation of service provision by, for example, Public Health Nurses (PHN), Social Workers, Speech and Language workers, Clinical Psychologists, so that an agreed percentage of time is spent in/with promotion and prevention initiatives.

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[240] Carneiro P and Heckman J (2003) Human Capital Policy. National Bureau of Economic Research Working Paper 9495. Accessed at: http://www.nber.org/papers/w9495.pdf

[241] HSE (2011) The Health Promotion Strategic Framework

[242] Department of Health and Children (2005) Report of the National Taskforce on Obesity.

[243] Department of Health and Children (2005) Breastfeeding in Ireland – a five-year strategic action plan.

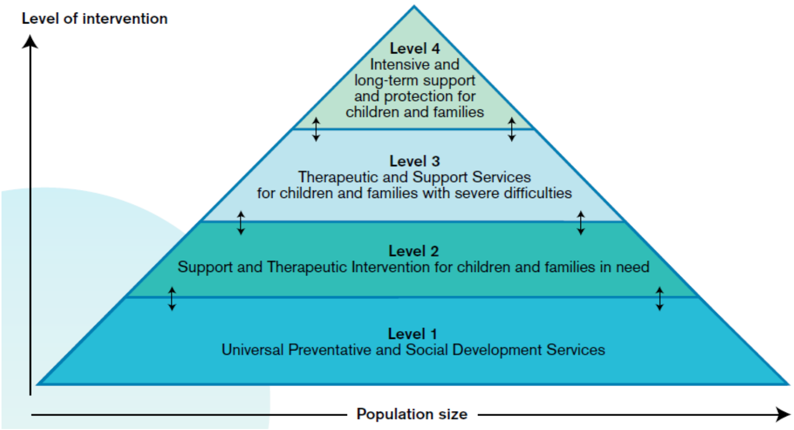
[244] FSAI (2011) Scientific recommendations for a national infant feeding policy, 2nd edition.

[245] Department of Health and Children (2006) A Vision for Change: Report of the expect group on mental health policy.

[246] Department of Children and youth Affairs (2012) Report of the Taskforce on the Child and Family Support Agency

[247] TUSLA (2013) Investing in Families: Supporting parents to improve outcomes for children.

Figure M: Hardiker Model



Source: Department of Children and Youth Affairs (2012) Report of the Taskforce on the Child and Family Support Agency

9.5 Parent Information and Skill Needs

The information needs of parents/carers have been studied in an Irish setting as part of the Child Health Information Service Project (CHISP). *Identifying the Child Health and related Support Service Information Needs of Parents/Carers from the Ante-Natal to Pre-School Years* examined parent information needs in relation to their child's health and well being, from their perspective, with a view to developing appropriate information and systems to meet these needs.[248] The conclusions from the literature review and from ten in-depth focus groups with parents/carers was that health information needs to be given in a timely and appropriate fashion. For the information to be useful, it needs to be based on individual perceptions of need and this can only be gained through careful assessment. Professional attitudes and listening skills were identified by the service users as areas of interpersonal communication requiring attention.

Within current service provision, there was a need for an appreciation that there are a diversity of groups and ethnic considerations and not one generic group requiring information. There is a need for appropriate and timely quality information in a variety of consumer friendly mediums, that best suit individual need at a given time.

In a similar study in the UK, parents had mixed views about child health surveillance and health promotion programmes.[249] While some valued the support of the health visitor, some found them judgemental and as making assessments of need based on socio-economic factors only.

More recently the NHS Heath Scotland published a 2012 research report, *Health and Parenting Information: meeting the needs of all parents*, which looked at the literature on effective approaches to providing information support for parents, and also conducted interviews/workshops with national and locally based service providers of parenting support.[250] This study only looked at the providers' perspective of information need rather than the view of parents themselves. The findings highlight that parents require information about a wide range of topics; about their child's health, parenting, child-parent

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[248] Conway, E. Identifying the Child Health and related Support Service Information Needs of Parents/Carers from the Ante-Natal to Pre-School Years 2003 South Eastern Health Board. Accessed at: http://lenus.ie/hse/bitstream/10147/78576/1/IDchildhealthsehb.pdf

[249] Roche, B et al. (2005) Reassurance or judgement? Parents' views on the delivery of child health surveillance

[250] Birth, A. and Martin, C. (2010). Health and Parenting Information: meeting the needs of all parents. Edinburgh: NHS Health Scotland. Available from http://www.healthscotland.com/uploads/documents/14027-Healthandparentinginformation.pdf

interaction, the wider family and about support services. They need this information, either on an ad-hoc, one-off or continuing basis.

Many groups of parents faced barriers to information support because of a lack of services, poor signposting to services, a lack of specific resources to meet their needs, child protection or financial concerns and fears of stigma. The study also found that parents who struggled to access or understand information needed personal support. This may be due to a lack of confidence, poor literacy or limited ability to understand complex information. Young parents wanted information which addressed them as young people as well as parents. The needs of fathers were unmet and attention is required for more father friendly materials. There is a need for an inclusive approach to service design and delivery for ethnic minority groups. The report recommended consultation with parents to understand what information they need and how they can best get it, e.g. through different media and technologies.

The companion report, *Exploration of the Information Support needs of Parents*, focused on parental perspectives of information support experiences, needs and preferences within three specific targeted groups: fathers, young parents and parents with literacy issues. [251] The report also looked at how parents obtained information and support in relation to parenting and child health issues. Information support was understood as the knowledge, skills or assistance provided by formal and informal sources to enable good parenting. Three overarching themes emerged from focus groups and interviews: parent information/support is undermined when parents feel marginalised; 'trust' shapes how information is sought, received and used; and parents respond most positively to personalised information and support.

Parents preferred personal, empathetic support from individuals in dealing with their specific needs for information and support on child health and parenting. They were not opposed to technological resources but regarded them as a supplement to individualised information and two-way respectful communication. They were keen to rely on medical and other health professionals to provide technical and immediate care for their children when required.

Parents spoke about being less confident about caring for newborns and about issues of feeding/diet, behaviour management, relationships and emotional/mental health. The lack of confidence carried with it their interest in acquiring additional information, advice and assistance to help improve their knowledge. They reported accessing a range of parent information/support sources and also indicated their openness to using a more diverse and more technological set of information/support sources. However, they particularly valued sources that provided personal, individualised, cumulative solutions to the issues and situations that they were currently facing in relation to their child.

Although parents in the study reported similarities in their parenting information support experiences, the report highlights the diversity within, as well as between the parent groups.

The New Zealand Ministry of Health report, *Parent Information Project*, looked at the best ways to provide on-demand Well Child information, advice and support to parents. [252] The Well Child programme is the national universal child health service in New Zealand. A literature review and survey of parents found that parents describe face-to-face contact with health professionals as the most important source of information. Therefore,

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[251] Allen, K., Collier, S., Kelly, C., Pates, A., Sher, J. and Thomson, C. (2012). Exploration of the Information Support needs of Parents. Edinburgh: NHS Health Scotland. Available from http://www.healthscotland.com/uploads/documents/19013-RE001FinalReport1112.pdf

[252] Ministry of Health. 2010. Parent Information Project. Wellington: Ministry of Health. Available from https://www.health.govt.nz/system/files/documents/publications/parent-information-project-report-final-v0.2-mar10.pdf

provision of information and advice on demand is intended to complement rather than be a substitute for face-to-face Well Child services delivered in the community. The main finding of this project has been that parents need different kinds of information, in different forms, at different times. These information services need to be reliable, accurate and trusted, and to reinforce the information, advice and support that parents receive through face-to-face services.

PHNs involved in the Growth Monitoring Pilot Project have requested that brief intervention (BI) and motivational interviewing (MI) training be made available to them to support the health promoting imperative in follow up work with parents of overweight/obese children picked up in school health screening.[253]

9.6 The principles of service provision as relevant to the promotion of children's health

One of the main principles in BHFC is the development by health professionals of a **partnership with parents and families**. There is substantial evidence confirming the effectiveness of parents in detecting problems with their children and identifying their needs.[172, 201] In addition, the physical, social and learning environment provided by parents has both a short term and long term effect on children's health. In order to foster this partnership work and in order to address a possible power imbalance between health professionals and parents, parents need good quality, evidence-based information to support them in their parenting tasks. Such information could include:

- Developmental norms
- Primary prevention, SIDS, injury prevention
- Promoting health, infant feeding and nutrition; parent -child bonding/attachment
- Promoting well being, reading
- Anticipatory guidance, sleeping difficulties; behavioural problems
- Links to additional information and supports

Parents are the most significant influence on children's development.[254] There is good evidence that using a strengths-based approach to support parents, by **promoting their self-efficacy** in their parenting role, works.[201,255] Core to encouraging this self-esteem and self-efficacy is understanding parents' beliefs and backgrounds and respecting their knowledge and skills.[256]

Developing the skill base of parents in their role is another key principle of promoting children's health, whether this is by encouraging positive parenting and good parent-child relationships or by developing parents' skills in promoting school readiness. Such support should include fathers, as well as mothers.[203,205,239,]

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[253] Roche M (2014) Personal communication

[254] Centre for Effective Services (2013) Prevention and early intervention in children and young people's services: Child health and development

[255] NICE (2007) Behavioural change: the principals for effective interventions.

[256] TUSLA (2013) What works in family support?

9.7 Evidence for Effectiveness of Health Education Interventions

There are different aspects in looking at the evidence base for health education for children's health services. These include looking at what works for:

(a) the approach or type of health education activity (whether this is information provision, anticipatory guidance, brief advice, brief intervention, promotional/motivational interviewing)
(b) more intensive parenting support (such as group parenting programmes; home visiting programmes, such as Family Nurse Partnership programme; peer-to-peer support, such parent and toddler groups)
(c) specific topics (such as SIDS, accident prevention)

Types of activities as outlined in (b) above are outside the scope of this review.

9.7.1 The approach or type of Health Education activity

A summary of the evidence supporting the approach to successful parenting[257] states that the core features include:

- relationship between practitioner based on trust, respect and careful listening
- recognising parents' knowledge about their own child and adapting elements of the service to align it with parents' goals and aspirations
- focusing on parents' strengths, building resilience and encouraging parents to find solutions for themselves
- the ability to promote attachment
- involving fathers
- ensuring that practitioners have the consultation skills required to be flexible and also the ability to assess risk and protective factors

The 2007 NICE guidance on behaviour change addressed the key techniques which should be used for behaviour change at individual, as well as at population and community level.[255] The 2014 review of this guidance re-confirmed the effectiveness of the 2007 guidance.[258]

The evidence for Brief Interventions and Motivational Interviewing, and guidance for practice, has been outlined in a HSE guidance framework document.[259] This focuses predominantly on alcohol intervention but does cover other issues.

Reviews of anticipatory guidance identified improved outcomes in child health.[260,261] In particular, the evidence supported improved outcomes on the parent-child relationship, sleep patterns, injury prevention and reading.

One example of targeted anticipatory guidance is the Bright Futures schedule in the United States which directs anticipatory guidance to the five priorities of each child health care visit. Guidance is provided in the form of questions to the parents to inform the health professional, identifying risks and providing strategies to parents on how best to manage particular situations.[262]

The evidence also suggests that non face-to-face formats, particularly web-based tools, could enhance anticipatory guidance.[263]

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[257] Department for children, school and families (2009). Healthy Child Programme.

[258] NICE (2014) Behaviour change: individual approaches

[259] Evans D et al (2011) Brief interventions and motivational interviewing: literature review and guidance for practice

[260] Nelson C, Wissow L and Cheng T (2003) Effectiveness of anticipatory guidance: recent developments

[261] Regalando M and Halfon N (2001) Primary care services promoting optimal child development from birth to age 3 years

[262] Hagan Jr J., Shaw J. & Duncan P. (eds.) (2008), Bright Futures, Guidelines for Health Supervision of Infants, Children and Adolescents, third edition, The American Academy of Pediatrics, Illinois.

[263] Tumaini R et al (2013) Well-child care clinical practice re-design for young children: A systematic review of strategies and tools

The HSE document *Good Practice Guidelines for Using Health Promotion Information Materials* is a useful resource for those using materials for different audiences.[264]

As mentioned above, it is important that professionals are skilled in adapting to the needs of parents and to opportunities presented. Parents value appropriate support during key transition points, such as transition to parenthood,[265] and professionals should develop the skill of recognising 'teachable moments.[266] If overloaded with information, however, messages lose their impact.[201] Parents recall of health promotion and anticipatory guidance decreases with increasing numbers of topics set for each discussion.[267] So the targeting and tailoring of messages at each contact is likely to improve the effectiveness of the activities.[255]

A review of the literature on work re-design and health promotion in healthcare organisations, commissioned as part of the *Making Every Contact Count* strategy which has been rolled out in some NHS areas, found that, as healthcare organisations still remain largely illness rather than health centred, some practitioners and managers exclude themselves from a wider 'community of public health practice', with the result that health promotion becomes de-prioritised.[268] The review suggests, therefore, that co-ordination, integration and capacity building are important in embedding organisational routines and sustaining behavioural change.

9.7.2 Evidence sources for different Health Education topics

While there is much evidence for a number of topic-specific interventions relating to early childhood health, many of these interventions are delivered over a number of visits and as part of a specific initiative on that topic. This review attempts to look at interventions which could be reasonably delivered as part of the core child health programme.
As described previously, anticipatory guidance has been shown to improve outcomes on the patent-child relationship, sleep patterns, injury prevention and reading.[261]

A recent review took four health topics (tobacco exposure, unintentional injury, obesity, and mental health), and explored whether health promotion efforts targeted at preschool-age children can improve health across the life span and improve future economic returns to society.[269] The review found that, while the cost consequences for such health problems across the lifespan is considerable, the evidence base for effectiveness and cost benefits for interventions in the prenatal to preschool period was patchy and needed more rigorous effort. Overall the evidence for effectiveness was strongest for tobacco exposure and injury prevention. Many of the interventions described in the review were more intensive than those envisaged by BHFC.

Literature reviews[270] carried out to support the development of Australia's National Framework for Child and Family Health Services identified effective brief interventions and health promotion activities suitable for a universal health service for the following topics:

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[264] O'Brien S (2004) Good practice guidelines for using health promotion information materials

[265] Fowler C and Lee A (2007) Knowing how to know: questioning 'knowledge transfer' as a model for knowing and learning in health.

[266] Foley G (2006) Introduction: The state of adult education and learning, in Dimensions of adult learning: Adult education and teaching in a global era

[267] Barkin SL et al (2005) Anticipatory guidance topics: Are more better?

[268] Kislov R et al (2011) Work redesign and health promotion in healthcare organisations: a review of the literature.

[269] Guyer et al (2009) Early childhood health promotion and its life course health consequences.

[270] Allens Consulting Group (2008) The (draft) national framework for universal child and family health services.

- Parent – child interactions
- Positive parenting
- Breastfeeding
- SIDS
- Oral health
- Smoking cessation
- Improving sleeping habits
- Injury prevention
- Promoting early literacy

High rates of relapse are known to exist among pregnant women who quit smoking during pregnancy and there is a consensus that the transition from pregnancy to the post-partum period is a critical stage for intervention to maintain smoking cessation, yet most interventions are targeted at the antenatal period.[270] A number of programmes which provide counselling to parents about reducing children's exposure to environmental tobacco smoke have been proven to be successful[270] but no evidence could be found on the provision of just brief advice or information provision to such parents.

In relation to unintentional injury, there is good evidence that supportive home visiting programmes with visits carried out by trained, professional visitors (e.g. nurses) can provide family support, lead to improvements in the home environment and be used for parent education and training.[271] [272] The NICE review also noted that:

- Information provided at the time of a child's birth was generally not retained while information provided subsequently, in a community or physician setting, was better retained
- It was important to devise information and advice in ways that suited the target community (in terms of language, style, examples used), especially in dealing with low income populations with many ethnic minorities
- Adolescent mothers found it difficult to deal with issues of blame, and that it was more effective, while challenging the idea that injuries were unavoidable, to help mothers to identify the risks to their specific child in their specific environment and to avoid assigning blame.

Structured promotion of, and support for breastfeeding, has been shown to be effective.[273] [274] Such support may be offered either by professional or lay/peer supporters, or a combination of both. Strategies that rely mainly on face-to-face support are more likely to succeed than those which rely mainly on telephone contact. Support that is only offered reactively, in which women are expected to initiate the contact, is unlikely to be effective. Interventions are more effective in areas with an intermediate or high initiation rate.

While good practice guidance on infant feeding beyond 6 months of age is available[244] evidence of effective interventions designed to promote good practice in infant feeding is limited.[271]
Good practice in relation to infant nutrition will also promote good dental health and there is evidence that anticipatory guidance can impact on oral health.[262]

The core advice that sleep position is causally related to Sudden Infant Death Syndrome (SIDS) has not changed over the years and the campaign to change sleeping practices has been very successful in reducing the incidence of SIDS.[275] However, evidence about

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[271] WHO (2010) Injury prevention and the attainment of child and adolescent health. Accessed at: http://www.who.int/bulletin/volumes/87/5/08-059808/en/

[272] NICE (2010) Preventing unintentional injuries among the under-15s in the home

[273] NHS Health Scotland (2012) Evidence Summary: Public health interventions to promote infant and child nutrition

[274] Renfrew M et al (2012) Support for breastfeeding mothers with healthy term babies – Cochrane review

[275] Mitchell E (2007) Recommendations for sudden infant death syndrome prevention: a discussion document. *Archives of Diseases in Childhood*, 92 (2): 195-199.

other infant care practices that may also be related to SIDS has changed and practitioners should keep up-to-date with new research.

In relation to immunisation, while it is important that practitioners are familiar with the diseases which the immunisations are designed to prevent, a firm commitment to immunisation among all primary care staff and an honest acknowledgment of areas of uncertainty are essential.[172]

The early years of development from conception to age six, particularly the first three years, set the base for the competence and coping skills that will affect capacity to learn, behaviour and ability to regulate emotions throughout life, and can affect physical health in adulthood, such as strokes, heart attacks and high blood pressure [276] [277] Of vital importance is an infant's attachment to their main caregiver/s and the sensitivity with which this caregiver responds to their cues. [276] [278] [279] This attachment occurs in the early months of life. Much of the evidence available on interventions to improve the parent-child attachment are based on 'at-risk' populations (whether this is child-related, such as irritability or low-birth weight, or family circumstances, such as young mother or low socioeconomic groups) and the interventions are usually more intensive than brief interventions.[280, 281] However a number of studies have shown the effectiveness of anticipatory advice or brief interventions on the parent-child relationship.[260,261,279] One review concluded that no single approach is effective for all populations, that the quality of the relationship between the parent and practitioner may be more important than the theoretical orientation of the intervention and that a strengths-based approach was more effective than psychodynamic programmes based on problems.[279]

In general, promoting positive parenting has been shown to prevent child behavioural and emotional problems.[279] While parental attachment is very important in the early years, boundary setting, discipline and behaviour management become important alongside parental sensitivity in pre-school and school-aged children and adolescents. Some structured parenting programmes, which are layered or needs-based, such as the Triple P program, provide both universal (information and brief interventions) and progressive interventions and have been shown to be effective on a population basis in promoting child emotional and mental health and in preventing behavioural problems.[282]
There is evidence that encouraging parents to share books with their children and book distribution during child care visits are associated with child language development and home literacy delivery.[260]

While there are guidelines on best practice in physical activity for infants and young children, on play and on infant sleeping in a semi-seated position, such as in car seats or

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[276] WHO (2013) Early years, family and education task force report. Accessed at: http://ww.euro.who int/_data/assets/pdf_file/006/236193/Early-years,-family-and-education-task-group-report.pdf.

[277] Best Health for Children (2002) Investing in Parenthood to achieve best health for children.

[278] Child Mental and Emotional Health Project Team, HSE Programme of Action for Children (2006) Child Mental and Emotional Health: a review of evidence.

[279] Stewart-Brown S and Schrader-McMillan A. (2011) Parenting for mental health: what does the evidence say we need to do? Report of Workpackage 2 of the DataPrev project.

[280] Eshel N et al (2006) Responsive parenting: interventions and outcomes. Accessed at: http://www.who.int/bulletin/volumes/84/12/06-030163.pdf

[281] NICE (2012) Social and emotional wellbeing – early years. Public Health Guidance 40.

[282] Fives, A., Pursell, L., Heary, C., Nic Gabhainn, S. and Canavan, J. (2014) *Parenting support for every parent: A population-level evaluation of Triple P in Longford Westmeath. Final Report.* Athlone: Longford Westmeath Parenting Partnership (LWPP)

bouncy chairs, no research on interventions involving information, advice or brief interventions has been identified.[283,284,285,286]

9.7.3 Health promotion/Education topics addressed in International programmes

Appendix 10 provides a review of some of the health education topics which are incorporated into international programmes of child health screening and surveillance or child health promotion.

9.8 Discussion

This review concentrated on the policy framework and the evidence base on which health promotion activities could be delivered in the context of the Child Health Screening and Surveillance (CHSS) programme and the core visits available to all parents and provided by health professionals.

For the reasons outlined, the term 'health education' will be used to describe the sub-set of health promotion activities which can be delivered as part of the CHSS programme. This term is defined as: 'any activity which promotes health through learning, i.e. some permanent change in an individual's capabilities or dispositions, and could include information sharing, opportunistic health promotion, brief intervention, role modelling and skill development.'

The current programme which was described in *Best Health for Children Revisited* is detailed in Table 12. It is unclear from the documentation and the training manual if health professionals are to provide information or brief interventions on all of the topics outlined in Table 12 or if they are to risk assess for each child to decide what is required. It is unknown to what extent this programme is being delivered.

There is now extensive evidence of the importance of childhood for adult, as well as for child, health. The early years of development from conception to age 6, particularly the first three years, set the base for the competence and coping skills that will affect capacity to learn, behaviour and ability to regulate emotions throughout life, and can affect physical health into adulthood. Investment in early years services is much more effective than investment in services in later life.

Parents are the most significant influence on children's development. The physical, emotional and learning environment provided by parents and families has both a short term and long term effect on children's health. While it is important to develop, and provide access to, targeted and more intensive family support services for those with greater need, there are several arguments for the need to provide a level of universal service. The first is the 'population paradox', where a relatively large number of lower risk people carry the main burden of risk of disease in the population as a whole, so that only targeting those at highest risk will only capture a small proportion of those with a problem. The second is the need to identify problems, and to intervene early, before they reach

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[283] Kernan, M. (2007). Play as a context for early learning and development. Dublin: Aistear; NCCA Accessed at: http://www.ncca.ie/en/Curriculum_and_Assessment/Early_Childhood_and_Primary_Education/Early_Childhood_Education/How_Aistear_was_developed/Research_Papers/Play_paper.pdf.

[284] Gleave,J. and Cole-Hamilton,I.(2012) 'A world without play' –a literature review (revised 2012). Available at: http://www.playengland.org.uk/media/371031/a-world-without-play-literature-review-2012.pdf

[285] Department of Health and Children, Health Service Executive (2009) The National Guidelines on Physical Activity for Ireland.

[286] Healthy Child Care Iowa (2008) Infant Sleep Considerations for Child Care Businesses. Accessed at: https://www.idph.state.ia.us/hcci/common/pdf/sleep_positioning.pdf

clinical levels and, finally, universal programmes reduce the potential of stigma attached to programmes for parents who are deemed to be failing.

Other developed countries, with the benefit of this evidence base, have expanded their concept of child health services to one of progressive universalism, linking child health services in a complex matrix or framework with other health, educational and not-for-profit services, such as maternity, immunisation, GP, educational, child protection and early intervention service providers. This is not yet the case in Ireland.

The objective of the provision of health education to parents should be:

- To provide information and skills which would support them in promoting their child's health, e.g. parent-child attachment, breastfeeding, smoking cessation; positive parenting
- To outline development norms to reassure parents and to support them in identifying deviations from the norm
- Primary prevention, e.g. unintentional injuries, SIDS
- Promoting wellbeing, e.g. reading, school readiness
- Anticipatory guidance, e.g. sleeping difficulties; behavioural problems
- Links to additional information, supports and services

Parents have said that what they want is:

- Reliable, accurate and trusted information
- provided in a timely fashion and based on their individual needs
- which could be provided in a variety of consumer friendly formats,
- but on demand advice formats should complement rather than replace face-to-face contact with trusted health professionals.
- A respectful relationship with such professionals is important, as are good listening skills.

Barriers include poor literacy, limited ability to understand complex information, lack of services, poor signposting to services, child protection and financial concerns and fears of stigma.

Resources specifically for fathers and for young parents are limited.

Overall, there is good evidence for the effectiveness of parenting support on child health outcomes.

Much of the literature on health education and parenting support for early years is based on more intensive interventions than could be provided by the CHSS as part of the core visits.

However, there is evidence for effectiveness for information provision, anticipatory guidance and/or brief intervention on:

- Parent – child interactions
- Positive parenting
- Breastfeeding
- Smoking cessation
- SIDS
- Oral health
- Improving sleeping habits
- Injury prevention
- Promoting early literacy

There is a lack of research on other topics. However, the CHSS service is delivered in the context of a partnership with parents and, from this perspective, information provision is essential to support this partnership.

Health education is a core part of the child health service provision. It is essential, therefore, that is given due regard, is underpinned by adequate training and does not get pushed out by other child health concerns, reduced resources or resources diverted to more acute problems in other care groups. In fact, what may be needed is more investment in the early years and that all health professionals, such as PHNs, practice nurses, GPs, speech and language therapists, involved in providing services to children, especially preschool children, should use a proportion of their time and all relevant contacts with parents to provide health education.

Partnership between parents and health professionals, which recognises parenting support as key to children's health and wellbeing is confirmed as underpinning the process of delivery of child health services. Training should incorporate recent national strategic and policy developments in this area.

The opportunistic potential of health promotion will be more fully realised if brief intervention/motivational interviewing training is incorporated as a standard into the core BHFC training.

In addition to offering timely anticipatory guidance and education on health promotion topics, health professionals will need to be attentive to how this is received and understood. Some families will require this work to be more targeted or tailored to their needs and/or to go beyond what is usually delivered at core health visits. Knowledge and skills for signposting to local supports or enhanced support for health and wellbeing may be necessary in the tailoring of some care plans.

Knowing what works in relation to the delivery of timely health information to parents and what constitutes good quality information continues to be important. The health promoting role will benefit also from having agreed information protocols that line up with national health indicators:

- Information content and sources should be agreed nationally (e.g. CHISP, child safety online sources) for both universal and targeted provision of health education/promotion.
- This will require ongoing review and updating.

Child emotional and mental health, prioritising an understanding of the need for healthy infant/carer attachments and emotional regulation is now much more fully recognised as a core child health issue requiring attention at the earliest opportunity:

- The Child Emotional and Mental Health training programme for PHNs should be delivered nationally as a priority.
- Criteria for referral and referral pathways need to be reviewed at the earliest opportunity.

The tools available in 2005 to health professionals involved in health promotion as part of the child health service were mainly their own knowledge base / interpersonal skills and leaflets / booklets which they could provide to the parent or to which the health professional could signpost to the parent (see Table 12). While the professional skill base is still essential, other information sources are increasingly available to many parents through different media, such as the internet, apps, discussion forums, on-line training, etc.

Finally, one of the issues identified by parents which undermines their trust in the services and their health professionals is the lack of services to which their child could be referred, or a delayed referral, once they, or a health professional, identifies a potential problem. Adequate provision of referral services needs to be considered as part of this review.

9.9 Recommendations:

1. It is recommended that the universal CHSS programme be incorporated into a broader framework of children's health services, which would include the links to more targeted services based on need (i.e. progressive universalism) and that such a framework would include antenatal care.
2. Health education, underpinning the partnership with parents and as an effective intervention in promoting child and adult health, is a core part of child health service provision. It is essential, therefore, that it is given due regard, is underpinned by adequate training and does not get pushed out by other child health concerns, reduced resources or resources diverted to more acute problems in other care groups. In fact, consideration should be given to increasing the emphasis given within the health and other services to health education and parenting support in the early years, with all families getting some support but those with greater needs getting additional support.
3. Key to the delivery of health education within the CHSS service is the personal abilities and skill set of its health professionals. Besides the ability to develop a trusting and respectful relationship with parents, health professionals need to have:
    - Knowledge and ability to provide surveillance of physical, emotional, developmental and social conditions.
    - Knowledge and appropriate use of nationally-agreed assessment tools.
    - Knowledge of the evidence base on key topics relevant to parents in promoting their child's health and the ability to provide health education interventions as relevant to each parent and each situation
    - Knowledge of quality information sources and how best to present or signpost to parents topics of particular relevance to them
    - Knowledge of any additional supports available in the community and how to access them
    - Ability to provide anticipatory guidance or management guidance for behavioural problems
    - Of particular importance is the ability to promote healthy parent-child bonding and positive parenting.
4. Training for such health professionals is, therefore, vital. Training in brief intervention and other health promotion techniques and in child emotional and mental health should be core to the training schedule.
5. Consideration should be given to having a core workforce of health professionals providing the CHSS service who are specialised in child health and development.
6. All health professionals, not only PHNs and SMOs/AMOs, who have contact with parents of young children should use these contacts to provide information, information signposting and brief interventions, where relevant, to such parents. Such health professionals should include GPs, practice nurses, allied health professionals, paediatricians, etc. Further work would be required to decide how this work might be aligned with the CHSS service and a possible national child health framework, and what training would be required for such health professionals.
7. Referral pathways and criteria for children and families with identified attachment and other problems need to be clarified.

8. The tools available for health professionals and parents for information and skill development should be evidence based and accessible, and available in different formats which are relevant to those who have identified barriers, such as those with poor literacy, young mothers, other cultures or those whose main language is not English.
9. More emphasis should be given to involving fathers and having relevant health education materials available for them.
10. There should be core written resources, such as the CHISP books and the Parent Held Record, which would be used as part of the health education element of the core visits. Such resources would need to be reviewed on a regular basis. These resources could provide signposting to other quality-assured information and supports.
11. Consideration should be given to developing on-line information and training resources for parents.
12. Where access to such on-line resources is not available or is difficult for a parent, such parents should be identified as requiring additional personal interventions.
13. There should be flexibility available within the CHSS service to allow for additional support for some parents based on additional need, whether this is because of child (e.g. irritable child), parent (e.g. young or first-time parent) or environmental and social factors (e.g. parent from other culture, rural-based). Available staff resources should be aligned to such additional needs, where this can be determined (e.g. areas of deprivation).
14. Health professionals already use their skills to identify families with additional health education needs. If a common needs assessment tool is introduced, the needs for additional health education interventions should form part of such a tool.
15. Consideration should also be given to whether or not it is useful to have a list of prescriptive topics to be addressed with parents at core visits, once the timing for these visits has been decided. Consideration might be given to having a number of priorities identified, on which the health professional would focus, for each core visit.
16. When deciding what visits should form the core of the CHSS service, the importance of health education at different stages, and especially in the early years, should be taken into account. It may be decided that health education would be the key intervention at some visits.
17. There is a need to build a measurement of Health promotion/education activity into a monitoring programme for child health surveillance and screening, if such a programme is being developed.
18. On-going evaluation of the effectiveness of the health education element of the CHSS service should be encouraged. This would build towards a stronger evidence base for health education in this setting.

Chapter 10 Review of Newborn Bloodspot Screening in Ireland

10.1 Introduction

All screening programmes bring a mixture of benefit and harm.[287] Good ones bring more benefit than harm. Screening programme takes an unsuspecting group of people and plants the seed of doubt in their minds by telling them that they (or their child) are at risk of something which they may (or most likely may not) have been worrying about. It then tests them for it, tells them that they may or may not be at greater or lesser risk of having the condition and then recommends further testing and treatment.

There has been a newborn bloodspot screening programme in Ireland since 1966, when the programme began with screening for Phenylketonuria (PKU). It was the first national programme of this nature in the world and has continued to be delivered by a single national screening laboratory at Children's University Hospital, Temple Street which analyse samples taken by midwives and public health nurses during the neonatal period. Since then five more conditions have been added to the programme, cystic fibrosis being the most recent addition in 2011.

Table 13: The conditions tested for are:

Currently screened:	**Introduced:**	**Irish incidence:**
Phenylketonuria (PKU)	1966	1:4,500
Homocystinuria (HCI)	1971	1:68,000
Maple Syrup Urine Disease (MSUD)	1972	1:125,000
Classical Galactosaemia (GALT)-	1972	1:19,500
Congenital Hypothyroidism(CH)	1979	1:3,500
Cystic Fibrosis (CF)	2011	1:2500 (2013 rate)
Discontinued:		
Toxoplasmosis	Pilot programme 2000-2007, discontinued following evaluation	
Proposed:		
Medium Chain Acyl CoA Dehydrogenase deficiency(MCADD)	-	1:14,600 in screened populations as under diagnosis likely in non-screened populations (18 diagnosed in Ireland 2003-2008)
Glutaric Aciduria Type 1(GA1)	-	1: 54,000 (1:2,000 for Irish Traveller) (1: 95,000 for non- Travellers)

Source: National Newborn Bloodspot Screening Laboratory A Practical Guide to Newborn Bloodspot Screening in Ireland 2011

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[287] Handbook of Public Health Practice 2nd Edition 2008 Oxford University Press

10.2 Policy Development and Governance Arrangements

In 1990, the Minister for Health appointed a Metabolic Disorders Working Group to review the screening programme. The objective of the Working Group was to draw up procedures and practices to ensure universal screening for metabolic disorders and to facilitate a co-ordinated approach by all Health Boards. Health Boards were asked to outline their practices and procedures in respect of hospital births and domiciliary births in their areas. Based on their findings the working group concluded that there was room for improvement regarding screening procedures.

The Group reported in 1992 endorsing the range of conditions for which screening was currently offered and made recommendations regarding:

- Responsibility for ensuring that all newborn infants were screened for metabolic disorders
- Practices and procedures to facilitate this
- Development of a co-ordinated approach by all Health Boards.

The publication of *A Practical Guide to Newborn Screening in Ireland*[288] first published in 1999 and up-dated in 2001 included recommendations from the Metabolic Disorders Working Group around practices and procedures of sample collection.

The report *Best Health for Children - Developing a Partnership with Parents*[169] which had been commissioned by the Chief Executive Officers of all the Health Boards in the Republic of Ireland, was published in 1999 and included the following recommendations:

- Responsibility for co-ordinating the NNSP should be assigned to one body.
- Nationally agreed protocols for screening should be drawn up.
- An audit of the screening programme should be performed addressing in particular the completeness of cover, and the timeliness of testing and reporting.

To facilitate implementation of the report, *Best Health for Children (BHFC*) was established by the Conjoint group of Chief Executive Officers of all the Health Boards in the Republic of Ireland in 1998. Under the auspices of BHFC this led to the establishment of 2 groups at the request of the Chief Medical Officer:

1) A ***National Newborn Screening Programme Working Group*** whose remit was as follows:

Audit of current practice throughout the country, with regard to;

a) Coverage
b) Timeliness of testing and reporting
c) Quality assurance
d) Consumer satisfaction

Development of an overall management structure with regard to;

a) Responsibility and accountability for screening
b) Development of nationally agreed protocols for screening
c) Set standards for quality assurance and determine performance indicators
d) Identification of resources required to support a high quality system

2) A ***Cystic Fibrosis Screening Working Group*** whose remit was identification of resources required to support a high quality newborn Cystic Fibrosis screening programme.

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[288] National Newborn Bloodspot Screening Laboratory A Practical Guide to Newborn Bloodspot Screening in Ireland 2011

Both groups reported in 2004[289,290] making key recommendations in relation to infrastructure, training, resource and governance arrangements.

However in 2005 the health service structure underwent change following the establishment of the Health Service Executive(HSE) - funding for implementation of Cystic Fibrosis (CF) Screening was made available in 2009 giving rise to the establishment of a Steering Group on implementation of CF Screening. This group again undertook an audit of current practice which had not changed significantly since the earlier audit. It identified the need for a national governance structure for the entire bloodspot screening programme as a prerequisite to the introduction of an additional screened condition.

In 2011 the Health Service Executive agreed a governance structure for Newborn Screening, based on a National Expert Group which includes four Area Child health leads and the Director of the Newborn Bloodspot Screening (NBS) Laboratory, with links to the HSE operational management structure with responsibility for development of nationally agreed procedures and standards for the NBS Programme.
The Newborn Bloodspot Screening Governance Group (NBSGG) has:

- Overseen the introduction of CF Screening to the list of screened conditions
- Introduced new written consent procedures to include storage of NSCs
- Set Key Performance Indicators(KPIs) for newborn bloodspot screening
- Sourced funding for a national Integrated Screening Management Information System and supported its design and implementation
- Audited the performance of the programme including the capacity to measure KPIs in advance of full implementation of the new Screening Management Information System
- Reviewed candidate conditions for addition to the suite of screened conditions
- Tasked a Performance Evaluation Sub-Group identifying appropriate screening timeline targets for each condition to support audit and outcome measurement(Encl)
- Supported a review of practice in relation to stored NBS cards (pre 2011) and the development and implementation of a policy in relation to management of these historical cards.
- Contributed to a process of development of Child Health Information Systems at local level to fulfil to function of NBS Registers

10.3 Evidence reviewed for bloodspot screening in Ireland to date

10.3.1 Is the range of conditions screened appropriate for the Irish population?

Newborn bloodspot screening is unusual because every country screens for a different combination of conditions based upon the incidence of these conditions in the population.
In 2013 the NBSGG considered and agreed a proposal for expansion of screening based upon:

a) The incidence between 1993 and 2008 in Ireland of conditions amenable to currently available screening technology
b) National Screening Committee (UK) criteria for screening

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[289] Report of National Newborn Screening Programme Working Group- BHFC 2004

[290] Report of National Cystic Fibrosis Screening Programme Working Group- BHFC 2004

Review of this proposal confirmed that the 6 conditions currently included in the screening programme fulfilled both conditions - the NBSSG also concluded that 2 further candidate conditions (MCADD and GA1) fulfilled the conditions and should be included in the national screening programme as soon as resources allowed.

10.3.2 Are the outcomes of screening comparable to internationally reviewed standards of screening?

It is important to distinguish the difference between the ultimate goal of screening (to improve long term outcomes) and the first distal goal of screening (early start of treatment).

A) Early start of treatment

The NNBSG asked its Performance Evaluation Sub-Group to:

- review available evidence and select the appropriate timelines which ensure that testing occurs early enough to allow prevention of complications and initiation of treatment but at the optimum time that will allow most affected individuals to be identified.

In 2012 a report was published on the practice of newborn screening programmes for rare disorders in European countries, including Ireland.[291] This was part of a project by the European Commission on rare diseases. This reviewed all aspects of screening programmes including the timelines associated with screening, initiating treatment and the presence of symptoms in screened infants. The key results are presented in Table 14 and Figure N below.

Table 14: European averages for age at points of screening process

Disorder	Age bloodspot is taken (days)		Age at the start of screening lab (days)		Age at the start of confirmation (days)		Age at the end of confirmation (days)		Age at the start of treatment (days)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
PKU/HPA	3.3	1.1	7.1	2.8	10.8	5.4	16.7	10.5	13.9	6.0
HCI	3.2	0.8	5.4	1.2	9.0	1.0	16	3.7	13.4	1.7
MSUD	2.9	0.8	5.0	1.2	8.3	1.9	12.8	4.4	13	4.4
GALT	3.2	0.8	5.3	1.3	8.0	1.8	12.8	5.4	10.3	3.5
CF	3.5	1.2	5.8	1.9	27.0	17.3	51.6	32.2	35.0	19.8
CH	3.0	1.3	6.6	2.9	10.5	4.9	14.9	9.4	12.8	4.6

Source: Report on the Practices of Newborn Screening for Rare Disorders implemented in Member States of the European Union, Candidate, Potential Candidate and EFTA Countries 2012[291]

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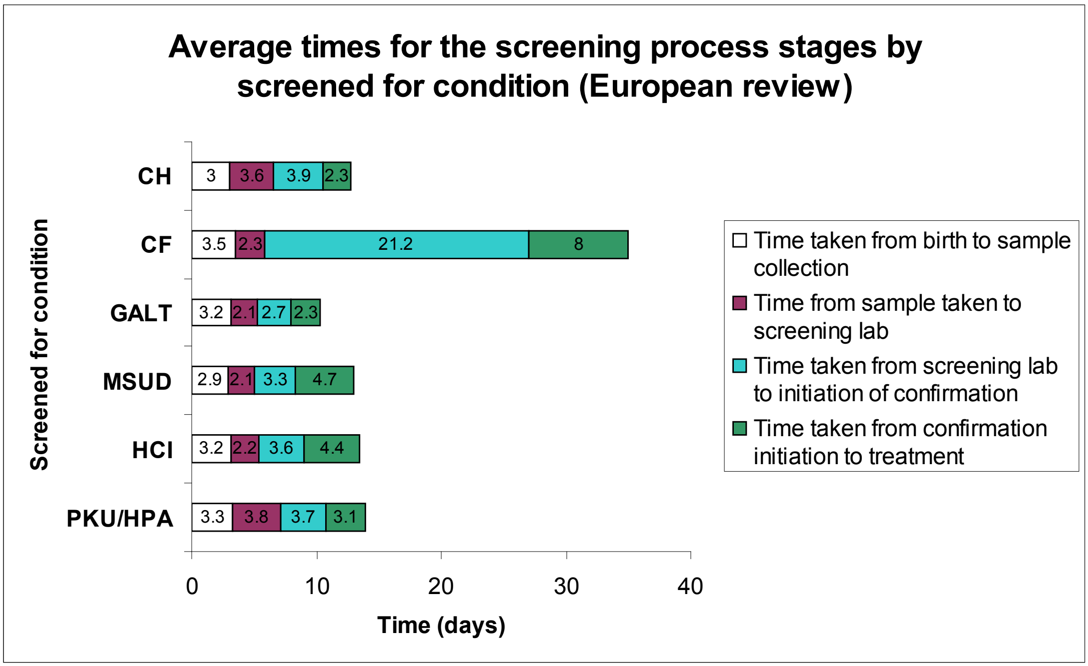
[291] Burgard, P. et al Report on the Practices of Newborn Screening for Rare Disorders implemented in Member States of the European Union , Candidate, Potential Candidate and EFTA Countries 2012

Figure N: Average timelines for the steps in a screening process (European review)



Source: Report on the Practices of Newborn Screening for Rare Disorders implemented in Member States of the European Union , Candidate, Potential Candidate and EFTA Countries 2012[291]

As these timelines provided programme averages it was decided to use them as an initial benchmark for the Irish screening programme. If the targets were easily met by the Irish newborn bloodspot screening programme, it was felt that further more ambitious targets could be established from this baseline.

The National Newborn Bloodspot Screening Laboratory reviewed Irish data from recent years as shown in Table 15 below which demonstrated shorter mean and median “time to referral” intervals for Irish children diagnosed with these conditions over the relevant period than average EU values. The analysis (based on a review of the most recent cases for each condition) excludes all infants diagnosed by high risk newborn screens and is based on the time of referral to the appropriate clinical team.
It was concluded that as Irish data confirmed that it was possible to achieve shorter “Time to referral“ in recent years than European average values it would be more appropriate to set targets using Irish data as outlined in Table 15.[291]

Table 15: Age of infant to referral following diagnosis In Irish NBSP*

Disorder	No.	Days to diagnosis			Proposed target 90% by Day
		Mean	Median	Range	
Phenylketonuria (PKU)	12	8.8	9.5	6-11	10
Hyperphenylalaninaemia	12	16.3	11	7-54	25
Maple Syrup Urine Disease (MSUD)	10	8.7	7.0	6-15	9
Homocystinuria (HCU)	13	8.3	7.0	7-15	12
Classical Galactosaemia (GALT)-	8	6.8	7.0	4.3-9.6	8
Congenital Hypothyroidism(CH)					10
Cystic Fibrosis (CF)					28

**The target set for Congenital Hypothyroidism and CF is that which was agreed with the clinical team and the Governance Group respectively*

B) Improving long term outcomes

The NNBSG has initially focused its work on ensuring early start of treatment (as outlined above, see also but has commenced an annual series of annual reports[292] which can be used as a basis for analysis of trends which will be used to evaluate the programme. Outcomes for aspects of individual conditions have been published by NCMID[293, 294, 295, 296, 297, 298, 299, 300, 301] indicating comparable outcomes to international practice for the conditions managed by their service.

Cystic Fibrosis screening was introduced in mid- 2011 so longer term outcomes will rely upon the data collected by the Cystic Fibrosis Registry of Ireland which has been part-funded by the HSE to measure outcomes in Ireland and now has over 90% coverage of the population.

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[292] HSE publishes National Newborn Bloodspot Screening Programme report for 2012 vailable from: HTTP://WWW.HSE.IE/ENG/SERVICES/NEWS/NEWSARCHIVE/2013ARCHIVE/FEB2013/BLOOSPOTREPORT.HTML.

[293] Coss, KP. et al Clasical Galactosaemia in Ireland: Incidence, complications and outcomes of treatment Journal of Inherited Metabokic Disorders 2013 36(1): P. 21-7.

[294] Hughes, J. et al Outcomes of siblings with classical galactosaemia Journal of Paediatrics 2009 154(5): P. 721-6.

[295] O'Sullivan S., T.E. Crushell, E. Monavari, A. Brinkley, A. Ley, A. Grant, T. Mayne PD. Long-term outcomes of patients with treated homocystinuria (CBS) deficiency in Ireland 1971-2009

[296] Yap, S. Clasical Homocystinuria Vascular Risk and its Prevention Journal of Inherited Metabokic Disorders 2003. 26(2-3): P. 259-65.

[297] Mulvihill, A. et al Ocular findings among patients with late diagnonsed or poorly controlled homocystinuria compared with screended well controkked population Journal of American Association for Pediatric Ophthalmology and Strabismus 2001 5(5): P. 311-5

[298] Yap, S. et al The intellectual abilities of early-treated individuals with pyridoxine-nonresponsive homocystinuria due to cystathionine beta-synthase deficiency Journal of Inherited Meatbolic Disorders 2001 24(4): P. 437-47.

[299] Yap, S. et al Vascular complications of severe hyperhomocysteinemia in patients with homocystinuria due to cystathionne beta-synthase deficiency: Effects of homocysteine-lowering therapy Seminars in thrombosis and hemostasis 2000. 26(3): P. 335-40.

[300] Yap, S. Naughten, E. Homocystinuria due to cystathionine beta-synthase deficiency in Ireland: 25 years experience of a newborn screened and treated population with reference to clinical outcome and biochemical control Journal of Inherited Metabolic Disorders 1998. 21(7): P. 738-47.

[301] Naughten, ER. Yap, S. Mayne, PD. Newborn Screenign for homocystinuria: Irish and World Experience European Journal of Pediatrics 1998 157 SUPPL 2: P. S84-7

Chapter 11 Growth Monitoring

Introduction

One of the relevant background issues for a review on growth monitoring is the possible expansion of GP involvement should the proposed decision to provide free GP services to children under 6yrs include changes in the current delivery of growth monitoring as part of CHSS in the primary care setting. Growth monitoring and infant/childhood nutrition are highly connected.

Recommendations as originally noted in Best Health for Children Revisited (p22)

a. *Reduced number of mandatory growth monitoring assessments (birth, 6 to 8 week check and school entry), but children should be weighed and measured at opportunistic times including birth, at immunisations and during child health surveillance checks.*
b. *Focus on accuracy of measurement, documentation and interpretation of findings*
c. *Development of nine centile growth charts based on Irish data*

11.1 Update on the Implementation of the Recommendations

a. The Growth Monitoring training module was reviewed and updated (new resources available on www.hse.ie/growthmonitoring) and signed off by a national steering committee in October 2012. A decision by the Department of Health to introduce new UK-WHO Growth charts for all newborns up to age 4 years was implemented from 1.1.2013. The Neonatal and Infant Close Monitoring Chart (NICM) was also introduced for very preterm (less than 32 weeks) and sick neonates. The mandatory and opportunistic measurement assessments as outlined in the accompanying standards remained unchanged.
b. A focus on accuracy of measurement, documentation and interpretation of findings was maintained.
c. There has been no documented national decision or project to proceed with the development of charts based on Irish data. A default position was outlined as follows:
   'As an interim measure until these new charts are available, the UK growth charts 2-18yrs will be used to assess growth in children over 4 years up to 18 years old.'[302]

Training of trainers on the introduction and use of the new UK-WHO 0-4yrs charts took place on two occasions to support local capacity to train PHNs at local level. No national training has taken place on the use of NICM charts. This was in line with the UK (RCPCH) experience at their new growth chart introductory phase. There is some anecdotal evidence of poor understanding of acceptable pre-term infant weight gain by PHNs. There is also some concern about the variable practice of newborn growth measurement, which takes place in maternity hospitals and is subsequently transmitted to local PHN services. Information was circulated recently regarding a head circumference plotting error on the NICM chart in the UK and a redesign is currently being considered by RCPCH.

A HSE eLearning project will commence shortly for new charts including NICM. The opportunity to address prevention issues for growth problems and family support for normal growth in CHSS was incorporated into the manual and the evidence base for this along with signposting to new supportive resources was included. Growth monitoring

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[302] HSE Training Programme 2012 accessed at: http://www.hse.ie/eng/health/child/growthmonitoring/trainingmanual.pdf

includes health education and anticipatory guidance on infant and child feeding /nutrition and physical activity.

11.2 Update on the Evidence for screening and surveillance for obesity

Screening of school children for obesity is a contested issue.[303, 304] Surveillance has been found to have a stronger evidential base[305] and in the UK an annual Child Measurement Programme was introduced in 2005, with legislation enacted for the provision of results to parents (ibid). Screening is defined as when members of a defined population are offered a test to identify who is more likely to be helped than harmed by further tests or treatment. Surveillance is defined as the routine collection of data at a population level to be able to describe changes in disease or risk factors by person, place, and time (ibid). The UK child measurement programme is arguably somewhere between the two and the same could be said for recent developments in CHSS growth monitoring practice in Ireland.

11.3 Update on the evidence on obesity prevalence and prevention

Growing Up in Ireland (ESRI)[306] and the WHO Childhood Obesity Surveillance Initiative (COSI) in Ireland (UCD) show that levels of overweight and obesity amongst Irish children are between 25%- 28%. Over 20% of children aged between two to four year old in Ireland are overweight or obese at school entry.[307] There is much evidence as to the harmful effects of childhood obesity, how it continues into adolescence and adulthood becoming increasingly difficult to treat. This is not covered here again. Maternal obesity at the point of conception is associated with a four-fold greater risk of childhood obesity by the age of four.[308] There is an increased risk of obesity for children with obese parents and those whose mothers had diabetes mellitus during the child's gestation. Young children with one or two obese parents are at high risk of obesity in young adulthood, even if their current weight is normal.[309] There is increasing evidence for an optimal sleep duration, with shorter sleep duration than is optimal associated with increased risk of obesity. Childhood is an opportune time to prevent or intervene on obesity, as eating and physical activity patterns are developed and established during this period.[310]
Early community-based interventions, by specially trained nurses over 7 visits, have been shown to be effective in reducing BMI at age two years.[311]

A pilot study was conducted in two Dublin urban GP practices in contrasting socioeconomic areas (deprivation index 10 & 7). The study determined if it was acceptable and feasible to prevent childhood obesity by an educational intervention with

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[303] US Preventive Services Task Force (2009) Screening for Obesity in Children and Adolescents: US Preventive Services Task Force Recommendation Statement. *Pediatrics*; originally published online January 18, 2010; DOI: 10.1542/peds.2009-2037

[304] Westwood M, Fayter D, Hartley S, RithaliaA, ButlerG, Glasziou P, et al. Childhood obesity: should primary school children be routinely screened? A systematic review and discussion of the evidence. ArchDis Child 2007; 92:416-22.

[305] Kipping RR, Jago R, Lawlor DA. Obesity in children. Part 1: Epidemiology, measurement, risk factors and screening . BMJ 2008; 337:a1848.

[306] Accessed at: http://www.growingup.ie/index.php?id=9

[307] UCC, UCD, University of Ulster, National Pre-school Nutrition Survey: Summary Report. June 2012

[308] Whitaker, R. Predicting preschooler obesity at birth: the role of maternal obesity in early pregnancy. Pediatrics *2004* 114 (1): e29-36.

[309] Barlow, S. Expert Committee Recommendations Regarding the Prevention, Assessment, and Treatment of Child and Adolescent Overweight and Obesity: Summary Report Pediatrics, 2007 120 (4) s164-192.

[310] Harper, M. Childhood obesity: strategies for prevention Family Community Health 2006 29:288-298

[311] Wen, L., Baur, L., Simpson, J., Rissel, C., Wardle, K. and Flood, V.(2012). Effectiveness of home based early intervention on children's BMI at age 2: randomised controlled trial. BMJ, 344: e3732 doi:10.1136/bmj.e3732

parents at the time they attended with their child for their last primary immunisations at 13moths – two years.[312] This demonstrated high levels of acceptability among parents (100%) who found it useful (87%). It is hypothesised that GPs are conflicted about routinely weighing children due to fear of eliciting negative reactions from parents and children, but that parents and children themselves do not feel negatively about this practice. A recent Irish study compared GP concerns with parental/child responses. GPs (n=393) were conflicted over acceptability but almost all parents (n= 457) believed it helpful. The children were aged 5-12years. Almost three out of four obese children did not respond negatively to being weighed. Children five to six years were most likely to respond positively.[313]

11.4 Way Forward/Recommendations

While this is the most recently revised area of BHFC work, some issues remain outstanding. There is no capture of data on children's measurements against the new standard. There is no knowledge of the compliance on new growth chart usage. Training in growth chart usage is incomplete. In the absence of a decision and action to develop an Irish growth reference population, the default decision by the growth monitoring steering group to adopt the UK 2-18yr charts following plotting on UK-WHO 0-4yr charts needs to be immediately confirmed. There are licensing and other implications for this decision. The growth measurement standard for practice for newborns (in maternity/other hospitals) is unclear. This has implications for what growth information is reported onto the PHNs service for base-line information relevant for the first CHSS visit.

The data captured as part of the growth monitoring in CHSS up to primary school entry (and beyond if this is agreed) should include agreed indicators as is the case in other countries.[270] Physical activity guidelines in Ireland address children from 2-18yrs of age, but not infants and toddlers.

- Carry out an audit of growth chart implementation.
- Investigate the growth measurement standards in hospitals as part of the universal clinical management of newborn.
- Consider the capture of agreed growth measurement surveillance data (and subsequent analysis) on all children in NICHIS
- The proportion of children whose BMI score is above the international cut off points for 'overweight' and 'obese' for their age and sex should be considered as a core child health indicator.
- Consideration needs to be given to the timely detection of primary growth disorders and growth disorders due to chronic disease if the schedule and nature of child health visits is altered. Currently, growth monitoring between 3 months and junior infants is done opportunistically at immunisation and child health visits. No immunisations are scheduled from 13 months to junior infants.
- A project to support training in the use of the UK-WHO 0-4 yr charts and the NICM charts through the development of an eLearning (HSE) online package is underway in 2014, Q4. The availability of this training should be communicated appropriately to all relevant stakeholders.
- Develop physical activity guidelines for 0-2yrs specifically addressing safe time periods for car and other restraint systems, and around screen time which is not recommended in this age group.

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[312] Doorley, E., Young, C. et al (2014). Is primary prevention of childhood obesity by education at 13-month immunisation feasible and acceptable? Results from a General Practice based pilot study (accepted for publication by IMJ)

[313] O'Shea, B., Lade, EL., Kelly, A, et al. Weighing children; parents agree, but GPs conflicted. Arch Dis Child Published Online First: 2014 January 15th, 2014 doi: 10.1136/archdisxhild-2013-304090