To Bleed or Not to Bleed?

An Investigation into Mandatory Newborn Screening in New Zealand

Rachael Irvine

2006

A dissertation submitted for the degree of Bachelor of Laws (Honours)

Faculty of Law, University of Otago, Dunedin

Acknowledgements

I would like to sincerely thank the following people:

To my supervisor, Professor Nicola Peart. I have learnt an incredible amount while working under you this year. Thank you for your thoughtful consideration of my topic, for challenging me, and for the time and effort that you put into commenting on several of my earlier 'attempts.'

To the staff of the Human Genome Research Project, especially Gen Matthews and Debbie Lawson, for so willingly answering my questions and challenging my views on this topic. Thank you also to Dianne Webster of the National Testing Centre, for showing an interest in my topic and answering all my questions so thoroughly.

To my family, for diligent proofreading and providing all the necessary 'supplies' for completing a dissertation. You have been incredibly supportive throughout my education and I would not have been successful without your help.

To Brendon and Hayley, for the hours spent proofreading and generally supporting me while I completed this dissertation.

To the law tutors and other friends, for answering my silly questions and generally making University an incredibly fun 5 years.

Table of Contents

Introduction

New Zealand began screening newborns for phenylketonuria in 1969 using a test designed by Robert Guthrie.[1] This test was developed because evidence indicated that several patients in mental institutions across the United States of America (USA) suffered from the disorder.[2] This screening programme has since grown. Newborns are now tested for seven inherited metabolic disorders.[3] It is set to be expanded further by the end of 2006.

The test requires a simple and minor intervention. A small blood sample is taken, by pricking the heel with a small needle, between two and four days after birth.[4] The test is commonly referred to as the 'Guthrie Test' or 'Guthrie Heel Prick,' and the stored sample as a 'Guthrie Card'.[5] They are more accurately called the newborn screening test (NBS test) and newborn screening card (NBS card) and will be described as such in this dissertation.

The disorders screened for are all rare, but there are serious consequences if an affected child does not receive early treatment.[6] Most children will appear normal when born, making clinical diagnosis difficult or impossible.[7] NBS identifies affected children before symptoms develop and irreversible damage is done.[8] If detected early enough, treatment can prevent death or serious mental and physical harm.

Given the significant benefits and minimal harm associated with NBS, it is important to ask, should NBS be mandatory? This dissertation aims to answer this question. Chapter one outlines the disorders currently screened for in New Zealand and why it is important that as many children as possible are screened. New Zealand's current NBS programme is

[1] D Gareth Jones, Katie Elkin, "Guthrie Cards: Legal and Ethical Issues" (2000) 1(2) *New Zealand Bioethics Journal* 22, 22. The first tests began in 1964. In 1969 the National Testing Centre began testing all newborns.
[2] Robert Guthrie, Ada Susi, "A Simple Method for Detecting Phenylketonuria in Large Populations of Newborn Infants" (1963) 32 *Pediatrics* 338, 338. Tests using urine had been developed but had proved to be an unreliable screening tool.
[3] Ministry of health website, National Screening Unit, *Conditions Tested*, online at http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/1cc77940747fe4a7cc2570c0000c061c?OpenDocument, updated 16 June 2006, accessed 4 October. All NBS cards are sent to Auckland hospital to be tested for these disorders.
[4] Auckland District Health Board website, *Newborn Services Clinical Guidelines*, online at http://www.adhb.govt.nz/newborn/Guidelines/Nutrition/MetabolicScreening.htm, accessed 3 October 2006.
[5] This is despite the fact that many countries actually use a different technique to the one designed by Robert Guthrie. Privacy Commissioner, *Guthrie Tests*, Privacy Commissioner, 2003, 2 online at, http://www.privacy.org.nz/library/guthrie-tests accessed 6 October 2006.
[6] Luciana Lara dos Santos, et al "The Time has Come: A New Scene for PKU Treatment" (2006) 5(1) *Genetics and Molecular Research* 33, 33.
[7] American College of Medical Genetics, Newborn Screening Expert Group, *Newborn Screening: Toward a Uniform Screening Panel and System* (Commissioned by the Maternal and Child Health Bureau, Health Resources and Services Administration, 2005), 14.
[8] American College of Medical Genetics, Newborn Screening Expert Group, (2005), 14.

voluntary.[9] Yet, 99% of 60,000 children born each year are tested.[10] Chapters two through four analyse whether parents should retain the right to refuse consent to NBS on their child's behalf.

The court has jurisdiction under the Care of Children Act 2004 to place a child under the guardianship of the court.[11] This jurisdiction has been used in New Zealand for the purpose of consenting to medical treatment such as blood transfusions and chemotherapy. Chapter two considers whether the court would use this jurisdiction to consent to NBS. This involves a close analysis of New Zealand case law as well as relevant cases from England and Ireland.

Chapter three assesses whether it would be appropriate to make NBS mandatory by legislation. Close analysis will be made of the form the legislation might take, the goals it must achieve, and whether it could achieve these goals. Legislative provisions in the USA, where NBS is largely mandatory, are considered as part of this assessment.

Chapter four examines whether mandatory NBS is a justified limitation on the rights of parents, as guardians, to determine the upbringing of their child. NBS is compared to other situations where parents' rights are limited by statute, to determine whether mandatory NBS is also a justified limitation.

There are also a number of issues surrounding the storage of NBS cards. Once the newborn screening test is completed the samples are stored indefinitely.[12] The cards can be returned on request at any time, but this is not always clearly communicated to parents before screening.[13] If NBS became mandatory, further analysis of this storage policy would be necessary. Long term storage and use of NBS cards is outside the scope of this dissertation and is only noted as an issue for further consideration.

---

[9] Jones (2000), 22.
[10] Ministry of Health website, National Screening Unit, *Newborn Screening in New Zealand Today,* online at http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/38a4fd0fef7aa870cc2570c0000bffef?OpenDocument, accessed 4 October 2006.
[11] Sections 30, 31, and 33 Care of Children Act 2004.
[12] Jones (2000), 22.
[13] Privacy Commissioner (2003), 10. See also, National Testing Centre, *Your Newborn Baby's Blood Test: Te Whakamātau Toto O To Peepi Hōu*, National Testing Centre, Ministry of Health, Auckland, 2004, online at file:///C:/Documents%20and%20Settings/Acer/My%20Documents/Dissertation/Chapter%20One/Newborn%20screening%20leaflet%20NZ.htm accessed 5 October 2006.

Chapter One: The Screening Process in New Zealand

1. Introduction

To understand the legal issues canvassed in this dissertation it is necessary to understand the medical reasons for conducting NBS. This chapter will briefly outline the features of the disorders currently tested for in New Zealand and the effect of early treatment made possible by NBS. This will highlight the severity of the disorders and the dramatic difference in outcome for children who are identified and treated early, compared with children who are diagnosed clinically.

2. Screening

Screening is different to diagnostic testing. Screening involves offering testing to an asymptomatic population, to identify those with a disorder before they present with symptoms requiring treatment.[14] Further tests are usually required to confirm a diagnosis. Diagnostic tests are done to determine the cause of existing symptoms, after a patient approaches their health provider.

2.1. Criteria for Screening

Guidelines developed by the World Health Organisation (WHO), often called the 'Wilson-Junger' screening criteria, have been used internationally to determine which disorders should be included in screening programmes.[15] The disorder should be well understood and an 'important health problem.'[16] It is not appropriate to screen unless early treatment is advantageous to the patient.[17] Therefore, the disorder must have a latent period and an available treatment, which is effective during that period.[18] The cost of screening must also be balanced against the overall expenditure on medical care for that disorder.[19] There is some concern that not every disorder screened for in expanded NBS programmes meets these criteria.[20]

---

[14] Howard S Cuckle, and Nicholas Wald, "Tests Using Single Markers" in Nicholas Wald, and Ian Leck (eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 3, 3-4.

[15] J M G Wilson, and G Junger, *Principles and Practice of Screening for Disease*, (World Health Organisation, Geneva, 1968) These criteria have been cited with support in a number of articles. See for example N J Kerruish, and S P Robertson, "Newborn Screening: New Developments, New Dilemmas" (2005) 31 *Journal of Medical Ethics* 393. This article refers to the Wilson-Junger criteria as the gold standard in screening criteria.

[16] Principles 1 and 7, Wilson (1968), 26-27. Defining an 'important health problem' requires analysis of several factors. For example, it may be appropriate to screen for a rare disease with severe consequences.

[17] Wilson, (1968), 28.

[18] Principles 2 and 4, Wilson (1968), 27 and 29.

[19] Principle 9 Wilson (1968), 27 and 35-37.

[20] Diane Paul, "Contesting Consent: The Challenge to Compulsory Neonatal Screening for PKU" (1999) 42(2) *Perspectives in Biology and Medicine* 207(1), 4. This author argues that the concepts of benefit and treatment have been widened to rationalise the inclusion of some tests in NBS programmes. This concern is discussed further in chapter four.

3. Disorders Currently Tested For[21]

3.1 Phenylketonuria

Phenylketonuria (PKU) affects 1 in 15,000 New Zealand newborns.[22] Patients have an enzyme deficiency which means that they cannot metabolise phenylalanine, an essential component of proteins.[23] If left untreated, toxic levels of phenylalanine accumulate in the blood,[24] causing severe and permanent mental retardation, seizures, and autistic like behaviour.[25] Clinical diagnosis is only possible once mental retardation is apparent, meaning irreversible brain damage has already occurred.[26] However, treatment started as soon as possible after birth prevents this damage.[27]

PKU patients must follow a restrictive, low protein diet for life,[28] avoiding dairy products, meat, eggs, wheat, nuts, and some fruit and vegetables.[29] Because screening for PKU has been so successful, very few untreated children are seen in clinical practice.[30] NBS facilitates early treatment, which has the power to prevent serious brain damage in children with PKU.

3.2 Congenital Hypothyroidism

Congenital Hypothyroidism (CH) is a disorder characterised by low levels of thyroid hormone.[31] It affects 1 in 4,500 newborns.[32] Most babies with CH appear normal when born.[33] If untreated, they progressively develop lethargy, hypothermia, growth failure, deafness, mental retardation, and other neurological problems.[34] Clinical diagnosis is not possible until irreversible damage occurs.[35] This damage can be prevented by taking daily

---

[21] A summary of this information is included in a table as appendix one, for easy reference while reading other sections of this dissertation.
[22] LabPLUS website, Auckland District Health Board, National Testing Centre, online at http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.
[23] George C Cunningham, "Phenylketonuria and Other Inherited Metabolic Defects" in Nicholas Wald, and Ian Leck (eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 353, 353.
[24] Cunningham (2000), 353.
[25] Committee on Genetics, "Newborn Screening Fact Sheets" (1996) 98 *Pediatrics* 473, 489-90.
[26] Cunningham (2000), 353. Newborn babies can have eczema, growth retardation, an abnormally small head, very fair skin and hair, and experience vomiting. However, these symptoms are not specific to PKU.
[27] Committee on Genetics (1996), 490. Children show normal growth patterns and IQ within the normal range. Some children suffer from minor conceptual and language problems which do not usually affect their social skills or ability to obtain employment in later life: Cunningham (2000), 363.
[28] Cunningham (2000), 362; dos Santos (2006), 35.
[29] dos Santos (2006), 35.
[30] dos Santos (2006), 34 .
[31] This can be caused by several different defects in the thyroid gland. Joseph G Hollowell, Bradford L Therrell, W Harry Hannon, "Congenital Hypothyroidism" in Wald, Nicholas, Leck Ian, (Eds) *Antenatal and Neonatal Screening*, (2nd Ed., Oxford University Press, Oxford, 2000) 370 p370-372.
[32] Lab plus website http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.
[33] Committee on Genetics (1996), 481.
[34] The level of disability suffered is related to the length of time before proper treatment begins as well as the type of CH suffered from: Hollowell (2000), 372-73.
[35] Clinical diagnosis is not usually possible until three to six months of age: Hollowell (2000), 370.

thyroid hormone supplements as soon as possible after birth.[36] NBS can accurately detect CH as early as 2-4 days after birth and is therefore an important tool for preventing mental retardation and growth defects.[37]

3.3 Galactosaemia

Galactosaemia affects 1 in 120,000 newborns.[38] Patients cannot metabolise galactose, formed when milk is broken down in the body.[39] Without early treatment this disorder is usually fatal.[40] Babies first present with feeding problems, lethargy, vomiting, diarrhoea, and reduced muscle tone.[41] If the child survives without treatment this soon leads to severe liver disease, mental retardation, cataracts, and blood clotting problems.[42] Galactosaemic infants are also highly susceptible to *E. Coli* infections, which is a common cause of death in these children.[43]

Early treatment dramatically reduces the risk of death and prevents growth problems, liver damage and cataracts.[44] Galactosaemic patients follow a strict galactose free diet for life.[45] Unfortunately, this cannot prevent all long term complications.[46] Some patients have speech and muscle coordination problems.[47] Others show mental retardation of varying severity.[48] NBS cannot prevent all harm but protects against many life-threatening risks for galactosaemic patients.

---

[36] In more severe cases some children still show minor problems with visual and spatial perception and motor movement in response to sensory information: Susan R Rose, et al "Update of Newborn Screening and Therapy for Congenital Hypothyroidism" (2006) 117 *Pediatrics* 2290, 2298-9.

[37] Rose (2006), 2294. Samples taken before 48 hours will detect most types of CH but not all.

[38] Lab plus website http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.

[39] Annet M Bosch, "Classical Galactosaemia Revisited" (2006) 29 *Journal of Inherited Metabolic Disease* 516, 516, 518.

[40] Committee on Genetics (1996), 486.

[41] Bosch (2006), 518.

[42] J B Sidbury, "Investigations and Speculations on the Pathogenesis of Galactosemia" in David Yi-Yung Hsia (ed), *Galactosemia* (C.C. Thomas, Springfield, Illinois 1969) 13, 13.

[43] Bosch (2006), 519.

[44] Committee on Genetics (1996),486, G N Donnell, Richard Loch, and W R Bergen, "Observations on Results of Management of Galactosemic Patients" in David Yi-Yung Hsia, (ed), *Galactosemia* (C.C. Thomas, Springfield, Illinois 1969) 247, 249.

[45] Bosch (2006), 519. The diet is also lactose free as break down of lactose produces galactose. Other treatment such as antibiotics for *E.Coli* sepsis and treatment for liver damage may be needed early in life.

[46] Bosch (2006), 519-20. The severity of the disorder seems to depend largely on the particular type of galactosaemia a patient suffers from. Long term harm is possibly caused by body producing its own galactose, which cannot be excluded by dietary restrictions.

[47] M Bhat, C Haase, and P J Lee, "Social Outcome in Treated Individuals with Inherited Metabolic Disorders: UK Study" (2005) 28 *Journal of Inherited Metabolic Disease* 825, 829.

[48] Committee on Genetics (1996), 486. IQ in galactosaemic patients is varied but usually below, or at the lower end, of normal. There is some evidence that neurological problems are related to time of treatment, so early treatment may still reduce intellectual impairment.

3.4 Biotinidase Deficiency

Biotinidase deficiency (BD) affects 1 in 50,000 newborns.[49] Patients have an enzyme deficiency,[50] which causes seizures, loss of muscle tone, skin rashes, hair loss, eyesight and hearing loss, mental retardation, developmental delay,[51] and acidosis which can lead to coma and death.[52] Clinical diagnosis is only possible once these symptoms develop.[53] Early treatment with daily biotin supplements prevents the onset of these symptoms.[54] Treatment of children at any stage leads to some clinical improvement,[55] but eyesight and hearing loss, and mental retardation are irreversible.[56] NBS is important because it allows early treatment before these symptoms develop.[57]

3.5 Maple Syrup Urine Disease

Maple Syrup Urine Disease (MSUD) affects 1 in 250,000 newborns.[58] The disorder is caused by an enzyme deficiency, which means patients cannot metabolise branched-chain amino acids (BCAA), found in proteins.[59] If untreated, MSUD leads to acidosis, lethargy, seizures, brain dysfunction, coma and death.[60] These symptoms develop rapidly during the first 2-4 days of life.[61] Children that survive without early treatment, suffer serious mental retardation.[62]

---

[49] Lab plus website http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.

[50] Patients have a defective biotinidase enzyme, which is needed to recycle biotin, a coenzyme in several important processes. The disorder presents in a variety of forms and severities: Dorothea Moslinger, et al, "Clinical and Neuropsychological Outcome in 33 Patients with Biotinidase Deficiency Ascertained by Nationwide Newborn Screening and Family Studies in Austria," (2001) 160 *European Journal of Pediatrics* 277, 278.

[51] Barry Wolf, et al, "Biotinidase Deficiency: Novel Mutations and Their Biochemical and Clinical Correlates," (2005) 25(4) *Human Mutation* 413 (Wolf No2) ,2 Electronic article, numbered from page 1, online at http://www3.interscience.wiley.com/cgi-bin/abstract/11 0431219/ABSTRACT?CRETRY=1&SRETRY=0 accessed 6 October 2006.

[52] Moslinger (2001), 278. Acidosis is an abnormal increase in the acidity of fluids in the body.

[53] Onset of these symptoms varies from 2 weeks to 3 years: Committee on Genetics (1996), 476.

[54] Wolf No2 (2005), 1.

[55] Barry Wolf, "Biotinidase: Its Role in Biotinidase Deficiency and Biotin Metabolism," (2005) 16 *Journal of Nutritional Biochemistry* 441, 441 (Wolf No1) Rashes, alopecia, loss of muscle tone and seizures improve.

[56] Wolf No2 (2005), 1-2.

[57] Peter Weber, Sabine Scholl, and E Regula Baumgartner, "Outcome in Patients with Profound Biotinidase Deficiency: Relevance of Newborn Screening (2004) 46 *Developmental Medicine & Child Neurology* 481, 483

[58] Labplus website http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.

[59] This leads to a toxic accumulation of these amino acids in the body: Karen Heldt, et al "Diagnosis of MSUD by Newborn Screening Allows Early Intervention Without Extraneous Detoxification" (2005) 84 *Molecular Genetics and Metabolism* 313, 313.

[60] Committee on Genetics (1996), 478.

[61] D. Holmes Morton, et al "Diagnosis and Treatment of Maple Syrup Disease: A Study of 36 Patients" (2002) 109(6) *Pediatrics* 999, 1000.

[62] Early treatment results in a better long term neurological outcome: C le Roux, "Neuropsychometric Outcome Predictors for Adults with Maple Syrup Urine Disease" (2006) 29 *Journal of Inherited Metabolic Disease* 201, 202.

MSUD patients must follow a severely restricted diet, similar to that used for PKU.[63] Patients cannot consume natural protein, such as meat, dairy products, and some fruit and vegetables.[64] Even with NBS, some children suffer irreversible brain damage because of the early onset of this disorder.[65] However, effective NBS is still more desirable than clinical diagnosis of MSUD, and is important for reducing mortality and long term damage.[66]

3.6 Congenital Adrenal Hyperplasia

Congenital Adrenal Hyperplasia (CAH) affects 1 in 20,000 newborns.[67] CAH patients have an enzyme deficiency which causes excess production of male hormones.[68] Some female children are born with ambiguous genitals[69] and can therefore be diagnosed quickly using clinical means.[70] Other symptoms include salt wasting shortly after birth,[71] accelerated growth initially, but a stunted and short final stature, early puberty, virilisation,[72] and fertility problems in females.[73]

CAH patients must take steroid hormone supplements for life, to suppress excess production of male sex hormones.[74] Early treatment usually prevents virilisation, early puberty, and accelerated growth, and reduces fertility problems.[75] Nevertheless, CAH patients are

[63] Morton (2002), 1000. It is hard to keep blood levels of BCAA stable, especially during periods of illness, stress or fasting, or exercise, which can lead to protein break down in the body and an increase in blood BCAA levels. They pose a risk of further brain damage, even in childhood or adulthood.
[64] Patients must also take supplements to provide other necessary amino acids and vitamins: Paula Hallam, M Lilburn, and P J Lee, "A New Protein Substitute for Adolescents and Adults with Maple Syrup Urine Disease (MSUD)" (2005) 28 *Journal of Inherited Metabolic Disease* 665, 666, 671.
[65] For this reason, fast turn-around of results is imperative: Committee on Genetics (1996), 479.
[66] Morton (2002), 1004; E Simon, et al, "Maple syrup urine disease: Favourable effect of early diagnosis by newborn screening on the neonatal course of the disease" (2006) 29 *Journal of Inherited Metabolic Disease* 532, 534.
[67] Labplus website http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.
[68] For example, testosterone: Heino F L Meyer-Bahlburg, et al, "Gender Development in Women with Congenital Adrenal Hyperplasia as a Function of Disorder Severity" (2006) August 11, electronic publication ahead of print *Archives of Sexual Behaviour* p(1).
[69] U Kuhnle, and M Bullinger, "Outcome of Congenital Adrenal Hyperplasia" (1997) 12 *Pediatric Surgery International* 511, 511. Ambiguous genitalia can be corrected by surgery.
[70] Committee on Genetics (1996), 480.
[71] This means that the kidney excretes large amounts of salt despite the body's need to retain it, which can lead to life threatening shock: Committee on Genetics (1996),480.
[72] This term refers to the development of male sexual characteristics in females and the premature development of sexual characteristics in males.
[73] Committee on Genetics (1996), 479-480.
[74] Kuhnle (1997), 511. Patients who suffer from salt wasting symptoms must also take further supplements to control salt imbalance. This is a balancing act, as negative consequences result from both under and over treatment: Irini Manoli, et al, "Early Growth, Pubertal Development, Body Mass Index and Final Height of Patients with Congenital Adrenal Hyperplasia: Factors Influencing the Outcome" (2002) 57 *Clinical Endocrinology* 669, 669.
[75] Committee on Genetics (1996), 480.

generally shorter than average.[76] NBS plays an important role in facilitating early treatment, where patients do not exhibit ambiguous genitalia.

3.7 Cystic Fibrosis

Cystic Fibrosis (CF) affects 1 in 3000 newborns.[77] It is caused by a deficiency in a protein which controls salt movement in the body.[78] CF patients excrete thick mucus, which causes lung obstructions and a vulnerability to respiratory infections. Lung disease, malnutrition, stunted growth, infertility in boys, and liver disease are also common.[79] CF is hard to diagnose clinically at birth because the symptoms appear progressively.[80] This delay is associated with malnutrition and increased lung problems.[81]

There is no diet or medication to prevent these symptoms. Nevertheless, early diagnosis has been associated with long term benefits. Early treatment with nutritional supplements reduces malnutrition,[82] resulting in improved long term growth and cognitive function. [83] Other studies indicate that early treatment provides the potential for good lung function, although the long term outcome is influenced by other factors.[84] While there is no miracle treatment for CF, NBS provides affected children with a better quality of life than clinical diagnosis.

4. Impact of New Technology

It is anticipated that a 'tandem mass spectrometer' will be used for NBS in New Zealand from December 2006.[85] The NBS programme will be expanded to screen for 29 disorders.[86]

---

[76] Ga´bor Hargitai, et al, "Growth Patterns and Final Height in Congenital Adrenal Hyperplasia due to Classical 21-Hydroxylase Deficiency" (2001) 55 *Hormone Research* 161, 169.

[77] Labplus website http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006.

[78] Brice Marcet, and Jean-Marie Boeynaems, "Relationships Between Cystic Fibrosis Transmembrane Conductance Regulator, Extracellular Nucleotides and Cystic Fibrosis" (2006) July 7 electronic publication ahead of print *Pharmacology and Therapeutics,* p(1).

[79] Committee on Genetics (1996), 483. The degree of severity depends on the particular genetic mutation. 70% of CF patients have a 'δ508' mutation. The other 30% suffer from a wide range of different mutations which have varying clinical outcomes.

[80] Philip M Farrell, et al, "Early Diagnosis of Cystic Fibrosis Through Neonatal Screening Prevents Severe Malnutrition and Improves Long-Term Growth" (2001) 107 *Pediatrics* 1, 2 (Farrell No1). Note that approx 10% of CF children are born with an intestine obstruction and are quickly diagnosed clinically. Up to half of CF patients diagnosed clinically are more than a year old and 25% are not diagnosed until they are more than 2 years old. Committee on Genetics (1996), 483.

[81] Farrell No1 (2001), 2.

[82] Malnutrition is caused by poor absorption of nutrients, particularly fat, protein and fat soluble vitamins and can be prevented by dietary supplements of vitamins, and pancreatic enzymes: Rebecca L Koscik, et al, "Preventing Early, Prolonged Vitamin E Deficiency: An Opportunity for Better Cognitive Outcomes via Early Diagnosis Through Neonatal Screening" (2005) 147(Supplement 3) *The Journal of Pediatrics* S51, S51.

[83] Philip M Farrell, et al, "Evidence on Improved Outcomes with Early Diagnosis of Cystic Fibrosis Through Neonatal Screening: Enough is Enough!" (2005) 147(Supplement 3) *The Journal of Pediatrics* S30, S35 (Farrell No2).

[84] Farrell No2 (2005), S35.

[85] Correspondence with Dr Dianne Webster, Director of the National Testing Center in New Zealand, 5 October 2006. This centre is responsible for carrying out NBS tests in New Zealand.

Tandem mass spectrometry is a new testing technique, which is quick, cost-efficient, and detects many disorders using a single test.[87] This technology is in use in parts of Europe, Australia, and the USA. For the purposes of this dissertation the legal issues remain the same. The NBS programme will operate in the same manner, with the only change being the number of disorders screened for.

5. False Positive and False Negative Results

False positive and false negative results are a risk in any testing procedure. A false positive result indicates a child has a disorder, when in fact they do not. It is estimated that 1% of screened newborns will return a false positive result.[88] These results can be corrected quickly using other diagnostic methods.

False negative results indicate that a child is healthy when they are actually affected by a disorder. The impact of false negative results varies depending on the disorder and there can be many reasons for a child being missed.[89] Statistics on false negative results are therefore harder to collate. However, the incidence of false negative results can be described as negligible.[90] Tandem mass spectrometry is proving to be highly accurate, with some studies reporting no false negative results for a wide range of disorders.[91]

6. Conclusion

NBS tests are simple, non-invasive, and identify children affected by serious metabolic disorders. Early diagnosis can prevent death, irreversible brain damage, and physical disabilities. There are also benefits for the families of affected children and the State, which will be addressed in chapters three and four. Given these benefits, should NBS be mandatory? This question is considered in detail in the following sections of this dissertation.

---

[86] Correspondence with Dr Dianne Webster, 5 October 2006. Note that this number can be interpreted differently depending on the way disorders are classified. Five disorders will be tested for using current technology.
[87] For a simple explanation of how a tandem mass spectrometer works, see the Pediatrix Screening website, Pediatric Medical Group, *Tandem Mass Spectrometry* at http://www.pediatrix.com/body_screening.cfm?id=343 accessed 6 October 2006. For more detail see Rodney J Pollitt, et al, "Neonatal screening for inborn errors of metabolism: cost, yield and outcome" (1997) 1(7) *Health Technology Assessment* (No1), 16-19.
[88] Pollitt No1 (1997), 140.
[89] Pollitt No1 (1997), 16, 18. For example, laboratory error, contamination, or inadequate food intake before testing.
[90] Kerruish, (2005), 394.
[91] Pollitt No1 (1997), 19; Donald H Chace, et al "Use of Phenylalanine-to-Tyrosine Ratio Determined by Tandem Mass Spectrometry to Improve Newborn Screening for Phenylketonuria of Early Discharge Specimens Collected in the First 24 Hours"(1998) 42(12) *Clinical Chemistry* 2405.

Chapter Two: The Court's Power to Consent to Newborn Screening

1. Introduction

This chapter examines whether the New Zealand courts would use their powers to consent to a NBS test, against parents' wishes. The scenario to be considered is where both parents are guardians, have been informed about the risks and benefits of NBS, and after considering this information, have refused to consent to a NBS test for their child.[92] The question is whether the court would interfere in these circumstances to override the parents' refusal. This chapter also briefly addresses the personal liability of parents who refuse consent to NBS.

2. Jurisdiction of the Court

The High Court has an inherent jurisdiction to exercise parens patriae powers over incompetent persons including children.[93] However, this power is rarely used and has largely been replaced by statutory powers granted to both the specialist Family Court and High Court, under the Guardianship Act 1968,[94] its successor The Care of Children Act 2004 (COCA), and The Children, Young Persons, and Their Families Act 1989 (CYPFA).[95]

The COCA provides the court with a statutory jurisdiction to grant an order placing a child under the guardianship of the court and ordering any person to be the court's agent, generally or for a particular purpose.[96] As a guardian, the court can consent to medical procedures on behalf of the child.[97] When exercising this power, the welfare and best interests of the child are the paramount consideration.[98] In the scenario being considered, an application will most likely be made by a health provider. They may apply only with leave from the court.[99]

---

[92] It is accepted that it is possible for complicated fact scenarios to arise in this area of law. For example, parents can be separated, parents don't always agree about providing medical treatment, not all parents are guardians of their children, and not all guardians will be parents of the child concerned. This dissertation will be limited to the basic scenario where both parents agree not to have their child screened.

[93] *Pallin v Department of Social Welfare*[1983] NZLR 266, 272. Cooke J expressly recognised that the court still has such a power in relation to children.

[94] Most New Zealand guardianship cases were decided under this legislation. The COCA replaced this Act on 1 July 2005.

[95] For the purpose of this dissertation nothing turns on whether the court exercises its inherent or statutory jurisdiction. In *Re Norma* [1992] NZFLR 445*,* 450 Tompkins J stated that the court might use its parens partriae jurisdiction where consent is sought to a specific single treatment. He considered the statutory jurisdiction to be more appropriate where ongoing supervision of treatment is needed.

[96] Section 33(1), COCA.

[97] The court has used this jurisdiction (largely under the Guardianship Act 1968) several times. See for example *Re J (An Infant): Director General of Social Welfare v B and B* [1995] 3 NZLR 73 (HC)*, Re Norma*, *Re CL* [1994] NZFLR 352*, Re V* [1993] NZFLR 369*, Re P* [1992] NZFLR 94*, Director General of Social Welfare v Ulutau* (1988) 5 NZFLR 631*, Healthcare Otago Ltd v Williams-Holloway* [1999] NZFLR 804.

[98] Section 4, COCA.

[99] Section 31(1), COCA states that an eligible person may apply. An eligible person is defined in section 31(2)(g), COCA to include any person with leave of the court.

The CYPFA provides the court with a wide range of powers, including the power to remove and appoint guardians, where a child is considered to be in need of care and protection.[100] Where the parents have failed to provide a child with the necessities of life the court can also impose criminal liability under the Crimes Act 1961 (NZCA).[101]

3. The Parental Right to Give Informed Consent on Behalf of Children

There is no legislation dealing specifically with procedural requirements or consent for NBS. The ordinary rules regarding consent to medical treatment therefore apply.[102] The Code of Health and Disability Services Consumers' Rights 1996 (Code of Rights) states that informed consent must be obtained from a consumer before health services are provided.[103] 'Consumer' is defined in the Code of Rights to include a person entitled to give consent on behalf of that consumer.[104] As a newborn is incompetent,[105] consent must be obtained from a guardian, who has the right to make decisions regarding medical treatment for that child.[106] This right is also recognised at common law.[107] Although it was assumed that parents had such a right, it was not clearly recognised by the English courts until the 1960s.[108]

3.1 Limitations on the Parental Right to Consent

Parents are permitted to make decisions on behalf of their children because they are in the best position to assess the child's unique needs and make decisions that benefit that child.[109] However, parents' right to consent or refuse consent to medical procedures is not absolute.[110] In *Gillick v West Norfolk and Wishbech Area Health Authority (Gillick)*,[111] it was held that the scope of parental rights is reflective of the duties parents owe towards children.[112] Guardianship rights exist for the benefit of the child rather than the parent.[113] Therefore, the

---

[100] 'A child in need of care and protection' is defined in Section 14(1), CYPF 1989.
[101] Under section 152 of the Crimes Act 1961 it is an offence to fail to provide a child with necessaries when under a duty to do so. The maximum sentence is 7 years imprisonment.
[102] Note: It is not doubted that informed consent is required before a NBS test can be carried out: Privacy Commissioner (2003), 8; Health and Disability Commissioner (HDC) Case Number 99HDC09011, 4 August 2000.
[103] Right 7(1), Code of Rights.
[104] Section 4, Code of Rights.
[105] They are not competent in terms of section 36(1) and (2) of the COCA nor are they '*Gillick* competent.'
[106] Sections 16(2)(c) and 36(3)(a) of the COCA state that the rights of a guardian include the right to make medical decisions on behalf of a child. A parent will usually be a guardian of the child.
[107] *Re J (An Infant): B and B v Director General of Social Welfare* [1996] 2 NZLR 134 (CA), 145, per Gault J.
[108] P D G Skegg, *Law, Ethics, and Medicine: Studies in Medical Law* (Clarendon Press, Oxford, 1988), 58; *Re L* [1968] P. 119, 131-132, per Ormrod J; *B. (B.R.) v B. (J.)* [1968] P. 446, 477 per Diplock J.
[109] Douglas Diekema, "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention" (2004) 25 *Theoretical Medicine* 243, 244. John Caldwell, "Parents, Courts, and the Sick Child" (2000) 3 *Butterworths Family Law Journal* 129, 130.
[110] See for example, *Re CL, Re Norma, Re V,* and *Re J* (HC).
[111] *Gillick v West Norfolk and Wishbech Area Health Authority* [1986] AC 112.
[112] *Gillick*, 184-5, per Lord Scarman, and cited with approval in *Re J* (CA), 145, per Gault J.
[113] *Gillick*, 170, per Lord Fraser. W J Brookbanks, "Religious Parents and Neglected Children" (2002) 4 *Butterworths Family Law Journal* 97. 99.

primary function of the parental right to consent to medical treatment is to protect the welfare of the child.[114]

3.2 Duties of Parents

In any guardianship proceedings, the court must decide what is in the best interests of the child.[115] Defining the duties of parents and how the 'best interests' test should be applied is critical to determining whether the courts should override a parental refusal of NBS. The fundamental concept behind the 'best interest' test is that no one should consent or refuse consent to procedures, on behalf of another, where it would risk the infliction of some harm to that person.[116] In practice though, application of this test is not always straightforward.[117]

The parental duty to act in the best interests of a child cannot mean that parents should never make decisions that place the child at some risk.[118] Society grants parents a high degree of freedom to determine the risks their child is exposed to.[119] For example, parents take children in cars and aeroplanes, cross busy roads with them, let them walk to school unaccompanied, provide them with unhealthy food, and allow them to get their ears pierced.[120] This list could be extended by numerous other examples. In each situation there is some risk of harm, yet neither the courts nor Parliament have prevented parents from taking such risks. This suggests that parents can expose their children to some risks even where, as in the case of providing a bad diet, there is no obvious benefit to the child.[121]

At the other extreme, there are situations where parents put their child at such risk that the court will step in to assist that child. The CYPFA and NZCA indicate the minimum standard of care that parents must provide to avoid court interference with their parental rights. That is, parents must not inflict harm on their children. If a child is in need of care and protection, the court may make a number of orders under CYPFA, including removing the child from the parents care.[122] For example, the court can intervene if a child is physically, emotionally, or sexually abused, ill-treated, or neglected.[123] Where a child suffers serious harm, or dies

---

[114] Ruth R Faden, Neil A Holtzman, A Judith Chwalow, "Parental Rights, Child Welfare, and Public Health: The Case of PKU Screening" (1982) 72(12) *American Journal of Public Health* 1396 (No2), 1397.
[115] As required by Section 4, COCA.
[116] John Harris, "Mark Anthony or Macbeth: Some Problems Concerning the Dead and the Incompetent when it Comes to Consent" in Sheila A M McLean (ed), *First Do No Harm, Law Ethics and Healthcare* (Ashgate Publishing Group, 2006) 287, 298.
[117] Skegg (1988), 59.
[118] Diekema (2004), 244. If this were the case, very few parents would ever meet the required standard.
[119] Skegg (1988), 66.
[120] Harris (2006), 297-298 and Skegg (1988), 66.
[121] Skegg (1988), 66.
[122] If the court is satisfied that the child is in need of care and protection, a declaration can be made under section 67 CYPF. This declaration gives the court the power to make a number of orders that will provide that child with care and protection, as set out in section 83 CYPF.
[123] Section 14(1)(a), CYPF 1989. See section 14(1), CYPF 1989 for more detail on the definition of a 'child in need of care and protection.'

because the parents fail to provide them with the necessities of life, the parents may also be criminally liable under the NZCA.[124] This liability will be given further consideration below.

The court can also intervene under the COCA in situations between these two extremes, when parents do not act in a child's best interests.[125] Drawing a line between the risks parents can and cannot expose their child to is difficult and much turns on the particular facts of each case. This chapter examines which side of this line refusing NBS should sit. Failure to screen puts a child at risk, albeit remote, of very serious physical and mental abnormalities. However, a child's best interests cannot be determined by a purely scientific or statistical analysis of medical outcomes.[126] Situations involving medical treatment of children also raise ethical and social value questions to which medicine has no answer.[127] Factors, such as the effect on the family when parental decisions are overturned, are also relevant.[128] These factors are considered as they apply to the NBS situation.

4. Use of the Guardianship Jurisdiction to Consent to NBS

The court has previously used its guardianship jurisdiction for a wide range of purposes,[129] but not as yet to consent to NBS. To predict the court's approach to the scenario being considered, this chapter examines a number of similar cases and how they might apply to this new fact scenario.

The Irish Supreme Court is the only court to have considered consenting to NBS, in *North Western Health Board v. W. (H.) (NWHB).*[130] In *Re C (A Child)*,[131] the English courts granted an order requiring a baby to be tested for HIV. There are also a number of cases dealing with consent to medical treatment more generally. Finally, there is conflicting case authority, both in the United Kingdom and New Zealand, regarding the use of the guardianship jurisdiction to consent to taking blood samples from children for paternity testing.

4.1 Decisions Regarding the Testing of Newborns

(a) Newborn Screening in Ireland: North Western Health Board v W. (H.)

The Irish Supreme Court case, *NWHB,* is the only time a court has considered overriding a parental refusal of NBS. The parents saw the test as invasive and harmful to their child,[132] but

[124] Section 152, NZCA.
[125] The inherent, parens partriae jurisdiction could also be used.
[126] *Re Norma*, 451, per Tompkins J.
[127] Goldstein, Joseph, "Medical Care for the Child at Risk: On State Supervention of Parental Autonomy" (1977) 86 *The Yale Law Journal* 645, 644.
[128] *Re Norma*, 451, per Tompkins J.
[129] These have included giving consent to medical procedures, such as blood transfusions and chemotherapy, and giving consent for DNA samples to be taken.
[130] *North Western Health Board v. W. (H.)* [2001] IESC 70
[131] *Re C (A Child)* [2000] Fam 48, [2000] 2 WLR 270, [1999] 3 FCR 289 (HC); *Re C (A Child)* [1999] 2 FLR 1004, [2000] Fam Law 16 (CA).
[132] This was because NBS involved puncturing the child's blood vessels.

did not put forward any religious or medical reasons for their refusal. The court unanimously accepted that NBS was in the best interests of the child medically, but the majority refused to override the parents' decision.

The decision must be considered in light of unique provisions in the Constitution of Ireland ('the Constitution'),[133] as the case was argued based on constitutional principles, rather than as a guardianship case. The plaintiff claimed that the parents' refusal was a failure to vindicate the rights of the child as required by the Constitution.[134] Determining the child's best interests required consideration of parental responsibility, the child's personal rights, and the family's right to determine what is in the best interests of the child.[135]

The majority emphasised the family's right to determine the upbringing of a child.[136] The family has a unique status in Ireland. The Constitution recognises the family as the "natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law."[137] The State can only interfere in exceptional circumstances, where "parents for physical or moral reasons fail in their duty towards their children."[138] The Court held that intervention is only appropriate where the "disastrous consequences of a particular parental decision are so immediate and inevitable as to demand intervention and perhaps call into question either the basic competence or devotion of the parents."[139] The majority of the Court thought that refusing NBS did not reach this threshold because the risk of harm was remote and the child was not in any immediate danger.[140]

This decision largely relied on particular terms of the Irish Constitution, and to that extent is not directly applicable to New Zealand. While New Zealand has no equivalent provision protecting the family's rights, the approaches of both jurisdictions to medical treatment cases are quite similar. The New Zealand courts are also reluctant to override parents' decisions.[141] They generally only intervene where treatment, such as a blood transfusion or chemotherapy, is needed to prevent death or serious harm. There are no similar, reported cases decided by

[133] The Constitution of Ireland has been in force since 29 December 1937.
[134] As required by Article 40.3.1 of the Constitution. The Plaintiff also applied for a mandatory injunction ordering the parents to give consent for the test as well as interlocutory orders allowing the test to be carried out without the parents' consent and preventing them from impeding the test being carried out: *NWHB* para [14], per Keane CJ.
[135] *NWHB* para [182], per Denham J.
[136] *NWHB* para [185], per Denham J.
[137] Article 41.1 of the Constitution.
[138] Article 42.5 of the Constitution
[139] *NWHB* paras [208]-[209], per Murphy J.
[140] See for example *NWHB* para [230], per Murray J and para [354], per Hardiman J.
[141] The approach of the New Zealand courts to overriding parental refusals of medical treatment is discussed below, in section 4.2 of this chapter.

the Irish courts. However, in *JM v The Board of Management of Saint Vincent's Hospital*[142] the court overrode an incompetent adult's decision to refuse a blood transfusion.[143] The Irish High Court recently ordered that a woman receive a blood transfusion against her wishes, after haemorrhaging while given birth, because it would be in the best interests of her newborn child.[144] These decisions indicate that the Irish courts would approach the medical treatment of children in a similar way to the New Zealand courts.

As in New Zealand, medical tests and treatment are generally not compulsory in Ireland. The Court in *NWHB* was also concerned that granting the orders sought would essentially make NBS compulsory. This would substantially change the State's approach to consent for medical treatment.[145] The court considered this policy decision more appropriate for the legislature.[146]

Chief Justice Keane dissented.[147] He did not consider that granting the orders sought in *NWHB* would necessarily mean that NBS would become compulsory. The parents in *NWBH* put forward no reason, religious, scientific, medical, or otherwise, to support their decision to refuse consent. The Chief Justice thought that sound arguments, based on religious grounds, or proof that reliable results could be determined using non-invasive means, would need to be considered by a court and could produce a different result.[148]

The majority has been criticised for placing too much emphasis on parents' rights rather than their responsibilities, and for creating a low threshold for satisfaction of parental duties.[149] One commentator has argued that the majority focussed too greatly on maintaining parental rights as against the state, and too little on the child's rights as against their parents.[150]

While the decision in *NWHB* was based on Irish constitutional provisions, as the only case to consider a refusal of NBS, the Court's reasoning is likely to be considered carefully in any New Zealand case. NBS is voluntary in New Zealand. If court consent to NBS in a single

---

[142] *JM v The Board of Management of Saint Vincent's Hospital* [2003] 1 IR 321.
[143] The woman had recently married a man of the Jehovah's Witness faith and adopted this religion. She had discussed consenting to blood transfusions when lucid but refused consent in circumstances which indicated she was not competent.
[144] Eithne Donnellan, "Woman in court transfusion case recovering in hospital" *The Irish Times*, 22 September 2006, online at http://www.ireland.com/newspaper/front/2006/0922/115859088 1290.html accessed 7 October 2006. This case has not yet been reported. The only reports of this case have been in the Irish media, so a clear statement of the Court's opinion is not available.
[145] *NWHB* para [177], per Denham J.
[146] *NWHB* para [316], per Hardiman J.
[147] Keane CJ would have ordered the test, as he believed the plaintiffs had established that the constitutional rights of the child could only be maintained if the test was ordered: *NWHB* para [125].
[148] *NWHB* para [123]-[124], per Keane CJ.
[149] G Laurie, "Better to Hesitate at the Threshold of Compulsion: PKU Testing and the Concept of Family Autonomy in Eire" (2002) 28 *Journal of Medical Ethics* 136 (No1), 137.
[150] Laurie (2002), 137.

case would result in NBS becoming compulsory, this may persuade the Court to refuse to grant any orders sought.

(b) HIV Diagnostic Testing: Re C (HIV Test)[151]

This case concerned a five month old baby born to an HIV positive mother. The mother had refused conventional treatment herself, treating the problem by living a healthy lifestyle.[152] The family's general practitioner urged the parents to have the child tested for HIV.[153] When the parents refused this recommendation, the local health authority, applied to the court for an order that a blood sample be taken and tested to determine the baby's HIV status. The High Court decision granting this order was later upheld by the Court of Appeal.

The important issue for the court was the need to know the child's state of health. Lady Butler-Sloss stated:[154]

> In my view, the child is clearly at risk if there is ignorance of the child's medical condition. The degree of intrusion into the child of a medical test is slight. The degree of intrusion into the family of taking the child to the hospital for a medical test would for most people be comparatively slight…Can it be in the child's best interests for the parents to remain ignorant of their own child's state of health? You only have to ask that question for most people to say no.

This reasoning is applicable to NBS. It is not in a child's best interests for parents or medical professionals to be ignorant of their condition. Knowledge that a child has a NBS disorder, combined with appropriate treatment, dramatically improves the short and long term outcome for that child. The potential for long term benefit is arguably greater from early diagnosis of NBS disorders than with HIV.[155] The heel prick procedure is less invasive than that used to obtain a blood sample for HIV testing and in most cases the parents will not need to bring the child to hospital for testing.[156] This case could therefore support an order giving consent for NBS.

However, there are some important factual differences that distinguish this case. In *Re C,* the child had a 20-25% of having HIV.[157] Without appropriate treatment she risked suffering

---

[151] *Re C (A Child)* [1999] 2 FLR 1004 (CA).
[152] There was evidence that the mother did not actually believe the HIV virus existed and therefore saw no point in conventional treatment.
[153] The baby may have contracted the virus during pregnancy, birth, or breast feeding.
[154] *Re C* (CA), per Butler-Sloss LJ, page numbers not available for this case. It can be accessed online at http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCA/Civ/1999/3007.html&query=+c+HIV&method=all.
[155] Children with HIV will eventually progress to AIDS and die, while many of those with NBS disorders can go on to lead relatively normal lives.
[156] The test is usually done before the child leaves the hospital. In the case of home births the lead maternity carer is responsible for collecting the sample and will usually come to the family home.
[157] *Re C (A Child)* [2000] Fam 48 (HC), 54, per Wilson J.

from AIDS related illnesses[158] and had a 4% chance of death before her first birthday.[159] There was a real risk that the child had contracted HIV, which cannot be said of most newborn children with regard to the NBS disorders.[160]

A further distinction of this case was made in *NWHB*.[161] The precedential value of *Re C* is limited. It is not an authority requiring all babies to be tested for HIV. Conversely, if a New Zealand Court held that a newborn child, with no family history of a NBS disorder, must be tested, then NBS would effectively become compulsory. The courts would be reluctant to apply this case to NBS because of the potentially far-reaching consequences of such a decision.

However, *Re C* may well support the court consenting to NBS if a child has an increased risk of having a disorder. For example, if a child has a sibling with PKU, there is a 25% chance that child will also have the disorder.[162] It would be difficult to distinguish *Re C* in such a situation and it is likely that this increased risk would persuade the court to consent to NBS.

(c) New Zealand: Health and Disability Commissioner (HDC) Decisions

The New Zealand HDC has commented on consent to NBS in two investigations. The commissioner found that it is a breach of the Code of Rights to conduct a NBS test without obtaining consent from the child's parents.[163] It is also a breach of the Code of Rights to threaten to contact the Children Young Persons and Their Family's Service when parents refuse consent.[164] These decisions confirm that NBS is voluntary in New Zealand. The Code of Rights would be relevant to a court considering an application under the COCA for the purposes of consenting to NBS.

4.2 Cases Regarding the Medical Treatment of Children Generally

None of the above decisions are binding in New Zealand. It is therefore important to examine the approach of the New Zealand courts to the medical treatment of children. The New Zealand courts have placed children under the guardianship of the court for the purpose of consenting to a number of treatments, including blood transfusions,[165] chemotherapy,[166] and

[158] Such as PCP (Pneumocystis Carinii Pneumonia): *Re C* (HC), 56, per Wilson J.
[159] *Re C* (HC), 56, per Wilson J.
[160] The risk of having a NBS disorder is much less than 1%.
[161] *NWHB* para [168], per Denham J.
[162] If an older sibling has PKU this means that the parents of the child are both carriers for the disorder. PKU is inherited in an autosomal recessive fashion. Where the parents are both carriers, there is a 25% chance that the child will have the disorder. See appendix one for further explanation.
[163] Case Number 99HDC09011, 4 August 2000. Auckland Healthcare was found to have breached rights 7(1) and 7(9).
[164] Case Number 99HDC09973, 19 December 2001, Ron Patterson. The conduct of a paediatrician was found to have breached right 2 and 5.
[165] *Re V, Re J, Re CL, Re P, Director General of Social Welfare v Ulutau.* Refusal in these cases is usually based on religious grounds.

removing tumours.[167] In each case, the court's paramount concern was the welfare and best interests of the child.[168] This section will address the factors that New Zealand courts have considered important and how they are relevant to NBS.

(a) Objective Medical Benefits

The medical benefits of any procedure, and the health risks associated with both treatment and failure to treat, are obviously relevant to the welfare of a child, and therefore important to the court.[169] However, there must be a serious risk to the health of the child before the court will intervene. In *Re J,*[170] the court held that a guardianship order 'should only be made where the child's life or well being is in serious jeopardy and there is no other reasonable medical or therapeutic treatment available.'[171] For example, in *Re J* the child would have died without a blood transfusion, therefore the child was at serious risk of harm.[172] This appears similar to the approach of the Irish Supreme Court in *NWHB*.[173] The court has also used the child's right to life, as protected by section 8 of the New Zealand Bill of Rights Act 1990 (NZBORA), as support for exercising its guardianship jurisdiction.[174]

The risks associated with NBS are slight and the benefits are potentially huge.[175] However, an argument that failing to screen places a child at an appreciable risk of death or serious disability, or that the child is being denied his or her right to life, would require a strained interpretation of previous medical treatment cases.[176] While affected children risk death or serious disability without treatment, the disorders tested are all very rare. This low risk of harm distinguishes refusing consent to NBS from cases where the court has exercised its

---

[166] *Auckland Healthcare Services Ltd v T* [1996] NZFLR 670*, Re Norma, Healthcare Otago Ltd v Williams-Holloway.*

[167] *Director General of Social Welfare v B* [1994] NZFLR 516.

[168] Section 4(1), COCA. See for example *Re Norma*, 451, per Tompkins J and *Re CL*, 357, per Robertson J. This has been a statutory consideration since the implementation of the Guardianship Act 1968 but is also a valid principle under the common law.

[169] *Re Norma*, 451, per Tompkins J.

[170] *Re J (An Infant): Director General of Social Welfare v B and B,* [1995] 3 NZLR 73 (HC); *Re J (An Infant): B and B v Director General of Social Welfare,* [1996] 2 NZLR 134 (CA)

[171] *Re J (*HC), 88 and cited with approval in *Re J* (CA), 139. Other cases support this approach. In *Re Norma,* 451 the Court held it had a duty to intervene where a child required 'essential medical treatment'. In *Re P,* 96 it was held there must be a 'real and substantial risk of death.'

[172] Another example is *Re Norma*, where medical evidence stated that without appropriate treatment for bone cancer Norma would die. See also *Healthcare Otago Ltd v Williams-Holloway* (the child required chemotherapy to have any chance of survival) and *Re CL* (the child may have required a life-saving blood transfusion during an important operation).

[173] See *NWHB*, para [208]-[209], per Murphy J, where he defines the exceptional circumstances required before the court will step in.

[174] See for Example *Re J* (HC), 80-82, per Ellis J and *Re J* (CA), 143, 146, per Gault J.

[175] See chapter one and appendix one of this dissertation for more details. It was unanimously accepted in *NWHB* that the benefits outweighed any risks associated with NBS.

[176] Ainsley Newson, "Should Parental Refusals of Newborn Screening Be Respected?" (2006) 15 *Cambridge Quarterly of Healthcare Ethics* 135, 138.

guardianship jurisdiction in the past. This would justify a court refusing to place a child under its guardianship.

NBS is a test rather than a treatment for a diagnosed disorder. However, the court is unlikely to refuse to excuse its guardianship jurisdiction on this ground alone. In both *Re Norma* and *Re C,* the Court used its jurisdiction to order tests for cancer and HIV respectively.

(b) Effectiveness of the Proposed Procedures

In *Re J,* Ellis J held that parents' rights should be upheld where there is no other treatment available, or there are serious doubts about the efficacy and suitability of the proposed treatment.[177] However, in all major New Zealand cases, the courts have refused to uphold the parents' decision to use 'alternative treatments.'[178] A court is more likely to override parents' decisions if they are based on religious or other unconventional grounds.[179] For example, in *Re Norma,* the Court preferred conventional cancer treatment over traditional Samoan healing.

In *Re T,*[180] a refusal to consent to a liver transplant, by parents who were also health professionals, was based on the medical prognosis for the child. There was no guarantee the surgery would be successful. The surgery was still experimental, and there would still be serious medical concerns for the child following surgery. Importantly, for these reasons, at least one practitioner was not prepared to conduct the surgery without the mother's consent. The Court thought this distinguished the case from those where the parents' decision was based purely on religious dogma, and refused to intervene.[181]

The use of blood spot analysis for NBS is widely recognised as the most effective way to detect a range of metabolic disorders and allow for early treatment.[182] While there is a possibility of incorrect results, the NBS test is very accurate.[183] The alternative method, clinical diagnosis, can take months, or even years and is often not possible until serious, irreversible symptoms are present.[184]

---

[177] *Re J* (HC), 82, observing with approval the Supreme Court of Canada's approach in *B(R) v Children's Aid Society of Metropolitan Toronto* [1995] 1 SCR 315.
[178] Caldwell (2000), 134. In this context 'alternative treatments' refers to treatment other than that adopted by conventional, Western medical practice.
[179] See *Re T (A minor) (Wardship: medical treatment)* [1997] 1 WLR 242, 254, per Waite J.
[180] *Re T (A minor) (Wardship: medical treatment)* [1997] 1 WLR 242.
[181] *Re T*, 254, per Waite J. Note this decision on appeal overturned the ruling of the lower court who would have ordered the treatment. This indicates that there is no clear 'right' or 'reasonable' answer in these complex cases.
[182] Kerruish (2001), 393.
[183] See generally Chace (1998).
[184] See chapter one, and appendix one for details about these disorders.

It is unlikely a refusal of NBS could be based on medical grounds, as in *Re T*.[185] It is therefore arguable that *Re T* can be distinguished, and the parents' decision overruled. However, while clinical diagnosis is not ideal, the risk that the child will have to rely on this less suitable diagnostic technique is very remote. Despite the fact any refusal cannot be medically supported, NBS is still fundamentally different to cases such as *Re Norma*. Without an immediate risk to the child, it is unlikely that the poorer results obtained using clinical diagnosis will persuade the court to exercise its jurisdiction.

(c) Effect on the Family

The welfare of the family is important because a child's welfare is at least partly determined by the family and their place in it.[186] Where a decision is likely to cause serious stress within a family, this is a factor to be considered.[187] Nevertheless, if the child's life is in danger, the court often adopts the approach suggested by conventional medicine.[188]

NBS creates minimal disruption to the family, especially when compared with cases such as *Healthcare Otago Ltd v Williams-Holloway,*[189] where the court ordered that the child receive chemotherapy. Chemotherapy requires serious commitment from parents, but the court still held that the best interests of the child lay in allowing treatment. By contrast, in *Re T*, where the court declined to intervene, the effect on the family was an important reason for the decision. The cooperation and dedication of the family in post-operative care was essential to the success of a liver transplant, and therefore an important consideration.

A NBS test is generally conducted when the child is still in hospital, and there is no need for subsequent care unless a positive result is returned. NBS therefore requires little commitment from parents. This might suggest that the courts should use their powers to consent to NBS. However, in previous cases, the court intervened in spite of the effect on the family because the child was in a perilous position. In *Re CL*, Robertson J held:[190]

> A court will always endeavour to intrude to the least extent possible on the family's circle, but the welfare of the child is the paramount consideration and…there will be times when there must be intervention.

Therefore, the court protects the family, unless there are serious reasons not to. As discussed earlier, it is unlikely that the remote risks associated with refusing NBS are sufficient to justify

---

[185] The risk of harm from the test is negligible. It is also unlikely that a medical practitioner would lodge an application if there were medical reasons for not having the test done.
[186] *Re Norma*, 451, per Tompkins J.
[187] *Re Norma,* 451, per Tompkins J.
[188] Blood transfusions are almost invariably ordered despite the stress this causes parents of the Jehovah's witness faith, as are treatments for cancer.
[189] *Healthcare Otago Ltd v Williams-Holloway* [1999] NZFLR 804
[190] *Re CL*, 357.

intervention. The small impact on the family cannot be considered in isolation, and is unlikely to be a determining factor in any NBS case.

(d) Conclusion

NBS is non-invasive, involves little impact on the family unit, and the alternative method of clinical diagnosis is far less successful in preventing death and irreversible harm. These features indicate the court should exercise its jurisdiction to give consent to NBS. However, in all major New Zealand cases, the courts have clearly stated that intruding on the family is only appropriate where there is a real risk of serious harm. The risk that a child will suffer any harm at all, as a result of the parents' refusal to consent to NBS, is very low for each child. This makes NBS fundamentally different to previous medical treatment cases. Therefore, it is likely that the court would refuse to exercise its guardianship jurisdiction to consent to NBS.

4.3 DNA Testing Cases

There is conflicting case authority regarding the use of the court's guardianship powers to consent to blood testing of children for the purpose of DNA paternity testing. In the recent case of *T v S,*[191] the Court of Appeal approved a High Court decision[192] placing a child under the guardianship of the court and consenting to the taking of a cheek sample for DNA analysis. The court analysed conflicting cases in both New Zealand and England.

In *Asomua v Thompson*[193] it was held (without reference to earlier authorities) that the court did have jurisdiction to appoint a guardian for the purpose of consenting to blood testing. In England, in *Re R (A minor)*,[194] the Court also used its guardianship jurisdiction for the same purpose. By contrast, in the earlier case of *Cairns v James*[195] Temm J refused to exercise the court's guardianship jurisdiction to consent to a blood test in the course of paternity proceedings. He believed it would be inappropriate "to use this power to oust the mother's right to decide for herself whether her child gives a blood sample or not."[196] In the English case of *Re O (A Minor)*,[197] Wall J refused to exercise the jurisdiction on the same grounds.

The Court of Appeal, in *T v S*, [198] distinguished *Re O* because the relevant legislation specifically required the consent of a person who had the care and control of the child before a blood sample could be taken.[199] The New Zealand paternity testing provisions only require

[191] *T v S* [2005] NZFLR 466 (CA).
[192] *S v T* [2003] NZFLR 223 (HC).
[193] *Asomua v Thompson,* unreported, FC, Blenheim, FP006/220/97, 10 December 1998 Grace J.
[194] *Re R (A Minor) (Blood Tests: Constraint)* [1998] 2 WLR 796.
[195] *Cairns v James* [1992] NZFLR 353.
[196] *Cairns v James,* 357.
[197] *Re O (A Minor) (Blood Tests: Constraint)* [2000] 2WLR 1284.
[198] *T v S* (CA), 479.
[199] Section 21(3) Family Law Reform Act 1969. This legislation has since been amended to permit the taking of a sample where the court considers it to be in the best interests of the child.

consent from a person that is competent to do so.[200] In *Cairns,* the Court was not prepared to grant the orders sought until the plaintiff established a prima facie case that he was the father.[201] The Court of Appeal criticised this approach because it could prevent the court from making decisions in the best interests of the child.[202] The Court stated "that in appropriate cases, where consent on behalf of a child to genetic testing is in the best interests of that child, the Courts will ensure that a person prepared to give that consent is authorised to do so."[203]

The Court held that it was in the best interests of the child to determine paternity conclusively, as there was potential for serious psychological harm if the child uncovered an error in their teenage years. In distinguishing *Cairns*, the Court in *T v S* thought it was important that there was a real likelihood the plaintiff was the child's father, while in *Cairns* the judge thought there was no such likelihood.[204]

NBS provides certainty for the child in a similar way to paternity testing. However, because the possibility of a child having a disorder is very small it is arguable that NBS is more like *Cairns*. However, if a child had a family history of a disorder, and therefore a real likelihood of having a disorder, *T v S* could support a decision to consent to NBS.

It was also relevant in *T v S* that the mother had given no substantive reason for refusing the test, other than it was her preference the test did not take place. This is sometimes a feature of newborn screening refusals.[205] Where parents cannot produce a specific reason for not consenting to the test, this may weigh against respecting their views. On the other hand, where parents have a religious or medical reason for refusing consent, the court may consider this to be relevant.[206]

The Court in *T v S* attempted to resolve the different approaches taken in *Asumoa* and *Cairns,* but only went as far as deciding that the court could use its jurisdiction to take a cheek swab. The court considered this to be 'less interventionist than a blood sample' and provided another ground on which to distinguish *Cairns*.[207] It therefore does not entirely clarify the position with regard to taking a blood sample, which NBS requires.

---

[200] Section 57, Family Proceedings Act 1980.
[201] *Cairns v James*, 357.
[202] *T v S* (CA), p479.
[203] *T v S* (CA), p480.
[204] *S v T* (HC), 228 and cited with approval in *T v S* (CA), 475.
[205] See HDC case number 99HDC09973, 19 December 2001 where the parents had given their doctor no specific reason for refusing consent.
[206] Such an approach was suggested by Keane J in *NWHB,* para [123]-[124].
[207] *S v T* (HC), 228 and noted with approval in *T v S* (CA), 476.

(a) Conclusion

T v S was decided in the context of the Family Proceedings Act 1980, which contains specific provisions for paternity testing. Despite this explicit regulation, the Court used its guardianship jurisdiction to circumvent these provisions because it was in the best interests of the child. The Court's approach in *T v S* suggests, that unless a child has a special risk of having a disorder, it is unlikely the court will use its powers to consent to NBS.

4.4 Conclusion: Exercise of the Court's Guardianship Jurisdiction

The court's approach to parents refusing consent to medical procedures is to interfere only where a child is at serious risk of harm. NBS offers certainty, is clearly the most effective method of preventing life-threatening and irreversible damage caused by NBS disorders, and requires only a small intrusion on the rights of parents. Despite this, it is unlikely that the court will use its guardianship jurisdiction to override a refusal of NBS.

The fundamental difference between refusing NBS and other cases where the court has intervened is that the risks associated with a failure to screen are very remote, and there is no immediate threat to the child's health. The court is also likely to be concerned that exercising its powers will lead to NBS becoming compulsory. Such a major policy change is more appropriate for Parliament. If a child had a higher risk of having a disorder or was showing symptoms of a disorder, the court may well find that the child is in serious and immediate danger and override parental consent.

5. Personal Liability of Parents

There is a remote risk that an untested child will have a disorder and suffer harm because they are not tested. The rest of this chapter examines whether parents who refuse consent risk criminal or civil liability if a child suffers harm as a result.

5.1 Criminal Liability

Section 152 of NZCA states that where parents and guardians, under a duty to provide a child with 'necessaries,' omit to do so without lawful excuse, they will be criminally liable if the child dies, his or her life is endangered, or health permanently injured.[208] Where the child dies and the parents' omission caused that death, this may also amount to culpable homicide under section 160(1)(b) of the NZCA,[209] making them guilty of manslaughter.[210]

---

[208] The maximum penalty is seven years imprisonment (Section 152(2), NZCA). For a more thorough discussion of the application of this and similar provisions see Manning, Joanna, "Parental Refusal of Life-prolonging Medical Treatment for Children: A Report from New Zealand" (2001) 8 *Journal of Law and Medicine* 263, 280-284.

[209] Section 160(1)(b), NZCA states that homicide is culpable, if it involves the killing of any person by an omission to perform or observe any legal duty, without lawful excuse.

[210] Unless their actions come within sections 167 and 168 of the Crimes Act 1961, in which case they will be liable for murder.

(a) Is NBS a 'necessary'?

The term 'necessaries' includes medical aid, care, and attention.[211] In *R v Moorhead,*[212] failure to obtain blood tests when clearly necessary was one of the parents' many failures to provide necessaries.[213] Therefore, the fact that NBS is a test and not a treatment, is unlikely to be a bar to prosecution.

It is useful to compare NBS with other cases where prosecution was successful. In *R v Laufau,*[214] the parents were found guilty under section 152 of the NZCA for failing to consent to cancer treatment after their 13 year old child refused further treatment. Without chemotherapy the child would die, making the treatment 'necessary'. In the *Moorhead* case, the parents were found guilty of manslaughter for failing to treat their child for severe vitamin B12 deficiency.[215] The *Moorhead* case and refusal of NBS are similar, as a simple test and injection, followed by dietary supplements would have prevented Caleb's death. However, Caleb was terribly ill for two months before his death, and the parents were told by several doctors that he would die without treatment.[216] The risk of death was clear and imminent, and the treatment was necessary to avoid this fate.

These two examples indicate the kind of treatment regarded as 'necessary' in previous cases. In both cases the court would have used its guardianship jurisdiction to ensure the child got that treatment.[217] As discussed above it is unlikely the court would do so if a parent refused NBS. Refusal of NBS is different because it requires the testing of an asymptomatic child for rare disorders. It is arguable that a NBS test is not 'necessary', as for most children it is not needed to prevent harm. If parents were criminally liable for refusing to consent to NBS they would also be liable in numerous other cases. For example, if a child died of meningitis and the parents had failed to have the child vaccinated, they could be criminally liable. If Parliament intended parents' duties to extend this far, routine procedures like NBS should be made compulsory by legislation.

---

[211] *Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235, 249.
[212] *R v Moorhead*, unreported, HC Auckland, T011974, 13 June 2002, Harrison J.
[213] See for example *R v Moorhead,* 5-6 and 9.
[214] *R v Laufau*, unreported, HC Auckland, T000759, 2 October 2000 Potter J
[215] The child's mother was a vegan and herself B12 deficient. As a result the child was not getting enough vitamin B12. He essentially starved to death.
[216] The child was pale, unresponsive, vomiting, suffering from a rash that became so bad it was often bleeding, his brain was wasting away, and he was suffering from malnutrition (when he died, aged 7 months, he weighed only 1.5kgs more than when he was born). See *R v Moorhead*, 5 and 12.
[217] See *R v Moorhead*, 16 where the judge indicated that the court would protect Mrs Moorhead's as yet unborn child from a similar fate. See also *Re Norma*, and *Health Care Otago Ltd v Williams-Holloway* for examples of cases where the court has overridden parents' decisions to refuse chemotherapy.

If a child had a higher risk of having a NBS disorder,[218] or became symptomatic, and the parents still failed to consent to a test, the court may regard this refusal as a failure to provide necessaries. There would be a clear indication that without the test the child could die or be seriously harmed, making the situation more like *Moorhead* and *Laufau*.

(b) A Lawful Excuse

The court has been clear that a conscientious objection to medical treatment, or an honest belief in alternative treatments based on religious grounds, does not provide a lawful excuse to failing to provide a child with necessaries.[219] Where parents intentionally or negligently fail to act as a 'reasonable parent', this is enough for a conviction.[220] Currently, 99% of parents, whose children have almost no risk of having the disorders, consent to the test. It would therefore be open to the court to find that a reasonable parent, knowing that their child is at real risk of having a disorder, would have their child tested.

5.2 Civil Liability of Parents

It is also conceivable that a child might sue his or her parents in negligence for failing to consent to NBS if that child suffers harm as a result of delayed diagnosis.[221] To be successful, the harm suffered by the child must fall outside the scope of the Injury, Rehabilitation, and Compensation Act 2001 (IRCA). This Act imposes a bar on common law claims when the plaintiff is entitled to compensation under the ACC scheme.[222] To be covered by the ACC scheme, the child must suffer 'personal injury'[223] of a kind described in section 20(1) of IRCA. The relevant kind of personal injury is 'treatment injury.'[224] A 'treatment injury' is an injury suffered when seeking or receiving medical treatment from a registered health professional. Treatment includes the diagnosis of a person's medical condition.[225] The injury must be caused by treatment and not be a necessary part, or ordinary consequence, of the treatment.[226] Treatment injury does not include personal injury that is wholly or substantially caused by a person's underlying health condition, or that is a result of a person unreasonably withholding their consent to undergo treatment.[227]

It is arguable that any harm suffered is caused by the child's underlying disorder and the parents' refusal to screen. The HDC found that a doctor breached the Code of Rights by

[218] For example, if the child had a sibling with a disorder, or the parents were known carriers.
[219] Manning (2001), 281.
[220] Manning (2001), 281 See this article for a discussion on the reasonable parent standard and how it is assessed.
[221] It is most likely that another person will sue on the child's behalf as many children who are not diagnosed with the relevant disorders have serious mental disabilities.
[222] Section 317(1)(a), IRCA.
[223] As defined in section 26(1), IRCA.
[224] Section 20(1)(b), IRCA.
[225] Section 33(1), IRCA.
[226] Section 32(1), IRCA.
[227] Section 32(2), IRCA.

pressuring parents, following a refusal of NBS.[228] Therefore it is unlikely that a failure to screen, following parental refusal, is a treatment injury. This means that harm suffered as a result of parents' refusing consent to NBS would not be covered by the ACC scheme.

If this is the case, then the child can pursue a claim in negligence. It could not be reasonably doubted that parents owe their children a duty of care. As indicated in this chapter, the conduct required by parents to discharge this duty is not always clear. Detailed analysis of the parents' duty of care for the purpose of the tort of negligence is outside the scope of this dissertation, but the issue remains one to be considered should such a case arise.

[228] HDC Case Number 99HDC09973, 19 December 2001, Ron Patterson.

Chapter Three: Mandatory Newborn Screening Statutory Regime

1. Introduction

Chapter two concluded that the NZ courts are unlikely to use their guardianship jurisdiction to consent to NBS, unless the child has an increased risk of having a disorder. The Irish Supreme Court observed that removing parents' rights to refuse consent to NBS was a policy decision for Parliament. Chapters three and four of this dissertation consider whether Parliament should make NBS mandatory by legislation.

This chapter outlines the forms a mandatory NBS programme could take and the aims of introducing such a scheme. It then considers whether mandatory screening would be effective in New Zealand. Chapter four considers whether an effective mandatory NBS programme is a justified limitation on the rights of parents to determine the upbringing of their children.

2. The Importance of Addressing this Issue Now, Not Later

There is a remote risk that an unscreened child will have a disorder and suffer harm because of late diagnosis. Society is rarely tolerant of parents making decisions that place a child at risk of death or serious harm.[229] If a child suffers because their parents refused consent to a non-invasive procedure such as NBS,[230] it is conceivable that the ensuing media coverage will lead to calls for mandatory NBS to prevent this occurring again.

A similar phenomenon can be seen in relation to child abuse. When a child is killed or seriously hurt as a result of child abuse, there are frequently calls for mandatory reporting of suspected abuse.[231] This fails to appreciate that children may stop reporting abuse if they are concerned that their confidant is under a duty to contact police. However, while the media are describing the horrific injuries suffered by the child, it is hard to present an argument against mandatory reporting. This example highlights the importance of considering major policy changes when the issue is out of media spotlight. This is the best way to ensure all sides of the problem are carefully addressed.

It is therefore important to consider whether mandatory NBS is appropriate in New Zealand, without the emotion that may be associated with a highly publicised case. If the issues are

[229] Caldwell (2000), 129. It is accepted this is not always the case. For example in the well publicised case involving Liam Williams-Holloway many people did not support the Court's decision requiring Liam to receive chemotherapy, when the parents had opted for alternative treatment. However, in subsequent cases the view of the public has been different. For example general public opinion was less supportive of the parents in the *Laufau* and *Moorhead* cases.

[230] This is particularly evident when NBS is compared with treatments such as chemotherapy and blood transfusions.

[231] Laurie O'Reilly, "Look back - step forward: Everyone an Advocate for Children" (1998) 2 *Butterworths Family Law Journal* 213, 220.

considered before a child is harmed by a failure to screen, then a well considered response to claims for mandatory NBS can be made.

Calls for mandatory screening could also be fuelled by health providers. Paediatricians, in New Zealand and internationally, strongly support NBS.[232] For example, in Maryland, 78% of paediatricians favoured mandatory NBS, although most thought that parents should still be informed about the procedure.[233] Paediatricians witness the results of NBS and have a better appreciation than most of the benefits it provides. However, because of this intimate involvement, they may fail to appreciate any negative consequences of mandatory NBS. Therefore, this dissertation considers the possible formats for NBS, and provides an objective assessment of the reasons for and against mandatory NBS.

3. Defining a Mandatory Screening Programme

In deciding whether a mandatory NBS programme is appropriate, it is important to outline the form it would take. This chapter examines the 'mandatory screening' programmes in the USA and why they would provide little change if introduced in New Zealand. Secondly, this chapter outlines a unique scheme, which places duties on both parents and health providers and provides criminal sanctions for non-compliance.

3.1 Mandatory Screening in the United States of America

NBS is run at a state level in the USA, and the individual states have all adopted different policies. NBS is considered by most states to be mandated by law, although in practice none of the schemes are truly mandatory. Most states permit exceptions and provide no enforcement measures.[234] In outlining the possibilities for New Zealand, it is useful to look at a variety of states to provide examples.

Rather than placing a duty on parents, most states impose a duty on health providers to ensure that all children receive a NBS test. For example, the Iowa Code states:[235]

> An attending health care provider shall ensure that every newborn under the provider's care is screened for congenital and inherited disorders in accordance with rules adopted by the department.

In other states, such as Georgia, health providers have a duty to ensure the test is done only when a child is born in a hospital. In the case of a home birth, health providers must inform parents, in writing, that the test must be completed and where the test can be done.[236]

---

[232] This was noted in HDC case number 99HDC09973, 19 December 2001, 7.
[233] Ruth Faden, et al "A Survey to Evaluate Parental Consent as Public Policy for Neonatal Screening" (1982) 72(12) *American Journal of Public Health* 1347 (No1), 1349.
[234] Only the states of Wyoming and Maryland require informed consent before the test is carried out.
[235] Iowa Code §136A.5(2) (2005).
[236] Ga.Comp.R. & Regs.r. 290-5-24.02(4) (2006). The duty is then on the parents to have the child tested.

Although NBS is mandatory, there is little in the way of real enforcement. There appear to be no direct consequences, set out in legislation, if health providers do not fulfil their duty. Health providers and parents are potentially liable in tort if a child is not tested, but only if the child suffers harm as a result.[237] Parents are not under any statutory duty to have a child tested. Imposing liability would therefore be difficult, and require a close analysis of the extent of parental duties for the purposes of negligence.[238]

While NBS is thought to be mandatory, most states allow exceptions. States in the USA generally operate on an opt-out basis.[239] All children must be tested, unless a parent provides a written refusal.[240] The exceptions allowed in each state vary. Seventeen states allow parents to refuse on any ground, for example, Iowa[241] and Florida.[242] Thirty three states allow parents to refuse NBS on religious grounds only, but the requirements vary between states.[243] In some states the parents must simply state in writing that they are objecting on religious grounds.[244] Others require parents to be more specific about their reasons for refusal. For example, Kentucky legislation states:[245]

> Nothing in this section shall be construed to require the testing of any child whose parents are members of a nationally recognized and established church or religious denomination, the teachings of which are opposed to medical tests, and who object in writing to the testing of his or her child on that ground.

South Dakota is the only state where NBS is fully compulsory, and allows no exceptions.[246] Information provided to parents is in accordance with this legislation.[247] However, practitioners are provided with information and refusal forms, to be used if parents refuse consent.[248] Even though the legislation allows no exceptions, in practice exceptions are permitted.

---

[237] For example, breach of a statutory duty or negligence may be available torts. Most states have a policy requiring written refusals where parents refuse consent, to reduce potential liability of health providers.
[238] The scope of parental duties in the tort of negligence is beyond the scope of this dissertation.
[239] By comparison, New Zealand has an opt-in system requiring consent for testing.
[240] Forty states require written refusal. The others, for example, Colorado, Georgia, Massachusetts, Iowa and Florida, all require a written record on the child's file. Elaine H Hiller, Gretchen Landenburger, and Marvin R Natowicz, "Public Participation in Medical Policy-Making and the Status of Consumer Autonomy: The Example of Newborn-Screening Programs in the United States" (1997) 87 *American Journal of Public Health* 1280, 1281.
[241] Iowa Code §136A.5(3) (2005).
[242] Fla Stat §383.14(4) (2006).
[243] Hiller (1997), 1286.
[244] See for example Georgia: Ga.Comp.R. & Regs.r. 290-5-24.02(1) (2006), and Massachusetts: ALM GL ch. 111, § 110A (2006).
[245] KRS § 214.155(4) (2006).
[246] S.D. Codified Laws § 34-24-17 (2006).
[247] South Dakota Department of Health Newborn Screening Programme, *Newborn Screening, Tests That Could Save Your Baby's Life*, South Dakota Department of Health, 2005, online at http://www.state.sd.us/doh/NewbornScreening/index.htm accessed 5 October 2006.
[248] South Dakota Department of Health Newborn Screening Programme, *South Dakota Newborn Metabolic Screening Practitioners Manual*, South Dakota Department of Health, 2005, online at http://www.state.sd.us/doh/NewbornScreening/NMS_Guide.pdf accessed 5 October 2006, 6-8.

NBS is given statutory force in the USA, to ensure that health providers test as many children as possible. The legislation does not significantly intrude on parents' rights, as they have a right to refuse the test in all states. In practice however, only thirteen states require that parents are given information before the test and even less require that parents be informed that they have the right to refuse the test.[249]

In New Zealand, informed consent must be sought from parents prior to testing. Parents have a right to complain if informed consent is not obtained, as evidenced by the HDC's decision in respect of a child born at National Women's Hospital.[250] New Zealand is different to the majority of states in the USA in this respect. Practically though, the differences between the jurisdictions are limited. As highlighted by the Privacy Commissioner[251] and HDC,[252] the procedures ensuring parents give true informed consent to NBS are "patchy at best" in New Zealand.[253] It is therefore probable that many New Zealand parents are also unaware of their right of refusal.

If New Zealand were to adopt an approach similar to the USA, there would be little practical change from the procedures currently used. Even if the exceptions were limited to religious objections, depending on the way such an exemption was framed, those who wished to object could quite easily bring themselves within that exception. It is therefore necessary consider alternative ways of making NBS mandatory.

3.2 A Unique Alternative: Placing Duties on Both Parents and Health Providers

Another option is to place a positive statutory duty on parents to have their child screened, allowing no exceptions.[254] This would require some method of enforcement, for example, by imposing criminal liability on those who refuse NBS. This duty should require parents to make their child available for testing.

Introducing mandatory NBS does not mean that parents should not be informed. The aim of mandatory screening is not to keep parents in the dark, but to protect children from harm. It is unlikely that Parliament would pass mandatory NBS legislation without some requirement to inform parents. An example of Parliament's reluctance to remove consent requirements completely can be seen in the Mental Health (Compulsory Assessment and Treatment) Act 1992. Even where the Act authorises treatment without consent, where practicable, consent

[249] Hiller (1997), 1281.
[250] HDC Case Number 99HDC09011, 4 August 2000.
[251] Privacy Commissioner (2003), 11.
[252] HDC case number 99HDC09011, 4 August 2000.
[253] Privacy Commissioner (2003), 11.
[254] It would be necessary to state that, where the health and safety of a child would be compromised by a NBS test, that child should not be tested until it is safe to do so.

must first be sought from patients.[255] Informing parents serves a number of useful purposes. Parents may be aware of a family history that makes it important to test the child as early as possible.[256] If parents understand the procedure they are also less likely to be anxious about the health of their child.[257]

In order to ensure parents can fulfil their duty, it is necessary that health providers have a duty to ensure that parents are aware of NBS, and make it possible for the tests to be carried out. The rationale behind imposing sanctions on parents would be to ensure all children are screened. However, many parents, particularly first time parents, may be unaware that NBS is available or required by law. If health providers fail to inform them, parents will be criminally liable for failing to perform a duty they knew nothing about. This would be an ineffective way of ensuring screening. Therefore, it is appropriate to place a duty on health providers to inform parents, as they have the necessary knowledge and are in the best position to arrange testing. Health providers should be subject to disciplinary proceedings for failing to discharge this duty.

The following sections of this dissertation will consider the appropriateness of a mandatory NBS system, allowing no exceptions and imposing criminal sanctions on parents for failure to comply, but requiring health providers to inform parents about the procedure.

4. Goals of a Mandatory Screening Programme

For mandatory NBS to be appropriate in New Zealand, it would need to achieve more than the current system. This dissertation will deal with two primary goals. Firstly, mandatory NBS would aim to increase the coverage of NBS so that no child misses out on a test. Secondly, mandatory NBS would aim to increase the number of affected children diagnosed early. It is not appropriate to implement a mandatory screening programme unless it would achieve these goals. The factors in favour of mandatory screening must also outweigh the factors against.

5. Factors in Favour of Mandatory Newborn Screening

5.1 Benefits for the Child

NBS is clearly in the best interests of all children.[258] There is virtually no risk involved in the procedure and the potential benefits are substantial. Children, who would otherwise have been confined to a lifetime of mental retardation and physical disability, are able to function and develop like normal children. Mandatory screening would, in theory, ensure all children received a NBS test, and therefore that all affected children receive the benefits of early

[255] Section 59(4) Mental Health Act (Compulsory Assessment and Treatment) Act 1992. This includes patients subject to compulsory treatment orders. Section 67 of the Act also requires that every patient be have the possible effects of any treatment explained to them before that treatment.
[256] Faden (No2) (1982), 1398.
[257] Faden (No2) (1982), 1398.
[258] See chapter one of this dissertation. See also *NWHB*

diagnosis. This is the most compelling reason for making NBS screening mandatory. Even if only a small number of children benefit from mandatory NBS, this supports introducing the scheme, because the benefits are so huge.

5.2 Benefits for the Family

NBS benefits the family group in a number of ways. Firstly, living with a mentally or physically disabled child can be extremely stressful for parents and siblings. NBS reduces this stress by preventing or reducing the child's disability. Affected children do need careful monitoring to ensure they follow their treatment plan closely. However, this is arguably less stressful than providing a seriously disabled child with lifetime care.

NBS can also confer direct health benefits on an affected child's younger siblings. NBS alerts parents to the fact they are both carriers for a disorder. This allows them to be particularly careful during any subsequent pregnancies. For example, some clinicians suggest that a pregnant woman should follow a strict galactosaemic diet during pregnancy to reduce the level of disability in a galactosaemic child.[259] Parents can also take steps to ensure that diagnosis of subsequent children occurs as soon as possible, either by prenatal diagnosis, or as soon as possible after birth. Such steps increase the likelihood that a child will develop normally.

5.3 Reasons of the State

(a) Policy Reasons

The World Health Organisation (WHO) has stated that NBS should be mandatory and free of charge, provided early diagnosis and treatment will benefit the newborn.[260] This observation was made in recommendations intended as a guide for genetics professionals and public health officials when developing policies and practices.[261] A recommendation by a leading international body should be given weight when considering an appropriate policy in New Zealand.

(b) Economic Considerations

Health funding is limited, so it is important that screening is cost effective. Studies have shown that it is more cost efficient to detect affected children by NBS, and treat them with life long therapies,[262] when compared with the cost of lifetime treatment for children who are

---

[259] Note though that the benefits from such restriction are far from conclusive. For more information see Cornelis Jakobs, et al, "Dietary Restriction of Maternal Lactose Intake Does Not Prevent Accumulation of Galactitol in the Amniotic Fluid of Fetuses Affected with Galactosaemia" (1988) 8 *Prenatal Diagnosis* 641.

[260] *Proposed International Guidelines on International Issues In Medical Genetics and Genetic Services*, WHO/HGN/GL/ETH/981 (World Health Organisation, Geneva, 1998), 7 (WHO No1) and Dorothy C Wertz, J C Fletcher, and K Berg, *Review of Ethical Issues in Medical Genetics: Report of Consultant to WHO,* WHO/HGN/ETH/00.4 (World Health Organisation, 2003), 39 (WHO No2).

[261] WHO No2 (2003), I.

[262] The treatments involve either dietary restrictions or drug based treatments.

diagnosed clinically.[263] Tandem mass spectrometry is generally even more cost-saving than current methods of testing.[264] NBS is most efficient when all affected children are identified using NBS, rather than by clinical diagnosis. If mandatory NBS could increase the number of affected children detected by NBS, then this would support implementation of such a policy.

5.4 Conclusion

The main reason for introducing mandatory screening is that the potential benefits of NBS are enormous, and should be available to all newborns. NBS also reduces the impact of a disorder on the family unit and the cost to the State of treating these children. Finally, international policy guidelines support mandatory NBS.

6. Reasons against having a mandatory scheme

Mandatory NBS must be considered in a New Zealand context. Despite the benefits of NBS, there are a number of factors which indicate that mandatory NBS may not be appropriate in New Zealand.

6.1 New Zealand's current compliance rate.

(a) Would Mandatory Screening Increase Coverage?

The primary aim of mandatory screening is to ensure that every child receives a NBS test. As 99% of newborns are screened under the current voluntary system, it is arguable that NBS is effectively compulsory already. It is also doubtful that 100% coverage is even possible.[265] Making screening mandatory may therefore be unnecessary.

While 99% coverage indicates that New Zealand's NBS programme is effective, in absolute terms, a reasonable number of children are still missed.[266] However, parental refusal is not the only cause. For example, home births, early hospital discharge, being born outside of the area where the parents reside, and being moved to a special care unit, are all factors that increase the risk of a child not being tested.[267] These factors result in more unscreened children than parental refusal. Therefore, removing parents' right to refuse NBS would not necessarily ensure that all newborn are tested.

If introducing mandatory screening would not increase the percentage of children screened then it is unlikely to be appropriate in New Zealand. Improving procedures in relation to

---

[263] Aaron E Carroll, and Stephen M Downs, "Comprehensive Cost-Utility Analysis of Newborn Screening Strategies" (2006) 117 *Pediatrics* S287, S294.
[264] Carroll (2006), S294.
[265] As discussed below, parental refusal is only one reason that children are not screened.
[266] If 1% of 60,000 newborns are missed, this amounts to 600 children.
[267] Donald W L Spady, Duncan Saunders, and Fiona Bamforth, "Who Gets Missed: Coverage in a Provincial Newborn Screening Program for Metabolic Disease" (1998) 102(2) *Pediatrics* e21, 5 Electronic Article, pages renumbered starting at 1, available online, http://www.pediatrics.org/cgi/content/full/102/2/e21 at 5 October 2006.

transferring newborns, and screening children who are delivered at home, may be a more effective way to increase the number of children tested.

(b) Would More Affected Children Be Detected Early?

The second goal of mandatory NBS is to increase the number of affected children who are diagnosed by NBS.[268] In theory, if every newborn was tested then all affected children should be diagnosed by NBS. It has been reported that the risk of missing a child with PKU, because of a failure to screen, is considerably less than the risk of missing a child because of a false negative test result.[269] If true, this would provide a strong argument against mandatory NBS, because it would be unlikely to increase the percentage of affected children identified using screening.

However, these statistics are based on older technology. Studies show that tandem mass spectrometry is more accurate than other screening methods.[270] In one research centre,[271] after screening more than 550,000 babies using tandem mass spectrometry, there have been no known false negative results for PKU.[272] With highly accurate technology, 100% of all affected children can be diagnosed using NBS.

However, as the current coverage rate is so high, mandatory NBS is unlikely to increase the absolute numbers of children diagnosed using NBS. A mandatory system would only achieve this second goal, if the percentage of parents consenting to NBS drops.

(c) Risk That Compliance Will Drop

The high compliance rate in New Zealand is a strong factor leaning against mandatory screening. However, there is no guarantee that in New Zealand this will always be the case. If only 70% of parents were consenting to NBS, a mandatory scheme could help increase the number of children tested.

There is a growing concern in New Zealand regarding privacy issues created by NBS. In 1995 there were no requests by parents for the return of a child's NBS card.[273] However, by 2002

---

[268] This is as opposed to relying on clinical diagnosis.

[269] See chapter one for an explanation of false negative results. Faden No1 (1982), 1351 states, with regard to the state of Maryland, that "the chance of missing a PKU infant at the observed rate of parental refusal (0.05 per cent) is 100 times less than the chance of missing a PKU infant because of a false negative test result." This was quoted in a New Zealand context in Jones (2000), 23.

[270] For more information on why this technology is more accurate. see Chace (1998). Pediatrix Screening website, Pediatric Medical Group, *Tandem Mass Spectrometry* at http://www.pediatrix.com/body_screening.cfm?id=343 accessed 6 October 2006. Note also, that this technology is soon to be introduced in New Zealand.

[271] That research centre being 'Neo Gen Screening.' This is now part of 'Pediatrix Screening,' one of the largest newborn screening centres in the USA.

[272] Chace (1998), 2409.

[273] These are stored indefinitely following testing but can be returned to parents by request. Many parents are not aware of this right: Privacy Commissioner (2003), 10.

the numbers had risen steadily, with parents requesting the return of 775 NBS cards.[274] Both the Privacy Commissioner[275] and the HDC[276] have expressed concern about the lack of regulation for the collection and use of NBS cards. In his 2003 report, the Privacy Commissioner stated that "New Zealand appears to have a voluntary screening scheme which has worked well, but its uptake is vulnerable to a decline in trust." Stored NBS cards have been released to third parties in a variety of circumstances.[277] The Commissioner was concerned that the lack of clear rules preventing the use of NBS cards, for reasons other than NBS, could already be leading to a lack of faith in the NBS system, as indicated by the increase in requests for the return of NBS cards.[278]

In an investigation following *H v G,*[279] the HDC noted a number of problems with the procedures for obtaining informed consent.[280] There, no one had obtained informed consent from the mother because all those involved thought that the responsibility for doing so lay with someone else. In many cases information was not getting to parents meaning that many would not have been aware that they could refuse NBS. For example, the distribution of a NBS information leaflet[281] appeared to be erratic.[282] This leaflet has also been criticised for being misleading, because screening is presented as something that will happen and does not highlight the fact that parents are able to refuse consent to this test.[283]

In response to the HDC recommendations, Auckland Healthcare modified its procedures to require informed consent to be recorded. More parents are therefore being given the chance to give real informed consent. Although, as noted in the Privacy Commissioner's report, there have been no steps taken to improve consent procedures at a national level.[284] Improved informed consent procedures, combined with a decrease in trust, may result in more parents exercising their right to refuse NBS.

---

[274] Privacy Commissioner (2003), 6. Figures were provided by the National Testing Centre.
[275] Privacy Commissioner (2003), 10.
[276] HDC case number 99HDC09011, 4 August 2000.
[277] For example, in the murder trial of Mr Scott Watson, NBS cards were used to identify evidentiary samples as belonging to missing victims Olivia Hope and Ben Smart: Jones (2000), 22. The court has also ordered that they be used for DNA testing in paternity cases: *H v G* unreported, HC Auckland M, 1868/98, May 1999, Salmon J (No1), *H v G* (1999) 18 FRNZ 572 (No2).
[278] Privacy Commissioner (2003), 11.
[279] *H v G* (No1), and approved in *H v G* (No2).
[280] HDC Case number 99HDC09011, 4 August 2000. In this case the Auckland District Health Board was found to have breached the Code of Rights by not obtaining informed consent from a mother before a NBS test.
[281] National Testing Centre, *Your Newborn Baby's Blood Test: Te Whakamātau Toto O To Peepi Hōu*, National Testing Centre, Ministry of Health, Auckland, 2004, online at file:///C:/Documents%20and%20Settings/Acer/My%20Documents/Dissertation/Chapter%20One/Newborn%20screening%20leaflet%20NZ.htm accessed 5 October 2006.
[282] HDC Case number 99HDC09011, 4 August 2000, 9. The commissioner noted that not all maternity carers had seen the pamphlet or distributed it to their patients.
[283] Jones (2000), 23.
[284] Privacy Commissioner (2003), 11.

(d) Conclusion: New Zealand's Current Compliance Rate

Mandatory NBS is not appropriate at this time because we currently have virtually 100% coverage. But, if the percentage of children being tested were to decrease significantly, the case for mandatory screening would be considerably stronger. Mandatory NBS may be required to reverse a decline in the number of children tested. However, even if compliance drops there are a number of other risks associated with mandatory NBS, which are addressed in the remainder of this chapter.

6.2 Risks for the Child

(a) Parental Fear of Prosecution and Health Providers

It is easy to assume all parents will abide by mandatory NBS legislation. However, as seen in some medical treatment cases, placing a legal obligation on parents to provide a child with treatment, does not guarantee that they will actually do so. A New Zealand example can be seen in *Healthcare Otago Ltd v Williams-Holloway*.[285] Liam was placed under the guardianship of the court, which consented to him receiving chemotherapy, against the wishes of his parents. Despite the Court order, the parents went into hiding to prevent Liam from receiving chemotherapy.

The risk of a child suffering harm without NBS is remote. Parents may therefore be even less concerned about breaching mandatory NBS laws, when compared with treatments such as chemotherapy. Forcing parents to break the law if they do not want their child screened, places the child in danger for a number of reasons.

One of the main factors in support of mandatory testing is that it is in the best interests of the child to ensure they are healthy. If parents, in breach of any statutory regime, do not have the child screened, fear of criminal conviction may keep them from taking the child to the doctor in the future. If a child begins to show symptoms of a NBS disorder or any other illness, but parents delay taking them to the doctor, the child could be worse of than if a mandatory scheme had not been in place. It is therefore arguable that mandatory screening is not appropriate because it could create a barrier between health providers and parents, resulting in harm to the child.

(b) Let Sleeping Dogs Lie

For most parents, NBS is a small detail in the week following the birth of their child. It is possible that most parents, when told NBS is for the benefit of their new child, agree to the test without much consideration of their right to refuse consent. Introduction of mandatory NBS legislation could not be done without attracting media attention. This may draw attention away from the medical reasons for the test, and focus attention on the removal of parents' rights. A small number of parents, who previously would have consented, may object to NBS

[285] The child, Liam, was 3 years old and suffering from a child cancer called neuroblastoma.

because it is made compulsory by the State, rather than because they actually object to NBS. Some parents are already fearful of the use of NBS cards for purposes other than NBS.[286] Mandatory screening may inflame these views. If this leads parents to avoid NBS, despite any enforcement provisions, this places children at risk of harm.

6.3 Risks for the Family

The primary objection to mandatory NBS is that it interferes with the parental and family rights to make decisions about the medical treatment of children. Chapter four will deal specifically with this concern and whether mandatory NBS is a justifiable limit on this right.

The mandatory scheme being considered imposes criminal sanctions for parents if their child is not tested. Any criminal liability is serious and should not be imposed lightly, as it can have far-reaching consequences for the parents and family. It could be argued that imposing criminal liability is out of proportion to the crime. It is unlikely that parents will be liable under section 152 of the NZCA for failing to screen, even where a child suffered harm.[287] It would therefore seem strange to impose criminal liability for failing to take this precaution, where a child does not suffer harm.

6.4 Reasons of the State

(a) Policy Reasons

The Human Genetics Society of Australasia (HGSA) has stated that NBS should not be mandatory.[288] The HGSA is a body that considers and comments on matters relevant to human genetics in New Zealand and Australia. It represents this field in public, professional, and governmental forums.[289] Their position conflicts with that of the WHO, but the HGSA gives no reason for this different approach. As a local body it may become involved should Parliament attempt to make NBS mandatory in New Zealand. For this reason its position is relevant.

(b) Economic Considerations

The Wilson-Junger screening criteria recognise that the cost of diagnosing and treating patients should be economically balanced in relation to possible expenditure on medical care as a whole.[290] NBS has been demonstrated to be a cost-effective scheme.[291] However, a

---

[286] See Privacy Commissioner (2003), 9 where he outlines privacy concerns raised by NBS and gives examples of political discussion centred on the used of Guthrie cards.
[287] See chapter two, section 5.1.
[288] Human Genetics Society of Australasia, Royal Australian College of Physicians Newborn Screening Joint Subcommittee, *HGSA Policy Statement: Newborn Blood-spot Screening* (2004) Human Genetics Society of Australia, 3.
[289] Human Genetics Society of Australasia, *Mission Statement*, online at http://hgsa.com.au/Index.cfm?pid=111125 accessed 7 October 2006.
[290] Principle number 9, Wilson (1968), 27. See chapter one of this dissertation for a brief discussion of these criteria.

mandatory scheme may generate extra costs because parents who refuse tests would need to be found and prosecuted. If the cost of NBS increased significantly because of enforcement costs, a mandatory scheme may not meet the Wilson-Junger screening criteria.

As only a few parents currently refuse consent, the added expense of enforcement will be small. The increase in cost may not prevent NBS from being a cost-saving programme. However, the increase in expenditure is unlikely to result in money being saved by early diagnosis and treatment. Only a handful of extra children would be tested and even fewer extra affected children would be identified. Further statistical analysis of the costs and savings would need to be completed before any mandatory screening programme could be introduced, to ensure its economic viability.

7. Conclusion

Mandatory NBS is not necessary in New Zealand because our current compliance rate is so high. It would not increase the percentage of children tested or the number of affected children diagnosed by NBS. Mandatory screening may even be counter-productive, as objections to state interference could lead to a reduction in compliance. There is therefore no case for mandatory NBS in New Zealand at present.

If the compliance rate were to drop to 70%, there would be a stronger case for mandatory NBS. The criminal sanctions would be likely to persuade a significant number of those who would otherwise refuse consent, to do so. However, even if this were the case, there are other risks in introducing mandatory NBS. For example, parents who are afraid of a criminal conviction may delay taking a sick child to the doctor, which is contrary to the child's interests. The increased costs of enforcement may also outweigh any benefit to the State. Serious consideration would therefore need to be given to these concerns before adopting a mandatory screening programme.

[291] Carroll (2006).

Chapter Four: Is Newborn Screening a 'Justified Limitation'?

1. Introduction

This chapter examines whether mandatory NBS is a justified limitation on the rights of parents. Chapter three concluded that mandatory screening would not be appropriate in New Zealand now, but a change in circumstances might make mandatory screening an effective option. However, this does not mean that introducing mandatory NBS would be a justified limitation on parents' rights.

Chapter two explained that the risks parents can expose their children to are not clearly defined. This chapter considers whether the risks associated with not screening, justify Parliament in introducing mandatory NBS legislation. This involves briefly outlining the rights of affected parties and comparing NBS with other situations where Parliament has limited parents' rights.

2. Rights and Interests at Stake

2.1 Rights of the Child

(a) The Right to Life and Adequate Health Care

The most basic right is the right to life,[292] which is explicitly recognised in section 8 of NZBORA.[293] The personal rights of parents, for example, to manifest their religious beliefs, do not extend to refusing consent to life saving treatment, where to do so will deny a child's right to life.[294] As the risk of any damage from failing to screen is remote, it is unlikely that refusing NBS is a violation of the right to life.[295] Other rights must therefore be identified to support a mandatory screening programme.

In Article 6(2) of the United Nations Convention on the Rights of the Child 1989 (UNCROC), State Parties agree to "ensure to the maximum extent possible the survival and development of the child." Article 24 provides that children have a right to "the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness." Delayed treatment of NBS disorders leads to irreversible mental retardation or serious physical defects. Therefore, allowing parents to refuse NBS does not ensure a child's right to survival,

[292] This is not an absolute right of children or adults. See for example *Auckland Healthcare Services Ltd v L & L* [1998] NZFLR 376 and *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235. The court will not compel doctors to provide life saving treatment where this is not in the best interests of the child, although this is a rare occurrence.

[293] This right is also specifically recognised in relation to children in Article 6(1) of the United Nations Convention of the Rights of the Child 1989.

[294] See for example *Re J* (CA).

[295] Newson (2006), 135.

development, and enjoyment of the highest possible standard of health. This interpretation is supported by the WHO's position, that NBS should be mandatory because newborns are vulnerable and deserve special protection.[296] UNCROC could therefore be interpreted as requiring State Parties to implement a mandatory scheme.

(b) The Right to an Open Future

A child possesses the right to make decisions for his or her self. However, as a newborn is unable to exercise rights of free choice, they are held on trust until they have that capacity.[297] This is sometimes called the 'right to an open future.'[298] Parents have an obligation not to interfere with a child's right to make autonomous decisions in the future.[299] This right can be violated before the child is able to exercise it. For example, if a parent does not consent to NBS and a child suffers irreversible mental retardation, the child will be incapable of exercising rights of personal autonomy in a wide range of circumstances.[300] Screening and early treatment gives a child the best chance of developing into a competent adult, capable of make their own decisions. It is therefore the best way to ensure that the child has an open future. In the unlikely event that the child regrets the parents' decision to test or treat them for a disorder, they are able to exercise their right to refuse further medical treatment.[301] The long term outcome may well be similar,[302] but the child has not been denied the right to make such a choice.

2.2 Interests of the State

Chapter three highlighted the state's need to provide quality health care in the most effective and cost-efficient way. NBS is a cost-efficient healthcare policy. If mandatory NBS could make NBS more cost-efficient, the state has an interest in adopting such a policy.

2.3 Rights of Parents as Guardians

(a) Right to Consent on Behalf of a Child

Chapter two outlined the rights of parents to make decisions for their children, the duty to act in the child's best interests and what this entails in some detail. Commentators, both supporting and opposing mandatory NBS, agree firstly, that parents have a right, although not absolute, to consent to medical treatment for their child and secondly, that this right exists to

[296] WHO No2 (2003) 39. The WHO is the United Nations specialist health body.
[297] Joel Feinberg, "The Child's Right to and Open Future," in W Aitkin and H La Follette (eds), *Whose Child? Children's Rights, Parental Authority, and State Power* (Rowman and Littlefield, Totowa, New Jersey, 1980) 124, 124.
[298] Feinberg (1980), 126.
[299] Newson (2006), 139.
[300] Feinberg (1980), 126 and Faden No2 (1982), 1397.
[301] As guaranteed by section 11 of the New Zealand Bill of Rights Act 1990. This will only apply when the child is 'competent' to do so.
[302] For many of the disorders, stopping treatment leads to disastrous consequences. Although, stopping treatment in adulthood may not cause as much harm as failing to treat at an early age.

enable children to develop and exercise their own autonomy.[303] However, there is still disagreement about whether the State should override this right by requiring NBS. This is considered below.

(b) Right not to know

The individual's 'right not to know' genetic information about themselves has been upheld in a number of legal and ethical instruments,[304] such as the UNESCO[305] Universal Declaration on the Human Genome and Human Rights,[306] and the WHO's Review of Ethical Issues in Medical Genetics.[307] This right is based on the right to autonomy or self-determination.[308] When competent adults refuse medical treatment this must generally be respected no matter how irrational the decision may seem.[309] This is supported by section 11 of the NZBORA which states that every person has the right to refuse medical treatment. A competent adult must give informed consent before any carrier test is done using their own blood.[310] As the NBS disorders are largely inherited disorders, if a child returns a positive result,[311] the parents will usually both be carriers for the disorder.[312] Mandatory NBS effectively removes the parents' right not to know their genetic composition, because the test results also establish whether the parents are carriers. The right not to know may be overridden where there is a risk of serious harm to others.[313] It is arguable that it is appropriate to do so here because without NBS a child risks serious and irreversible harm.

3. What is a Justified Limitation?

Deciding if a legislative provision imposes a justified limitation on the rights of citizens is different to the analysis undertaken by the courts when exercising guardianship powers. The rights in the NZBORA are subject to reasonable limitations that can be justified in a free and democratic society. The NZBORA does not explicitly recognise a right to consent to medical

---

[303] George J Annas, "Mandatory PKU Screening: The Other Side of the Looking Glass" (1982) 72(12) *American Journal of Public Health* 1401, 1402.

[304] R Andorno, "The Right Not to Know: An Autonomy Based Approach" (2004) 30 *Journal of Medical Ethics* 435, 436.

[305] United Nations Educational, Scientific and Cultural Organisation.

[306] Universal Declaration on the Human Genome and Human Rights, adopted by the General Conference of UNESCO at its 29th session on 11 November 1997.

[307] WHO No2 (2003).

[308] Andorno (2004), 435. Note, this is one possible basis for the right not to know. Some commentators argue that the right does not, or should not exist at all and others argue that it is based on other rights such as the right to privacy. See for example the response to Andorno (2004) in Laurie, G "A Response to Andorno" (2004) 30 *Journal of Medical Ethics* 439, 439 (No2).

[309] This was stated clearly in *St George's Healthcare National Health Service Trust v S; R v Collins & Ors ex parte S* [1998] 3 All ER 673, 685. This right is also clearly stated in Right 7 of the Code of Rights.

[310] A carrier test determines whether a person, who does not suffer from a genetic disorder, carries one copy of a defective gene which could be passed on to offspring.

[311] This refers to true positive results as opposed to false positive results discussed elsewhere in this chapter.

[312] See appendix one for details on the means of inheritance of all the disorders.

[313] Andorno (2004), 437. This will usually be family members. Some commentators argue that it is not always straightforward to determine where this is appropriate. See Laurie No2 (2004) for more discussion on this point.

treatment on behalf of a child.[314] Nevertheless, the approach taken to defining 'justified limitations' in a NZBORA context provides a basis for deciding whether mandatory NBS is a justified limitation on parents' rights.

The courts have held that this analysis requires determining the objective of the legislation, and whether limitation is proportional to the importance of that objective.[315] Any limitation should involve as little interference with the affected right as possible.[316] The primary goal of mandatory NBS legislation would be to increase the percentage of children screened.[317] Mandatory screening would only be justified if this could be achieved.[318]

Mandatory NBS must also be a reasonable way to achieve this objective. In *Moonen*,[319] the Court held that defining a justified limitation is ultimately a matter of judgement requiring an analysis of all social, legal, moral, economic, administrative, and ethical considerations.[320] The rest of this chapter analyses whether mandatory screening legislation is a proportionate response to the object of ensuring all children receive a NBS test, with these considerations in mind.

4. Previous Statutory Intervention on Parental Rights

It is useful to start by considering other examples of State intervention. Parents can expose their children to some risk. However, Parliament has legislated in a number of areas to control parents' decisions. For example, all cyclists must wear a securely fastened helmet.[321] Previously, parents could control whether their child wore a helmet.[322] Parents could therefore place their child at risk of brain damage from a cycling accident. Parliament found this inappropriate and now requires everyone, even adults to wear a helmet.[323]

---

[314] Some parents have argued that overriding parents' right to consent to medical treatment limits their right to manifest their religious belief as protected by section 15, NZBORA. See for example *Re J* (CA). If parents refuse NBS on religious grounds this section might be relevant. However, unlike blood transfusion cases, the reasons for refusing NBS are not necessarily religious. See *NWHB* and HDC case number 99HDC09973 where no religious objections were put forward by parents for refusing NBS.

[315] *Moonen v Film Literature Board of Review* [2000] 2 NZLR 9, 16; *Hopkinson v Police* [2004] 3 NZLR 704, 711.

[316] *Moonen*, 16, per Tipping J; *Hopkinson*, 711, per France J.

[317] See chapter three, section 4 for an outline of the goals of mandatory screening. The benefits of NBS and the reasons for having a child screened have been highlighted in earlier chapters.

[318] As outlined in chapter three, this is not the case at present. This discussion of whether the limitation is justified would only be relevant if a change in circumstances meant that NBS would be effective in New Zealand.

[319] *Moonen v Film Literature Board of Review* [2000] 2 NZLR 9, 17.

[320] *Moonen,* 17 per Tipping J.

[321] Land Transport (Road Users) Rule 2004, rule 11.8. This rule was introduced in New Zealand in 1993 in section 38A of the Traffic Regulations 1976.

[322] In practice parental control in this area would have got less as the child got older.

[323] This is enforced by a $55 infringement fee for those who do not comply: Land Transport (Offences and Penalties) Regulations 1999, Schedule 1.

Parliament also requires all children under the age of five to be restrained by an approved child restraint when travelling in a vehicle.[324] In practice, this limits the power of parents to expose their child to the risks associated with travelling in a car without a proper child restraint.[325] More generally Parliament also requires everyone travelling in a car to wear a seatbelt.[326] This is a further restraint on parents' rights to expose their children to risks.[327] These limitations are imposed to reduce the risks associated with travelling on bikes or in cars and reduce the harm suffered by individual children and adults.

5. Comparison of NBS with Other Statutory Limitations

5.1 Benefit to the State and Individuals

In each of the above examples[328] the State compels parents to take safety precautions they might not otherwise have taken. A large percentage of children would never have suffered serious harm if these laws were not in place, because many would never have been in a serious accident. For the small number of children who will be involved in an accident, the chances of making a full recovery are increased by using child restraints, seat belts, and cycle helmets. These rules help protect the child's right to an open future and their right to have their survival and development ensured to the maximum extent possible.

It is also in the State's economic interests that these laws are enforced. The State may have to pay for some treatment following an accident, but the overall cost is likely to be less than if the use of such protective measures was not compulsory. This legislation therefore benefits the State and its citizens generally, as well as a smaller number of individuals personally.

A similar argument can be made in relation to NBS. The risk of any particular child having a disorder is slim, but compulsory screening reduces the chance of any child suffering life threatening and long term complications from a disorder, should the risk eventuate. If less money is spent treating these children, the money saved is available for other State funded programmes. Therefore, mandatory NBS also provides benefits to the State generally as well as a small number of affected children.

This feature distinguishes NBS from some situations where parents are allowed to expose their children to risks. For example, when parents let a child get their ears pierced, the cost to the State if something goes wrong is likely to be small, and does not warrant interference. Other parental decisions can affect the state more directly, such as where parents feed their children unhealthy food, leading to increased spending on cardiovascular disease. However, situations

[324] Land Transport (Road Users) Rule 2004, rule 7.6. If this rule is not followed, the driver can receive a fine of $150: Land Transport (Offences and Penalties) Regulations 1999, Schedule 1.
[325] This is because it is generally parents, or guardians of a child that carry children in a car.
[326] Land Transport (Road Users) Rule 2004, rules 7.8, 7.9, and 7.10.
[327] This is also an area where the parents' personal rights are limited.
[328] Cycle helmets, child restraints, and seat belts.

like this are much harder to control. For example, how much is too much food? What food should not be given to children at all? There are too many differences between each child, and types of food, for the State to effectively control diets to prevent childhood obesity.

NBS cards are also a potential source of DNA.[329] This could be a valuable resource for fighting crime and could therefore provide further benefits to the State. NBS cards are not currently used to link an accused with a crime, but they have this potential.[330] This raises a number of concerns which are outside the scope of this dissertation but would need to be considered when implementing mandatory NBS.

Mandatory NBS provides social, economic and administrative advantages to the State and therefore society generally. This supports a claim that mandatory NBS is a justified limitation on parents' rights.

5.2 Using the 'Blunt Instrument' of the Law

It is often argued that the State should not control the decisions of parents unless a child's life is in immediate danger, because the law is a blunt instrument, incapable of coping with such complex situations.[331] In relation to many medical treatments this is accurate. Parents are given the power to consent to medical treatment for their children because they generally know more about the child's needs than Parliament or the court. They have a personal interest in the development of their child and are therefore the best equipped to make decisions on behalf of the child.[332] The court and the State should therefore be reluctant to interfere with parental autonomy. However, it is arguable that the blunt instrument of the law can adequately address NBS.

(a) Variability of Risk Between Children

In passing legislation requiring the use of child restraints, seatbelts, and cycle helmets, Parliament is indicating that there are no particular circumstances where those rules are inappropriate.[333] The type of car you are in, the size of the car's airbags, and the driver's skill in handling a car or bicycle are all irrelevant variables when applying these rules. Each time someone wears a cycle helmet the circumstances are slightly different but the differences are not material to whether the helmet should be worn.

---

[329] See for example, *H v G* (No1), where a child's NBS card was used for DNA paternity testing.
[330] See the *Memorandum of Understanding between the Ministry of Health and the New Zealand Police relating to the disclosure of newborn blood spot samples and related information*, in effect since 28 February 2006, clause 2.2, for a list of situations in which police may request access to samples.
[331] Goldstein (1977), 650.
[332] Caldwell (2000), 130.
[333] There are some very specific exceptions in the legislation which are not relevant to this discussion.

If some children would be better off without NBS then parental consent should be required.[334] Conversely, if only one reasonable decision can be made, that is, to consent to a NBS test, then mandatory screening is a justified limit on parental rights.[335] As with child restraints and cycle helmets, there are arguably no variables, specific to each child, which affect the desirability of NBS. There are no reported cases of children experiencing complications as a result of the NBS test itself.[336] Regardless of the genetic make-up of the child, the risks associated with NBS are the same. Newborns, as a group, also have the same risk of having a disorder, despite their genetic differences. There is therefore no reason to deal with each child on a case by case basis. There are a small number of children with an increased risk of having a disorder, making them different to other newborns.[337] However, the difference provides an even more compelling reason for them to be tested and does not support the position that each child should be considered separately.

In this regard NBS is different to other medical treatments, such as chemotherapy. The effectiveness of chemotherapy varies depending on the type of cancer, how far it has advanced, and other treatment the child has received. For every cancer patient, the prognosis is different and it is impossible to direct on a global basis that all children who suffer from cancer be given certain levels of chemotherapy. In each case there is often more than one reasonable choice, so it is not appropriate for Parliament to intervene. [338]

Mandatory screening is an appropriate use of the 'blunt instrument' of the law, because parents have no special knowledge about their child that could affect whether NBS is in the child's interests.[339]

(b) False Positive Results

Those who oppose mandatory NBS, argue that it is too simple to say that there is only one reasonable choice, because this fails to consider events after the test is completed. A large majority of newborns will receive negative test results for all disorders and have no further concerns. However, 1% of newborns will receive a false positive result.[340] Such diagnoses can quickly be identified and corrected with further tests.[341] Despite this, some studies

[334] Faden No2 (1082), 1398.
[335] Faden No2 (1982), 1397.
[336] The only reported case of a baby being hurt in New Zealand involved a midwife accidentally using a cup of boiling water to warm the baby's foot instead of a cup of warm water. This accident was not related to the safety of the NBS test but rather the negligence of the midwife concerned. For more information see HDC case number 00HDC06573, 3 April 2002.
[337] The child could have a family history of the disorder, parents who are known carriers, or an older sibling who suffers from a disorder.
[338] Where appropriate, the court can intervene under the guardianship jurisdiction to ensure a child is treated. See for example, *Re Norma.*
[339] Faden No2 (1982), 1397.
[340] Newson (2006), 140. See chapter one, section 5 for a description of false positive results.
[341] Some of these tests can take a few days.

indicate that parents continue to be anxious about their child's health long after the correct diagnosis is made.[342] It is argued this anxiety leads to problems in the parent-child relationship.[343] However, this research has been criticised for not using proper control groups or reliable sampling methods.[344] It is therefore far from conclusive that children suffer any long term harm from false positive results.

As more disorders are tested for using NBS, the chance of a child returning one false positive result increases, meaning any risks associated with false positive results may become a bigger problem.[345] However, this concern fails to consider improvement in technology. Methods such as tandem mass spectrometry now produce significantly less false positive results for most disorders.[346] Even if the effect of false positives is a valid concern, rejecting mandatory NBS will not eliminate this problem. It is better to deal with this problem separately, rather than overlook an affected child.[347]

(c) Variation in Clinical Outcome

For some NBS disorders there is a clear clinical outcome. For example, most PKU patients who receive early and continued treatment have a particularly good outcome and are otherwise normal people. For some disorders, such as galactosaemia and MSUD, the outcome is not so predictable. Early treatment prevents death and many children do go on to lead valuable and relatively normal lives, but this is not always the case. A significant number of children still suffer from mental and physical problems even with early treatment. It could therefore be claimed that there is not simply one reasonable decision to be made by parents.[348]

To an extent, disorders such as MSUD, are similar to cancer because each child responds to treatment in a different way. However, unlike chemotherapy, NBS provides parents with the information to determine the likely outcome for their child. It is not a treatment in itself. Once this information is available, parents can then decide whether treatment is in the best interests of their child. If it becomes clear that the child is likely to respond well to the available treatment then this child has not been denied the right to grow and develop.

---

[342] Paul (1999), 6. For a summary of the findings in a number of studies see J M Green, et al "Psychosocial Aspects of Genetic Screening of Pregnant Women and Newborns: A Systematic Review" (2004) 8(33) *Health Technology Assessment,* chapter 9.

[343] Annas (1982), 1402.

[344] For example, the studies do not compare parental stress of parents with newborns who had false positive results and parents with newborns that received a correct negative result. Pollitt No1 (1997), 92.

[345] Annas (1982), 1402.

[346] See Chace (1998) for a full discussion on why this is the case.

[347] Paul (1999), 5.

[348] *Re T* provides an illustration of the difficulties of deciding whether treatment is reasonable. There, Court of Appeal and High Court differed on whether the likely medical prognosis for the child meant that refusing treatment was reasonable.

Supporters of mandatory screening have accepted that such a scheme may only be appropriate for disorders where the results from early treatment are generally very good.[349] Where, despite NBS, there is still a significant chance of a child being seriously disabled, a claim that parents have only one morally defensible option is not as strong.[350] Some commentators have suggested that the State should make screening mandatory for some disorders, such as PKU, and require consent before screening for disorders where the outcome is more variable.[351]

This approach would respect the rights of the child to a degree, while preserving the rights of parents to make choices for their child where there is arguably more than one reasonable option. However, such an approach also poses practical problems. Most countries, including New Zealand, operate on an all or nothing basis. It would be time consuming and therefore costly to determine which tests are to be completed for each newborn. One of the rationales for imposing NBS is that it is a cost-efficient health care programme. Increasing the available options may reduce this efficiency.[352] This concern is particularly relevant with the introduction of tandem mass spectrometry. All molecules of interest are measured in a single test, making it difficult to efficiently test each child for a different combination of disorders.[353]

(d) Conclusion

The blunt instrument of the law can adequately cope with NBS, as consenting to this minor procedure will always be in the best interests of the child. Any limit on parents' right to consent is therefore minimal and Parliament is justified in removing the parents' right to choose.

6. Vaccinations: An Example Where Parliament Has Not Intervened

The New Zealand public health system provides access to a number of vaccines against a variety of diseases.[354] The consequences of contracting these diseases vary but a number of people, often children, die or suffer serious long term harm from diseases for which there is a vaccine.[355]

Vaccinations are similar to NBS because they confer benefits on the individual vaccinated as well as society more generally. More individuals benefit personally from vaccinations compared with NBS, because vaccination protects against diseases which are more common

[349] Faden No2 (1982), 1400.
[350] This is arguably the case with respect to galactosaemia, MSUD, and cystic fibrosis.
[351] Faden No2 (1982), 1400.
[352] Faden No2 (1982), 1400.
[353] For a simple explanation of the way that tandem mass spectrometer works see the Pediatrix Screening website, Pediatric Medical Group, *Tandem Mass Spectrometry* at http://www.pediatrix.com/body_screening.cfm?id=343 accessed 6 October 2006.
[354] Ministry of Health, *Immunisation Handbook 2006*, Ministry of Health, Wellington, 2006, online at http://www.moh.govt.nz/immunisation.html accessed 29 September 2006.
[355] For example, meningitis, measles, and influenza.

than the NBS disorders.[356] Effective immunisation schemes also prevent diseases from spreading, in some cases almost eliminating them.[357] This benefits the State by reducing the costs associated with treating the disease.

Despite these benefits, vaccinations are not compulsory. NBS confers similar benefits but to a smaller number of individuals. It could therefore be argued that it is also inappropriate for NBS to be compulsory. Nevertheless, there is one important difference between NBS and vaccinations. Most vaccinations have side effects that affect a proportion of the community, meaning there are risks associated with the vaccinations themselves. The lack of risk involved in NBS is a feature that supports mandatory screening, distinguishes it from vaccinations and justifies adopting different approaches to these procedures.

7. General Slippery Slope Argument

Opponents of mandatory screening have also expressed a variety of 'slippery slope' arguments. Firstly, it is feared that mandatory NBS will lead to state interference in other routine procedures where to do so would be morally reprehensible.[358] This so far does not appear to have eventuated. Mandatory screening has existed in the USA for four decades without such a result.

It is also arguable that mandatory screening makes it too easy to expand screening programmes to include other disorders, with little analysis of the benefits and risks of testing and early treatment.[359] This could remove the right to consent, where to do so is unjustified.[360] It is true that some disorders, for example cystic fibrosis, have been added to NBS programmes where there was inconclusive evidence of any benefits from early treatment. However, it is far from clear that mandatory screening is to blame for these developments. New Zealand has an informed consent system, yet screens for similar disorders to parts of the USA, where screening is mandatory.[361] Maryland, a USA model of informed consent, currently tests for 32 disorders. This is more disorders than screened for in some states with mandatory NBS. For example, Georgia currently screens for nine disorders. While there is legitimate reason for concern about the addition of inappropriate tests to NBS programmes, it is not clear that mandatory screening is responsible for this problem.

---

[356] Of diseases that are less common, this is generally because the vaccination programmes have been so successful. For example, between 1914 and 1961 there were 10,000 cases of poliomyelitis (polio) in New Zealand. Once vaccines were introduced the virus was halted. There is now virtually full immunization in New Zealand. For more information see the Post-polio support society website, http://www.everybody.co.nz/page-c96b6b4a-fa1a-4c46-9672-e05c8a4a5376.aspx accessed 7 October 2006.
[357] For example, poliomyelitis.
[358] Faden No2 (1982), 1400.
[359] Paul (1999), 4.
[360] Paul (1999), 4.
[361] New Zealand's NBS programme will be even more similar to many states in the USA once screening is done using tandem mass spectrometry.

8. Conclusion

Parents have a right to consent to medical treatment on behalf of their child. However, mandatory NBS is a justified limitation on this right. The objective of this legislation would be to screen all children to protect them from harm. NBS is a proportionate response to this objective. As in other situations where Parliament has limited parents' rights, NBS confers benefits on society generally as well as a small number of individual children. Mandatory NBS would be a minimal intrusion on parents' rights, as consenting to NBS is the only reasonable decision for parents to make. This conclusion is weaker in relation to disorders where, despite NBS, a good outcome is not guaranteed. However, children with these disorders still derive substantial benefits from NBS and it would be impractical to make screening mandatory for some disorders and not others. In introducing a mandatory scheme it would be appropriate to address the effects of false positive results and regulation of additional screening tests. These concerns are potentially valid but can be handled within a mandatory system.

Conclusion

NBS identifies newborns with inherited metabolic diseases, and facilitates early treatment, to prevent irreversible mental retardation and physical abnormalities. NBS benefits the families of affected children, by reducing the child's disability. It also benefits the State, by reducing treatment costs. Because NBS confers substantial benefits on the child, their family and the State, this dissertation has considered whether NBS should be mandatory.

The court is unlikely to use its guardianship jurisdiction to consent to NBS, to protect the best interests of the child. The risks associated with a failure to screen are too remote to justify the court overriding parental refusal. If a child has an increased likelihood of having a disorder, or exhibits symptoms, the court may find that the child is in immediate danger and override the parents' refusal to consent. The courts may also impose criminal liability where a child, at special risk of having a disorder, suffers harm because the parents refused consent to NBS.

NBS is a justified limitation on parents' right to consent to medical treatment on their child's behalf, because the risk of harm is minimal, and the potential benefits for individual children and society generally, are huge. This conclusion is weaker in relation to disorders where, despite NBS and early treatment, a good outcome is not guaranteed. However, these children still receive substantial benefits from early treatment, and it is impractical to make screening mandatory for some disorders and not others.

Although mandatory NBS is a justified limitation on parents' rights, New Zealand's high compliance rate means it is unnecessary at present to introduce mandatory NBS legislation. Mandatory screening could even cause compliance to drop because of parental objection to State interference.

There would be a stronger case for mandatory screening if the compliance rate dropped significantly. However, mandatory screening raises a number of other concerns. Criminal sanctions may place children at risk of harm, by creating a barrier between parents who refuse consent and the child's health provider. The state would also incur extra costs from enforcing screening provisions. Careful consideration would need to be given to these issues before implementing any mandatory screening programme.

Mandatory screening is a justified limitation on parents' rights. However, there is no case for mandatory NBS in New Zealand at present. Even if the compliance rate dropped, careful analysis of the costs and risks for children would need to be undertaken before implementing mandatory screening.

Bibliography

Legislative Instruments

New Zealand
Care of Children Act 2004
Children Young Persons and Their Families Act 1989
Crimes Act 1961
Family Proceedings Act 1980
Guardianship Act 1968
Health and Disability Commissioner (Code of Health and Disability Consumers' Rights) Regulations 1996
Injury, Rehabilitation, and Compensation Act 2001
Land Transport (Offences and Penalties) Regulations 1999
Land Transport (Road Users) Rule 2004
New Zealand Bill of Rights Act 1990
Traffic Regulations 1976

United States of America
Florida Statutes 2006
Iowa Code 2005
Kentucky Revised Statutes 2006
Laws of Massachusetts 2006
Rules and Regulations of the State of Georgia 2006
South Dakota Codified Laws 2006

England
Family Law Reform Act 1969

Ireland
Constitution of Ireland 1937

International Instruments
United Nations Convention on the Right of the Child 1989
Universal Declaration on the Human Genome and Human Rights, adopted by the General Conference of UNESCO at its 29th session on 11 November 1997.

Cases

New Zealand
Asomua v Thompson, unreported, FC, Blenheim, FP006/220/97, 10 December 1998 Grace J
Auckland Area Health Board v Attorney General [1993] 1 NZLR 235
Auckland Healthcare Services Ltd v L & L [1998] NZFLR 376
Auckland Healthcare Services Ltd v T [1996] NZFLR 670
Cairns v James [1992] NZFLR 353

CL, Re [1994] NZFLR 352
Director General of Social Welfare v B [1994] NZFLR 516
Director General of Social Welfare v Ulutau (1988) 5 NZFLR 631
H v G unreported, HC Auckland M, 1868/98, May 1999, Salmon J (No1)
H v G (1999) 18 FRNZ 572 (No2)
Healthcare Otago Ltd v Williams-Holloway [1999] NZFLR 804
Hopkinson v Police [2004] 3 NZLR 704
J (An Infant): Director General of Social Welfare v B and B, Re [1995] 3 NZLR 73 (HC)
J (An Infant): B and B v Director General of Social Welfare, Re [1996] 2 NZLR 134 (CA)
Moonen v Film Literature Board of Review [2000] 2 NZLR 9
Norma, Re [1992] NZFLR 445
P, Re [1992] NZFLR 94
Pallin v Department of Social Welfare [1983] NZLR 266
R v Laufau, unreported, HC Auckland, T000759, 2 October 2000 Potter J
R v Moorhead, unreported, HC Auckland, T011974, 13 June 2002, Harrison J
S v T [2003] NZFLR 223
T v S [2005] NZFLR 466
V, Re [1993] NZFLR 369

Health and Disability Commissioner Cases
Case Number 00HDC06573, 3 April 2002
Case Number 99HDC09011, 4 August 2000
Case Number 99HDC09973, 19 December 2001, Ron Patterson

England
B. (B.R.) v B. (J.) [1968] P. 446
Gillick v West Norfolk and Wishbech Area Health Authority [1986] AC 112
C (A Child), Re [2000] Fam 48, [2000] WLR 270, [1999] 3 FCR 289, 50 BMLR 283 (HC)
C (A Child), Re [1999] EWCA Civ 3007, [1999] 2 FLR 1004, [2000] Fam Law 16 (CA)
L, Re [1968] P. 119,
O, Re (A Minor) (Blood Tests: Constraint) [2000] 2WLR 1284
R, Re (A Minor) (Blood Tests: Constraint) [1998] 2 WLR 796
St George's Healthcare National Health Service Trust v S; R v Collins & Ors ex parte S [1998] 3 All ER 673
T, (A minor) (Wardship: medical treatment), Re [1997] 1 WLR 242, [1997] 1 All ER 906, 35 BMLR 63, [1997] 1 FLR 503, [1997] 2 FCR 363, 96 LGR 116

Ireland
JM v The Board of Management of Saint Vincent's Hospital [2003] 1 IR 321
North Western Health Board v W.(H.) [2001] IESC 90

Canada
B.(R). v Children's Aid Society of Metropolitan Toronto [1995] 1 SCR 315

Books and Texts

Andrews, Lori B, et al, *Assessing Genetic Risks: Implications for Health and Social Policy,* (National Academy Press, Washington DC, 1994)

Bainham, Andrew, *Children and the Modern Law* (3rd ed., Family Law, Bristol, 2005)

Skegg P D G, *Law, Ethics, and Medicine: Studies in Medical Law* (Clarendon Press, Oxford, 1988)

Wilson J M G, and Junger G, *Principles and Practice of Screening for Disease* (World Health Organisation, Geneva, 1968)

Articles and Chapters in Edited Texts

Andorno, R, "The Right Not to Know: An Autonomy Based Approach" (2004) 30 *Journal of Medical Ethics* 435

Annas, George J, "Mandatory PKU Screening: The Other Side of the Looking Glass" (1982) 72(12) *American Journal of Public Health* 1401

Bhat, M, Haase, C, and Lee, P J, "Social Outcome in Treated Individuals with Inherited Metabolic Disorders: UK Study" (2005) 28 *Journal of Inherited Metabolic Disease* 825

Bosch, Annet M, "Classical Galactosaemia Revisited" (2006) 29 *Journal of Inherited Metabolic Disease* 516

Bridge, Caroline, "Parental beliefs and medical treatment of children" (1994) 1 *Butterworths Family Law Journal* 131

Brock, David J H, "Cystic Fibrosis" in Wald, Nicholas, and Leck, Ian (Eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 325

Brookbanks, W J "Religious parents and neglected children" (2002) 4 *Butterworths Family Law Journal* 97

Caldwell, John, "Parents, Courts, and the Sick Child" (2000) 3 *Butterworths Family Law Journal* 129

Campbell, Elizabeth, and Ross, Lainie Friedman, "Parental Attitudes Regarding Newborn Screening of PKU and DMD" (2003) 120A *American Journal of Medical Genetics* 209

Carroll, Aaron E. and Downs, Stephen M, "Comprehensive Cost-Utility Analysis of Newborn Screening Strategies" (2006) 117 *Pediatrics* S287

Chace, Donald H et al, "Use of Phenylalanine-to-Tyrosine Ratio Determined by Tandem Mass Spectrometry to Improve Newborn Screening for Phenylketonuria of Early Discharge Specimens Collected in the First 24 Hours"(1998) 42(12) *Clinical Chemistry* 2405

Committee on Genetics, "Newborn Screening Fact Sheets" (1996) 98 *Pediatrics* 473

Cuckle, Howard S, Wald, Nicholas, "Tests Using Single Markers" in Wald, Nicholas, and Leck, Ian (Eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 3

Cunningham, George C, "Phenylketonuria and Other Inherited Metabolic Defects" in Wald, Nicholas, and Leck, Ian (Eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 353

Diekema, Douglas, "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention" (2004) 25 *Theoretical Medicine* 243

Donnell G N, Loch Richard, and Bergen W R, "Observations on Results of Management of Galactosemic Patients" in Hsia, David Yi-Yung (ed), *Galactosemia* (C.C. Thomas, Springfield, Illinois 1969) 247

dos Santos, Luciana Lara, et al, "The Time has Come: A New Scene for PKU Treatment" (2006) 5(1) *Genetics and Molecular Research* 33

Faden, Ruth, et al, "A Survey to Evaluate Parental Consent as Public Policy for Neonatal Screening" (1982) 72(12) *American Journal of Public Health* 1347 (No1)

Faden, Ruth R, Holtzman, Neil A, Chwalow, A Judith, "Parental Rights, Child Welfare, and Public Health: The Case of PKU Screening" (1982) 72(12) *American Journal of Public Health* 1396 (No2)

Farrell, Philip M, et al, "Early Diagnosis of Cystic Fibrosis Through Neonatal Screening Prevents Severe Malnutrition and Improves Long-Term Growth" (2001) 107 *Pediatrics* 1 (Farrell No1)

Farrell, Philip M, et al, "Evidence on Improved Outcomes with Early Diagnosis of Cystic Fibrosis Through Neonatal Screening: Enough is Enough!" (2005) 147(Supplement 3) *The Journal of Pediatrics* S30 (Farrell No2)

Feinberg, Joel, "The Child's Right to and Open Future," in Aitkin W, and LaFollette H (eds), *Whose Child? Children's Rights, Parental Authority, and State Power* (Rowman and Littlefield, Totowa, New Jersey, 1980) 124

Garg, Uttam, and Dasouki, Majed, "Expanded Newborn Screening of Inherited Metabolic Disorders by Tandem Mass Spectrometry: Clinical and Laboratory Aspects" (2006) 39(4) *Clinical Biochemistry* 315

Goldstein, Joseph, "Medical Care for the Child at Risk: On State Supervention of Parental Autonomy" (1977) 86 *The Yale Law Journal* 645

Green, J M, et al, "Psychosocial Aspects of Genetic Screening of Pregnant Women and Newborns: A Systematic Review" (2004) 8(33) *Health Technology Assessment* 1

Guthrie, Robert and Susi, Ada "A Simple Method for Detecting Phenylketonuria in Large Populations of Newborn Infants" (1963) 32 *Pediatrics* 338

Hallam, Paula, Lilburn, M, and Lee, P J, "A New Protein Substitute for Adolescents and Adults with Maple Syrup Urine Disease (MSUD)" (2005) 28 *Journal of Inherited Metabolic Disease* 665

Hanley, W B, et al, "Newborn Phenylketonuria (PKU) Guthrie (BIA) Screening and Early Hospital Discharge" (1997) 47 *Early Human Development* 87

Hargitai, Ga´bor, et al, "Growth Patterns and Final Height in Congenital Adrenal Hyperplasia due to Classical 21-Hydroxylase Deficiency" (2001) 55 *Hormone Research* 161

Harris, John, "Mark Anthony or Macbeth: "Some Problems Concerning the Dead and the Incompetent when it Comes to Consent" in McLean, Sheila A M (ed), *First Do No Harm, Law Ethics and Healthcare* (Ashgate Publishing Group, 2006) 287

Heldt, Karen, et al, "Diagnosis of MSUD by Newborn Screening Allows Early Intervention Without Extraneous Detoxification" (2005) 84 *Molecular Genetics and Metabolism* 313

Hiller, Elaine H, Landenburger, Gretchen, and Natowicz, Marvin R, "Public Participation in Medical Policy-Making and the Status of Consumer Autonomy: The Example of Newborn-Screening Programs in the United States" (1997) 87 *American Journal of Public Health* 1280

Hollowell, Joseph G, Therrell, Bradford L, Hannon, W Harry, "Congenital Hypothyroidism" in Wald, Nicholas, and Leck, Ian (Eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 370

Jakobs, Cornelis, et al, "Dietary Restriction of Maternal Lactose Intake Does Not Prevent Accumulation of Galactitol in the Amniotic Fluid of Fetuses Affected with Galactosaemia" (1988) 8 *Prenatal Diagnosis* 641

Jefferson, Simon "Little Liam and civilisation as we know it" (1999) 3 *Butterworths Family Law Journal* 29

Johannsen, Trine H, et al, "Impaired Cognitive Function in Women with Congenital Adrenal Hyperplasia" (2006) 91(4) *Journal of Clinical Endocrinology and Metabolism* 1376

Jones, D Gareth, and Elkin, Katie, "Guthrie Cards: Legal and Ethical Issues" (2000) 1(2) *New Zealand Bioethics Journal* 22

Kemper, Alex R, Fant, Kathryn E, and Clark, Sarah J, "Informing Parents About Newborn Screening" (2005) 22(4) *Public Health Nursing* 332

Kerruish, N J, and Robertson, S P, "Newborn Screening: New Developments, New Dilemmas" (2005) 31 *Journal of Medical Ethics* 393

Khoury, Muin J, McCabe, Linda L, and McCabe, Edward R B, "Population Screening in the Age of Genomic Medicine" (2003) 348 *The New England Journal of Medicine* 50

Koscik, Rebecca L, et al "Cognitive Function of Children With Cystic Fibrosis: Deleterious Effect of Early Malnutrition" (2004) 113 *Pediatrics* 1549 (Koscik No1)

Koscik, Rebecca L, et al "Preventing Early, Prolonged Vitamin E Deficiency: An Opportunity for Better Cognitive Outcomes via Early Diagnosis Through Neonatal Screening" (2005) 147(Supplement 3) *The Journal of Pediatrics* S51 (Koscik No2)

Kuhnle U, and Bullinger M, "Outcome of Congenital Adrenal Hyperplasia" (1997) 12 *Pediatric Surgery International* 511

Laurie G, "Better to Hesitate at the Threshold of Compulsion: PKU Testing and the Concept of Family Autonomy in Eire" (2002) 28 *Journal of Medical Ethics* 136 (No1)

Laurie, G "A Response to Andorno" (2004) 30 *Journal of Medical Ethics* 439 (No2)

le Roux, C, "Neuropsychometric Outcome Predictors for Adults with Maple Syrup Urine Disease" (2006) 29 *Journal of Inherited Metabolic Disease* 201

Lussky, Richard C, and Cifuentes, Raul F, "False Positive Newborn Screens Secondary to a Maternal Inborn Error of Metabolism" (2006) 45 *Clinical Pediatrics* 471

Manning, Joanna, "Parental Refusal of Life-prolonging Medical Treatment for Children: A Report from New Zealand" (2001) 8 *Journal of Law and Medicine* 263

Manoli, Irini, et al, "Early Growth, Pubertal Development, Body Mass Index and Final Height of Patients with Congenital Adrenal Hyperplasia: Factors Influencing the Outcome" (2002) 57 *Clinical Endocrinology* 669

Marcet, Brice, and Boeynaems, Jean-Marie, "Relationships Between Cystic Fibrosis Transmembrane Conductance Regulator, Extracellular Nucleotides and Cystic Fibrosis" (2006) July 7 Epub ahead of print *Pharmacology and Therapeutics*

Meyer-Bahlburg, Heino F L, et al "Gender Development in Women with Congenital Adrenal Hyperplasia as a Function of Disorder Severity" (2006) August 11 Epub ahead of print *Archives of Sexual Behaviour*

Morton, D. Holmes, et al, "Diagnosis and Treatment of Maple Syrup Disease: A Study of 36 Patients" (2002) 109(6) *Pediatrics* 999

Moslinger, Dorothea, et al, "Clinical and Neuropsychological Outcome in 33 Patients with Biotinidase Deficiency Ascertained by Nationwide Newborn Screening and Family Studies in Austria," (2001) 160 *European Journal of Pediatrics* 277

Newson, Ainsley, "Should Parental Refusals of Newborn Screening Be Respected?" (2006) 15 *Cambridge Quarterly of Healthcare Ethics* 135

Ogier de Baulnya, H, and Saudubrayb, J M, "Branched-chain Organic Acidurias" (2002) 7 *Seminars in Neonatology* 65

O'Reilly, Laurie "Look back - step forward: Everyone an Advocate for Children" (1998) 2 *Butterworths Family Law Journal* 213

Paul, Diane, "Contesting Consent: The Challenge to Compulsory Neonatal Screening for PKU" (1999) 42(2) Electronic article *Perspectives in Biology and Medicine* 207(1) online at file:///C:/Documents%20and%20Settings/Acer/My%20Documents/Dissertation/Chapter%20Three/US%20and%20consent%20etc/Contesting%20Consent%20The%20challenge%20to%20compulsory%20neonatal%20screening%20for%20PKU.htm This article is not divided into pages. Page numbers cited reflect the document when printed from the above address.

Pollitt, Rodney J et al "Neonatal Screening for Inborn Errors of Metabolism: Cost, Yield and Outcome" (1997) 1(7) *Health Technology Assessment* 1 (No1)

Pollitt, Rodney J, "International Perspectives on Newborn Screening" (2006) 29 *Journal of Inherited Metabolic Disease* 390 (No2)

Rose, Susan R, et al, "Update of Newborn Screening and Therapy for Congenital Hypothyroidism" (2006) 117 *Pediatrics* 2290

Sidbury, J B, "Investigations and Speculations on the Pathogenesis of Galactosemia" in Hsia David Yi-Yung (ed), *Galactosemia* (C.C. Thomas, Springfield, Illinois 1969) 13

Simon E, et al, "Maple Syrup Urine Disease: Favourable Effect of Early Diagnosis by Newborn Screening on the Neonatal Course of the Disease" (2006) 29 *Journal of Inherited Metabolic Disease* 532

Skene, Loane and Nisselle, Paul, "Could Parental Refusal of Newborn Screening be Overridden by a Court?" (2003) 4 *Medicine Today* 60

Spady, Donald W L, Saunders, Duncan, and Bamforth, Fiona, "Who Gets Missed: Coverage in a Provincial Newborn Screening Program for Metabolic Disease" (1998) 102(2) *Pediatrics* e21 Electronic Article online at http://www.pediatrics.org/cgi/content/full/102/2/e21 accessed 5 October 2006

Strong, S I, "Between the baby and the breast" (2000) 59(2) *Cambridge Law Journal* 259

Thomas, Cordelia, "The Intolerable Dilemma: Refusal of Consent for the Medical Treatment of Children" (2000) 3 *Butterworths Family Law Journal* 173

Wald, Nicholas, and Leck, Ian, and Gray, Muir J A, "Ethics of Antenatal and Neonatal Screening" in Wald, Nicholas, Leck, Ian (Eds), *Antenatal and Neonatal Screening* (2nd Ed., Oxford University Press, Oxford, 2000) 543

Walter J H, Collins J E, and Leonard J V, "Recommendations for the Management of Galactosaemia" (1999) 80 *Archives of Disease in Childhood* 93

Weber, Peter, Scholl, Sabine, and Baumgartner, E Regula, "Outcome in Patients with Profound Biotinidase Deficiency: Relevance of Newborn Screening (2004) 46 *Developmental Medicine & Child Neurology* 481

Weetch, E, and MacDonald, Anita, "The Determination of Phenylalanine Content of Foods Suitable for Phenylketonuria" (2006) 19 *Journal of Human Nutrition and Dietetics* 229

Wilckin, Bridget, et al, "Screening Newborns for Inborn Errors of Metabolism by Tandem Mass Spectrometry" (2003) 348 *The New England Journal of Medicine* 2304

Wildeman, Sheila, Downie, Jocelyn, "Genetic and Metabolic Screening of Newborns: Must Health Care Providers Seek Explicit Parental Consent?" (2001) 9 *Health Law Journal* 61

Wolf, Barry, "Biotinidase: Its Role in Biotinidase Deficiency and Biotin Metabolism" (2005) 16 *Journal of Nutritional Biochemistry* 441 (Wolf No1)

Wolf, Barry, et al, "Biotinidase Deficiency: Novel Mutations and Their Biochemical and Clinical Correlates," (2005) 25(4) *Human Mutation* 413 (Wolf No2) Electronic article, numbered from page 1, online at http://www3.interscience.wiley.com/cgi-bin/abstract/110431219/ABSTRACT?CRETRY=1&SRETRY=0 accessed 6 October 2006

Woolford, Mark, "R v Laufau: Manslaughter Trial August 2000" [2001] *Journal of the Auckland Medico Legal Society* 19

Papers and Reports

American College of Medical Genetics, Newborn Screening Expert Group, *Newborn Screening: Toward a Uniform Screening Panel and System* (Commissioned by the Maternal and Child Health Bureau, Health Resources and Services Administration, 2005)

Human Genetics Society of Australasia, Royal Australian College of Physicians Newborn Screening Joint Subcommittee, *HGSA Policy Statement: Newborn Blood-spot Screening* (Human Genetics Society of Australia, 2004)

National Screening Unit, *Improving Quality: A Framework for Screening Programmes in New Zealand* (National Screening Unit, Ministry of Health, 2005)

National Newborn Screening and Genetics Resource Centre *National Newborn Screening Status Report* (National Newborn Screening and Genetics Resource Centre, Texas, USA, updated 25 September 2006) online at http://genes-r-us.uthscsa.edu/nbsdisorders.pdf#search=%22National%20Newborn%20Screening%20Status%20Report%22 accessed 5 October 2006

Ministry of Health, *Immunisation Handbook 2006* (Ministry of Health, Wellington, 2006) online at http://www.moh.govt.nz/immunisation.html accessed 29 September 2006

Privacy Commissioner, *Guthrie Tests*, 2003, available online, http://www.privacy.org.nz/library/guthrie-tests, accessed 6 October 2006

Proposed International Guidelines on International Issues in Medical Genetics and Genetic Services, WHO/HGN/GL/ETH/981 (World Health Organisation, Geneva, 1998) (WHO No1)

Wertz, Dorothy C, Fletcher, J C, and Berg, K, *Review of Ethical Issues in Medical Genetics: Report of Consultant to WHO,* WHO/HGN/ETH/00.4 (World Health Organisation, Geneva, 2003) (WHO No2)

Internet Resources

Auckland District Health Board website, *Newborn Services Clinical Guidelines*, available at http://www.adhb.govt.nz/newborn/Guidelines/Nutrition/MetabolicScreening.htm, accessed 3 October 2006

Donnellan, Eithne, "Woman in Court Transfusion Case Recovering in Hospital" *The Irish Times*, 22 September 2006, online at http://www.ireland.com/newspaper/front/2006/0922/115859088 1290.html accessed 7 October 2006

Health and Disability Commissioner, *Guthrie Tests and Informed Consent Issues* http://www.hdc.org.nz/publications/articles?Guthrie%20tests%20and%20informed%20consent%20issues accessed 5 October 2006

Human Genetics Society of Australasia, *Mission Statement*, online at http://hgsa.com.au/Index.cfm?pid=111125 accessed 7 October 2006

Post-polio Support Society website, online at http://www.everybody.co.nz/page-c96b6b4a-fa1a-4c46-9672-e05c8a4a5376.aspx accessed 7 October 2006

LabPLUS, Auckland District Health Board, National Testing Centre, online at http://www.labplus.co.nz/nationaltest.htm accessed 6 October 2006

Ministry of Health Website, National Screening Unit, *Conditions Tested*, available online at http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/1cc77940747fe4a7cc2570c0 000c061c?OpenDocument, accessed 4 October 2006

Ministry of Health website, National Screening Unit, *Newborn Screening in New Zealand Today,* online at http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/38a4fd0fef7aa870cc2570c0000bffef?OpenDocument, accessed 4 October 2006

National Testing Centre, *Your Newborn Baby's Blood Test: Te Whakamātau Toto O To Peepi Hōu*, National Testing Centre, Ministry of Health, Auckland, 2004, online at file:///C:/Documents%20and%20Settings/Acer/My%20Documents/Dissertation/Chapter%20One/Newborn%20screening%20leaflet%20NZ.htm accessed 5 October 2006

Pediatrix Screening website, Pediatric Medical Group, *Tandem Mass Spectrometry* at http://www.pediatrix.com/body_screening.cfm?id=343 accessed 6 October 2006

South Dakota Department of Health Newborn Screening Programme, *Newborn Screening, Tests That Could Save Your Baby's Life*, South Dakota Department of Health, 2005, online at http://www.state.sd.us/doh/NewbornScreening/index.htm accessed 5 October 2006

South Dakota Department of Health Newborn Screening Programme, *South Dakota Newborn Metabolic Screening Practitioners Manual*, South Dakota Department of Health, 2005, online at http://www.state.sd.us/doh/NewbornScreening/NMS_Guide.pdf accessed 5 October 2006

Other

Memorandum of Understanding between the Ministry of Health and the New Zealand Police relating to the disclosure of newborn blood spot samples and related information, in effect since 28 February 2006

Diane Webster, Director, National Testing Centre. Correspondence via telephone and email on July 17 2006 and 5 October 2006.

Appendix One: Table of Disorders Tested for By Newborn Screening in New Zealand