

MAKING MEDICAL DECISIONS FOR CHILDREN: ETHICS

Paul Bruce Baines

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Medicine, Ethics, Society and History
School of Health and Population Sciences
College of Medical and Dental Sciences
Birmingham University
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ABSTRACT

Children are largely ignored in medical ethics, which concentrates on adults with capacities that children lack (including competence, or rationality). This thesis answers how medical decisions should be made for unquestionably incompetent children.

The dominant approach to medical ethics in the West depends on respect for autonomy and this distorts medical ethics for children in two ways. Firstly, parental decisions for children may be taken to have the same authority as respect for autonomy. Secondly, theories of general well-being have focused on adult's well-being with an endorsement of the components of that well-being by the adult themselves. This has hindered the development of an objective, impartial, conception of interests, arguably, the best fit for making decisions for very young children.

I argue that although children are clearly demarcated from adults in medical ethics, there is not a clear explanation of why this is. For young children others must make decisions or be prepared to override the child's decisions. More recently, the distinction between adults and children have become blurred, exemplified by the use of terms such as 'young person'.

Children's rights at best draw attention to children and their interests, but do not help in resolving the medical treatment of incompetent children.

The most promising approach depends on articulating an account of children's interests. For several reasons the best interests standard is not defensible. I argue that a reasoned, or reasonable, agreement upon the child's interests should determine medical treatment. Neither the child's parents (nor the clinicians) can be taken to have an incorrigible grasp of the child's interests, all should justify the reasons for their choices.

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“I can only say that, while my own opinions as to ethics do not satisfy me, other people's satisfy me less”

Bertrand Russell quoted by Mackie in *Ethics*, 1977: 34

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ACRONYMS AND ABBREVIATIONS

| | |
|----------|---|
| BASC | British Association for Shooting and Conservation |
| BMA | British Medical Association (UK) |
| CIOMS | Council for International Organizations of Medical Sciences (Europe) |
| DSD | Disorders of sex development |
| EAC-RCPC | Ethics Advisory Committee, Royal College of Paediatrics and Child Health (UK) |
| GMC | General Medical Council (UK) |
| HFEA | Human Fertilisation and Embryology Authority |
| MMR | Measles mumps and rubella (vaccine) |
| MRC | Medical Research Council |
| NICE | National Institute of Clinical Effectiveness |
| PVS | Persistent vegetative state |
| QALY | Quality adjusted life year |
| RCGP | the Royal College of General Practitioners (UK) |
| RCPC | Royal College of Paediatrics and Child Health (UK) |
| ROP | Retinopathy of prematurity |
| SEWA | Self-Employed Women's Organisation (India) |
| SES | Socioeconomic status |
| SMA | Spinal muscular atrophy |
| TGA | Transposition of the great arteries |
| UN | United Nations |
| UNICEF | United Nations International Children's Emergency Fund |

CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

The dominant approaches in Western medical ethics tend to consider how adults should be treated but largely ignore children. Children are visible only in so far as the conventional methods may apply to them (for example one way that children are considered is in the stage at which children may be able to consent, that is to be treated as an adult) but children, as *children*, are rarely considered in these approaches. I will argue that methods of medical ethics developed for adults are unsuitable for children, cause confusion and encourage us to treat children in the wrong way. We need to think clearly about the nature of children and how medical decisions should be made for them. It is important that the approach specifically addresses children because there are many problems of medical ethics that are particular to children.

In this chapter, I will set out the problem of children and conventional medical ethics, as I see it, in more detail. Having done this, I describe the structure of the thesis.

1.2 TRADITIONAL MEDICAL ETHICS

The most widely used approaches to medical ethics in clinical practice, and perhaps in academic medical ethics, are based on respect for the autonomy of a competent adult¹, though the pre-eminent position of autonomy has been criticised. The particular approach that is most often used is Beauchamp and Childress' Four Principles approach² [Beauchamp and Childress, 2009]. If respect for autonomy underpins

¹ "Without much exaggeration it can be said that all of medical ethics is but a footnote to informed consent." [Kuczewski, 1996: 30]. The legal origin of informed consent is often traced in medical law back to Justice Cardozo's finding from New York State's Court of Appeal "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault..." [Schloendorff, Appellant, v. The Society of the New York Hospital, 1914].

² For example in clinical practice: "I am now an examiner for the RCGP [the Royal College of General Practitioners UK] membership exam and expect all candidates to not only be conversant with the four principles but also to be able to apply them appropriately..." [Gardiner, 2003: 297]. Although respect for autonomy is only one of the four principles, its force extends into two other principles as there is a strong sense in which a competent individual defines their own interests (which are a combination of beneficence and non-maleficence). For example "Competent adults are allowed to define their own concept of 'best interests'..." [Ethics Department BMA, 2004; 136].

medical ethics, then there will be problems dealing with children because it is widely accepted that most children are not autonomous. An important strand of respect for autonomy is the need for consent, often phrased as informed consent³. However, young children⁴ cannot consent in any meaningful sense, and the consent of almost all older children falls short of the stringent standards advocated for consent (see for example the General Medical Council's requirements in *Consent: patients and doctors making decisions together*, 2008)⁵. Although other approaches to medical ethics have their adherents, these too, often depend on the idea of a rational, or skilled decision-making person, paradigmatically an adult. Children are likely to be excluded as they lack, or are believed to lack, the appropriate skills or rationality that adults have. For example Scanlon's contractualism (as summarised by Ashford and Mulgan) requires that "...agents are morally motivated by an intrinsic desire to justify themselves to others." [Ashford and Mulgan, 2012]. On this view, the way that agents achieve justification is through reasoning in ways than others cannot reasonably reject. Reasoning is a skill that some children (as they become older but are not yet adult) may have, but many children will not. And even children who can reason, may be imperfect reasoners and so their reasoning will be subject to oversight. Another popular approach, virtue ethics, is even more demanding. The virtuous person will "... assess each situation individually, searching for action guidance in considering what a characteristically virtuous person would do..." [Gardiner, 2003: 300]. A virtuous person "...has a deep understanding of the social and interpersonal nature of our human existence and how this can affect and be influenced by our moral behaviour" [ibid 298]. The virtuous person has the abilities of an autonomous person, and more, their abilities are tempered by emotional intelligence. A virtuous person will behave virtuously towards children, but many children will not have virtuous characteristics and the virtuous characteristics are unlikely to be fully developed in children that do

³ "...informed consent has been central to discussions of ethically acceptable medical practice..." [O'Neill, 2003(a): 4].

⁴ A 'young child' is a child under the age of 5 or 6. They are usually able to make their opinions known, but there is no sense in which they could be taken to be able to make their own decisions about important or complex matters, so somebody else has to make medical decisions for them.

⁵ "Informed consent has its place in relationships 'between consenting adults'; it is possible only when we are, as John Stuart Mill puts it, 'in the maturity of our faculties'..." [O'Neill, 2003(a): 4].

have them⁶. Regardless of which of these approaches is taken to be correct, my claim is that approaches to medical ethics rarely consider how children should be treated, as they tend to focus on mature adults (though what is meant by ‘mature adult’ may differ between approaches to ethics). Children are marginalized in ethical approaches that focus on adults⁷. In demonstrating the way that approaches to ethics that depend on mature adults ignore children, I will concentrate on the principle of respect for autonomy because it is widely seen to be dominant in medical ethics [Gillon, 2003].

Autonomy can be understood as the ability to live one’s life as one chooses: “...to be autonomous is to be one's own person, to be directed by considerations, desires, conditions, and characteristics that are not simply imposed externally upon one, but are part of what can somehow be considered one's authentic self” [Christman, 2011]. Autonomy may seem straightforward, but it is a highly contested concept containing several different strands, see, for example, Christman and Dworkin amongst many others [Dworkin, 1988; Christman, 2011]. For example autonomy includes at least the requirements of freedom from external manipulation (neither physical nor emotional control by others) as well as the internal ability to control oneself (so that a person does not make unwise decisions driven by impassioned urges or addiction). The principle that medical interventions are justified by a competent person’s informed consent is often derived from respect for autonomy. However, autonomy is not all there is to medical ethics, welfare is another important principle in medicine. That physicians should make people better, or act in their patient’s interests is often taken to be the goal, or amongst the goals, of medical care⁸. Sometimes an autonomous person

⁶ Campbell comments on the standard example of the child of Jehovah’s Witnesses whose parents refuse life-saving transfusion. Despite being broadly favourable to virtue ethics, he writes, “I do not think the VE [virtue ethics] approach has the kinds of conceptual tools required to make such a judgment”. [Campbell, 2003: 295].

⁷ Narveson states this explicitly “...our rights *against each other*, as adults, are the proper source of rights for children...” [Narveson, 1999: 269 Narveson’s italics].

⁸ In the time-honoured Hippocratic Oath physicians swear to “...follow that system of regimen according to my ability and judgment, I consider for the benefit of my patients.” [Adams, quoted by Hurwitz and Richardson, 1997: 1671, my italics]. The oath does not mention respect for autonomy nor anything similar. In the House of Lords judgment considering whether withdrawal of feeding from Tony Bland was lawful, Lord Kinkell stated “...the object of medical treatment and care was to benefit the patient...” [*Airedale NHS Trust and Bland* [1993]:857]. More recently, two ethicists who advise on decisions made by the National Institute for Clinical Effectiveness (NICE) stated, “Patient welfare is the ultimate purpose of it [NICE’s assessments] all.” [Claxton and Culyer, 2006: 375].

makes a choice that seems (at least to others) to be detrimental to that person's welfare. Usually, but not always, respect for autonomy is taken to be preeminent for competent individuals and so in a situation where a competent person chooses a course that compromises their well-being, although a clinician may reason with them to seek to persuade them to another course of action, the choice of a competent person should be accepted. But, if there is uncertainty about a person's competence, or uncertainty about whether the person is fully informed, and the consequences of the decision are sufficiently grave, concerns for welfare may override autonomy.

However, most children are not autonomous and so regardless of the subtleties or the exact meaning of autonomy, a child's decisions may usually be overridden. A child's decisions at the least, are subject to oversight by their parents and sometimes other adults. The child's welfare or interests guide the decisions that are made for the child. Schapiro summarises the contrast from the way that adults are treated as "To treat someone like a child is, roughly to treat her as if her life is not quite her own to lead and as if her choices are not quite her own to make." [Schapiro, 1999: 715]. Therefore the standard approach that depends on respect for autonomy demands modification before it can be applied to children. My task in this thesis is to develop and justify an approach to the way that medical decisions should be made for unquestionably incompetent children.

1.3 CHILDREN

Children are recognised to be different from adults. Although there are many ways in which children are different from adults, there is a large overlap in ability between children and adults so that some adults have features that are more characteristically seen in children and some children have the central attributes of adults. This means that although much rests on the distinction of adult from child, what that distinction is, is unclear. At least in medical ethics, the core idea is that decisions for children will be made by others: children do not make their own choices, or when a child does make a choice that choice is subject to oversight by others. Children are not autonomous, and the sort of decisions that adults make for themselves, when made by a child, may be overruled by that child's parents or by others in authority over them (teachers, for example).

I have argued that children are often ignored in medical ethics. Even when children are considered, many of the discussions of children's medical ethics address only one or other end of childhood. At one end are arguments for and against abortion (or indeed whether or not infanticide is acceptable [Tooley 1972; Giubilini & Minerva 2013]). At the other end of childhood are disputes over the age at which children are competent to make their own decisions, the stage at which children leave childhood to become adults [*Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]]. How we should deal with unquestionably incompetent children is rarely addressed. Much less attention has been paid to children between these two extremes: the way that we should deal with unquestionably incompetent children. This thesis will consider how medical decisions should be made for unquestionably incompetent children.

Incompetent children are a tremendously heterogeneous group, ranging from a newly born baby, unable to survive independently, unable to walk, unable to talk, dependent completely on others to adolescents on the verge of competence who soon will be living independently. A one day old baby and a twelve year old – or thereabouts - adolescent, are very different beings. Humans generally grow seamlessly from a fertilised egg through childhood to become an adult. Birth is a significant event in the course of a child's life but it does not mark a significant change in the child's ability to survive independently of his mother. Babies born close to term (40 weeks gestation) have been sufficiently mature to survive outside the womb for several weeks⁹. The process of growth and development continues on in a gradual fashion. Babies are initially dependent on others for all of their needs; to be fed, to be kept warm and for protection etc. When cared for, babies continue to grow and develop new abilities: to sit, to talk, to walk, to calculate and so on. At some much later stage children become adults. The opinions, wishes or desires of a 12 year old may influence the decisions that are made for them (and more so than the expressed opinions of a six-year old) but there is no sense in which a one day old baby has important, meaningful, desires or

⁹ This has led some to argue that there is no moral difference between abortion and infanticide (see for example [Tooley, 1972]). More recently the debate has been reinvented, with infanticide described as 'afterbirth abortion' [Giubilini and Minerva, 2013]. This academic controversy attracted more furore than some contested decisions about the treatment of existing children.

opinions, or can contribute to a decision at all. What unites them all is that they are all incompetent children and that others have decision-making authority for them.

The dichotomous division of humans into adults and children imposes a discrete, step change, on what is a gradual process. Competent adults can choose their own course through life, reaping the rewards, but also accepting the penalties of their decisions, in general bearing responsibility for their choices. But before that time, the decisions that children make are subject to oversight by their parents and other adults. There are many interesting questions about competence and children. Much work in medical ethics and law for children considers the age that the child should be, or the skills that are required for a child to be, competent to make their own decisions (see for example the House of Lords judgment in *Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]; Melton, Koocher and Saks, 1983; Archard, 2004). Another interesting problem of competence is posed by the asymmetry between consent and refusal of consent. If competence is taken to be specific to a decision, then as the consequences of refusing an intervention may be different from the consequences of accepting it, a particular child may be competent to consent to, but not to refuse, the intervention (or vice versa). Some deny this asymmetry, taking it that the very meaning of consent requires that one is also able to refuse the intervention¹⁰. Others solve this problem by describing that the asymmetry is best explained through shared agency [Manson, 2014]. Be that as it may, I do not intend to consider the ability of children to consent, nor what competence means. In this thesis, I intend only to consider how medical decisions should be made for children who are unquestionably incompetent to decide on medical treatment.

I will address questions about the way that we should make decisions for children who are unquestionably incompetent for two reasons. Firstly this is a problem which is rarely scrutinised, but presents significant challenges. Secondly this is the area in

¹⁰ “The idea that a child (or anyone) might competently consent to a treatment but not be competent to refuse it is palpable nonsense...” [Harris, 2003: 12] and “In the end, both legally and morally, consent or refusal of consent by a competent child must be opposite sides of the same coin.” [Grubb, 1993: 62]. And the other way round - in discussing consent to sexual interactions - “...the ability to say ‘no’ must presuppose the ability to say ‘yes’...” [Archard, 2004: 76].

which more children are more seriously ill¹¹. There is no sense in which babies can make any sort of reasoned decision. Older children are able to express their views or thoughts which may be taken into account by an adult in coming to a decision. The law in England and Wales presumes that those over the age of 16 should be able to make their own decisions (though they often turn to their parents and others for advice). Those below the age of 16 may be competent to make their own decisions. The age that a child must exceed to no longer be *unquestionably* incompetent is disputed. I believe that a child is not able to make complex medical decisions until they are in their early teens¹². Others disagree¹³. Be that as it may, a four year old cannot be taken to have the decisional authority to make choices about health care

¹¹ Despite the publicity that contested decisions for older children may attract, the vast majority of disease is in younger children. For example, in my clinical speciality of paediatric intensive care, between 2011-2013 almost 60,000 children were admitted to paediatric intensive care units in the UK. One half (47.7 %) were under 1 year old, three-quarters (74.3%) were under 5 years old and 85.9% are under 10 [PICANeT, 2014]. Mortality rates in children (per 1000 population) are highest by more than ten fold in the neonatal period and under 1 year olds and then drop until rising in the 15-19 age group (for males, but later for females). [Office for National Statistics, 2012].

¹² I do not believe that I am alone in this. In the Gillick judgment, reference is made to an earlier case, addressing whether a child's consent could be a defence to a charge of kidnapping. Lord Brandon said "...I should not expect a jury to find at all frequently that a child under 14 had sufficient understanding and intelligence to give its consent". [*R v D* [1984] at 457]. Schrag, in addressing the exclusion of children from democratic voting draws a line at a different age in stating "...very young children, who presumably do not know what voting is and who are unreasonable, if anyone is. Since the very young (let us say those younger than seven, just to make the argument a bit more concrete) are not reasonable, they are not owed reasons for their exclusion." [Schrag, 2004: 370].

¹³ Glover writes "Priscilla Alderson's work...has described how she and her colleague Jill Siddle first assumed that competence to consent to surgery might evolve around the age of 10 or 12 years. But their research suggested that children's abilities depend less on age than on high expectations. So under-rating children's competence may be self-confirming. Priscilla Alderson ended up urging that school age children should be presumed competent, with the onus on those who want to show that a particular child is not." [Glover, 2005]. The Royal College of Paediatrics and Child Health have followed this route at times in stating "The EAC-RCPCH believes that there should be a presumption of competence, unless a child is obviously incompetent e.g. extreme immaturity" [Royal College of Paediatrics, Child Health, 2004: 22-23]. This is wishful thinking. If competence is taken to involve understanding, coming to a reasoned decision and communicating that decision, then school aged children (of the age of 5 years or more in the UK, though children may start in reception class at the age of 4) are not competent. If children are presumed to be competent from the age of 4, then the routine in overturning a presumption of competence will be deeply ingrained and perhaps prevent serious consideration of whether some (older) children are competent. This is not to claim that we should not consult or listen to children, but to recognise that many children are not competent to make decisions, even though they may have wishes, desires, beliefs and even strong opinions about some matters. The challenge for those who argue for young children's competence to consent to medical decisions is to be consistent and allow children to vote, or to consent to sexual relations and so on [Archard, 2004].

interventions for themselves for a wide variety of reasons. Two reasons seem clear. First, the child themselves is changing dramatically and rapidly as a person, so in one sense the child may not know what “they” want. Secondly the child will not be able to understand the complexities of the risks and benefits of the medical treatments available. The children that I will concentrate on in this thesis, then, are those who may be to talk and communicate their wishes and wants but who are unquestionably incompetent.

If, as I have argued, respect for autonomy is often the core concept when making medical decisions for individuals, and children are not autonomous, how should medical decision be made for children? There are two plausible possibilities. Firstly, that parental authority takes the part for medical decisions for children that autonomy plays for adults: parents should choose for children. Sometimes this is expressed as a parental right to make decisions for children. Secondly, medical decisions could be guided by the interests, well-being or welfare of the child: what would be good for her¹⁴.

1.4 PARENTAL AUTHORITY

Parents make many decisions for their children every day: what their children will eat or wear, what time they will go to be bed, and so on. It seems normal, then, that parents should make medical decisions for their children.

In the past, parents had strict authority over their children in two ways, children were expected to be obedient, and the state intervened less in parental power. Parents were responsible for caring for their children, but were also entitled to benefit from the work or wages that children brought to the family’s resources. The Roman law concept of *pater familias* [Saller, 1999; Thomson, 2006], awarded the male head of the

¹⁴ There is a third option: that the state should make decisions for children Plato argues in the Republic “...the children, in their turn, will be in common, and neither will a parent know his own offspring, nor a child his parent.” [Plato Book V 457d]. A concern when the Baby Doe Rules were instigated in America was that the government would take the decisions regarding the medical treatment of children out of the hands of their parents and clinicians. Although the state may place limits on how children may be treated by their parents, these are very broad limits. It is unlikely that any approach to parenting that depended on a government making the important decisions for children or even just for their health care would be either possible or tolerated and it is even more unlikely that such an approach would be successful. I will not consider this option further (though others have discussed it, for example Munoz-Darde in *Is the family to be abolished then?* 1999).

family authority (at times enormous authority) over his children even once they had grown to be adults¹⁵. The power that parents had then may have gone too far, but there are many reasons why parents should have authority over their children, and these reasons involve the interests of both children and parents. One parent-based reason is the idea that parents can shape their children in ways that the parents choose. Parents can develop their children in the way that the parents believe their children should be brought up. It is for these reasons that we consider having and rearing children as reproduction and not just production. Other reasons parents have authority over children are child-based justifications: one such justification is that being brought up in a family may be the best way for a child to be brought to maturity, and so the fact that parents have authority over a child is a benefit to the child. Importantly, here parental authority is justified by the benefits for the child, it is not parental authority as an end in itself that provides the justification. For these reasons there is a strong sense that parents should, and, indeed, must, make decisions for their children. However as children will grow to become persons, beings of the highest moral status, the decisions that parents make are constrained by the child's welfare¹⁶ and are fundamentally different to the decisions that parents make for themselves which are justified by respect for autonomy. An analogy here is the limits to the decisions that a husband may make for his wife (and vice versa). The same sort of decisions may be made by a parent for a grown child, and in both situations the decisions are made with attention to the other's well-being, but also with attention to the values that the others hold. The analogy draws attention to the fact that the child's well-being is an important component of the decision that a parent makes and that parental authority is constrained by the child's welfare.

¹⁵ Judge Munby describes similar authority in more recent times (1883) in the UK "Time was when the solution to a case such as this would have been simple. The court would have declined to become involved and deferred to parental authority, that authority being of course exclusively the father's. According to Sir William Balliol Brett MR, the court could not interfere with 'the sacred right of a father over his own children.' A father had a legal right to control and direct the education and bringing up of his own children, and the court would not interfere with him in the exercise of his paternal authority, unless by his gross moral turpitude he forfeited his rights or had by his conduct abdicated his paternal authority." [*Re G (Children)* [2012] paragraph 20].

¹⁶ "...parental powers to authorise the medical treatment of a living child derive from their responsibility to safeguard the *welfare* of their child. The child's health is the law's priority" [Brazier, 2003: 31, Brazier's italics].

Strong conceptions of parental authority are sometimes called parental autonomy. Parental autonomy is a misnomer, however, as autonomy describes self-rule (contrasted with heteronomy which describes rule over others). Parental autonomy then cannot be autonomy as it involves decisions for others, the child. There is however a sense in which the choices that a person makes in being a parent are autonomous in that it is a person choosing how they want to be a parent, as a component of the parent's own life. A parent can choose to be strict or lax, loving or stern and so on. However, when medical decisions are made for children, decisions are made for another, and so parental authority is a more appropriate description than parental autonomy. And recognising this distinction identifies the difference between the autonomous choices that an adult makes for him- or herself, and the decision that an adult may make for their child. It is clear that although parents do have authority over their children, the authority has limits, and the power of parental autonomy is similarly limited¹⁷.

1.5 WELFARE OR INTERESTS

Another core concept when making decisions and in particular medical decisions for children is that of the child's interests or well-being. There is a strong intuition that medical decisions for children (and others who are unable to decide for themselves) should be made in their interests, or should seek to optimise the child's well-being or welfare. A common assumption is that all, parents, teachers and clinicians, want what is best for a child. Sometimes, and indeed more usually, the claim is more onerous and is for actions that will be in the best interests of the child. So, for example, an early iteration of the Children's Rights Convention stated "...mankind owes to the child the best it has to give" [United Nations, 1959]. However, although there is agreement that we should do what is best for children, what is best for children can be, and often is,

¹⁷ Though this is not always recognized by those who write about paediatric ethics, for example Gillam argues "The greatest change in medical ethics more broadly in the last 50 years has been the rise and rise of informed consent, underpinned by increasing recognition of the value of personal autonomy. In paediatrics, this has meant more information being given by doctors to parents, and increasing involvement of parents in decision-making for their child." [Gillam, 2015: 8]. Here Gillam suggests that the authority of the decisions that parents make for a child have the same sort of authority that autonomous decisions have. Decisions made for a child are not autonomous.

disputed at many different levels. And if the child's well-being is to guide or determine medical decisions then it needs to be clear what a child's well-being is. And if there can be a clear and consistent conception of a child's well-being, then the interaction between parental authority and a child's well-being needs to be explored, as I have argued that it is important that parents have authority over their children. The popular press, and case law, contains many examples where those responsible for children have been unable to agree on what would be best for a child¹⁸.

I have argued that conventional approaches to medical ethics are unsuitable for children, and that the solutions advocated for children - parental authority and the child's interests - do not resolve the problems that confront clinicians. I will now describe some of the problems that are found only in paediatric medicine, emphasising the importance of an ethics that specifically considers children.

1.6 WHY ARE CHILDREN IMPORTANT IN MEDICAL ETHICS?

Children are important in medical ethics for a wide variety of reasons. One reason is the sheer number of children: 45% of the world's population is aged under 15 [Population Reference Bureau, 2012; The Worldbank, 2014]. However, this average figure for the world conceals an enormous variation between countries. As the lifespan is short in many developing countries there is a higher proportion of children than in many developed countries. If I am correct to argue that a medical ethics developed for

¹⁸ There are many examples. MB was a child who needed ventilation and had an progressive paralysing disorder (SMA). Clinicians argued that treatment should be withdrawn, MB's parents wanted treatment to continue [*An NHS Trust v MB* [2006]]. Charlotte Wyatt was baby born very prematurely who suffered many complications of her early birth, again the treating team thought that treatment should be limited, her parents disagreed [*Wyatt and Portsmouth Hospital NHS Trust and Charlotte Wyatt* [2005]]. In my practice on the intensive care, I have been troubled by many cases with similar themes. A recent example (2014) of the complete breakdown of a therapeutic relationship which played out in the popular press is Aysha King, a child with a malignant brain tumour who was removed by her parents from Southampton Hospital where she was an inpatient. She was taken to Spain *en route* to Prague for proton beam treatment, which her parents preferred to the treatment offered in Southampton. A European arrest warrant was taken out against Aysha's parents to ensure he would be returned. Under the head line "Ashya's parents feared doctors would kill him" the Times reported "...his father said that doctors in England were going to 'kill him' or 'turn him into a vegetable'." [Keeley and Kennedy, 2014]. A medical opinion from a distant hospital stated "Parents should be reassured that doctors do offer the best treatment." [Craft, 2015]. It is clear that there were deep divisions in the country about what should have been done for Aysha.

adults is unsuitable for children, then this is a large (and unrecognised) gap in medical ethics.

Secondly, children are different from adults in many ways. Medical research recognises that children differ from adults, both in the diseases that they suffer from and in the effectiveness of treatment. The diseases that adults die from are different from those that are responsible for children's deaths. In the UK, neoplasms (cancers) caused 39% of the deaths of adults aged 45-54, 28% of deaths of children aged 5-14 years, but only 0.4% of deaths of children aged under one in 2012. Adults more commonly die from cancers of the lung or gut, but these are rare in children. Children more commonly get developmental tumours and tumours of the white blood cells (leukaemias and lymphomas). Similarly, mortality from diseases of the circulatory system caused 1.6% of the deaths of under one year olds, 4.3% of the deaths of children aged 5-14, but 21.3 % of deaths of 45-54 year olds [Office for National Statistics, 2012]. And these figures underestimate the degree of difference, because the causes of cardiovascular diseases in children (usually congenital cardiac disease) are different from the causes of cardiovascular disease in adults (usually atherosclerotic or rheumatic heart disease).

These differences have increased the priority for research involving children. It has been recognised that specific attention must be paid to research on (for example) drug treatments for children because the drugs used to treat children's diseases have often been tested only on adults. One third of hospitalised children were treated with drugs that were either not licensed for children or were used outwith the conditions of their licensing [Turner, 1998]. In response to this problem, both the US and Europe have adopted legislation that requires drug manufacturers to develop a paediatric investigation plan to test drugs in children as a condition of licensing (see for example, the European legislation [European Parliament, 2006]).

Analogously, a medical ethics that has developed for autonomous adults may not address the ethical problems that children pose. Firstly, in concentrating on respect for autonomy, undue prominence may be given to the parent's authority, because this approach comes closest to the traditional idea of respect for autonomy. This is particularly likely because parents have to make decisions where young children

cannot. As well as this, with older children, adults are more able to make their views heard. Given these facts, a parent's consent for medical treatment for a child may wrongly be taken to have the same authority as the parent's consent for medical intervention on his or her own behalf. A justification of the authority for a person's consent is derived from respect for autonomy, the particular concern that we should all have for the decisions that a person makes about their own life. A parent's consent for a child's medical intervention has a different justification carrying less authority. If children's ethics is a hand-me-down version of ethics developed for adults, this distinction may remain unrecognised (and so, for example, in disagreeing with a parent's choice of therapy a clinician may be labelled 'paternalistic', but there is, surely, some sense of appropriate paternalism¹⁹ when dealing with children).

An example of the distortion that an ethics developed for adults imposes on the way that we deal with children's ethics is shown in the justification of medical research with children. Consent is taken to be fundamental to an adult's participation in research²⁰. Assent, alongside parental consent, is taken to be the equivalent for children's research participation. The national and international guidance governing children's participation in research emphasises the participating child's assent [Baines, 2011]. Despite this, assent has not been characterised clearly. For example, some standards suggest that assent applies to all children [De Lourdes Levy et al, 2003], some suggest that assent applies only to school age children [Paediatrics & Child Health Division, 2008], and some argue that assent is relevant only to children over the age of 14 years [Wendler and Shah, 2003]. The variability of the ages from which assent should be sought (and so the very different abilities which are taken to be necessary for assent) indicates that there is not a single concept of assent. Another demonstration that there is not a consistent notion of assent, is that assent is described in very different ways in official guidance from different sources. For example, European guidance states "Assent...The willing cooperation of the child should be sought..." [Council for International Organizations of Medical Sciences, 2002] but in

¹⁹ The idea of appropriate paternalism is expressed by Feinberg "... 'paternalistic' in an innocent, non-pejorative sense, namely that of 'protective in a manner characteristic of parents'..." [Feinberg, 1980: 141-2]. Softer forms of paternalism are sometimes called 'maternalism'. See for example Taylor, 1989 or Holm, 2007.

²⁰ An early example: "The voluntary consent of the human subject is absolutely essential" [Nuernberg Military Tribunal, 1946-1949; 181].

UK guidance “... ‘assent’ refers to acquiescence...” [Royal College of Paediatrics, Child Health, 2000]. Willing cooperation is very different from acquiescence. Other examples of inconsistency in the description of assent are given by Baines, 2011. My claim here is that an ethics handed down from adults too readily accepts the idea of assent without a critical evaluation of what is involved.

A further example of the confusion over assent can be found in UK legislation. In England and Wales a child under 16 years old can be competent to consent to medical treatment, if they meet the conditions of Gillick Competence “...when the child achieves sufficient understanding and intelligence to enable him or her to understand fully what is proposed” [Lord Scarman in *Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]]. However UK statute law prevents under 16 year olds from consenting to take part in drug trials, requiring that their parents consent [European Parliament, 2001]. There is no attempt to justify the distinction between a child’s ability to consent to medical treatment, but their inability to consent for research. One way to understand this problem is to see it as the imposition of an ethics developed for adults on children. Assent is an attempt to mirror consent for those who are incompetent. As the importance of consent is taken to be self-evident, the concept of assent has been assumed to be important, without critical evaluation.

A further reason why it is important that medical ethics are developed for children is that increasingly decisions that clinical teams make for children are challenged. The growing number of challenges of clinicians’ decisions may be for several reasons. Firstly, the more that respect for autonomy is emphasised and encouraged for adults’ own decisions, the more adults become used to making medical decisions for themselves and so the more that parents may expect to make medical decisions for their children. Another reason is that the internet has made information more readily available and so those who would not normally be regarded as experts can become knowledgeable (or can believe themselves to be knowledgeable) more easily than in the past. Evidence that the decisions that clinical teams make are likely to be challenged is seen in the many court cases where medical decisions cannot be agreed between the family and the treating team [*Glass v UK* (Application No 61827/00) [2004]; *Wyatt and Portsmouth Hospital NHS Trust and Charlotte Wyatt* [2005]; *An NHS Trust v MB* [2006]]. If attempts at informal and perhaps more formal resolution

through the intervention of a hospital ethics committee fail, a dispute between the family and medical team will be dealt with by Family Courts. Many of these cases are not reported publicly (I am aware of many legal cases only by personal communication from my colleagues in other Intensive Care Units), so the numbers of published court cases are not a reliable indicator of the number of decisions that are challenged²¹. Information from a brief survey published in a survey of critically ill children in the UK supports my claim. Directors of all the Paediatric Intensive Care Units (PICUs) in the UK were sent a questionnaire. In analysing 21 returns of 31 forms dispatched, the care delivered was felt to be ‘futile’ (defined as “will not achieve its physiological goals”) or ‘inappropriate’ (“extremely unlikely to be of benefit, is extremely costly, or of uncertain benefit”) in 21% of the 111 children being treated on the PICUs at that time (Vemuri, 2005: A35). If the care of one fifth of the children on PICUs is either futile or inappropriate, then a significant number of children are being treated in a way that does not have the full commitment of the doctors delivering the care (although the question was not phrased in terms of the child’s interests, futile treatment must be against a child’s interests, and inappropriate treatment is unlikely to be in a child’s interests). There may be several reasons for this, but one is that parents demand care for their child that clinicians believe to be wrong

I have argued that medical ethics has concentrated on adults. I have then argued that there are good reasons why ethics developed for adults will not necessarily apply to children. I have given reasons why we need to consider ensuring that we have a suitable ethics for children. I will now describe particular problems for children that are not seen in general adult medicine. This provides another reason for producing an ethics for children.

²¹ As Holman noted of legal process in a case considering the medical treatment of a child, most of those involved in these sorts of disputes prefer privacy “... ‘The general rule is that a hearing is to be in public’. Rule 39.2(3) permits, however, that in certain circumstances a hearing or any part of it may be in private. At the outset of the hearing the applicant hospital and the parents both strongly urged me to hear this whole case and to give judgment in private. The parents desperately wish to avoid any publicity or intrusion into the lives of themselves and their family. The hospital wish to avoid any intrusion into their vital and sensitive work...” [*an NHS Trust v A and others* [2007] paragraph 4].

1.7 IMPORTANT QUESTIONS IN CHILDREN'S MEDICAL ETHICS

I have given examples of medical decisions for children which have been contested as may be seen in general medical practice. As well as this there are situations that are particular to paediatric practice.

One self-evident problem is end of life decisions for children. End of life decisions for children are more challenging than are end of life decisions for competent adults for a wide variety of reasons²². The problems are different too from decisions involving incompetent adults, because of the different position that parents have in the lives of children. There are many examples of end of life decisions to be found in court cases. MB was an infant with SMA (spinal muscular atrophy, a lethal degenerative neuromuscular disease presenting in infancy). MB's parents wanted aggressive treatment to continue but doctors claimed that it was not in the interests of MB. Withdrawal of ventilation would most likely result in the immediate death of MB: this was the course that the clinical team advocated [*An NHS Trust v MB* [2006]]. Similarly, the parents of Charlotte Wyatt, who had developed overwhelming complications following extremely premature birth, wanted Charlotte to be given all treatments to prolong her life. The treating clinicians believed that there should be limits to the treatments offered to Charlotte because of the extent and severity of the complications [*Wyatt and Portsmouth Hospital NHS Trust and Charlotte Wyatt* [2005]]. Neither child can make the decision, nor is there the prospect that they ever will be able to, in the way that an adult can. Another example of the particular problems of end of life care in paediatric medicine is the development of perinatal hospices. In some pregnancies the baby is recognised to have a lethal and untreatable condition (the sort of situation in which some parents choose abortion) some families prefer to continue the pregnancy accepting that the child will die but preferring that their baby should have a life, however brief. A mother described her son who was

²² And different in ways that are often not fully recognised. An example is an argument that was made for a "prenatal advance directive" to be completed by expectant mothers to designate "...my feelings about the care given to my child if born at or before the margins of viability..." [Catlin, 2005: 174]. The concern of the author was that a woman who has just given birth may know little about neonatal medicine and be overwhelmed by the enormity of the decisions they are asked to make if their baby has significant disease. It is a laudable initiative, but is completely different from advance directive as they are usually understood, made for those "...who are competent to make autonomous decisions for the end of their [own] lives..." [ibid 174] and so naming the approach an advance directive leads to confusion.

diagnosed with a lethal heart condition at 25 weeks gestation: “ ‘He lived for nine months before he was born,’ says Kuebelbeck, ‘and for two and a half peaceful hours afterward.’ ” [Collier, 2011: 267]. Other parents take a different approach. For some time there was a programme in which altruistic parents and clinicians treated children diagnosed *in utero* with anencephaly to full intensive treatment after their child was born, not palliative care. The intention was that the babies would then donate organs (and in particular their hearts) after they became brain dead. When this approach was attempted, none of the children became donors [Peabody, 1989]. I do not intend to argue what would be correct, just the recognition that these situations are peculiar to paediatrics.

There are many other questions. For example, should recombinant growth hormone be given to a small, but otherwise normal child? It is established that this is an effective treatment to increase the height of children who lack growth hormone. As well as this, growth hormone increases the height of children who are not deficient in it. Is it the right treatment for a short but normal child? Would regular treatment with growth hormone to make a boy taller be ‘in his interests’? And if it is the right treatment what bearing does his parents’ opinions have on whether or not the treatment should be given? His parents would need to consent to treatment. Some parents may actively seek growth hormone, others may refuse growth hormone should it be offered. An example in the opposite direction is given by Ashley, an American girl with overwhelmingly severe neurological injury which was obvious soon after birth (her parents describe her as a “pillow angel”). Ashley’s parents and clinicians undertook a course of treatment to make sure that she did not become too big and so she would be easier to care for. ‘Sizing for wellness’ involved hormonal treatment to limit growth, by inducing early puberty. As well as this she had an appendicectomy and at the same time hysterectomy with breast bud removal so that she would not be troubled by the changes of puberty. This treatment meant that Ashley’s parents would be better able to care for her [Ashley’s Mom and Dad, 2012: 4]. Is it right that Ashley’s growth should be stunted, her physical development thwarted, for her parents’ convenience in caring for her?

A further example of problems peculiar to paediatric practice is the whole question of a child’s participation in research which I have touched on. The participation of adults

in research is justified by their consent, but what justifies the participation of children in research? Some claim that participation in *therapeutic* research may be in a child's interests, though if the intervention is research it is not clear that is in the child's interests²³. In brief, if a decision is made to treat a child because the treatment is thought likely to benefit the child, then this is not research, this is medical treatment (though research may be added on to the medical treatment, as extra data collection or extra measurements of growth or biological response or whatever). In research on therapies (which may be what is meant by therapeutic research) the way that therapies are assessed is to compare equally matched children who have been treated differently. To make sure that the children are equally matched, they are randomly allocated to new treatment or conventional treatment. Although the new treatment *may* be better than the old treatment it may be worse too (in the FEAST trial of fluid resuscitation, children who were given the 'better' treatment were twice as likely to die as those who were treated routinely [Maitland et al, 2011]). As well as this, because of random allocation the child may or may not get the new treatment (which may, or may not, be better than conventional treatment). For both these reasons, the claim that research is of therapeutic benefit to the child is wrong. Therapeutic research does not describe research that will therapeutically benefit the child who participates. Another argument that research on a child cannot be in that child's interests is that as research is an intervention to find out new knowledge then whether it will benefit the child cannot be known. If the treatment is known to have benefit, then it would not be new knowledge; the intervention would not be research. There may be scientific reasons justifying the intervention, there may be belief or hope that the intervention will benefit the child, but if the intervention is research, then the possible degree of benefit (or harm) is unknown. Attempts have been made to claim that research is in a child's interests [McCormick, 1976; Wendler, 2010] though these attempts have been limited to attempts to justify non-therapeutic research with minimal risk. Their arguments, if successful, would not justify the participation of children in research such as the FEAST trial which had mortality as a primary endpoint (it was expected that more children would die when treated in one way than the other). Some would argue that

²³ There is research that is clearly not therapeutic, research which involves studying the course or the pathology of a disease is clearly non-therapeutic. Labelling some research as non-therapeutic may lead people to believe that there is then a category of therapeutic research.

parents can consent only to treatments or interventions that are in a child's interests²⁴. If research is not in a child's interests, then parents cannot legitimately authorise their child's participation²⁵.

There are many important questions that come from the conflict between a child's interests and their parent's authority to make medical decisions for them. Parents must consent for a child's routine metabolic screening to recognise and diagnose serious disease before the child is harmed (including, for example, neonatal hypothyroidism or Phenylketonuria). Screening is in a child's medical interests and it is difficult to make arguments – based on the child's interests – that there are any sufficiently weighty competing interests of the child which could outweigh the benefits to the child of early recognition and treatment for the diseases that are screened for. Arguments against screening are usually based on parental authority to make decisions for their child²⁶. It is not clear that parental consent should be an important requirement for screening [Nijsingh, 2007]. Vaccination is a further example. Parents must consent to a child's vaccination despite clear evidence that vaccinations reduce the incidence of infectious disease and the adverse consequences of infections to individuals and populations²⁷.

²⁴ "...a parent can only validly consent to something that is in the child's best interests." [Foster, 2011: 116].

²⁵ This is not to claim that we should not do research on and with children, it is the claim that research is not in the child's interests. We should do research and perhaps can do no better than 'sin bravely' as Ramsay recognized years ago: "Either way they do wrong. It is immoral not to do the research. It is also immoral to use children who cannot themselves consent and who ought not to be presumed to consent to research unrelated to their treatment. On this supposition research medicine, like politics, is a realm in which men have to 'sin bravely.' The researcher you can trust...however, is the man who does not deny the moral force of the imperative he violates." [Ramsay, 1976; 21].

²⁶ The summing up of the Irish judge in a case to decide whether a child would have the 'routine' blood test for metabolic disease stated "...whether this objective benefit to Paul overrides the rights of his parents, in effect, to decide that they do not want Paul to have the discomfort, and discomfort is as strong a word as could be used for it, of a pinprick in his heel, and are prepared to take the risk that he does not suffer from any of the relevant conditions." [North Western Health Board v HW and CW [2001]].

²⁷ Not all vaccines are effective, some have side-effects, a recent example is rotavirus vaccination which although effective in preventing rotavirus increased the chance of intussusception [Center for Disease Control, 2004]. Importantly, the problem was recognised and the vaccine withdrawn. Vaccinations offered as part of a community-based programme will pass a further test over and above a medical justification, as they are cost-effective. The attention that is focused on vaccination programmes is shown by the history of polio vaccination. There are two forms of polio vaccine, the first inactivated injected vaccine (Salk) and the second, live and so more immunogenic, oral vaccine (Sabin). Initially the Sabin vaccine was more effective in reducing polio. As polio rates fell, the rare event that the Sabin

And as higher levels of vaccination protect the community, making epidemics of disease less likely, vaccination protects those who cannot be vaccinated for reasons such as allergy to vaccine components or immunosuppression. These people are rendered susceptible as vaccination rates fall so there are good reasons over and above the child's well-being for vaccination, and yet it is accepted that a child's parents may refuse. The once-common diseases that are prevented by vaccination may not be as feared as they once were, but they can still cause significant disease and even the death of children. Again there is a conflict between the child's interests and parental authority to choose for the child.

Another situation that provokes controversy is organ or tissue donation by a child. There are many different situations. Some children are deliberately conceived as potential donors, the children may be called saviour siblings, donating for example bone marrow or stem cells [Steinbock, 2009]. Some children may donate tissue which can regenerate (for example bone marrow) where the risks are those of the anaesthesia, pain, unpleasantness and the dangers of a day or so's hospitalisation (for example when donating bone marrow for a sibling with leukaemia). The risks are summarised by Bosi and Bartolozzi, 2010). Some children may donate solid organs – such as kidneys – where there are risks associated with donation as for tissue donation, but also longer term risks related to the fact that the child will be left with only one kidney. In all these cases, there is not a medical benefit to the donating child, only to the recipient. There is a sense in which allowing a child to donate may be the right option, and yet it is important to make sure that the donating child is not exploited, that donation does not harm the donor or if it does, that it does not harm the donor too much.

There is another situation in some children towards the end of life, where a dying child is kept alive so that the cause of his death may be determined (by scans or a biopsy or for fuller investigation). This may be so that parents have certainty about why the

vaccine could itself cause a form of polio became relatively more of a problem following the successful reduction in wild polio. As this happened, the vaccine that was used was changed from the Sabin to the Salk vaccine [Blume & Geesink, 2000]. The important point is that expert virologists and public health practitioners are more knowledgeable and are likely to know what is best for children and best for a child (what would be in the child's interests) but the parents must consent to the child's vaccination.

child died. Sometimes the investigations are to determine if future pregnancies may need to be screened (in one of several different ways to determine whether a future child will have the disease) or perhaps so that a genetic marker can be found to allow selection of embryos to be implanted in IVF procedures. If these are the reasons for continuing treatment, the intervention is not in the child's interests but for other reasons.

And there are esoteric situations, the like of which will not be seen in adult medicine. One example is conjoined twins: some conjoined twins can progress perfectly happily, living a good life of reasonable length with or without surgical separation. At the other extreme, survival of one twin may be possible only if the twins are separated. Together both twins will die, apart one may survive. Jodie and Mary (the subjects of a legal case in the UK) were conjoined, but unbalanced twins (the pair had only one heart between them, which principally served Jodie). Together, both twins would die within a few months of birth. If the twins were separated, the twin without the heart (Mary) would inevitably die immediately, but Jodie would grow to be a healthy adult. The parents decided that no surgical intervention should take place and refused to consent to surgery. The treating clinical team sought a court review, and after appeal, the Court of Appeal ordered that the twins be separated leading to the inevitable death of Mary [*re A (children) (Conjoined Twins: Surgical Separation)* [2001]]. If the intuitions that underpin our approach to ethics are parental authority and a child's best interests, they offer little guidance in this kind of case.

I have not attempted to find the correct course of action in these examples. They are given to demonstrate that some of the problems of ethics that are seen in paediatric medical practice are markedly different from the problems that are seen in adult practice. This means that if I am correct to argue that our conventional approach to medical ethics does not deal well with children, then we need to develop an ethics that does help in the analysis of children's medical ethics problems.

1.8 STRUCTURE OF THE THESIS

In this thesis I will suggest how medical decisions should be made for incompetent children. I have demonstrated that children present particular problems to traditional

approaches to medical ethics. In the three following chapters I will consider three broad themes: children, rights, and interests.

Children

Children are different from adults, it would be as wrong to treat an adult as a child, as it would be to treat a child as an adult, albeit in different ways. I examine what a child is and how children have been conceptualised in philosophy and ethics. What distinguishes an adult from a child is rarely examined. I argue that what distinguishes the two (at least for medical decisions) is that the child's decisions are made, or at least overseen, by others, usually a parent. Children do not have the decisional authority of an adult.

A dichotomous distinction between adult and child imposes a step change on the continuous, progressive, growth of a child. This, and the way that children may be competent to make some, but not other, decisions, can lead to disagreement about medical decisions for older children. These are important points to address, but as my subject is how we should make decisions for unquestionably incompetent children, I do not need to answer them here.

Rights

Rights are invoked in the analysis of many problems. After a brief introduction to human rights and a discussion of their philosophical underpinning, I ask whether children are the sort of beings that have rights, arguing that there are good reasons to doubt that children do have rights. I consider two arguments for children's rights, the potentiality argument and the genetic argument of Liao, arguing that neither are successful. I then argue that there are good reasons why rights are problematic for children and that rights are particularly unhelpful in analysing disputed medical decisions for children. I dismiss claims that family rights can be used when medical decisions must be made for children.

Interests

I suggest that the most promising way to make medical decisions for children is to consider their interests (which I take to be synonymous with welfare or well-being).

The approach that is most commonly advocated is that decisions should be guided by the child's 'best interests'.

Despite the appeal of interests, there are several problems with a best interests approach. For example, it is clear that different authors have different conceptions of interests and that there is no agreement on a conceptual framework for interests. Given this, it is important to establish a clear conception of interests. Having stipulated the approach that I will use, I consider particular problems with decisions that are guided by an individual child's best interests. First, I address the criticism that interests are indeterminate and uncertain and so cannot guide decisions. Second, I consider the view that a child's best interests are too individualistic and neither can, nor should, determine the medical decisions that are made for a child. Third, I address the concern that a best interests standard is too demanding. Fourth, I argue that other standards are inappropriate and I argue against the suggestion that family interests can offer guidance when medical decisions should be made for children. I conclude by arguing that medical decisions should be guided by a reasonable assessment of the child's interests, developing and explaining what I mean by a reasonable assessment of the child's interests.

CHAPTER 2: WHAT IS A CHILD?

2.1 INTRODUCTION

The word ‘child’ has multiple meanings. I start with a discussion of these multiple meanings and the confusion it may cause. I define the way that I will use child for the purpose of deciding the way that medical decisions should be made for children. I review what philosophers have written about children, concentrating on two aspects, firstly conceptions of children and secondly what it is that distinguishes children from adults. I argue that the distinction between adult and child remains unclear and that the distinction does not depend solely on whether or not the child is competent. I explore the differences between incompetent adults and children to demonstrate that there are several important differences and that children are not just those who are incompetent to make their own decisions.

2.2 WHAT IS A CHILD?

The word ‘child’ has many different, sometimes overlapping, meanings. I will use child to describe an immature human from birth to becoming an adult. ‘Child’ includes all the stages of growth beginning with a newborn baby and ending with an adolescent on the verge of maturity²⁸.

There are other senses of the word child. In one sense, a person remains a child of their parents throughout their life. The parents of a 40 year old adult could refer to their daughter as ‘my child’. Although this use of the word child may be important when considering the duties or responsibilities that grown children may owe to their parents (and vice versa) [Keller, 2006; Austin, 2007; Richards, 2010; Blustein 1982], this is not the sense that I will use in this paper.

In another use ‘child’ is sometimes used to identify only one of the stages of young humans. In this use, growing up is divided into several separate stages, starting with a new born baby or neonate, progressing through infant, followed by toddler then on to a

²⁸ As others do, for example, the BNF states “The terms infant, child and adolescent are not used consistently in the literature to avoid ambiguity... The terms child or children are used generically to describe the entire range from infancy to adolescence.” [British National Formulary for Children, 2013: xi].

child, followed by adolescent (perhaps passing through preadolescence *en route*) continuing through young person and then onto adulthood, or perhaps some variation on this approach²⁹. In this more limited approach to children, a child (4-10 years or so) would be able to walk, and use language, becoming increasingly able through childhood. However, this use excludes many immature humans for whom medical decisions must be made. There is no reason to believe that an approach to medical decisions for this more limited group of children should be different, in principle, from the approach taken for babies or adolescents and so I include all phases of immaturity in the way that I use the word child. This means that humans are either children or adults. What is common to all children is that others make decisions for them, or can correct decisions that a child makes. Babies are unable to make decisions in any meaningful sense, and someone has oversight over an older child's decisions: the child's decision may be overruled by an adult, and this is what distinguishes adults from children. The same sort of decision made by an adult would stand, only children are overruled³⁰. For children, as Schapiro has it "...her life is not quite her own to lead and as if her choices are not quite her own to make" [Schapiro, 1999: 715]. This is not to claim that this is the only feature which separates children from adults, but that this is the important feature in dealing with the ethics of medical decisions for children³¹.

²⁹ Discussions may be confused by the different ways in which these words are used. For example, in the Gillick Judgement Lord Scarman quotes Lord Nathan describing "...an infant who is capable of appreciating fully the nature and consequences of a particular operation...can give an effective consent thereto..." [*Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]] whereas, within medicine and public health, an infant is (by definition) an under-one year old child [Office for National Statistics, 2010]. At less than 12 months a child is unlikely to have any understanding of any healthcare intervention.

³⁰ As an example, the Mental Capacity Act states "Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise" and "A person is not to be treated as unable to make a decision merely because he makes an unwise decision." [Mental Capacity Act 2005].

³¹ Though this is not the only important difference between children and adults. Amongst other differences, we lie to children without qualm: we tell them of Santa Claus, we dissemble about sex (most ludicrously that a stork brings babies), and death is hidden from most children. These are not just innocent 'white' lies. Medical law gives the example where an adolescent Jehovah's Witness girl was judged not competent to refuse transfusion. Amongst the reasons she was judged not competent was because no one had told her how she would die [Montgomery, 2003; 292]. Lying to, or deceiving, adults is wrong, but it seems not to be so for children. Another difference between adult and child is that in the UK, parents are allowed to smack children, provided that this is 'reasonable punishment'. This power dates back to 1860 where parents "...may for the purpose of correcting what is evil in the child, inflict moderate and reasonable corporal punishment, always, however, with this condition, that it is moderate

Children are sometimes defined by age. As an example, the United Nation's (UN) convention of Children's Rights states "...a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier" [Article 1 United Nations, 1989]³². Underpinning this is the idea that the child's parents (and perhaps other adults) will make decisions for the child until they achieve the age at which they are able to make their own decisions. For example, in England and Wales, children may not get married until they are 16 but at that age only with the permission of their parents (though if their parents do not agree, the couple may apply to the court). The point of distinguishing adults from children is to separate those (children) who are not sufficiently able to run their own lives, as adults would be. Schapiro writes "...we think of children as people who have to be raised, whether they like it or not." [Schapiro, 1999; 716]. Age may be a marker to distinguish those who can or cannot run their own lives, but it is only a surrogate marker and is not important of itself, there must be a further justification for why that age is important.

The meaning of child that I use is that it covers the immature stages of a human being, from birth, until the child becomes an adult. The defining feature of children as they are understood in medical ethics is that a parent (and sometimes other adults) has the authority to make or amend decisions that a child makes. Importantly because others make decisions, or have oversight over the child's decisions a feature of children is that they are in relationship to at least one adult. Usually, and more successfully, children are in a family. Some children are not brought up in families, they may be brought up in orphanages or foster homes but for several reasons³³ this is less

and reasonable". An amendment in 2004 limited parental powers "to remove the defence of reasonable punishment to any charge of assault occasioning actual bodily harm, wounding or grievous bodily harm" [Department for Children, Schools and Families, 2007: 6]. Similar mistreatment of adults is criminalised.

³² Some claim that children should be protected *until* the age of 18 not - as the convention suggests - that by the age of 18 children must have adult rights. For example Human Rights Watch, in describing, and suggesting solutions to prevent child marriage in Yemen recommend "Set the minimum age for marriage at 18 in accordance with the definition of a child in the Convention on the Rights of the Child." [Human Rights Watch, 2011: 5].

³³ These reasons are both child-based, for example that children will be happier as children and more successful as adults if adopted than when brought up in care, and parent-based reasons in that an important part of a parent's life may be their relationship with the child and the child's progress through life.

successful than when children are reared by one or two adults in an intimate relationship. Because children are necessarily in a relationship, they are different from adults who can be taken to be independent, autonomous, individuals (whether or not this is actually true). As children are unable to live independently they cannot be considered to be independent. The children that I will concentrate on in this thesis are children who are unquestionably incompetent to make their own decisions.

2.3 THE DICHOTOMY OF CHILDREN AND ADULTS

In society in general, and in medical ethics in particular, patients are described as either child or adult. Children are taken to be distinct from adults in many different ways. Children's behaviour is often constrained to forbid them, or to oblige them, to perform certain acts (or forbid or oblige those responsible for the child in similar ways). Amongst many examples, children are compelled to go to school, adults may attend school or its equivalent; children are forbidden from voting, adults are permitted to (or required to in some states); children may not smoke cigarettes, adults are permitted to, and so on. In medical ethics "...there has always been a substantial degree of shared understanding that childhood implies a separate and safe space, demarcated from adulthood, in which children can grow, play and develop."

[UNICEF, 2005; 3] and importantly "There is a bright line between how we treat adults and how we treat children." [Baker, 2013; 311]³⁴. A step change is imposed on the incremental development of a child through life into adult, and the incremental development continues in adults until eventually the changes of senescence follow. The progression from newborn baby to adult (and beyond) is a gradual, seamless, change. There is not (as with insects) an immature (larval) stage, a distinct metamorphosis and then the emergence of the adult form. Insects show a clear physical separation between their life stages, but in distinguishing human adults from human children a clear distinction is imposed on the gradual change through life³⁵.

³⁴ An example of this distinction from medicine is that emergency contraception in the US is available only to those who are 17 or older, despite clear evidence that it is safe for women between 15-20 years old, and has fewer side-effects than paracetamol which a 12 year old can buy. The Health Secretary overruled the Food and Drug Administration (FDA) Commissioner [Wood, 2012; 101].

³⁵ Or perhaps it is even more complex. Some argue that newborn babies are valued less highly than older children and adults [Tooley, 1972; Ross, 2007]. In a provocative recent paper, Giubilini and Minerva argued that when problems are discovered after birth, but if known

The situation is, of course, more subtle than a straightforward dichotomy of adults and children. Older children have more say over their lives than younger children. This is recognised within the UN's Convention on Children's Rights which "...shall assure to the child...the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'. [Article 12 United Nations, 1989]. Parents of older children recognise the growing maturity and abilities of the child and that the concerns of the older child carry more weight than those of a younger child. The parents of many older children allow them to make at least some of their own decisions. And if the parents don't, then the child can appeal to others inside or outside the family, and perhaps eventually to law, (when it may be recognised as Gillick competence). The multiplicity of terms used to describe children (discussed above) recognises these different stages of childhood, but what unites them as stages of childhood is that children do not have the decisional authority of adults.

In recent times there has been a drive to involve children in decisions that are made for them. So the principle of 'no decisions about me without me' applies to children [Department of Health, 2012] and a child's right to 'express' themselves freely. Some may encourage older children to believe that they have, and should have, decisional authority equal to those of adults. But a child's right to express her views is different from decisional authority. These together may encourage an older child (and others) to believe that older children will be treated differently from other children. In one sense

before the birth would have justified abortion, then infanticide (or as they call it, after-birth abortion) should be permitted [Giublini & Minerva, 2013]. I believe that their arguments fail for several reasons. That the authors use the term 'after-birth abortion' instead of infanticide suggests that they need to ease their conclusions in and are less confident in the strength of their arguments. However, the important point is the claim that newborn babies are (in at least some people's eyes) not quite the equal of older children, and so the dichotomy of children and adults is incorrect. Janvier and colleagues described that newborn babies are less valued than older children in clinical practice. In withdrawing care from a baby, a family may say "It won't be fair to our other children" [Janvier, 2007; 418] but the authors doubt doubts parents would give the same reason when making decisions about an older child's treatment. Furthermore, when clinicians prioritise treatment allocation for imaginary severely ill patients by ranking patients of different ages and diseases, they prioritise babies' need for treatment less highly than seems justified (seventh of eight cases on average) given the likelihood and completeness of recovery of the patients of different ages. Again the claim here is that newborn babies may not be the equal of older children. I do not intend to consider this matter further here.

this is true: if a young person has made a wrong choice (by this I mean a decision that seems wrong to others), they should be reasoned or argued with, in a way that would be impossible with a one year old child. But in another sense it is not true: if a child makes a wrong decision, then the decision would be overruled (if the harm is significant) in a way that is not true for an adult. If the harm is limited a child may learn some things by being allowed to make a wrong choice. Discussion afterwards may be important in helping the child to learn to make decisions and take responsibility. But, for a child, another is responsible for the decisions that are made. If a child makes a decision, another (an adult) has allowed the child the authority to make the decision and so another - not the child - is responsible for the consequences. It is not enough (as it would be for an adult) to say that the child made their own decision.

It is often claimed that children should be allowed to make decisions to teach them how to make decisions³⁶. And this is true: if decision-making is not practiced then decision-making will be more difficult when the time comes to take decisions. Anyone may be overwhelmed if suddenly confronted with an enormous number of decisions having previously taken none. However, there is an enormous difference between teaching a child something and allowing a child to do something. Teaching a child to make decisions is very different from allowing the child to make decisions³⁷. In teaching children to make decisions, a parent will discuss the relevant concerns and considerations with the child, explaining the prioritising of different reasons, probing the child for her opinions and views, and perhaps aiding the child's reasoning. As the child becomes more skilled, the adult may argue against the child's decision to test her resolve. Towards the end supervision may be from a distance, the child may not even know that they are being supervised. All of these are different from allowing the child to make decisions. Even when supervising from a distance the adult retains responsibility for the child. Piker describes this process stating that for children we assign "...decision-making authority to adults: they not only make treatment

³⁶ "This epitomises the growing trend in law and social policy towards nurturing children's eventual independence by supporting autonomous choices in the spheres in which they are capable of exercising such choice" [Bielby, 2005; 362].

³⁷ Teaching a person to fly a helicopter differs from allowing someone to fly a helicopter. Allowing someone to fly comes towards the end of training.

decisions, but also decide how much evidential weight (if any) to give to adolescents' input in specific cases when making judgments about their best interests. It is also collaborative to the extent that adolescents actively participate in and contribute to the decision-making process along with adults..." [Piker, 2011: 208]. Swift writes of children's schooling that "...it needs to be made absolutely clear - all the way through - that the decision will be taken by the parents" [Swift, 2003: 157]. For all these reasons, although interactions with older children may differ from interactions with younger children, adults make decisions for children.

One reason why there is confusion in approach to older children is that terms such as young person, adolescent, youth and young adult can be used to avoid describing a person as an adult or child. And by using 'young person' without being clear about its meaning, a young person can be treated at times as a child and at other times as an adult, with no one being clear about what *should* be done or how they should be treated. Hard choices can be obfuscated. Young person is a particular troubling example as it is used widely and it is used with directly contradictory meanings³⁸. With agreement on a consistent meaning, then a conception such as young person might be a useful staging post on the way from child to adult. There could be serious consideration of the way in which young people, as a stage between childhood and adulthood, could develop. But because young person can mean a child (or adult) over such a wide range of ages and abilities, the term hinders clear discussion of the way that older children should be treated. Falling back on a term like 'young person' prevents a clear consideration of the way that we should deal with older children³⁹.

³⁸ The General Medical Council issued guidance *0-18: Guidance for all doctors*, with the definition "... 'children' usually mean younger children who lack the maturity and understanding to make important decisions for themselves. Older or more experienced children who can make these decisions are referred to as 'young people'." [Appendix 1 General Medical Council, 2007]. For the GMC young people are clearly children. The Department of Justice states "Children between 10 and 17...are treated differently from adults... Young people aged 18: Young people aged 18 are treated as an adult..." [Department of Justice]. For the Department of Justice young people then must be at least 18 years of age and are clearly adults (in law) and will be treated as adults but for the GMC young people are older children. More broadly in official sources 'young people' can be between anywhere the ages of 11 years [North Somerset Council; BARCA-Leeds] and 25 years old [Bolton Young Persons Housing Scheme; National Express].

³⁹ An example of the confusion between adult and children from the medical ethics literature is given by Salter: "There are significant differences that characterise health care decision making for children when compared with adults. First the consent of the patient is given much

I have claimed that we do not think clearly about children and one particular example lies in the distinction between children and adults. I will give two examples. First, contrast the age of criminal responsibility in England and Wales (of 10 years) [UK Government] with the fact that the courts have consistently overruled the medical decisions of considerably older children (15 and 16 years old) [*Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1992]; *re E (A Minor) (Wardship: Medical Treatment)* [1993]; *re L (A Minor)* [1998]]. What is taken to underpin competence to make medical decisions is that the child has "...sufficient understanding and intelligence..." for the choice under consideration [*Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]]. The features that underpin competence to make medical decisions (the ability to take in information, to analyse that information and to make and express a choice that reflect sustained personal choices) must be the same sort of abilities that underpin the concept of moral agency and moral responsibility and these must underpin the notion of criminal responsibility. Both medical decisions and criminal responsibility are united by the thought that people with sufficient reasoning powers should navigate their own way through life, reaping the rewards and bearing the consequences of their own choices. Usually when making health care decisions the child can be given full information, which can be presented repeatedly and the child can be given time to consider the information. The child has the opportunity, for calm reflection and discussion with their parents or others that the child chooses to turn to for advice. Contrast this with the sort of decisions for which children are held criminally responsible. Full information of the consequences is not guaranteed and is, often, unlikely. Actions often occur in the heat

less weight, and the views of the caretaker are given much more weight, especially where the caretakers are the child's parents. When dealing with a competent adult, doctors will lay the most weight on the patient's consent or refusal, even sometimes at the expense of the patient's best interests and, in some instances contrary to the family views... On the other hand when dealing a minor, doctors will lay most of the burden on the views of the parents and less, if any, on the child (particularly in cases where the child is unable to formulate or express a view)... [Salter, 2012: 180]. When dealing with a *competent* adult, best interests do not come into it; it all depends on the adult's consent, and the doctor's willingness to deliver treatment. When dealing with a child, treatment depends on the consent of the parents, again accepting that a doctor will act in the child's interests. No sense can be made of the child's views 'particularly in cases where the child is unable to formulate or express a view'. The mischief that Salter does lies in failing to recognise the clear difference between the way that we approach children and the way that we approach adults.

of the moment, and certainly without time for calm reflection. Responsible and wise adults are likely to be absent. For a child of given age or ability, factors which are likely to increase their powers of reasoning and understanding, and so their competence, are present for medical decisions, but not for the times when criminal responsibility is invoked. If this is true, children's medical decisions should be respected at younger age than the age from which they may be held criminally responsible. Meynen discusses the relationship between competence to make medical decisions and forensic assessment of criminal responsibility for adults but does not touch on children [Meynen, 2009].

A second example comes from gun law. The power of air rifles is strictly limited by law, but even with this children under 14 years cannot own an air rifle⁴⁰, an air rifle that a child uses must be owned by their parents. This seems to be a reasonable age limit. Older children may be allowed progressively more responsibility by their parents and can learn under declining adult supervision. However, shotgun licences can be awarded to children at younger ages, and some have been awarded to children under the age of 10 years⁴¹. A shotgun is a far more powerful and potent weapon than is an air rifle. There can be no reason why it would be appropriate that a 13 year old is denied an air rifle, but a 10 year old is granted a shotgun licence. I do not want to discuss the age at which children should be allowed to own a gun (though I believe that 10 is too young), but to point out that we do not have a clear and coherent approach to children given the clear inconsistencies in the way that we treat them.

In conclusion I have argued that although it is widely agreed that there is a clear distinction between children and adults, when it is examined the distinction becomes less clear. In writings about children the use of some terms, in particular young person, has blurred clear discussion and confused our approach especially to older children. These problems are less important for this thesis as I discuss the approach to treatment for unquestionably incompetent children.

⁴⁰ "Under 14 years... You cannot buy, hire or receive an air rifle or its ammunition as a gift, or shoot, without adult supervision. Parents or guardians who buy an air rifle for use by someone under 14 must exercise control over it at all times, even in the home or garden." [BASC].

⁴¹ "Thirteen children under the age of 10 have been issued with shotgun certificates in the UK over the past three years." [Shaw, 2011].

2.4 PHILOSOPHERS AND CHILDREN

In the past only limited attention has been paid to children by philosophers. David Archard describes Locke's writings on children as

“...typical of most philosophers in that his account of childhood has to be extracted from scattered remarks and is not to be found explicitly and systematically expressed in a single work. Moreover what Locke has to say about children in one context does not always sit easily with what he has to say about them in another. These tensions are due to writing about children from different perspectives.” [Archard, 2004; 1].

More recently, some philosophers and ethicists have paid more attention to children and parents. Some aspects, in particular parenthood and children's rights, have attracted more attention, but others, such as what distinguishes children from adults, or what counts as a child's welfare, have been neglected.

More generally, philosophers have created (and other philosophers have criticised) accounts of how people interact (or should interact) and in doing this have concentrated on adults, seen as persons (in a technical, philosophical, sense) acting with moral agency and moral responsibility. Children are usually ignored. This has led to two problems. Firstly, the way that children fit into the ethical schemes that have been constructed for adults is unexamined. Regan asks “Why have most moral philosophers failed to pay much attention to ethical questions about the treatment of children?” [Regan, 1989: 203]. Ruddick recognised the problem and gives a reason for its presence: “We do not think clearly about parents and children...There is also a metaphysical cause of confusion: children become distinct beings only gradually...We have no criteria apart from legal convention for deciding when in pregnancy there are two human bodies rather than just one, or when in adolescence there are two distinct lives, that of the ‘child’ and that of the parent(s), independently pursuable.” [Ruddick, 1979: 124]. The second problem is that it is just accepted that children and adults are different, but that what justifies the distinction in the way that children and adults are treated remains mainly unexamined. Schrag writes “...an enormous philosophical weight is made to rest on the adult/child distinction, yet the basis of the distinction is left unexamined” [Schrag, 1977: 169]. Part of the reason for this is that the interactions involved in ethics are characterised in different ways (I have drawn attention to autonomy, contractualism and virtue ethics in the previous chapter: there are many more) and the distinction between adults and children would need to be characterised

differently for each scheme. Within many of the approaches to ethics there is often a dichotomy of ‘persons and things’. Beings that are not persons are treated as non-persons, but within non-persons are an enormous range of beings, amongst which are children, bonobos, dolphins and spiders⁴². It is unlikely that this diverse group should be treated in the same ways. A more nuanced approach is needed.

In philosophical approaches to children, two broad approaches can be discerned, firstly that children are seen in some sense as their parent’s property. The second is that children are special, as they are potential persons and so demand to be treated in almost the same way that persons would be treated. I will then discuss what philosophers have said about the distinction between adults and children.

Children as Owned Contrasted with Children as Potential Persons

In discussion of children two concepts are prevalent, but difficult to reconcile one with another. The first conception is that children ‘belong’ to, or are owned by, their parents. Aristotle described this in several different ways: “...a parent is fond of his children because he regards them as something of himself.” followed by “...a person regards what comes from him as his own as the owner regards his tooth or hair...” and “A parent then, loves his children as [he loves] himself. For what has come from him is a sort of other himself...” [Aristotle Book VIII Chapter 12]. More recently, Nozick wrote of children as being “...part of one’s substance” [Nozick, 1989: 28]. That parents reproduce through their children and do not just produce their children reinforces the link between parents and child, and the perception that parents have authority to mould their child in particular ways. It is these thoughts that are underlined by the statements describing a child as ‘...a chip off the old block...’ or remarking of a child ‘...the apple doesn’t fall far from the tree...’ alongside ‘...she is her mother’s daughter...’.

⁴² “To say that a being is a person is merely to say that the being has morally significant interests, that the principle of equal consideration applies to that being, that the being is not a thing...for the moral universe is limited to only two kinds of beings: persons and things. “Quasi-persons’ or ‘things plus’ will necessarily risk being treated as things because the principle of equal consideration cannot apply to them” [Francione, 2004: 131]. Francione’s solution (discussing animal rights) is to elevate the status of animals to that of (non-human) persons. This leaves the dichotomy of persons and things. Children challenge any dichotomous divide because of their incremental change from zygotes to adult humans.

The sense is that children are part of their parents, they are not separate individuals. And from the ownership comes authority, Hobbes wrote

“...children therefore, whether they be brought up and preserved by the father, or by the mother, or whomsoever, are in the most absolute subjection to him or her...and they may alienate them, that is, assign his or her domination, by selling them or giving them in adoption or servitude to others; or pawn them for hostages, kill them for rebellion, or sacrifice them for peace...” [Hobbes, 1640: paragraph 8 Chapter 23].

These claims suggest that children are almost owned by their parents, and so are not individuals in their own right. Following on from this it suggests that parents have authority over their children (as they would over their own property) and that others, and indeed children themselves, should not interfere with decisions that parents make for their children.

The second important conception is that children are special: they have potential, children will become persons and persons cannot be owned. Children will almost inevitably become persons. And if so they are ‘special’ analogously to the way that persons are special. Locke stated this second concept clearly in recognising the limits to parental authority:

Children, I confess, are not born in this full state of *equality*, though they are born to it. Their parents have a sort of rule and jurisdiction over them, when they come into the world, and for some time after; but it is but a temporary one. The bonds of this subjection are like the swaddling clothes they are wrapped in, and supported by, in the weakness of their infancy: age and reason as they grow up, loosen them, till at length they drop quite off, and leave a man at his own free disposal. [Locke, 1689: § 55, Locke’s italics]

Locke’s approach contrasts with the concept of child as ‘owned’ by their parents. And more recently his approach was echoed by Schapiro, “Our basic concept of a child is that of a person who in some fundamental way is not yet developed, but who is in the process of developing.” [Schapiro, 1999: 716]. Because a child will become a person, a child deserves special treatment. Children are not like other things that are owned by their parents, distinct even from the animals their parents own, because the child will become a person. Because they are developing, children cannot be treated as persons, but because children will become persons there must be particular constraints in the way that we treat children. Together both are important concepts for children, but the different conceptions are stronger at opposite ends of childhood - ownership for young

children, developing persons for older children. But both are present throughout childhood.

One approach is wrong: sometimes, children seem to drop out of sight altogether. Narveson gives an example of this. He grounds responsibilities to children in our responsibilities to each other, or society more broadly “...our rights *against each other*, as adults, are the proper source of rights for children. Children are potential adults. To treat them well is to set them on the road to being the sort of adults we want to have around, to treat them badly is virtually to invite them to become the sort of people we don't want around. Parents who fail towards their children are parents who fail their neighbours and fellow humans, as well, of course, as the adults those children become when they grow up.” [Narveson, 1999: 269 (his italics)]. There are many different claims at work in Narveson's arguments, but a thrust of his claim is that the child herself is not the focus of consideration. Regan criticises the sort of approach in which children are not considered directly, arguing that this misses the fact that children themselves can be wronged, it is not just that others around the children can be wronged (for example the child's parents who ‘own’ the child). Children deserve to be recognised directly for themselves [Regan, 1989]. Narveson's approach, and others like it, will not work. Others express similar claims to Narveson's but allow acknowledgment of the child in her own right “...we must face the problem that a newborn is a different sort of individual than an adult - more of a stand-in for a person-yet-to-be than a person already.” [Brody, 1988: 39].

These arguments produce the conflicting requirements that children should be treated with the same significance that a person should be treated (for example that a child's right to life is the equal of an adult's right to life), and yet at the same time children cannot be treated in the way that adults are (their decisions may be overridden, and they cannot consent as adults may) because they are immature. A straightforward demonstration of this problem is the way in which the rights in the Children's Rights Convention Rights are different to, and distinct from, the rights listed in the Declaration of Human Rights. And the conflict between these requirements is compounded by the gradual growth and development of children into adults so the

point at which an individual becomes an adult is not marked by a distinct objective change. Children must be recognised as developing persons⁴³.

Distinguishing Adults From Children

I have described the dichotomy of adults and children. What distinguishes children from adults, justifying the difference between the ways that they are treated? I will consider two responses to this distinction. The first is to deny that there is a difference between adults and children. The second is to base the distinction on reasoning or capabilities. The most plausible approach is one that depends on practical reasoning, though even this approach is an incomplete justification of the way that children are treated.

Denial: Child Liberationists

The first response is to deny that there are important differences between children and adults and that there is no justification for the different approaches, as the child liberationists do⁴⁴ [Holt, 1974; Farson, 1974; Franklin, 1986]. Broadly, child liberationists take a rights-based approach to argue that children should have all the rights that adults have. “I propose instead that the rights, privileges, duties, responsibilities of adult citizens be made *available* to any young person of whatever age, who wants to make use of them.”⁴⁵ [Holt, 1974: 1, Holt's italics]. Children's liberation advocates were most vocal in 1970's America, arguing that the then current child-rearing practices had been influenced by past abuses of children - such as child labour. On this view, the responses to past abuses of children had been such that children were now over protected, and were harmed by being overprotected. The segregation of children from the adult world allowed children to be treated wrongly. There were many different reasons for this. In protecting children from participation in the adult world, children were unable to develop their abilities and were thereby

⁴³ Children are “...developing beings whose moral status gradually changes” [Archard & Macleod, 2002: 4].

⁴⁴ “Children must have the right to full participation in society...valued for themselves not just as potential adults” [Farson, 1974: 3].

⁴⁵ Holt distinguishes between having a right and having a right available, but what lies in this distinction is, is not made clear. A feature of many rights is that they are available. A right holder is not obliged to demand the fulfillment of the right: a right holder may waive the right, or negotiate the terms of the right and so on.

infantilised. In preventing children working, children were unable to become self-sufficient. In law, once the processes of protection were invoked the child was lost in a Kafkaesque world of paternalistic officialdom. A child would be better protected by having rights equivalent to an adult's rights (this is comprehensively, though polemically, described in the first and second sections of Gross & Gross, 1977 and de Mause, 1974). The special 'protections' afforded to children contributed further to the problems they suffered.

Liberationists used two ways to argue for equal rights for children. Firstly, they argued for equal rights for children on libertarian grounds "...self-determination is at the heart of children's liberation. It is, in fact, the only issue, a definition of the entire concept." [Farson, 1974: 27]. Their second approach was to argue that the differences between adults and children are exaggerated and do not justify treating children differently from adults.

The first approach is a variant of liberalism. Farson writes "...asking what is good for children is beside the point. We will grant children rights for the same reason we grant rights to adults, not because we are sure that children will then become better people, but for more ideological reasons...expanding freedom as a way of life is worthwhile in itself" [Farson, 1974: 31]. This is a political or philosophical position, prioritising freedom in contrast to the usual approach that a child's well-being should be the concern,⁴⁶ not the child's liberty. The child liberationists criticised the conventional welfare-protecting approach as "...more committed to the protection of children than to the protection of their rights." [Farson, 1974: 74].

There are many problems with the liberationists' approach. Firstly, a newborn baby is not free to choose in any meaningful sense. A baby of this age could not choose whether to stay with birth parents or to be adopted, or if abandoned at birth to choose between potential adoptive parents. And even for older children, freedom may be

⁴⁶ In the preamble to the original version of the Children's Rights Convention it states "...mankind owes to the child the best it has to give" [United Nations, 1959]. In the current version of the Declaration the commitment to the "...best it has to give" is watered down to "The child, by reason of his physical and mental immaturity, needs special safeguards and care..." [United Nations, 1989].

inadvisable as others may take advantage of their immaturity: ‘freedom for the pike is death to the minnow’ [Tawney, 1931: 208]. A further objection to rights for young children lies in Farson's use of *self*-determination. For at least some children (again a baby will serve), there isn't a self in the idea of a being that has awareness of itself as the same person continuing through time. And even for older children, the 'self' is not fully formed. A child's values will likely change as they grow. Allowing children's decisions to stand will, in all likelihood, result in the adult that the child becomes (and others) regretting the decisions the child was allowed to make⁴⁷.

A third response is to agree with child liberationists that expanding freedom is worthwhile, but to deny that granting freedom to children, when they are children, will increase their freedom. This point may be expressed using Berlin's two concepts of liberty. If children are given freedom (negative liberty) then they are free from control by their parents and other adults, but then children are less likely to develop the skills and self-control that are needed to choose one's own course throughout life (positive liberty) which will allow children to do the things that they would choose to do. The liberationist's argument that we should expand freedom for children fails because children are different from adults. Increasing a child's freedom (as negative liberty) will not increase the freedom (as positive liberty) that they have or will come to have in life [Purdy, 1992 and 1994]. For all of these reasons, the child liberationist's first argument in favour of freedom for children as an end in itself fails.

A second way to argue for equal rights for children is to claim that children's abilities are similar to those of adults, and so claims that children are unable to make their own choices are exaggerated. If so, the justification for the distinction between adults and children (liberationists claim) does not exist. Evidence may be presented that the skills

⁴⁷ “If children were regarded by law as the equal of adults, the result would be something infinitely worse than barbarism. It would involve a degree of cruelty to the young which can hardly be realized even in imagination” [Stephen quoted by Schrag, 1977: 174]. And in an example from medical ethics, a married 18 year old man with one child who had myasthenia gravis had a vasectomy after he himself had consented for it. He later claimed that as the age of majority was 21 he was unable to consent and sought damages because the procedure had been performed. He was unsuccessful [Smith v Seibly 1967].

of older children are the same as the skills of adults⁴⁸ though others disagree⁴⁹. The liberationists then follow this with examples of the ways in which some adults make unwise choices in risk-taking, taking drugs or consuming alcohol to excess. That there is little difference between older children and adults may be true, but it is certainly not true for younger children. And for very young children there is no sense in which they can make a choice that is in any sense reasoned. The liberationist's argument (if true) is not that there is no difference between adults and children but that there is no difference between *some* adults and *some* children. This argument claims that the dividing line between adults and children is wrong because it is arbitrary, or that it is in the wrong place. The argument that the distinction between adults and children is set at an arbitrary age may be true, but the response can be to try to set the distinction in the correct place, not to abolish it altogether. It is also true that an easily definable characteristic (like age) that distinguishes adult from child may well misclassify individuals, allowing some decisional authority too early (when they choose unwisely) and preventing others from having decisional authority when they are more than able⁵⁰. Either way, the liberationists' second argument against the distinction between adults and children fails⁵¹. When decisions, and especially medical decisions, are made for children, children are treated with regard to their interests, welfare or well-being. Adults, however, are recognised to be free to make their own self-regarding decision: they are autonomous.

Reasoning

So how may children be distinguished from adults? What justifies the difference in the way that adults and children are treated? For Locke, adults had reason "The *freedom*

⁴⁸ Piker describes empirical evidence demonstrating the "...decision-making capacity of older adolescents is well-developed and not significantly different from that of adults." [Piker 2011: 204]. Others make similar claims [Buchanan and Brock, 1990; Steinberg, 2013].

⁴⁹ "...the empirical psychological and neuropsychological data regarding the decisional capacity of adolescents and the impact of authoritative parents run contrary to the claims advanced by the Convention on the Rights of the Child." [Partridge, 2010: 524].

⁵⁰ But it is likely that any feature that is chosen to discriminate between adults and children will depend on more than just the abilities of the child. As well as that, the consequences of the decisions may be important, or the ease of separation of adult from child, amongst other features.

⁵¹ And even if the liberationist's argument were to succeed, the argument is against the adult-child distinction. One response is to reject the dominance of autonomy in our approaches to adults, and so treat adults as we treat children.

then of man...is grounded on his having *reason* which is able to instruct him..."

[Locke, 1689: §63]. Of children, he wrote

"To turn him loose to an unrestrained liberty, before he has reason to guide him, is not allowing the privilege of his nature to be free; but to thrust him out amongst brutes, and abandon him to a state as wretched, and as much beneath that of a man, as their's. That is that which puts the *authority* into the *parent's* hands to govern." [Locke, 1690: § 63].

Locke cedes authority to the child's parents, because of the child's lack of reason.

Mill follows Locke, in stating in *on Liberty* "...over himself, over his own body and mind, the individual is sovereign...It is perhaps hardly necessary to say that this doctrine is meant only to apply to human beings in the maturity of their faculties. We are not speaking of children or of young persons below the age which the law may fix as that of manhood or womanhood." [Mill, 2002: 12]. Mill here suggest two facts that separate children from adults, 'maturity of their faculties' and law. He settles on law, though it may be that the law is justified by the child's maturity. Perhaps Mill believes that age tracks the distinction in maturity well. However, another explanation may be that children have not completed their education. In justifying why adults may not be constrained, Mill argues: "It [society] has had the whole period of childhood and nonage in which to try whether it could make them capable of rational conduct in life." [Mill, 2002: 85]. However able a child is, until the child's training is complete, she may become more able. The distinction that separates children from adults then is that adults have completed their training (successfully or not) but children haven't. If this is what Mill intended, a child may be as able as an adult, but does not have authority to make their own decisions until they reach the age of maturity because they may become more able. The decisional authority of children does not depend on the achievement of a certain standard, but on their place in a trajectory through life. It is not clear that Mill intended this interpretation, it is more likely that he was arguing that adults, however able, should make their own decisions.

The dominant approach today follows Locke and Mill by distinguishing children from adults because they are imperfect reasoners and so lack competence, or lack

capacity⁵². An example of this approach in medical ethics is “By ‘children’ I mean individuals below the ‘age of reason’, that is, those individuals whom we think, by reason of their lack of years, are unable to make rational decisions on those matters which affect their long or short-term interests, or who are unable, because of age, to make rational moral choices in a great many areas.” [Redmon, 1986: 77]. This leads to the problem of specifying what is meant by ‘reason’. Children may be able to reason a solution to a problem in logic or mathematical reasoning, but not be able to reason through practical problems in their life. Children may not have the skills in real-life reasoning to understand the complexity and consequences of real-life decisions. If children are allowed responsibility on a too simple version of rationality, then a child may make immature (wrong) choices which are harmful. These are the sorts of decisions that a child should be protected from. A child with limited understanding, may grasp that an operation will cause pain, and so refuse it and so seem able to reason. But if the intervention is for a pain-causing condition, and overall the child’s pain will be lessened by the operation, the child could be taken to be irrational. In real life practical reasoning, one of the challenges is deciding what information to take into account in coming to a decision.

If we accept that the skills that are needed are not abstract theoretical reasoning but practical reasoning skills⁵³ then we would need to be clear what is meant by sufficient practical reasoning skills. Harris, in discussing children’s political status describes that children acquire adult status when they are “...reasonably competent language-users, who have wants for themselves and their future which they can plan plausibly, not necessarily most successfully, to achieve and who are reasonably responsible for their

⁵² These terms are used widely but are not well defined. Some authors separate different meanings to the terms, as an example “The conflation of competence and capacity in English medical law...” [Bielby, 2005: 357]. But the terms are often used interchangeably. All share the idea of having sufficient reasoning skills to make the sort of choices that should be accepted. As an example, “If children are not legally competent (do not ‘have capacity’) to give consent for themselves...” [Department of Health, 2001: 1]. And also from the NHS “Children under the age of 16 are presumed to lack capacity, but can consent to their own treatment if it is thought that they have enough intelligence, competence and understanding to fully appreciate what is involved in their treatment...” [NHS Choices (b)].

⁵³ Though there will be other attributes too. Doris wrote “...a capacity for first-personal responsibility attribution is one thing that separates adults from children...Moral maturity has much to do with acknowledging what one has done - admitting one's hand has been in the cookie jar instead of trying to hide the crumbs on one's face.” [Doris, 2002: 164].

options” [Harris, 1982: 49]. Harris’ approach suggests skills similar to those needed to reason so that the child could live independently, or as an independent member of a family. This is a move from an abstract notion of ‘reason’ towards the sorts of skills needed to live as an adult. Purdy’s answer comes in responding to the child liberationist’s demands for children’s rights. A child is someone who lacks the “...capacity for planning systematic utility-enhancing projects or having a rational life plan” [Purdy, 1992: 27]. She dismisses instrumental rationality and weaker versions of reason. Children differ from adults because they need to “...develop enabling virtues and the self-control on which they are based. These are habits that can help them achieve their goals and that therefore ought to be considered uncontroversial. Hence the case for limiting children’s freedom...” [Purdy, 1992: 49]. Kraut argues that what separates adults from children is “...the powers of a human being – the cognitive, affective and social powers...are mature enough to make consent a meaningful act. Adults should not be treated like children...” [Kraut, 2009: 235]. Swift answering the question whether a child who opposes their parents’ choice of school should be overridden writes “The answer is yes. Assuming the kid is not yet old enough to be thought of as controlling his own life, parents should base the decision on their best judgement of where the balance of reasons lies. Of course what he thinks may be one reason to be put into the equation...the parents should *consult* their child...But it needs to be made absolutely clear - all the way through - that the decision will be taken by the parents [Swift, 2003:157 Swift’s italics]. The theme of planning and achieving a particular life plan runs through all four, and underpins the important distinction separating adults from children. The idea that is common to these authors’ distinction of child from adult is that the child has agency, the ability to develop and communicate a plan for the future⁵⁴. These are the sorts of abilities that philosophers have taken to underpin the distinction between children and adults.

⁵⁴ But a child’s ability to plan is not the same as the child’s ability to institute a plan. An ability to institute the plan depends on the child’s circumstances and the context in which the child lives. For example, a child’s ability to make ‘consent a meaningful act’ depends not just on the child’s ability to consent (to understand, to reason, to communicate his decision) but also whether those around the child make the child’s consent ‘a meaningful act’. If those around the child neither explain the decisions that must be made nor allow her the ‘space’ to make the decision, then the intrinsic abilities of the child are necessary but not sufficient for her to institute a plan. What I mean by ‘space’ is that a child must be able to negotiate competing responsibilities and has the resource to institute her plan. For example if a child plans to take part in research, if those around the child do not allow the child to rearrange her

There are several problems more generally with a distinction based on practical reasoning. Firstly, what is meant by practical reasoning is only vaguely specified (as in the examples that I have given above) and there are reasons why it would be difficult to establish a threshold to distinguish child from adult. Secondly, if what is important in distinguishing an adult from child is practical reason sufficient to navigate through life, then the circumstances of the person's life, both the general way that society is constructed and the particular context of an individual's life will be important in determining whether the person has sufficient practical reasoning ability. The maturation of child into adult does not then depend solely on the abilities of the person being considered, as it is often taken to. Thirdly, even if progression to adulthood depends on practical reasoning, it may be that a surrogate marker, such as age or school leaving would be preferred for broader implementation for pragmatic reasons. And this, compounded with the gradual change in abilities, may lead to claims that this is the wrong way, or the wrong level, at which to separate adults from children.

To deal with the first concern: a threshold of practical reasoning ability that will serve to separate adult from child will be difficult to specify for many different reasons. One reason is that a person needs abilities in many different domains of practical reasoning, including as examples health care, personal economics and relationships amongst many other domains. Even within individual domains there is an enormous amount of information that must be known and processed for a person to plan even one aspect of one's own life. An attempt to assess practical reasoning would have to cover an enormous range of information and reasoning. A person may be variably competent even within one domain of practical reasoning. For example in discussing pregnancy testing before treatment the Royal College of Paediatrics states "...it is known that competence to make one decision does not necessarily indicate competence to make all decisions." [Royal College of Paediatrics and Child Health, 2012: 8]. Furthermore, abilities in different domains need not be equivalent. Children may have sufficient practical reason in one domain but not in another, are they then children or adults? Glibly, a parent may overrule a child's medical decision but allow their choice of ice

school or household commitments or if she has no independent ability to travel then regardless of her ability to plan cannot, she cannot institute her plan.

cream flavour to stand. If practical reasoning is what matters, there will be those who lack practical reasoning in all domains (children), those who have achieved a threshold standard of reasoning in all domains (adults) and a third group who have achieved the threshold level of reasoning skills in some, but not all, domains (the inbetweeners). Are the inbetweeners adults, children or a third group?

The second concern is that the child's abilities alone cannot determine a distinction between adult and child. Even if practical reasoning is a component of the distinction of child from adult then, the circumstances of the person's life, both the general way that society is constructed and the particular context of an individual's life will be important in determining whether a person has sufficient practical reasoning ability such that they should make their own choices. A stronger emphasis is placed on the adult-child distinction in the West where grown children are more independent of their parents than are grown children in (for example) Asian countries⁵⁵ [Chen, 2010; Li, 2010]. There are several points here. Firstly, to at least some extent, whether an individual is a child is defined by what a society believes a child should be, with policy set by laws, courts and governments. The laws are upheld (or sometimes widely ignored if they are felt to be wrong) by society more broadly. Whether an individual is a child or not is not a fact just about the child, as it is sometimes taken to be. A second point is that the sort of abilities that are needed depend on the circumstances, and it is possible for the health care team to foster, or hinder, the practical reasoning of a patient. The Mental Capacity Act states "A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken

⁵⁵ As a medical example, Chen describes that even for adult patients "...on the Chinese model, the locus of moral responsibility for medical decision making is the family. The patient in this model is always treated as a member of a family, with the result that the family plays a cardinal role in decision making for its sick members in grave medical contexts [Chen, 2010: 574]. This approach describes the approach to a child in the West. And as a second medical example, "In the case of significant medical issues, the physician usually informs a family representative of the patient, rather than the patient him- or herself, about his /her medical problem and therapeutic recommendations. A family representative, who is usually a close family member of the patient, such as a spouse, parent or adult child, will consult other family members before a final decision is made... If formal consent is require, it is usually the family representative, rather than the patient, who will sign the consent form" [Li, 2010: 588]. These descriptions are close to what may happen in the West if the patient was a child or incompetent, but are not the way that an adult would be dealt with.

without success” [1.1 (3) Mental Capacity Act 2005]. A child might be competent to make a decision in calm situations with sufficient time but not in other situations.

Accepting that any test of practical reasoning (if it is possible to define a threshold that distinguishes adult from child) is likely to be arduous as a large range of skills will be assessed, it is likely that a surrogate test, such as age, or leaving school or the ability to live independently (as the emancipated minor in the US) will be used instead as a threshold of adequate practical reasoning. And if this approach is taken it leads to the criticism that the chosen threshold is arbitrary and so is not the correct level to separate adult from child. An abandoned newborn will die unless cared for by another. And although older children can survive and even thrive independently, they are more likely to survive, and survive with better prospects if others care for and have oversight over the child. Children whose upbringing is supervised beyond the absolute minimum needed to survive are likely to have better lives than those who have been left to guide themselves. Conversely, dependency will be encouraged if a child is not allowed decisional authority: she will be caused to be childish. In *the Subjection of Women* Mill argued that a true appreciation of women's abilities could not be formed because “What is now called the nature of women is an eminently artificial thing - the result of forced repression in some directions, unnatural stimulation in others. It may be asserted without scruple that, that no other class of dependent have had their character so entirely distorted from its natural proportions...” [Mill, 1874: 144]. The same could be true of children. For reasons such as these, some have argued that the concept of childhood is a sociological construction and in particular that the concept of childhood is a modern construction⁵⁶. Their argument is that although there may be psychological and physiological differences between adults and children, those facts need not determine how children are treated. The way that children are separated from the adult world to protect them, creates some of the inabilities of children making them dependent when they need not be. It is true that some aspects of childhood are constructed. This is demonstrated by the changes over time in the way that children are treated, and over recent years the changes have been to recognise decisional

⁵⁶ “Adult[s] impose their conceptions of childishness on beings whom they consider to have lesser capacities... Childhood then is a man-made construction.” [Freedman, 1983: 21-22]. Aries in *Centuries of Childhood* argues that the concept of childhood is a modern construction [Aries, 1965].

authority at an earlier age⁵⁷. But it is also true that there are physiological, psychological and developmental differences between adults and children. The important point is to recognise that some of children's inabilities are a result of their physiological or psychological immaturity but some are created by circumstances, both of the child's upbringing, and the immediate medical situation. And having recognised this distinction, it is important to scrutinise whether the inabilities that are caused by circumstances could and should be minimised. That the adult-child distinction is just accepted and not examined suggests that this, too often, does not happen.

I have argued that although a threshold of practical reasoning skills is an appealing approach to distinguish child from adult, there are several problems with a distinction based on practical reasoning. Firstly, in specifying an appropriate threshold. Secondly, if what is important is practical reason sufficient to navigate through life, then it is likely that different skills and abilities will be needed in different times and societies and if so, there is not a single set of abilities that is needed to be an adult, the skills needed depend on factors other than something related to the person herself. Furthermore, the abilities that a child needs to be an adult depends on the ways that those around the person behave. And even if it were possible to overcome these problems, a method to assess practical reasoning skills is likely to be enormously complex and would be replaced by some other distinction.

That abilities in practical reasoning or competence are not solely what distinguishes adults from children is recognised by the existence of competent children⁵⁸. In the UK, Gillick Competent children [*Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]] and in the US mature or emancipated minors [Holder, 1989] are recognised to be competent to make decisions, and yet are children. If there are children recognised to have sufficient reasoning so that they have decisional authority equivalent to that of adults in medical and other matters, then competence

⁵⁷ An example is voting age in the UK which was 21 until 1969, and is now 18, though 16 year olds could vote in the Scottish referendum of 2014.

⁵⁸ As an example in describing the conditions for acceptable research with children, the Medical Research Council states "Researchers can only involve competent children if they have obtained their informed consent beforehand." [Medical Research Council, 2004: 6].

alone cannot be what separates adults from children. In the Gillick case, the UK courts recognised that a child is able to consent to medical treatment “...if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed.” [*Gillick and West Norfolk and Wisbech Area Health Authority and Another* [1986]]. In the US, the concept of mature minors is similar “...age is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood.” [*In re E.G., a Minor (The People of the State of Illinois, Appellant, v. E.G., a Minor, Appellee*; 106]. If practical reasoning, or competence, is what separates adults from children, these individuals are adults, they are not children, the phrase ‘competent child’ would be an oxymoron. What distinguishes *the* competent child from the adult that they will shortly become? One answer to this question is given by Buchanan and Brock:

“In decisions about health care treatment for children, however, a *third substantial value* is commonly recognised: the interest of *parents* in making important decisions about the welfare of their minor children. In our view the determination of whether a child is to be accorded decision-making authority must take account of this third value. Thus, the determination of *competence*, which involves only the patient-centred values of self-determination and well-being, cannot by itself resolve the issue of the child's *decisional* authority.” [Buchanan and Brock, 1990: 226 their italics].

Buchanan and Brock suggest that as parents have significant interests in their child, they may retain authority over the choices that a minor child makes. Buchanan and Brock do not continue on to resolve the question of decisional authority for a competent child (though they do note that there are “...large and complex issues that cannot be pursued further here.” [ibid: 234]). In their analysis of an adult’s decisional authority there is no suggestion that the interests of parents (nor indeed any other family member’s interests) should be included in the analysis. Parents’ interests in their child’s well-being do not terminate when their child becomes an adult: it is a life-long concern. Buchanan and Brock do not explain why the interest parents have in their children is admissible for a competent child, but becomes inadmissible for an adult. Here they may be relying on a particular distinction between adults and

children, but if so, it is not the usual distinction, that children become adults when they are have the abilities of adults⁵⁹. Buchanan and Brock's answer is incomplete.

A different approach is taken by Nussbaum who developed (following Sen) an approach to well-being, based on human dignity and respect, the capabilities approach. Capabilities are what a person is able to do. Nussbaum lists ten central capabilities⁶⁰ that are needed to live a life of human dignity. Governments should ensure that all citizens are provided with a threshold level of these capabilities and the extent to which these capabilities are achieved is a measure of person's well-being. What a person actually does is their functioning. Capabilities need not be exercised, a limitation which is needed in order to respect a "...plurality of different religious and secular views of life..." [Nussbaum, 2011: 26]. Nussbaum argues that an adult's well-being should be measured by their capabilities - what a person is able to do - not what they actually do. An example that she gives is that some religions oppose involvement in politics so her theory requires that a person is capable of voting, but not that she actually votes. This respects the person and the choices she makes. However, for children, Nussbaum argues "Children, of course, are different. Requiring certain sorts of functioning of them (as in compulsory education) is defensible as a necessary prelude to adult capability" [p 26 Nussbaum, 2011: 26]. In discussing education she argues "...governments will be well advised to require functioning of children, not simple capability. Why is this case different from most? It is different only when we are thinking about children whose choice capabilities are immature and who may face parental pressure to work rather than to study, since they are economically dependent on their parents and have few exit options" [ibid: 156]. Children differ from adults because they may be coerced into choosing unwisely. However, in the opening chapters of *Creating Capabilities* Nussbaum, 2011, describes adult women who lead impoverished and unhappy lives with few opportunities. They were enabled to live better lives with the help of women's organisations such as Self-Employed Women's Organisation (SEWA). A large part of the improvement in the women's lives was that they took control of their own lives, whereas before they did so, they were living

⁵⁹ As Locke described parental authority "...age and reason as they grow up, loosen them, till at length they drop quite off..." [Locke, 1689: § 55].

⁶⁰ *Women and Human Development* Nussbaum, 2000: 78.

unhappy lives that they had not chosen. Their choices were constrained by the pressures of society, and sometimes their families, that the women were able to escape only with the aid of organisations like SEWA. These women then seem to be suffering the same injustice that Nussbaum would protect children from. As Nussbaum argues that children should be protected (by requiring functioning) from making unwise choices as a consequence of external pressure, then so too should vulnerable adults (as these women were) be protected from unwise choices made as a consequence of pressure. And if not, we are owed an explanation for why children, but not adults, should be protected from the wrong choices made as a consequence of external pressure. This then would be what distinguishes adult from child. In another book a different argument is used: “If we aim to produce adults who have all the capabilities on the list, this will frequently mean requiring certain types of functioning in children, since, as I have argued, exercising a function in childhood is frequently necessary to produce a mature adult capability” [Nussbaum, 2000: 89]. It is true that children will not have capabilities unless they have practised them. But it is also true that if capabilities are unpractised or unused they will be lost by adults. I was a competent French speaker at school but after thirty, unpractised, years, this is no longer true. Although Nussbaum relies on the adult-child distinction to justify her requirement that children should be required to have abilities and not just capabilities, she follows many other philosophers in failing to explain why children should be treated differently from the way that adults are dealt with.

In conclusion, although practical reasoning abilities may be one of the factors that are important in determining the distinction between adults and children, there are many other factors that are important too. A distinction between adults and children that relies on practical reasoning - that adults have the ability to live and interact independently in and with society, but children do not - is a justifiable point to place the adult-child distinction, but there are many reasons why this cannot be the sole justification of the distinction between adults and children. As I described, the thesis considers how to make medical decisions for unquestionably incompetent children and so the approach to more able children is not an important matter to resolve for the purposes of this enquiry, though it will be for older children. Furthermore I have argued that in practice it is not the way that the distinction between adults and children

is made. One way in which we may better understand what is distinct about children is to examine the differences between children and others who are incompetent.

2.5 CHILDREN CONTRASTED WITH ADULT INCOMPETENTS

If a limit is set in whichever way to separate adult from child, some older people (conventionally adults) will fall on the unable (child) side of the barrier (and some children on the adult side of the divide). Should these adults then be treated as children? One way to consider what is special about children is to examine the differences between incompetent children and incompetent adults. Buchanan and Brock stated, but did not expand on, the claim: “It is worth emphasizing that incompetence due to developmental immaturity, as in the case of a child, is in many respects quite different from the increasing incompetence due to a degenerative disease such as Alzheimer’s” [Buchanan and Brock, 1990: 39] There are several important differences between incompetent children and incompetent adults that may have provoked their claim.

Decisional Authority

Firstly, a difference between incompetent children and adults is that incompetent adults were once competent, whereas children have never been competent. For adults, decisions can be based on the settled choices of the competent adult that they were before they became incompetent. The choice that the incompetent adult would have made can be indicated by the choices they made, the values they expressed and the way they lived their life⁶¹. The approach for incompetent adults relies on a selection of techniques: an advance directive; decisions made by people who have been appointed to choose in the way that the once-competent adult would have chosen⁶²; or evidence supplied by friends, family and colleagues of the once-competent adults' preferences⁶³.

⁶¹ This approach depends on the persistence of personal identity from the ‘original’ person to the now incompetent person. The incompetent person may have no memories of their past and some deny the persistence of personal identity. The persistence of personal identity is broadly accepted, certainly in law (by the existence of advance directives) and is summed up by the claim ‘...it’s what she would have wanted’.

⁶² Though there is evidence that the decisions made for incompetent adults by proxies are often different from the decision that the patient would have made. “Patient-designated and next-of-kin surrogates incorrectly predict patients’ end-of-life treatment preferences in one third of cases” [Shalowitz, 2006: 493].

⁶³ This is explored by Buchanan & Brock, 1990 in Chapter 3.

Obviously, this approach is not applicable to children who have never been competent. There seem to be three ways in which medical decisions for incompetent children could be justified. Firstly, decisions could be based on the consent of the competent person that the child will become, secondly parents should make medical decisions for their child, as they make all other decisions (parental authority) and thirdly decisions could be based on what would be best for the child, what would be in the child's interests.

Firstly, in prioritising autonomy, but recognising that a child is not competent, decisions can be justified by the choices that the child would make when she becomes competent in the future. The idea here is of a future 'retroactive consent' [Brennan and Noggle, 1997] sometimes phrased as a 'hypothetical' consent. Kraut asks if "...the mother should do for her child only those good things that the child *would* consent to if he were able to..." but answers "...that suggestion is equally absurd. We have no idea what a baby would consent to." [Kraut, 2009: 234]. And even for older (but not competent) children, although parents must have regard to the views, opinions and wishes of the child, someone other than the child makes the decision for the child. The child's views are one component in the decision-making process, which are given more or less weight by the person who chooses. Importantly, even if the child, when competent, comes to agree that the choice that was made was the correct one it is not consent in the same way as an adult consents. The consent that the older child gives is altered by the actions that the child is retrospectively consenting to. This solution is not consent, and is perhaps incoherent. Either way this approach is problematic.

Second, (and more prominently in the past) parents have authority over their children, parents make decisions for their children. These decisions need have no regard for the child's welfare, the decisions are justified because parents have authority over their children⁶⁴. The basis and justification of parental authority is disputed, but the more plausible approaches base parental authority in the child's interests. So, in an approach that he traces back to Locke, David Archard argues for conceding "...a certain power or authority to parents, that they may bring up children in the way they think appropriate. It further seems plausible to believe that this power is closely related to an obligation on the parent's part to care for their children and rear them to the point when they can act and decide for themselves." [Archard, 2004: 10]. And this is

⁶⁴ This approach is exemplified by the ancient doctrine of *pater familias*.

phrased even more strongly by Brighouse and Swift “Parents’ rights are considerably more limited than is commonly believed and are conditional on parents meeting children’s interests...” [Brighouse and Swift, 201: 26]. If this is true, then the second way in which decisions should be made for children becomes similar to the third, that decisions should be based on the child’s welfare. As Archard describes, parents have some freedom to choose the way that a child is brought up, but parental choices are limited by the well-being of the child.

The third approach, that decisions must be made in the child's interests or welfare, has become more prominent. However, this approach demands a robust or objective conception of well-being. The conception of well-being that can be used for adult incompetents, allowing the “...past and present wishes and feelings of the person...” [paragraph 32 Mental Capacity Act Notes 2005] to determine the person’s interests will not serve for children. Given this, there are particular challenges in determining a child's well-being, which are absent when an adult’s well-being is determined.

The problem of decisional authority indicates that the basis of medical decisions for children are different from those that must be made for the vast majority of adult incompetents. Only those adults who have never been competent pose the same sort of problems that children do.

Opposite Ends of Life

A second difference between incompetent adults and children is that children and the elderly are at opposite ends of their lives. The child grows towards the important part of their life, towards moral personhood, and towards their life’s goals and achievements. The adult incompetent (if the incompetence is sustained, as the vast majority are) falls away from personhood and moral agency leaving behind the best parts of their life. In progressive dementia, the adult will never recover the abilities that underlie competence to make their own decisions.

This means that decisions that are made for an incompetent child are more important than those made for adults with progressive dementia, because the child will become an individual of the highest moral standing, a person, but the incompetent adult will not regain their personhood. The incompetent adult is progressively and irreversibly deteriorating. For this reason, decisions for children assume more significance than decisions for adult incompetents.

Compounding this, the way that a child is treated affects the person the child becomes. Because this is so, decisions that are made for children are even more important than the decisions that are made for adults. An example of this is given by Jeanette Winterson in her autobiography *Why be Happy When You Could be Normal?* She describes her unusual adoptive mother and childhood, reflecting on the fact that had she not been adopted (had she stayed with her birth mother) although life would have been more comfortable, she would have become a different person and “Yet I would rather be this me - the me that I have become - than the me that I might have become without books, without education, and without all the things that happened to me along the way” [Winterson, 2012: 227]. Had she stayed with her adoptive mother she would have become a ‘different me’. Children are not ‘freeze-dried’ versions of the adult that they will become when subject to appropriate care. Feinberg suggests otherwise in *the Right to an Open Future* “Right from the beginning the newborn infant has a kind of rudimentary character consisting of temporal proclivities and a genetically fixed potential for the acquisition of various talents and skills. The standard sort of loving upbringing and a human social environment in the earliest years will be like water added to dehydrated food, filling it out and actualizing its stored-in tendencies... [Feinberg, 1980: 148]. However Feinberg’s claim is wrong: a child’s course through life is determined by their upbringing understood in its widest sense⁶⁵. The way that children are brought up has important effects on the adult the child becomes.

Both of these then are reasons why decisions that are made for incompetent children are more important than similar decisions made for incompetent adults. Children’s interests are important because they will develop the highest moral status and the way that a child is brought up determines, to at least some extent, the adult the child becomes.

⁶⁵ That children’s development is importantly affected by their circumstances is demonstrated at many levels. The Barker Hypothesis - or foetal programming hypothesis - that the fetus’ environment affects the later development of adult chronic diseases [Delisle, 2002] is broadly accepted to be true. Epigenetics gives a mechanism through which the effects of the Barker Hypothesis are produced [Cutfield et al, 2007]. Brighouse and Swift review the widely different levels of the ‘standard sort of loving care’ that may be given, arguing (amongst other claims) that there should be limits to the way that parents are allowed to benefit their children [Brighouse and Swift, 2014]. Their argument is predicated on the fact that children’s upbringing will have important effects on children’s outcomes.

Despite these reasons, vastly more academic ethics work addresses approaches to incompetent adults than incompetent children⁶⁶. There may be a variety of reasons for this, perhaps the need to make decisions for incompetent children has always been with us whereas the problem of the elderly incompetent is a more recent problem. Certainly, the number of adults with dementia is dramatically increasing both in absolute number and as a proportion of society, and this may have concentrated attention on the problem of adult incompetents.

A further reason why a justification of decisions for incompetent children has been ignored may be that as it is natural that young children are incompetent so it is taken to be *natural* that parents should make decisions for children. Medical decisions for adult incompetents may be taken to be a more recent and unnatural problem demanding a solution. The perceived naturalness of parental authority does not mean that parental authority is the correct approach, nor is it a reason to leave parental authority unexamined. That something is natural need not mean that it is good or correct as Mill argued [Mill 1874]. Much of modern medical practice is ‘unnatural’.

I argued that the problem of decisional authority means that a child’s interests are an important factor when decisions are made for children, but the particular problems that children present mean that decisions based on the interests of children are different to and more challenging and important than those for incompetent adults.

Parents

A further way in which children are different from adult incompetents lies in their relationship with their parents, in particular, and the intimate family more generally.

⁶⁶ Buchanan and Brock’s seminal work *Deciding for Others*, 1990 is an example. In Buchanan and Brock’s work, of 369 pages (386 pages including appendices) only 53 pages (14%) address children. The opening chapters develop a theory of decision making for incompetents, and so this may be an unfair comparison. However, as their theory depends on the balance of autonomy and wellbeing, and children are not autonomous this is a fair reflection of the attention children get. In the ‘applications’ section of the book only 31% of the pages are applications of their theory to children. I have argued that children deserve more attention than this. And children are ignored to a greater extent than this demonstrates because the approach to incompetents is only one part of the medical ethics literature for adults.

This is much stronger in many different ways than is an incompetent adult's relationship with those who care for her.

Because of a child's dependency, young children *have* to live in a relationship with those who care for them. Children are almost⁶⁷ defined by the relationship that they have with their parents. As children develop and become more mature they achieve a stage where they could survive independently, but will fare better in a relationship with their parents, who can guide and protect them. As children mature, their parents are best placed (because they know their child best) to decide when children have sufficient practical reasoning to become independent. More able children are allowed to make their own decisions as their parents recognise the developing abilities of their children, but even so the child's decision may be overridden. A child's decision may be overridden for reasons unrelated to the competence of the child, it may be because of the parent's obligations to other children or commitments parents have made themselves⁶⁸. These are the practicalities of living with others in an intimate relationship with competing demands. Adults are different because they can choose for themselves the ways in which their wants and interests are compromised by the wants and interests of others in the intimate family including the extreme option that an adult can divorce or leave an uncaring partner, children cannot dissolve the relationship with

⁶⁷ Almost, because not all children have parents who rear them. A child's parents may be absent, have abandoned their child, or have died. In these cases, usually the state, sometimes other relatives, will adopt responsibility for the child, and so another adult or other adults adopt the responsibilities of parent, they become the child's 'social' or 'rearing' parents. In institutions children may be reared almost by committee which is less often successful than when children are reared by stand in parents following adoption or fostering.

⁶⁸ And in the medical context, practicalities sometimes override the way that children should be treated. Sometimes children refuse treatment that their parents have consented to, and would be in the child's best interests, but it is not possible to negotiate an acceptable (to the child) way in which treatment would be delivered. Some treatments can be delivered regardless of the child's dissent (for example a brief intervention like tetanus vaccination). But, some medical treatments cannot be delivered without the child's cooperation, examples of these would be dialysis (requiring that child is connected to a dialysis machine for several hours three times a week or more) or transplantation which demands a lifelong complex immunosuppressive regime which needs a child's cooperation. In these cases attempts at treatment may produce worse outcomes (following complications or failure of treatment, or from the distress caused to the child – or staff) than allowing the disease to follow its natural course. These sorts of situations fall out of the usual approaches to ethics, those based on the consent of autonomous patients and the welfare of those who are not competent. Here an incompetent patient refuses treatment that cannot practically be delivered. And although this may cause distress to her relatives and the clinical staff, in some cases the pragmatics of the situation are decisive.

their parents until they are grown themselves. In contrast to adults, parents, must choose for children and how much attention to pay to the child's concerns.

Young children interact with society through their parents. In some ways young children are almost 'provisional' members of society. There is a gradual relinquishing of the parental role as a child becomes more able, but if the child does not develop in normal ways, the parental role will be continued. Alderson describes an example in a book named *Young Children's Rights*:

“...parents were invited to sign home-school agreements promising regular and punctual attendance, good discipline and behaviour and homework...” but objects to this arguing “These do not allow for children's reasonable reactions to things they are unhappy about at school, and are the opposite of real contracts which are specific agreements between equal informed and unpressured people or groups...What is not clear is the point of parents making promises, such as those about their child's future behaviour, if the child is seen as unable to understand the promise” [Alderson, 2008: 159].

The example is taken from the section named 'methods and levels of involving young children', so I take this to be children of primary or nursery school age. Alderson's example demonstrates how children are treated, and she argues for the way that she believes that they should be treated. A young child may not understand what it is to promise (or to contract, which seems to be what is described) and so could not rightly be criticised if they failed to honour a promise in the way that an adult could be criticised. Because of this, the promise is made by the parents alongside, and on behalf of, the child. The parents *and* the child are then responsible together for honouring the promise. But more than this, the child is learning what it is to promise: the parents are responsible for educating the child in promising. As the child matures the balance of responsibility changes. When a child is very young, the commitments of promising lie with the parents, even though the child is part of the promising process. But as the child becomes older the parents' role becomes less important. Parents may have a supervisory role, reminding the child of their promise, even when the child would prefer to forget, or the parents may be important in fulfilling the promise (perhaps taking the child to wherever he needs to be). Parents can even override a promise made by a young child if a parent takes it that the promise was unfair or coerced in some way. This situation changes as the child matures and has come to learn what promising means, and then parents cannot (or should not) override the promises of

their adult offspring. This example demonstrates the way that children interact with others partly through their parents, not just as individuals. Anderson misunderstands this. The position that she argues for is that children should be the equivalent of adults, not, as they are, as children who are developing into adults who can be promise keepers. Her criticisms would be reasonable if they were directed at home-school agreements for sixth formers, but not for young children.

Parents have much greater authority over their children than would the carer of an incompetent adult “...parents are now typically and uncontroversially accorded substantial, although of course not unlimited, rights to positively shape their children through non-genetic means in the course of childrearing. They can determine to varying degrees what schools their children attend, what activities they pursue, who their friends will be, what talents they develop, and so forth.” [Brock, 2005: 381]. The powers given to the carers of incompetent adults are tightly limited⁶⁹.

A further difference between children and incompetent adults is the parents’ strong interest in their children’s well-being, it is an important concern of most parents. For many parents their child’s well-being is an important component of the parents well-being and parents may invest enormous amounts of resources, time and energy in ensuring that their child progresses as best they may. Although carers of incompetent adults will have concern for their charge’s well-being their concern is less than the concern that a parent invests in a child’s well-being. One way in which this is demonstrated is the way that adult incompetents are often ‘farmed out’ to be cared for in nursing homes, in a way that is rarely considered for children (and then only if the child has special needs which cannot be met in the home). There may be practical reasons why incompetent adults are far more likely to be cared for in institutions than are children⁷⁰. But even with these pragmatic reasons, the concern that parents have

⁶⁹ An example is found in the Mental Capacity Act, which creates the position of a deputy (who has the authority to make decisions for an adult who lack capacity). Amongst the limitations on the powers of the deputy is that they may not “...prohibit a named person from having contact with P” [section 20 Mental Capacity Act 2005]. Parents may uncontroversially choose who their children (or at least their younger children) are friends with.

⁷⁰ The practicalities may include factors such as there may be no space for an adult in the family home; there may have been no time for preparation for care for the adult incompetent, whereas child birth is often planned; the demands of child care have a clear end as the child

for their immature children's interests is enormously different from the concern that the carers of incompetent adults' will have for their interests.

For all these reasons, an important difference between incompetent adults is the position of the child's parents in the child's life and medical decisions that may need to be made for children.

2.6 CONCLUSIONS

I have stipulated that the way that I will understand children in this thesis is as immature humans of all stages. I have argued that the important distinction in medical ethics between adults and children is that a parent, alongside other adults, makes decisions for children, or at the least has oversight over the decisions that children make. That children are different from adults is an important distinction in medical ethics, but the weight placed on the distinction contrasts with the weak justification for the distinction. There is at the least confusion, and most likely disagreement, over the way that older children on the verge of maturity should be treated. This is less important in considering how medical decisions should be made for unquestionably incompetent children, but will be needed for a full answer to the question of how medical decisions should be made for children.

Children are different from incompetent adults in many different ways, and in particular in the importance of the choices that must be made for children and also in the position that parents have in the lives of incompetent children. It is important to recognise these factors and so avoid a flat or too thin depiction of the ethics of medical decisions for children.

grows and develops whereas there is no anticipated end to the needs for care of an incompetent adult; an incompetent adult may need 24 hours of care whereas young children can be relied on to sleep for reasonable periods allowing the carers some respite; young children are small so one person can lift and care for them easily whereas adults may need 2 or 3 people to lift and care for them.

CHAPTER 3: RIGHTS

3.1 INTRODUCTION

Moral claims are often (and increasingly often) phrased as rights-based claims. Following this trend, claims are made for children's rights and rights are often invoked when dealing with children. In this chapter, I will briefly discuss different conceptions of rights and examine the history of human rights. Following that, I review the justifications offered for rights. I argue against some of the ways in which children are claimed to be rights holders (the potentiality argument and Liao's genetic argument). I then argue that even if there was a justification for children's rights, rights are unhelpful in considering how children should be treated by those who care for them, and that specifically a rights-based analysis does not help when there are contentious medical decisions to be made. After that I consider whether claims for family rights are sustainable, arguing that they are not. I conclude that a rights-based approach is unjustified and unhelpful when making medical decisions for young children.

3.2 A BRIEF DESCRIPTION OF RIGHTS

To make sense of children's rights it is important to describe clearly what is meant by rights, both generally and in particular for children. Firstly, some rights are legal rights (sometimes called positive rights). A legal right is stated in case law or in statute law or is based on the ratification of conventions such as the United Nation declarations and is the subject of legal argument and legal resolution. It is clear that children have legal rights in many jurisdictions [see, for example, Bainham, 2005: 97-125].

Legal rights are contrasted with human rights⁷¹. If the only rights that existed were legal rights, then the citizen of a country where the law does not permit free speech

⁷¹ I will use the term human rights through this chapter, as this is the most commonly used term, but they are also called philosophical, natural or moral rights. Naming them philosophical or moral rights recognises that it is possible that aliens, or sufficiently advanced artificial intelligence machines could be rights holders. Naming them 'human' rights, as they often are, is problematic if (as I argue) young children do not have these rights. Others have taken this approach. Liao claims "...children have a right to be loved...this right can be grounded as a human right..." [p440 Liao, 2006: 440] but denies that adults have this 'human' in saying "Given this, there may not be any general rights of adults to be loved." [Liao, 2006: 426].

could not make the claim ‘I have a right to free speech’. Or, in the absence of human rights, the claim is nonsense: there is (in that country) no *legal* right. The claim for a right to free speech depends on a claim for human rights that exist independently of legal rights. However, although human rights are often asserted, the basis of human rights is clouded in dispute. Some deny that human rights exist, most famously Bentham who wrote: “...right with me is the child of the law... a natural right is a son that never had a father” [Bentham quoted by Waldron, 1984: 4]. Bentham also famously described natural rights as “...simple nonsense: natural and imprescriptible rights rhetorical nonsense, - nonsense upon stilts” [Bentham, 1843: 914]. Another example is given by Russell in writing of his mother who “...shocked the ‘sixties by addressing meetings in favour of equality for women. She refused to use the phrase ‘women’s rights,’ because as a good utilitarian she rejected the doctrine of natural rights.” [Russell, 2003: 402]. Others assert that human rights exist, the preamble to the United Nations Declaration of Human Rights bases human rights on the dignity of man “...reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women...” [United Nations, 1948]. A more reasoned justification bases human rights on the conditions needed for an individual to be a person (Griffin, 2008). As a consequence of the disputed basis of human rights, so too is the content of human rights.

Some legal rights are grounded in human rights, others are not and there is not, nor need there be, a relation between legal rights and human rights. I will use the declarations and conventions of rights (which may have received legal recognition) as examples of human rights. When human rights cases are used, I use the law as an example to demonstrate the way that the law, and society more broadly, approaches rights and children’s rights.

Another distinction lies in the strength that rights are taken to have. Waldron characterises the strengths of rights in three ways [Waldron, 1984: 14-18]. Firstly, rights may designate that one interest amongst many is particularly important, one that deserves a greater weight than other interests, when interests are considered. Secondly, rights may designate interests that have lexical priority over other interests (rights are ‘trumps’). The third, most demanding strength, is that rights are absolute constraints on what may be done. When rights are conceptualised in this sense, it is never morally

permissible to override a right⁷². In this conception, there are certain ways to treat a person which are just prohibited (or demanded) by rights. The different strengths of rights require different justifications and provoke different problems. For example, the weaker forms of rights are more easily understood and justified. The rules of rule-utilitarianism may be taken to generate a form of rights, but the rights are not fundamental, their origin is justified by the consequentialist's calculation. The strongest form of rights provokes several problems. Firstly, why is one constraint a right but another just a matter of etiquette or social convention? When rights are fundamental, the justification for an individual right is often unclear. A further puzzle of stronger versions of rights is the constraint that a person must not violate a right, even though if a rights violation were permitted, overall there would be fewer rights violations. How can this be justified? I will not attempt to answer these questions here, the reason for introducing the questions is to argue that although rights have become an important political tool, there are several different senses to rights and importantly many questions about rights remain disputed.

There have been an increasing number of rights, declarations and conventions of rights and rights-based claims since 1948 when the United nation's Declaration was promulgated, though the notion of rights has a much longer history extending certainly to the middle ages, but it is likely to be true that the conception of a right has evolved through time [Chapter 1 Griffin, 2008; Wenar, 2012]. One claim is that the recent enthusiasm for rights was a result of the atrocities of the Second World War [Griffin, 2008].

In the human rights tradition, the demand is that all humans are equally deserving of respect and that all humans should be treated (or sometimes never be treated) in

⁷² Clearly described by Dostoevsky's challenge in *the Brothers Karamazov* "... imagine that you are charged with building the edifice of human destiny, the ultimate aim of which is to bring people happiness to give them peace and contentment at last, but that in order to achieve this it is essential and unavoidable to torture just one little speck of creation, that same little child beating her chest with her little fists, and imagine that this edifice, has to be erected on her unexpiated tears. Would you agree to be the architect under those conditions? Tell me honestly!" [Singer, 1994: 332]. And Nozick contrasts the strength of different conceptions of rights as "The side-constraint view forbids you to violate these moral constraints in the pursuit of your goals; whereas the view whose objective is to minimize the violation of these rights allows you to violate the rights (the constraints) in order to lessen their total violation within society" [Nozick, 1974: 31].

particular ways. The ways in which they must, and must not be treated, are the content of human rights. The strong claim that human rights makes is that other humans (*all* humans) have inalienable rights (be they terrorists, or those convicted of child sexual offences, to choose some current bogeymen). Rights are particularly important when interactions between us (and those like us) and those perceived as *others* (for whatever reason) are considered. Out of this then comes the idea that we all (as individuals⁷³) have rights. Although rights are individual rights (rights for particular persons) they are often recognised where there is discrimination against a group (particular examples of this include race and gender). Even amongst those who are favourable towards rights, the claims that count as human rights are disputed. Griffin is positive about rights in general but objects to the inclusion of paid holidays: “The Universal Declaration of 1948...blunders at one point in asserting a right to periodic holidays with pay, which as I mentioned in the introduction, is widely rejected.” [Griffin, 2008: 16]. In the absence of a human right to paid employment, the existence of a right to holidays with pay is an inconsistent approach to human rights.

This brief description points to some ways in which children cause problems for rights. Firstly, children are not individuals. Young children generally are part of a family group. If rights protect individuals, then rights will not be the correct way to approach our treatment of children who must be nestled in a family to survive and flourish (and if children are not in a family group then others will try to recreate a family group by adoption).

Another problem is that children need to be cared for, needing more than just recognition that children are equally human with all others. If all that a child gets is acknowledgement that they are different, separate, an individual who should not be mistreated: that is not enough. In another way of stating it, children may have human rights, but if that is all that they have, then for young children this is nowhere near enough. Because children are different from adults, treating children as adults will not be enough (and treating adults as children will not be right either). This doesn't mean that children don't have rights, the claim is that it is unlikely that a generic 'human'

⁷³ A persistent criticism of rights from both the left and right is that rights are too individualistic [Waldron, 1984: 1-2].

right will work for all humans, both adults and children. These ‘human’ rights will either infantilise adults or allow children to be harmed. If this is true then several solutions are possible. We may agree (as I will argue) that some children do not have rights. Alternatively we may maintain the claim that there are human rights, but that children’s rights are a specific subgroup of human rights, or we may claim that children have rights but that these are different in some specified way from adult human rights and parallel to adult rights. Either way it is important to work out what it is that we mean when we talk of children’s rights, and what the content of children’s rights are, but this is rarely done when children’s rights are asserted.

However, notions and assertions of rights, and rights-based language dominate the current zeitgeist and as a natural extension, moral problems involving both children and animals⁷⁴ have been analysed in rights-based approaches: rights are a political reality. The UN’s Convention of rights for children is referred to widely [United Nations, 1989]. There is a journal named *the International Journal of Children’s Rights* amongst others. The mainstream argument has moved on from whether children have rights to a dispute over the content of children’s rights. Freeman argues that the concern of children’s rights advocates has moved from children’s ‘salvation’ (protection) to children’s ‘liberation’ [Freeman, 1983: 26]. Regardless of the enthusiastic adoption of rights, it is important to understand rights and to agree what is meant in claiming rights for children.

3.3 THE PHILOSOPHICAL JUSTIFICATION OF RIGHTS

There are two approaches to the justification of rights, the *will* (or choice or option) theory and the *interest* theory of rights [Kramer, Simmonds and Steiner 1998; Archard 2011]. The will theory claims that rights secure a person’s ability to choose between options, their agency. Rights protect a person’s autonomy, the ability to make significant decisions about the rights holder’s life. Rights holders are responsible for the consequences of their choices, they reap rewards and accept the penalties of the

⁷⁴ “It [Switzerland] recently changed its constitution...and made a law last year establishing rights for creatures such as goldfish and canaries. Pigs, budgies and other social creatures cannot be kept alone; horses and cows must be regularly exercised outside their stalls and dog owners are required to take a training course to learn how to properly care for their pets...If citizens had voted for the initiative, each canton would have appointed a lawyer to act on behalf of animals at taxpayers' expense.” [Williams, 2010].

decisions that they make. This may or may not be a correct justification for adults (who can choose in a way that makes sense to call choosing: they can understand available information and choose – however imperfectly – between options). But as young children cannot make choices, and the choices of older children may legitimately be overridden, this justification does not work for children. An adult's right allows them to choose which of two or more options to pursue. And with that choice comes responsibility. Young, incompetent children cannot choose in any meaningful sense. An infant, who cannot talk, cannot meaningfully choose whether or not to have measles vaccine, or even what time to go to bed. The claim that rights protect a child's will or choices is wrong for young children and the way that it could be instantiated for older children (whose decisions may be overridden) is unclear. The alternative justification for rights, the interest theory, suggests that rights protect an individual's significant interests. Some of an individual's interests are very important to being a person (in the philosophical sense of person), and unless the person's interests are protected, they will not be a human person, living the sort of fulfilling life that a person should. It is these sorts of interests that are protected by rights, the core interests needed to be truly human. The sorts of interests that individuals may choose, that are particular to an individual, may not be protected by rights. As such the rights-protected interests include the right to life, the right to free expression, and so on.

The will theory of rights has the appeal that protecting choice protects agency and autonomy, the important features that define the beings who are rights holders, usually taken to be the group that is of the highest moral standing. However some features of rights sit poorly with the will theory. For example, rights forbid some choices: one cannot sell one's own organs for donation [Wilkinson S, 2012], nor can people sell themselves into slavery. In these examples, rights prevent choice, they do not protect choice. That rights protect a person's important interests seems a better explanation of the role of rights in these cases.

Children are a test case between the two justifications of rights. Young children cannot choose in a meaningful sense and parents may override an older child's choices. If so a child's rights cannot be justified by the fact that rights protect the child's choices, a child's rights must protect their interests. Therefore, the will theory cannot justify rights for children. However from here the argument can go two ways. Firstly a

response can be that because children *have* rights the will theory cannot be the correct justification for rights and so the will theory must be dismissed. And so, *because* children have rights, the interest theory must be the correct justification for rights (assuming we only have these two potential justifications). The second response is to insist that the will theory is correct, acknowledge that children's rights are not justified by the will theory, and accept that young children do not have rights.

This may be too quick. Some separate rights into two sorts: welfare rights and agency rights, with different underlying justifications. Welfare rights (the right to health, education and so on) are justified by an appeal to interests. Agency rights (to free speech, to vote and so on) are justified by protection of choice. If this is so, children's welfare rights may be protected by an appeal to their interests (as may adult's welfare rights). Adults may have other rights too: their agency rights. Here however, the move is away from 'human' rights but to particular rights for particular groups, undermining universalism, one of the strongest appeals of rights.

A further way in which the will theory may justify children's rights is by recognising that children may have proxies (their parents) to make the choices and exercise the child's rights on the child's behalf: "...children still have rights but the choices, which are constitutive of these rights according to the will theory, are made by representatives of the children." [Archard, 2011]. The claim is that children have agency rights, but that others hold and exercise these rights for the children. Feinberg describes one particular group of children's rights as "rights-in-trust". These are rights that "...are to be *saved* for the child until he is an adult, but which can be violated 'in advance', so to speak, before the child is even in a position to exercise them...His right while he is still a child is to have these key options kept open until he is a fully formed, self-determining adult capable of deciding among them." [Feinberg, 1980: 126]. However, the appeal to proxies for children is a marked difference from the way that rights are usually understood. An adult would not recognise that they had a right, if they were not allowed to exercise the right and furthermore the right could be exercised by another with the adult's active dissent.

The arguments for and against the will and interest theories on the basis of the claim for children's rights are not decisive, but it is clear that children present particular problems when claims are made for children's rights.

Recognising that children's and adults' rights are different brings another question. What is the relation between human rights and children's rights? Do children (because they are human) claim the full list of human rights no more and no less? The preamble to the Declaration on Human Rights states "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of..." and the first Article states "All human beings are born free and equal in dignity and rights" [United Nations 1948]. The Declaration makes the strong claim that *all* humans, and so children too as human children, have equal rights, and this claim is reinforced by the note that all humans are *born* equal, indicating that the rights are considered equal from birth. At least in the proclamations, there is no gradation between humans: it is not true that rights differ as a consequence of age. However, this is no more than the language of rhetoric. Some rights may be common to adults and children, but it is clear from the content of the Declaration's and the Convention's rights that children's rights are different, and should be different. What is less clear is what distinguishes adult from child and what the justification for the different content of rights might be.

Some rights may be common to both children and adults – for example the right to life⁷⁵. Other rights may be particular to adults or children. Human rights include the right to free choice of religion. In the Declaration (of human rights), Article 14, the adult's right is phrased as "Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his

⁷⁵ Article 3 of the Declaration states "Everyone has the right to life, liberty and security of person" [United Nations, 1948] which is analogous to Article 6 of the Convention "...every child has the inherent right to life. States Parties shall ensure to the maximum extent possible the survival and development of the child" [United Nations, 1989]. Another example, Article 5 of the Declaration states "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment" [United Nations, 1948] is the same as the start of Article 37 of the Convention "No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment" [United Nations, 1989].

religion or belief in teaching, practice, worship and observance” [United Nations, 1948], but in the Convention (of children’s rights), the child’s right is curtailed by parental authority. Article 14 reads “States Parties shall respect the right of the child to freedom of thought, conscience and religion...shall respect the rights and duties of the parents...to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.”[United Nations, 1989]⁷⁶ The child’s right is not the same as the adult’s *human* right. As a further example of the differences between adult and children’s rights, in Article 28 of the Convention a child’s rights include the right to education “States Parties recognize the right of the child to education...Make primary education compulsory...” [United Nations 1989]. But this is a right to education understood as an obligation or a requirement to be educated. The right to education does not allow the child to waive the right. Furthermore, the education is (by a parental right) not necessarily chosen by the child, nor in the children’s interests as “Parents have a prior right to choose the kind of education that shall be given to their children” [United Nations, 1948: Article 26]. Children may be treated in ways that would infringe an adult’s rights. Another example can be found in a claimed right to be loved, which may be held by children, but not by adults⁷⁷.

My arguments in this section have demonstrated that although rights-based claims are made prominently and often, the justification for rights in general and children’s in particular are unclear and contentious. It is likely that rights-based approaches will be less useful in the absence of a clear basis and justification for children’s rights.

3.4 DO YOUNG CHILDREN HAVE RIGHTS?

Some sorts of beings have rights (paradigmatically adult humans) and some do not (paradigmatically a fly). The line separating rights holders from non-rights holders is disputed. For example, there is vocal [PETA] and reasoned [Regan 1983] support for

⁷⁶ It is easy to see how the child’s rights and the parents’ rights can come into conflict unless the limitations and scope of the rights are clearly stated, which they are not.

⁷⁷ Liao argues that children have a right to be loved, and that this is a ‘human’ right, but that adults do not have a right to be loved. “...a reason why children have a right to be loved, because being loved is, as we have said, a primary essential condition for children to have a good life...there may not be any general rights of adults to be loved.” [Liao, 2006: 423-4].

animal's rights, but animal rights are rejected by many and that animals are not rights holders is broadly demonstrated by the way that animals are treated (or if animals do have rights, then the way that animals are treated indicates that 'rights' must be understood in a different way from the usual way that rights are understood).

Furthermore, the distinction between rights holders and those who did not hold rights was different in the past. There are many examples of this including the exclusion of women and other races from the ranks of rights holders. What separates rights holders from non-rights holders?

Several different responses have been made to this question. I will dismiss one group of responses immediately. This group includes versions of a religious response, and is based on the claim that men are different because men are made in the image of God, or men are different because the Lord made man to "...rule over the fish of the sea and the birds of the air, over the livestock, over all the earth, and over all the creatures that move along the ground." [Genesis 1:26]. A variant is that God ensouls man at birth (or fertilization, or quickening or some other stage) and that this is why man is different from all other creatures. This justification is available only to those who believe in God and often only to those who believe in one particular God, and will not work as a more general justification to those who do not (and will not work as a justification for those whose god is Darwin and see the common underpinnings of molecular biology as a clear indication that humans are different only in degree from other animals).

The approaches that are more likely to be successful concentrate on the differences between the most accepted group of rights holders - adult humans - and those that are not taken to have rights. There are many and varied claims for the significant difference between rights holders and those that don't have rights, amongst them that men have freewill and with that the ability to reflect and interpret choices in the light of what the person believes to be right (going beyond merely doing the correct action to achieve a goal – instrumentally). Another justification is that adult humans are rational. Or the claim may be made that men have moral agency and can be held to account for their choices and blamed or praised. Kant claims that humans are rational members of a Kingdom of Ends and so are distinct from those who may be used merely as means, develops a similar theme in separating adult humans from all others. In these various ways, rights holders are clearly distinguished from non-rights holders.

These distinctions have an overlap with the characteristics that distinguish adults from children, which were discussed in the previous chapter.

Whatever distinguishing feature is chosen, the puzzle that follows is that not all human beings will have that skill or attribute. Young children and people with severe brain injury will lack whatever is recognised to be the distinguishing feature of human rights holders. Rights may be granted to adult humans because they have moral agency (for example), but newborn babies do not have moral agency and so do not have rights if moral agency is the justification to be a rights holder. And if the criteria needed to be a rights holder are relaxed so that young children and babies are included, then the criteria will admit many animals as rights holders, the sorts of beings that have not been taken to be rights holders. For example the abilities of mature monkeys may be the equal of, or exceed younger children⁷⁸. On all the grounds that have been proposed to distinguish rights holders, many mature animals have greater abilities than many young children. And so if there is consistency, the animal, but not the young human child, deserves the status of rights holder. This failing is common to all justificatory arguments for human rights that are based on the abilities, or functioning of rights holders.

Two claims together cause difficulty. Firstly, that all humans and only humans have rights. And secondly, that rights holders have rights because rights holders have abilities or can function in ways that those who do not have rights cannot. These claims together fail because young children and neurologically damaged older children and adults have abilities that are surpassed by many animals. Not all humans have whatever is taken to discriminate rights bearers from those who do not have rights.

⁷⁸ As an example "...the chimpanzee was toilet trained, could dress himself, brush his own teeth, took his own bath and 'ate at the table and drank wine from a stemmed glass'. He could also log on to the computer and look at pictures, and used the remote control to watch television. 'He's been raised almost like a child by this family,' Captain Conklin said. 'He rides in a car every day, he opens doors, he's a unique animal in that aspect.' " [Tredmanson, 2009]. Another example is Washoe the chimpanzee who was taught sign language, living with American psychological researchers. Young children and some others, whose medical condition determines that their lives will be short or their brain development limited will never achieve the reasoning, independence and agency that such chimpanzees demonstrate.

There are several responses to this puzzle. One is to recognize that rights holders are a special class of being and accept that young children do not have rights. Griffin takes this view, "...I am inclined to conclude that human rights should not be extended to infants..." [Griffin, 2008: 95]⁷⁹ though he argues that older children – with agency – have rights. Others reject this position, for example "To exempt children from human rights is to designate them as less than human." [McGillivray, 1994: 256]. This misunderstands what is at stake. Young babies are human, but they do not have (human) rights. Griffin's response retains the elite position of rights holders, which is needed if rights claims are to retain their meaning.

A second response is to reduce the criteria to be a rights-holder to a sufficiently low level and so include all children, babies and neurologically injured humans (however severe). Even if this were to happen, there would still need to be a clear standard justifying the distinction between rights holders and those who do not have rights. And if the bar is lowered so that all children meet the standard including many beings who were not previously rights holders, this would fundamentally alter what it is to be a rights-holder. Rights-based claims are powerful claims because rights-holders are special beings (in a morally-relevant sense). If rights are granted to different sorts of beings, then in broadening the class of rights-holders, rights become less powerful claims. What it is to have a right will change. Furthermore, because many animals will now be rights holders, the way that we treat those animals will likely have to change. For all these reasons, to lower the criteria is the wrong response, expanding the ranks of rights holders to this extent would require a fundamental reappraisal of what rights are.

Several further arguments then make the claim that children have rights, accepting that they do meet the criteria set to be rights holders because particular reasons apply to children. I will consider three of these arguments, the potentiality argument, the argument from the fact that human children are members of the species *Homo sapiens* and thirdly Liao's genetic argument.

⁷⁹ As have others "Most liberals have made at least one exception. Children, especially when they are very young, do not have rights to control over their own lives" [Brighouse and Swift 2006: 80].

The Potentiality Argument

The claim here is that although the child as she is *now* fails to meet the standard to be a rights holder, the child has the capacity to, and will naturally develop to, become a rights holder [John Harris, 1985:11]. For this reason, although the child doesn't yet qualify as a rights holder, children should be treated as if they were rights holders, and certainly differently from those beings that will never be rights holders.

One problem with the potentiality argument is that it claims too much. Because human fetuses have the potential to develop into rights holders, the potentiality argument should also grant rights to the human fetus. To grant that a fetus is a rights holder is wrong, for many reasons. The human fetus is so far from the criteria that are needed to be a rights holder that it is wrong to treat a fetus as if it were a rights holder (nor are they treated as if they are rights holders - they have no right to life). Another concern is that the limits to the potentiality argument are unclear. How far back does the potentiality argument go, should fertilized eggs in an IVF clinic be treated as if they were potential rights holders? An unfertilised egg has the potential to become a rights bearer once fertilised. Does the potentiality argument apply here too? Perhaps as the unfertilized egg will not develop into a particular individual (it requires fertilisation with sperm to become a potential individual) this is where the potentiality argument stops. There is no individual on whose behalf claims to be a potential rights holder can be made. But if this is the limit to the potentiality argument, as somatic cells have been successfully cloned, does a somatic cell (with complete genome) then have the potential to become a rights-holder after cloning? I will not try to resolve these questions, they are to demonstrate some of the failings of the potentiality argument.

There is another way in which the limits to those who should be considered potential rights holders are unclear. Some beings can develop the capacities of rights holder, but only in an appropriate environment. A chimpanzee, if schooled intensively at an early age may develop the capacities that overlap with those of rights holders (as the animals described in footnote 78 are able to) but this depends on the circumstances. Do chimpanzees in the wild then have the potential to develop into rights holders? In one sense they have the potential to become rights holders (because in the right circumstances they can develop the attributes of rights holders. Washoe the

chimpanzee who learned to sign was caught from the wild) but in another sense they do not (because the right circumstances are extraordinarily unlikely to exist). There is no clear dividing line between those with the potential to become rights-holder and those without that potential.

Another problem is that although the potentiality argument offers the prospect of claiming rights for normal children, this does not extend to severely neurologically damaged infants, who will never develop neurologically, nor infants with lethal diseases who will die when young, as neither group have the potential to develop the criteria needed (whatever they are) to be a rights holder. Given this, the potentiality argument is successful in arguing for rights for only a proportion of human children.

The potentiality argument does not lead to the conclusion that we should treat those with the potential to develop into rights holders as rights holders. It notes that there is a difference between the beings that have the potential to become right holders and those that do not have this potential. And in describing potentiality, the argument underlines the difference between rights holders and those with the potential to become rights holders. This supports the conclusion that children have particular moral relevance, but does not entail the conclusion that they are rights holders. An acorn is not an oak tree, or as Harris argues “We will all inevitably die, but that is, I suppose, an inadequate reason for treating us now as if we were dead.” [Harris, 1985: 11].

Human Children Are Members of the Species *Homo sapiens*

A further response to the puzzle that infants do not have the abilities to be rights holders is to appeal to the idea that biologically we are all humans (members of the species *Homo sapiens*). Members of *Homo sapiens* are accorded rights because they are the only sort of being (so far) that can have moral agency or rational thought, whichever are taken to be the criteria of being a rights holder. As such all humans (however young or incapacitated) have right because they are members of the human species.

This is a scientific version of the religious argument dismissed above. Many different objections may be made to the species argument. Species are defined as groups of individuals that can breed one with another⁸⁰. Separation into species may be made in several different ways (the simplest being geographical separation across an impenetrable barrier such as a mountain range, or large expanse of water) but in whatever way that species are different one from another, the difference is a biological not a moral difference. The step that is missing is to explain why a biological difference entails a morally relevant difference in the way that members of different species should be treated. There need be no moral difference between the same sort of beings on opposite sides of an ocean (one way that speciation may occur).

Furthermore this response does not work for those who can feel the strength of Singer's speciesist objection [Singer 1993]. In brief, the argument is that we should treat beings in the way that they should be treated for morally justifiable reasons (in Singer's eyes, concerns for a being's interests). If humans are right holders and should be treated differently from other beings there should be good reasons for this. If humans are rights holders merely because they are human then we are discriminatory in favour of beings like us. If we treat creatures like *us* as rights holders, then where does the *us* end? Do we draw the lines around rights holders more tightly so that only Caucasians have rights (as happened in the past) or do we draw them more loosely so that all other mammals have rights too? Singer argues that in the future speciesism will come to be recognised to be as objectionable as racism or sexism is today. If animals, extra-terrestrials or machines meet the same criteria as humans, then it is wrong to treat humans preferentially as rights holders, excluding others who are not like us.

The Genetic Argument

There are many problems with the species argument and it should be rejected. However, recently Liao sketched out, and offered a brief defence of a related argument claiming "...all human beings are right holders because they all have the genetic basis

⁸⁰ A species is a "(biology) taxonomic group whose members can interbreed" [Princeton University]. More problematically for a theory of rights that depends on speciation "...we still do not all accept a common definition of what a species is." [Mallet, 1995: 294]. A problem with the definition of a species is demonstrated by the phenomenon of ring species, which are species that do not demonstrate transitivity of interbreeding.

for moral agency and it seems that having this genetic basis is sufficient for one to be a right holder...the genetic basis for moral agency is the set of physical codes that generate moral agency” [Liao, 2010: 164]. Having described that both rationality and empathy are needed for moral agency he argues “...if the capacity for moral agency did not have a genetic basis, then development of its essential component would not be so regular.” [ibid 164]. Liao claimed “...the genetic basis for moral agency...gives rise to a capacity and not a behavioural trait” [ibid 165] with two qualifications. Firstly, there may be many different ways that this genetic basis can be “sequenced or realized” not just one unique way that genes generate rights holders. Secondly the genes must be “activated and coordinating with each other in an appropriate way” [ibid 165]. It is not enough for the genes to be present but inactive or scrambled in some way in the genome.

Accepting this, Liao argues for the conclusion that as brain damaged humans have the genetic code underlying moral agency (their lack of moral agency results from the trauma, or stroke or whatever, not from underlying genetic problems) and so do normal children, both are rights holders. Furthermore many children who are neurologically damaged because of specific syndromes have a specific abnormality undermining only one aspect of metabolism or development. Although one component of their genome is abnormal, the rest of the genome (including the part which underpins the capacity for moral agency) is normal and so these children too are rights holders.

Liao gives further reasons to support the genetic basis for moral agency as sufficient for being a rights holder. Firstly, he notes that the approach accords with the intuition that all humans are rights holders. Secondly, he describes a genetic basis as an “...identifiable, actual, physical attribute” [ibid:168] and so avoids speciesism (or as he describes it, his argument fulfils the “Species Neutrality Requirement”).

Liao’s argument is wrong for a variety of reasons. Firstly, what matters in assigning rights to individuals is whether they have moral agency, or whichever criteria are thought appropriate to be a rights holder. It is not the more distant *capacity* for moral agency, nor the, still more distant, DNA sequence underlying the capacity for moral agency.

Secondly, there are enormous practical problems which rule out the likelihood of explaining the *capacity* for moral agency, not just moral agency, on the basis of DNA sequences. And this is compounded by the way that the capacity may be realisable in different ways as he recognises. Although geneticists have been remarkably successful in explaining much in a broad range of living beings, their understanding of the way that structural differences in DNA translate into differences in molecular biology within cells has been limited because of the remarkable complexity of the genome. The way in which the components at a molecular biological level interact to produce the phenotype of the whole organism is complex and is largely unresolved in humans apart from a limited number of single genes disorders (Liao notes the example of Phenylketonuria). For example, only a small amount of the human genome is transcribed into protein⁸¹ the function of the rest of the DNA is as yet unclear. The task that Liao sets - to determine the genetic basis underpinning the capacity for moral agency – will be extraordinarily difficult; at least in part because philosophers do not agree what is meant by moral agency, but also because of the difficulties of equating the capacity for moral agency to the function of the whole brain and then equating that to neuronal biochemical cell function and then relating that cell function to DNA sequences.⁸² The breeding experiments of genetic researchers involve fast reproducing species such as the fruit fly. To demonstrate the genetic causes of ‘moral agency’ requires the study of animals (presumably man) that demonstrate moral agency, and these have much longer generation times. This is regardless of the problems of experimenting on beings that have moral agency: man cannot be subject to the experimental approaches favoured by genetic researchers. For all these reasons, it is unlikely to be possible in the foreseeable future to demonstrate the DNA sequences underlying the ‘genetic basis of the capacity for moral agency’. This does not mean that Liao is wrong, just that, at least in the near future - if ever - his claim cannot be tested, and so is idle speculation.

⁸¹ “...analysis of the draft human genome sequence...by the International Human Genome Sequencing Consortium on February 15, 2001, the paper estimated only about 30,000 to 40,000 protein-coding genes, much lower than previous estimates of about 100,000... With about 30,000, the human gene count would be only one-third greater than that of the simple roundworm *C. elegans*” [Human Genome Project].

⁸² Reviews in the field describe the difficulties in determining the function of genes, noting “Proteins are simply cleverer than computers.” amongst other problems [Rubin, 201: 821].

However, Liao's approach is specifically unhelpful for my particular project (to determine whether children have rights) because from the start Liao assumes "...some merit to the belief that all human beings are rightholders." [Liao, 2010: 162] though he has already described the difficulties with ascribing rights (on some theories of rights) to "anencephalic children...comatose persons...and...newborn infants"[ibid 160-1]. Liao assumes the answer to my question. Furthermore, Liao then notes as a favourable feature of his theory that "this account practically supports the widely held intuition that all humans beings are rightholders" [ibid 168]. In making an assumption and then using the same initial assumption as evidence in favour of the theory, Liao demonstrates circular reasoning. For all these reasons, Liao's argument fails.

If a being does not fulfil the criteria to be a rights holder, then they do not have rights and treating a non-rights holder as a rights holder is wrong. It may be useful in recognising rights holders to have some more easily recognised feature, for example being human. But if human *children* are not rights holders, then we should acknowledge that distinction. In an analogy, having a British passport identifies individuals who can freely enter Britain without 'let or hindrance', but sometimes passports are forged, and if there is a ready way to recognise forged passports from those that are not, then we expect those with valid passports and those with forged passports to be treated differently. In the same way, we can recognise that children, although close to the kind of thing that has rights, do not themselves have rights.

It is time to return to the first response and accept that young children are not rights holders. Griffin argues (on the basis of the claim that personhood underpins rights) that young children are not rights holders, but he recognises that rights language does not exhaust morality. There can be very stringent requirements or demands on the way that we act towards children even though children themselves are not rights holders. Griffin argues that we must "...remind ourselves of the destructive modern tendency to turn all important moral matters into rights...recover our sense of the power of the rest of our moral vocabulary – for example the language of justice and fairness" [Griffin, 2008: 95].

It is important not to overstate the case. Some children will have some rights (and if children are defined as those under the age of 18 then, many children will have some rights and some children will have the full set of human rights). But some children will have no rights. This does not mean that we can treat children in any way that we choose: it just means that they are not rights holders.

Furthermore if the status of rights holder depends on a particular skill, capacity, or ability then if these capacities are gained at different stages or ages, it will be true that the individual rights are acquired at different stages. If this is true then there will not be a clear division between those who are rights holders and those who are not. There would be a tripartite division of those who hold no rights, those who hold some rights and those who hold all rights.

Children and Parent's Rights

A claim for children's rights is provoked by the claim that parents have rights. If parents have rights, and if these are rights over their children, then unless children have rights too, then in a rights-based analysis, there is nothing to counterbalance the weight of the parent's rights. In the absence of children's rights, parents would have absolute authority over their children. This seems intuitively wrong, as parents do not have absolute authority over their children. One response is that parent's rights are not rights over their children but rights to privacy within the intimate family, a freedom from scrutiny by those outside the family (though some will call these family rights). This right may be amongst parental rights, but parents are often taken to have rights of authority over their children (the right to make medical decisions for a child, the right to choose a child's education, the rights to choose a child's religion and so on) and indeed rights of authority over their children are needed so that parents can rear their children successfully. The response here is that parents have rights over their children but they are predicated on acting in their child's interests.

Some claim that parents have rights over their children that exist independently of the child's welfare⁸³. But if this is a reason for children to have rights, then a different

⁸³ A father in a court case deciding whether a child should have an HIV test expressed this. The child's doctors argued for testing the child, the parents argued it was not needed. At the conclusion of the case (decided on the welfare of the child) the father said "Whatever the outcome of this case, we would have lost if we had not stood up for our rights." [*re C (A*

route would be to reject the claim for parental rights that are not justified by advantages to the child. And if this response were rejected, then at the least there would need to be a clear exposition of the justification and content of parental rights⁸⁴, which would inform the content of children's rights.

I have argued that as young children lack the criteria to be rights holders, it is wrong to grant them rights. This does not mean that we can treat children in any way that we choose, just that to claim rights for children is not justifiable. We should approach our children in other ways.

3.5 REASONS WHY RIGHTS ARE NOT RIGHT FOR CHILDREN

I have argued that the problems in attempting to justify rights for children have not been overcome. One possible approach then is to accept that children do not have rights, and that the way we approach medical decisions for children should be based on their interests. A further argument is that rights are particularly wrong in interactions between children and those who care for them. I will argue that not only are rights-based approaches unhelpful in children's medical ethics, but they may also exacerbate any dispute that occurs.

Child) (HIV Testing) [2000]: 61]. Here he seems to suggest that parental rights are rights that parents have as parents, in that parents rights are entirely independent of the child's welfare. And if this is true, then unless children have rights too, in a rights-based analysis there is no counterweight to the parents' rights. This may be one reason for children to have rights. Notably, the judge refers consistently and repeatedly to the parents' 'wishes', not parents' rights.

⁸⁴ Montague argues that if parental rights exist, they are a special sort of right which he calls a half-liberty right. A liberty right is a permission to act or not act. Half-liberty rights "...are permissions to act, and do not include permissions to refrain" [Montague, 200: 59] and so are rights understood as duties or obligations. Montague notes that Feinberg recognised 'mandatory' rights which are "...best understood as ordinary duties with associated half-liberties....the performance of the duty is presumed to be so beneficial to the person whose duty it is that he can claim the necessary [means to exercise the right]..." [ibid 58]. Because these rights are very different from the ways that rights are usually understood, Montague argues that to avoid confusion, we should discard the idea of parental rights and instead talk of parental obligations. "Assuming...morally speaking, the parent/child relation centers on the interests of children rather than parents, there are very good reasons to reject the idea of parental rights in favor of the idea of parental obligations" [ibid 68]. And if parental rights are rejected there is no need to balance them with children's rights.

Schoeman argues that rights are not the best way to characterise the relationships with children and their parents⁸⁵. Broadly, as rights are the language of moral independence, but intimacy and interdependence are needed within flourishing families, Schoeman's concerns are that "The danger of talk about rights of children is that it may encourage people to think that the proper relationship between themselves and their children is the abstract one that the language of rights is forged to suit...it may cause parents in intimate relationships with their infants to reassess the appropriateness of their blurring the boundaries of individual identity and to question their consciousness of a profound sense of identification with, and commitment..." [Schoeman, 1980: 9]. Schoeman recognises that children have rights, but argues that their relationship with their parents is characterised by needs "As persons, children ought to be thought of as possessing rights; but as infants in relationship to their parents, they are to be thought of primarily as having needs..." [ibid 9]. The relationship is two way: the parent's need for intimacy as well as other interests of the parents are fulfilled by having a close relationship with their children⁸⁶. Schoeman does not deny that children have rights, but argues that their relationships (specifically with their parents) should not be thought of in terms of rights. Schoeman limits his argument solely to children's relationship with parents, but if this is true for parents, then it may also be true for others whose relationship with children is characterised by caring for a child (and so many adults, but amongst them in particular teachers, nurses and doctors). Those who see children as having needs and a need for care, will care better for a child, than when the relationship is characterised in terms of rights for the same reason that this is true for parents. Schoeman rejected the extension of his approach beyond the family, developing the concept of family autonomy and rights. Schoeman argued "Parents can be seen as representing the interests of the family as an integrated whole in addition to representing their own particular interests" [Schoeman, 1980: 19].

⁸⁵ As an example of this, children need to be loved but cannot have a right to be loved: "Parents cannot be taken to court, for example, for not loving their child. It would be useless and cruel to prosecute a mother who is too depressed to love her baby." [Alderson, 2008: 18].

⁸⁶ "Parents beget, bear and raise children to fulfil certain aims, sometimes eccentric or personal." [Ruddick, 1979: 125].

O'Neill argued that we should not characterise our relationships with children in terms of rights, but instead in terms of obligations. Rights allow no space for imperfect obligations (obligations that some of us have to unspecified others), which are crucial in our relationships with children⁸⁷. In recognising that children are different from many of the groups who have benefited from rights based claims she concludes "If we care about children's lives, we will have a number of good reasons not to base our arguments on appeals to children's fundamental rights... The view we get from the perspective of rights is not merely indirect, but blurred and incomplete" [O'Neill, 1988: 463]. Her arguments are broader than Schoeman's as they are not limited to children's relationships with their parents, but to our approach to children more generally.

A further argument can be made against rights-based approaches specifically when they are used to attempt to resolve medical decisions for children. In this context, rights do not take us further in trying to work out an appropriate course of action. Remember MB, an 18 month old, who had been in hospital since the age of a month or so, was dependent on artificial ventilation and had a progressively paralysing disease, such that he was almost completely immobile (he could, at best move, his toes). He was unable to keep his eyes open. His condition had and would continue to progress relentlessly. In court his parents argued that treatment should continue, but his doctors sought to withdraw treatment. One of the doctors caring for MB stated to the court that treatment was "cruel" [*An NHS Trust v MB* [2006]]. Here different rights conflict. Most prominently MB's "...inherent right to life..." [United Nations, 1989; Article 6] conflicts with a right not to be subjected to "...to torture or other cruel, inhuman or degrading treatment or punishment..." [United Nations, 1989, Article 37]⁸⁸. Here

⁸⁷ The advantage of starting with obligations is that it avoids "This narrowing of ethical vision makes it hard for rights-based approaches to take full account of the ways in which children's lives are particularly vulnerable to unkindness, to lack of involvement, cheerfulness of good feeling. Their lack may be invisible from the perspective of rights. This may not seem significant if we think only of children in danger but is vital if our concern is the quality of the lives children lead." [O'Neill, 1988: 452].

⁸⁸ And in other examples, Dianne Pretty (when dying of motor neurone disease) argued in the British and then European Courts that she had a right to assistance in committing suicide, based on the Article 3 [United Nations, 1948] that she had a right not to be subjected to 'inhuman and degrading treatment' [*Pretty v. Director of Public Prosecutions and Secretary of State for the Home Department* [2001]]. Other adults, with similar diseases, have argued for assistance in suicide based on the argument that the current laws regulating suicide fall foul of

taking a rights-based approach to the disagreement between MB's parents and clinical team over the future treatment for MB leads to a clash of two rights, neither of which should obviously take precedence. Some believe that sufficient specification of the scope of a right will allow resolution of what seems to be a conflict between rights, because with full specification, the apparent conflict will be eliminated. It is not clear that this is true. Even turning to the Convention's right to health does not help. The UN Convention on Children's Rights states a right to the "...highest attainable standard of health..." [United Nations, 1989: Article 24]. For a child with an inexorably progressive disease it is not clear what that means.. An alternative approach, when two rights conflict, is to look at the basis or justification of the rights. I have argued that the justification for rights is disputed and unclear. In cases where medical decisions need to be made for children, the overriding concern is actually the child's interests⁸⁹. And without recourse to considering interests, which is the step that the court took, there is no clear way to resolve the dispute. If this is true, then rights-based claims do not add anything to an interest-based analysis. Or to phrase it differently, the overall right of the child is that her interests deserve consideration⁹⁰.

And these are not just theoretical concerns about rights-based analyses. In practice, rights-based approaches may not just fail to resolve problems, they actively promote conflict. In a rights-based analysis an individual will assert their rights. To reinforce the strength of their position a person must reflect on the role and strength that their rights have, and reflect on the way that their rights should be presented and so offer the strongest case that they can muster, so reinforcing their conviction in their own rights. The individual must reject the other side's countervailing rights, and to do so must demonstrate the weakness of the other's claims, justifying why the other side's

the "...right to respect for private life under Article 8..." [*R (Nicklinson) v Ministry of Justice* [2012]]. And so although it may be thought that the right to life should take priority over other rights, it is clear that not all would agree.

⁸⁹ As an example of the way that interests are used to resolve rights-based conflicts there is a court case to decide the management of an 11 year old girl. The court clearly states that the case involved the "...basic human right to reproduce..." [*re D (A Minor) (Wardship: Sterilisation)* [1976]; 186] but in giving their reasoning the court states "...the operation was neither medically indicated nor necessary and would not be in D's best interests..." [ibid 186] and later on "It is of course beyond dispute that the welfare of this child is the paramount consideration and the court must act in her best interests." [ibid 194].

⁹⁰ Most of the healthcare rights that are specifically stated in Article 24 of the Convention [United Nations, 1989] are public health commitments.

rights are weaker or should be rejected. Each side defends their own right or rights and seeks to undermine the other side's rights claims. And so if there is a resolution one right will triumph, one right will be overridden. One person is victorious, the other aggrieved because their rights have been dismissed, ignored or trampled on. It is true that rights can be waived, or rights in apparent conflict may be negotiated to an agreed solution, but my claim is that it is likely that if rights-based approaches are used in contested medical decisions, they are likely to lead to more intractable conflict. Wenar writes "Since rights assertions suggest conclusive reasons, people can be tempted to assert rights when they want to end a discussion instead of continuing it. One plays a right as a trump card when one has run out of arguments. Similarly, the ready availability rights language may lead parties initially at odds with each other toward confrontation instead of negotiation, as each side escalates an arms-race of rights assertions that can only be resolved by a superior authority like a court" [Wenar]. My claim is that it is likely that using rights-based approaches may be more likely to lead to intractable conflict when medical decisions for children are unclear and come to be disputed.

Having argued that the grounds for children's rights are incomplete, and that the content of children's rights are unclear, I have argued that there are good reasons why rights-based approaches are the wrong way to deal with children, and that using a rights based approach to medical decisions may make resolution of contested medical decisions for children harder.

3.6 FAMILY RIGHTS

A response to these varied criticisms of children's rights is to recognise the concerns and respond by arguing that there are family rights⁹¹. The family must be given rights,

⁹¹ Claims for Family Rights come from a wide variety of sources. Erickson argues that the core of humanity is relationships, not rationality or agency, and that as a consequence families, but not individuals, have rights [Erickson, 2010]. In traditional – Confucian – Chinese medicine, clinicians interact with the family by choice, not as in the West by default when the patient is incompetent. Chen gives examples of Chinese ethical guidelines including "...it is still better to tell the diagnosis of cancer to his or her family members first; only after...should the physician select a suitable time to tell the patient..." [Chen, 2010: 575]. The Irish Constitution "...recognizes the Family...as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law." [Article 41 the Irish

so that the family can perform its various functions (amongst which are child rearing, and providing fulfilling intimate relationships for children and adults).

Family rights are a particular form of group rights. Group rights are not rights that individual members of the group have because they are members of the group (for example that the members of the cricket club have the right to play at the club). Group rights are rights that the group as a whole have and are exercised only by the group, but if so the group must be constituted in particular ways so that it would be meaningful to talk of group rights [Jones]. It makes sense to talk of some groups as right holders. Examples of these groups include some sporting teams, or some cooperative movements. Other groups do not have group rights: for example a bus-stop queue isn't a group that could be a rights holder (the examples are from Jones, 2014).

The groups that are potential rights holders function in ways that may make them akin to people: they have agency, continuity and responsibility amongst other attributes. If any groups were to claim the sort of cohesion that could justify the claim to be a rights holder, then families would seem to be a paradigm. Most families are tight knit groups, with individuals with a strong interest in each other's welfare. The family as a group persists through time, with a sense of common purpose to family goals. And if so, it may be that young children themselves do not have individual rights, but that children (as part of the family) have a share of family rights. The family rights ensure that the family as an entity flourishes and that children flourish within the family.

One question is whether the family is the sort of group that has rights. I have given some arguments why the family should have group rights, but I do not believe these arguments are decisive. Remembering that group rights are rights that the group as a whole has and which the group exercises, families are different from most of the groups for which group rights can plausibly be claimed. There are two powerful objections. Firstly, that the family is not a group of equals with shared-decision

Constitution]. Schoeman argues that "...the family is to be understood as entitled to certain rights of privacy and autonomy..." [Schoeman, 1980: 10].

making responsibilities. Parents have authority in families⁹². Some parents may choose to share responsibility taking consensual decisions with their children's involvement, but this remains the parent's choice: parents need not pay attention to their children's wishes or welfare. And even if decisions are made consensually, the parents will almost certainly have influenced the children's choices. The idea of group rights sits more easily with the sort of group constituted of equals who share decision-making. A second feature of groups where plausible claims for group rights can be made is that the group is constituted voluntarily. Members can choose to join (though individuals may be selected) and choose to leave (though there may be penalties). This means that groups will be composed of like-minded people, sharing goals, participating voluntarily. This is not true of families, which are usually made by biology not by choice. And if there is choice, it is choice by the adults (in having or adopting children). Adults may choose to leave families (for example by divorce) that they find unsuitable, but this option is not open to children, children must be cared for. These two concepts: participation in shared decision making and choice in participation are important when the tension between an individual's rights and group rights are kept in mind. For these reasons, although some families are constituted in ways that make claims for family rights tenable, most are not. And in particular families with young, incompetent, children are not structured so that claims for family rights are tenable. When claims are made for family rights, they are claims not for rights that the family as a whole exercises, but for the right of parents to make decisions. Family rights may be taken to be different from parental rights in two ways. Firstly because the claim is for family rights they may be taken to be more holistic than parental rights, but for young children this is not true as I have argued. The second difference of family rights from parental rights is that as some families extend further than the Western nuclear family more distant relatives, an uncle or grandparent, may make decisions for other relatives. In these cases parental authority is just transferred to another relative within a more extended family. Either way, if my criticism is correct, then claims for family rights fall foul of the criticism that I have already made of parental rights.

⁹² In Schoeman's argument "The right to autonomy entitles the adults of the family to make important decisions." [Schoeman, 1980: 10].

A second question is that if there were family rights, what would the content of family rights be? There seem to be two broad areas to family rights, a right to freedom from interference in the affairs of an intimate family from the outside, and a right of family members to make decisions for those within the family⁹³. I have already argued that a family right to make decisions collapses into an equivalent parental right. I will now consider a family right to privacy

That an intimate family should have privacy from external scrutiny seems reasonable. However, in considering healthcare decisions, the family has already opened up to outsiders, the healthcare professionals who will deliver the interventions. These are then not decisions that can be left just to the family, as those outside the family are already involved. Secondly, if a family right to privacy is respected, there is a tension between the rights of an individual family member and the group rights of the family, thereby allowing potential rights violations of individual members of the family to be ignored⁹⁴. So as Schoeman recognised: “Neither the right to privacy nor the right to autonomy associated with the family is absolute.” [Schoeman, 1980: 10].

Can family rights contribute to the analysis of medical treatment decisions? I argue that they do not. Firstly, family rights could be taken to replace parental rights. When treatments are disputed, what help could family rights offer? At best it would seem to be a right that the family should make the decisions. Family rights in this context are subject to the criticisms that I made of parental rights. Secondly, if family rights are

⁹³ Schoeman argues for “...the family is to be understood as entitled to certain rights...The right to privacy entitles the adults of the family to exclude others from scrutinizing obtrusions into family occurrences. The right to autonomy entitles the adults of the family to make important decisions about the kinds of influences they want the children to experience and entitles them to wide latitude in remedying what they regard as faults in the children’s behaviour.” [Schoeman, 1980: 10].

⁹⁴ An extreme example of family rights conflicting with the human rights of individuals within the family are ‘honour’ killings where (particularly but not exclusively) women who have offended against the family’s code (perhaps by making an unsuitable match) are killed. More than 5000 women each year are killed in honour killings, and this is almost certainly an underestimate with many deaths going unreported and others being misdescribed as suicides [van Eck, 2003; Solberg, 2009]. Another example where a family right to privacy conflicts with human rights is demonstrated by younger children who are harmed by neglecting parents or through wilful ill treatment One child a week is killed in Britain by their carers or parents [Milmo, 2009].

taken to encompass the child's human rights then parents will assert the family's rights and this runs the risks that a child's interests (or the child's rights) would be ignored.

Furthermore, as with children's rights, family rights do not contribute to the analysis of contentious medical decisions for children. For example, remembering MB (who was ventilated with a diagnosis of SMA) MB has rights to life, and a right to avoid inhuman treatment. His parents wanted treatment to continue, but the treating team thought treatment should be limited. Does a family right override the individual rights of MB? I would argue that it does not and it cannot without a clear explication of what family rights are and how they interact with an individual's rights. Here the use of family rights is unhelpful.

I have argued that there are good reasons why family rights should not be recognised and that even if they were recognised, they would not resolve the way that medical decisions should be made for young children. For all these reasons, family rights are unhelpful in general for children.

3.7 CONCLUSIONS

I have argued that the justification of human rights in general is unclear, and that there are particular problems in formulating and justifying rights for children. These particular problems for children have not been successfully overcome. I have argued that rights-based approaches are not the best way to understand our interactions with children and that specifically they are not useful in resolving medical decisions for young children. Rights-based approaches may even worsen disagreements. I argue that family rights are as unsuccessful as children's rights in contributing to the analysis of medical decisions for children. As rights are not the best way to characterise our interactions with children, we should join Griffin in recognizing that "...once we recover a sense of the full range of our moral vocabulary, we shall no longer feel the need to turn all important moral claims into claims of rights" [Griffin, 2008; 95]. Given these problems with rights, and given the way in which interests may guide medical decisions when rights conflict, I will argue for an interest-based approach in the next chapter.

CHAPTER 4: CHILDREN'S INTERESTS

4.1 INTRODUCTION

The justification that is usually offered when medical decisions are made for a child is that the choice is in the child's best interests. This standard has broad appeal: parents want what is best for their child. The treating clinical team are exhorted to use it by the General Medical Council when they say that: "Doctors should always act in the best interests of children and young people." [General Medical Council, 2007: 5], the Royal College of Paediatrics and Child Health in the UK suggest that doctors should "Above all...plac[e] the child's best interests at the center of all clinical considerations." [Royal College of Paediatrics and Child Health, 1999] and also in considering treatment towards the end of life "...The background to all treatments, now and in the future, must be that they should be in the child's best interests." [p12 Royal College of Paediatrics and Child Health, 2004: 12]. Other examples include the Nuffield Report considering the medical treatment of premature babies "...the best interests of a baby must be a central consideration in determining whether and how to treat him or her." [Nuffield Report, 2006: xvii]. In deciding research participation "...parent(s) or legal guardian(s) generally have ethical and legal responsibility for weighing information and making decisions in the best interests of their child." [Paediatrics & Child Health Division, 2008: 15]. In UK law, the Children Act states "...the child's welfare shall be the court's paramount consideration." [Children Act 1997] and the UK courts turn to it when they are asked to decide on contentious medical treatment for children: Mr Justice Holman in setting out the law for decisions about a child's medical treatment said "The matter must be decided by...the best interests of the patient" [*An NHS Trust v MB* [2006] paragraph 16]. Academic medical ethicists use it, for example in the debate on male circumcision "...we apply a child's best interest standard." [Schuklenk, 2012: iii] and "...the basic analysis is applicable in any part of the world that uses the best interests of the child as a touchstone..." [Wilkinson D, 2013: 47]. And in the preamble to an early version of the Children's Rights Convention "...mankind owes to the child the best it has to give" [United Nations, 1959].

Despite this broad appeal, there are several problems with a standard that requires that others act in the best interests of those incompetent to choose for themselves. These

problems are particularly severe for children, as they may be side-stepped when dealing with incompetent adults because a previously competent adult (as the vast majority of adult incompetents have been) can make preparations (before their descent into incompetence) to stipulate what their decisions would be. Firstly, they may have stated what they would choose in particular situations in an advance directive. Secondly, by the appointment of a proxy, they can select a person who will choose in a way that they would have chosen. And even if a previously-competent adult has made no preparations, the views that they held (as reported by their friends and family) may be used to determine (by the clinicians, or the courts if it comes to that) which choice should be made⁹⁵. None of these routes are available in deciding a child's best interests, as children are yet to become competent, and although the child and their views should be taken into account when decisions are made (if appropriate), a child's views are not determinative of their interests, as an adult's views would be. For incompetent children a robust concept of best interests is needed to guide deliberation, when interests are unclear, or to assess and perhaps correct mistaken or disputed decisions.⁹⁶ Although the term 'interests' or 'best interests' is used often and in many

⁹⁵ For previously competent adults, these methods to make medical decisions are often called a substituted judgment reflecting respect for autonomy, not the person's interests (see for example Buchanan and Brock, 1990: 88). In the hierarchy of decision-making (with autonomy at the top) this approach carries more authority than a best interests assessment. However, the distinction may not always be clear. For example, UK law (the Mental Capacity Act 2005) conflates substituted judgment and best interests, in describing what seems to be substituted judgment but calling it an objective test of best interests. The Notes state "Best interests is not a test of 'substituted judgment' (what the person would have wanted), but rather it requires a determination to be made by applying an objective test as to what would be in the person's best interests" [Mental Capacity Act 2005 Explanatory Notes, paragraph 28]. The test for the objective assessment of best interests secures a substituted judgment by seeking the patient's "...reasonably ascertainable... 'past and present wishes and feelings' of the person concerned. Such wishes and feelings would include any relevant written statement. Even where people cannot make their own decisions, they can express preferences and feelings which should be taken seriously. For those who have lost capacity (for example because of progressive dementia) it may be particularly important to consider past wishes and feelings as well as current ones" [ibid paragraph 29]. The MCA's test makes a substituted judgment, it does not find an objective conception of best interests.

⁹⁶ The General Medical Council's guidance is unhelpful: "Well-being includes treating children and young people as individuals and respecting their views, as well as considering their physical and emotional welfare." [General Medical Council, 2007: 4]. Children are not individuals, until mature most are members of an intimate family, with parents and close relatives playing an important role. What it is to 'respect' a child's view is not made clear. Respect for a child's views must be different to the respect given to an adult's views. Whereabouts a young person is in this hierarchy depends on what a young person is taken to be which also is not made clear.

different contexts, what interests mean is rarely made explicit⁹⁷. And if concepts are not made explicit, then discussions about interests will be confused and the term becomes unhelpful or sometimes worse than that⁹⁸.

Firstly, there is disagreement about what is meant by interests and other words that have the same meaning. And even if we can agree what is signified by the term ‘interests’, more problems arise at a meta-ethical level in relation to how the question of what a person’s interests are should be approached. A second problem lies in the way that interests are often, or usually, taken to be subjective, but at least for children, interests cannot be subjective (as is usually understood for adults) where the individual who is under consideration determines their interests. If interests are taken to be subjective, there is the problem for young children in that the person, in a philosophical sense, does not yet exist.

There are challenges in applying best interests to medical decisions, amongst which are that a child’s interests are uncertain in several different ways. A further problem lies in the standard that is advocated: that of the individual child’s *best* interests. There are two objections, firstly that this is too demanding and secondly the individual child’s best interests demands an individualistic view of children, which describes neither how children are, nor how decisions should be made. One option that has been proposed by many is that the family’s interests, rather than the child’s interests, should be considered when making decisions. Despite these concerns, an interests-based approach remains compelling for those who must make decisions for children in

⁹⁷ A telling example is found in the Mental Capacity Act. The Notes state “It is a key principle of the Act that all steps and decisions taken for someone who lacks capacity must be taken in the person’s best interests. The best interests principle is an essential aspect of the Act.” but the text continues to state “Given the wide range of acts, decisions and circumstances that the Act will cover, the notion of ‘best interests’ is not defined in the Act” [Mental Capacity Act 2005 Explanatory Notes, paragraph 28].

⁹⁸ So, continuing with the Mental Capacity Act, as an example, the House of Lords report on the Mental Capacity Act, states “...the term ‘best interests’ is probably the most abused and misunderstood phrase in health and social care. It has too often been the vehicle for poor decision-making...” [House of Lords, 2014: 45].

general and for medical decisions in particular⁹⁹. Others deny that best interests offer any guidance and argue that the best interests standard should be rejected¹⁰⁰.

This chapter will consider what is meant by interests and then sketch out and briefly defend the claim that medical decisions should be determined by reasonable agreement over the child's interests.

4.2 WHAT ARE INTERESTS?

Interests, or best interests, are taken to mean what is good (or best) for a person. This is one of several ways to assess, or value, how well off a person is. Other ways that things may be evaluated for a person include aesthetic value, perfectionist value and ethical value (for a discussion, see Sumner, 1996 chapter 1 part 3). A life may score very differently when evaluated in these different ways. The other evaluations need not be beneficial to, nor valued by, the person themselves. For example, what may be good in a perfectionist sense (that a person becomes a better mathematician) may not be in that person's interests. Just because they become a better mathematician they may not be better off overall. Perhaps they would lead a more comfortable life, or would develop their limited sporting abilities better if they were not such a good mathematician. The feature that distinguishes a person's interests from the other assessments is that interests matter to the person living the life: it is the value of life for the person living the life and so (in one sense of subjective) is necessarily subjective. Interests describe that a person's life goes well, seen through their own eyes. Griffin described this conception (in a book named *Well-being*) as "The notion we are after is...the narrower notion of a life's being valuable solely to the person who lives it." [Griffin, 1986: 21]¹⁰¹.

⁹⁹ "I propose that we think about 'the best interests of the infant' as a directional beacon to be sought and used by those attempting to deal with the conceptual swamp; as a light in the fog that permeates the context in which they struggle to make decisions about appropriate health care of the infant." [Bartholome, 1988: 40].

¹⁰⁰ Brody dismissed best interests in arguing "... 'the infant's best interests' is a rhetorical flourish that does no useful work in the discussion" [Brody, 1988: 38] and Salter argued against best interests "... while the BIS [best interests standard] has potent rhetorical power, its invocation and application is actually quite inconsistent, and that ultimately, it should be rejected." [Salter, 120: 180].

¹⁰¹ And others too: Nagel writes "I shall not discuss the value that one person's life or death may have for others, or its objective value, but only the value it has for the person who is its subject..." [Nagel, 1979: 2]. The President's Council's analysis of care points this way too

In this sense, a person's interests are at the core of ethics. Or, describing it another way, when acting or choosing between actions, a significant (although perhaps not the only) factor is the effect the action will have on our own, and other's, interests.

Usually, there will be a need to balance gains and losses of well-being to individuals. Sometimes the balancing is within one person, sometimes the balancing is between different individuals, or groups of individuals, or individuals at different times.

There are a broad range of words which are used alongside interests. These include well-being, welfare, quality of life, and a person's good. Other ways are to say that the person's life goes well, that things are good for the person or that the person flourishes. Some authors take all of these terms to have the same meaning. Darwall takes this approach in saying "I shall take it that a person's welfare is the same as any of the following: her interest, benefit, well-being, or good (her life's being good for her)..." [Darwall, 2002: 25]. So too do Buchanan and Brock "Best Interest: acting so as to promote maximally the good (i.e. well-being)..." [Buchanan and Brock, 1990: 10]. As does the Nuffield Council in asking how new born babies should be treated "...interests can be understood in terms of the factors that affect a person's quality of life. They are the constitutive elements of wellbeing: a person's wellbeing prospers or declines as their interests grow or wane. A person benefits from having their interests promoted and suffers from having their interests neglected." [Nuffield Council, 2006: 15]. Dworkin lumps them altogether in defining paternalism "...by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the persons being coerced." [Dworkin, 1972: 66]. Sumner states "...welfare...faring or doing well...welfare attaches pre-eminently to the lives of individuals, and...is more or less the same as her well-being or interest or (in one of its many meanings) her good." [Sumner, 1996: 2]. Kraut also takes this position in stating "Good...When followed by the preposition 'for' or 'of', it purports to tell us where our interests lie...'good for', 'in his interest', 'to his advantage', 'beneficial to'..." [Kraut, 2007: 1]. Wolff equates "what would increase my well-being to the greatest degree" with "what would make my life go best" [Wolff, 2003: 339]. "Wilkinson uses 'quality of life', 'happy',

"The goal of ethical care giving in a clinical setting is...always to benefit the life the patient still has." [President's Council, 2005: 212] so the life the *patient* still has, not just life itself.

‘flourishing’ and ‘welfare’ interchangeably in a discussion of the welfare of disabled children [Wilkinson S, 2010: Chapter 3]. Another Wilkinson states “Well-Being: how well or how badly a life goes” [Wilkinson D, 2013: 84]. Wendler states that he will “...regard human interests very broadly as those aspects of a better life for a given individual” [Wendler, 2010: 112]. UK law takes these terms to be interchangeable, for example, in deciding on the medical management of a child “The judge must decide what is in the child’s best interests. In making that decision, the welfare of the child is paramount...” [*Wyatt and Portsmouth Hospital NHS Trust and Charlotte Wyatt* [2005] paragraph 87]. And in the Human Tissue Act: “...a court ruling on best interests should be in place...If the court is asked to consider the matter, the welfare of the prospective donor child will be the court’s paramount consideration...” [Human Tissue Act 2004 Code of Practice 2: A9].

But other commentators distinguish different meanings in these words. For example, Griffith may do in writing “...a judge is called upon to decide in which parent’s custody the child’s welfare and interest are best served.” [Griffith, 1991: 283]. Griffin asks if the words have different meanings in writing “Is it so clear that there is a univocal notion of ‘welfare’, ‘well-being’, ‘eudaimonia’, ‘benefit’, or ‘a good life’?” [Griffin, 2006: 443]. And Parker does in writing “...the best life itself, which can moreover have a meaningful use only in relation to other similarly rich and complex concepts such as those of the good life, human flourishing, well-being and of what it is that makes lives go well.” [Parker, 2007: 281]. Scanlon lists four concepts that he argues are confused with well-being, though these are more usually described as quality of life. Firstly the “conditions under which life is lived...illness and danger, access to nutrition, the availability of education...” [Scanlon, 1998: 111], these are the day to day matters of life and describe the ‘comfortableness’ of a person’s life. The second use is the experiential quality of life, life “...from the point of view of the person who lives it” this is the well-being of hedonism. But for Scanlon “...the question of well-being and the question of experiential quality are not the same thing.” [ibid 112]. Scanlon’s third meaning of well-being is the “...degree to which it [a life] is particularly admirable and worthy of respect - what I will call its worthiness or value.” [ibid 112] this conception of well-being is what others might call a perfectionist evaluation of a life, an objective list approach. Lastly, Scanlon lists the choiceworthiness of a life, recognising that the other three factors contribute to it,

though it is distinct from them. The correct conception of well-being for Scanlon is “...broader than material and social conditions, at least potentially broader than experiential quality, different from worthiness or value, and narrower than choiceworthiness...” [ibid 113].

One of the problems lies in the nuances the words may come to have. Welfare is a good example. In some uses it is synonymous with well-being and interests, but in other uses welfare has come to have connotations of meeting the poor or dispossessed’s needs, best exemplified by the term the ‘Welfare State’ in Britain. Sumner describes that in his research he discovered “...if a book written in the post-war era includes ‘welfare’ in its title, then it is reasonable to expect it to deal, in one way or another, with the range of social programmes...whose declared purpose is to secure a fair distribution of basic goods and services or to establish a safety net for the least advantaged.” [Sumner, 1996: i], but his subject was “...the deeper and more traditional sense of...faring or doing well, my welfare is the same as my well-being or my interest or (in one of its many meanings) my good” [ibid ii]. He broke with the tradition he described by including welfare in the title of his book although he did not deal with social programmes. The point here is that these words all have the same meaning on occasions, but on other occasions, they may have subtly different meanings. If this is not recognised, then discussion may be confused.

Another way in which there may be different meanings of ‘interests’ comes from the different forums in which the term interests are used. Doctors and other health care practitioners, lawyers, sociologists, ethicists, parents, and others, all use the term best interests, and it may well be that in different circumstances the words have different meanings. Furthermore even within a discipline there may be multiple conceptions. Axford describes five different conceptions of a child’s well-being that are used in children’s social services, giving the concern that this may lead to “...initiatives that are inherently contradictory” [Axford: 2009,381]. Scanlon’s concern was that “it is a mistake to think that there is a single notion of well-being that plays all the roles I have mentioned.” [Scanlon, 1998: 109]. I will explore some of these distinctions in conceptions of interests and develop the conception of interests that will be used in this chapter.

Distinguishing being ‘well-off’ from having a good life

Kagan argues that a person’s well-being is distinct from how well their life goes: “...when we ask how well-off an individual is or how well that individual’s life is going, it is generally assumed that these are two different ways of asking the same question. But it seems to me possible that these two questions are in fact asking about two different subjects - the individual and his life...” [Kagan, 1994: 310]. He supports this claim in two ways. First consider

“...a man who dies contented, thinking he has achieved everything he wanted in life: his wife and family love him, he is a respected member of the community, and he has founded a successful business. Or so he thinks. In reality, however, he has been completely deceived: his wife cheated on him, his daughter and son were only nice to him so that they would be able to borrow the car, the other members of the community only pretended to respect him for the sake of the charitable contributions he sometimes made, and his business partner has been embezzling funds from the company which will soon go bankrupt.” [ibid 311]

Kagan suggests well-being depends on the person’s mental state “from the inside...everything was perfect...” and distinguishes this from the deceived and cheated person’s life “...it is difficult to believe that it is all a life could be...” [ibid 311]. Kagan argues that although well-being and a person’s life are often taken to be the same thing, they are separate in arguing “The judgment that we seem most confident about making involves the claim that something is amiss in the deceived man’s life, that his life is not going as well as it might be. But holding this is quite compatible with also claiming that the man himself is still well-off.” [ibid 321].

Kagan’s second line of support for the claim comes from the argument “(1) Changes in well-being must involve changes in the person. (2’) A person simply is a body and a mind...well-being, whatever its precise nature, constitutes a benefit to the individual. And it is hard to see how it could do this unless it consisted of changes in the intrinsic state of the person...It is not nearly as plausible to assert that a person’s *life* is comprised solely of facts about that person’s body and mind.” [ibid 315]¹⁰². And (to

¹⁰² Scanlon’s limits of well-being line up with Kagan’s limits of well-offness. Scanlon asks “...whether there are factors that contribute to well-being but are neither experiential nor dependent on a person’s aims in the broad way just described. It might be argued that there are not. In order for something to affect a person’s well-being, the argument might run, it must affect how things go *for that person*. Both experiential good and factors involved with that

continue with the deceived businessman) unless the businessman is aware of the deception, the businessman's well-being is unaffected (*his* mind and body are unchanged), but the man's life does not go well (he is deceived and his life would be better if he were not). Kagan is right that how well a person's life goes is clearly distinguishable from whether the person believes that their life has gone well. One is a collection of facts about a person's life, the other is the person's (or someone else's) assessment of those facts. The constituents of a person's life (their family, dwelling and employment, their future and their past and so on) will influence the person's assessment of their well-being, but are distinct. Two individuals with near-identical lives may have very different levels of satisfaction with their lives. Both a good life and the person's satisfaction, are important components of a person's interests. A person will be miserable and have a miserable life however rich they may be, if they continually feel hard done by.

Axford draws a similar distinction to Kagan's recognising that both are important: "...children should be enabled to lead 'a life worth living' - but also children's subjective perception of their situation - we want them to love life." [Axford, 2009: 380]. As does Darwall in writing "... what I would wish for my own children...it seems to matter both that they have the relevant experiences - that their lives *seem* valuable to them in these ways - *and* that their lives really do exemplify these values." [Darwall, 2002: 19 Darwall's italics] and both combine to make up a person's welfare¹⁰³.

Several distinctions are made by Kagan. Firstly there is a difference in perspective: being well-off (in Kagan's sense) is necessarily the person's assessment of their own life and situation, but an assessment of a person's life may be made by others. So one distinction is between the first person perspective and a third person perspective. This

person's aims satisfy this condition, but it is difficult to see how anything else could do so." [Scanlon, 1998: 124 Scanlon's italics].

¹⁰³ Darwall makes the person's assessment the primary assessment 'that their lives seem valuable to them' whereas usually (and elsewhere) Darwall turns this round arguing that welfare is what would be good for someone, when assessed by another. Darwall states "I shall be arguing that a person's good is constituted, not by what that person values, prefers, or wants (or should value), but by what one (perhaps she) should want *insofar as one cares about her.*" [Darwall, 2002: 4 Darwall's italics].

can lead towards the distinction between subjectivity and objectivity, which will be discussed later. Secondly, a 'life' perspective implies an overall assessment, a summation, which may be over time, or over different domains of a person's life at a particular time. The latter allows that a person could be well-off *given their situation*. For example, some people with terminal disease are miserably breathless, tortured by unremitting pain, continuously uncomfortable, and unforgettably fearful of their impending death. Others, with similar terminal disease, are reasonably well off and enjoy an acceptable, though shortened, time. A person may not seem to have a good life, but given the constraints (and what their life *could* be like) a person may have a reasonably good life, given the circumstances. There is a third distinction in Kagan's example, which I will concentrate on here, that of knowledge of the situation.

Kagan's example opens up the difference between being well off and the man's life going well because the businessman does not know of the deceit. This is a problem because we can't ask the man if he wants to know, because by then the cat is out of the bag. The deceived businessman thinks his life goes well, but others disagree. They disagree not because they have different values; they disagree because they have more information. Kagan's distinction (of a good life from being well-off) depends on the difference in knowledge of what is going on. Imagine that the businessman knew of the deceit. He may discuss his problems with his friends. The businessman and his friends would be likely to share the same assessment of the state of his life and his well-offness (because as friends they have much in common). When this happens, Kagan's distinction between being well off and the businessman's assessment of his own life disappears. The act of telling him may dramatically reduce both how his life was going (as he falls out with his wife, children and business partner) and also how well-off he was (as he now knows that he is unsuccessful in love, as a father, and in business). And the businessman might say that all-in-all he would have been better off not knowing (preferring happy deceit to uncomfortable reality). Equally, he might be glad to be told, preferring harsh reality to comfortable lies.

Kagan's example of the contrast between being well-off and the person's life is unusual as the businessman is deceived by those who have particular reasons to be honest with him: his family and friends. Deceit is a *prima facie* wrong. In one sense, the businessman is not treated as a philosophical 'person' trusted with full information

and able to take his own decisions, he is dealt with almost as a child: others make decisions for him, in choosing not to inform him of the deceit. The separation between the businessman's well-offness and his life is only possible because the businessman does not have the information that would let him see his life as others see it. Were he fully informed (which in general is how he should be treated) the distinction between the businessman's assessment of his life and the businessman's well-offness would be removed.

However, having recognised that the difference in knowledge is a source of concern in Kagan's distinction, the correct response to Kagan's example is to recognise that a person's life is distinct from the person's satisfaction with their life, and that both are important components of a person's well-being. A competent person, with information, can attempt to resolve the tension (if there is one) between their life and their satisfaction with their life. However Kagan's example reminds us that children, and other incompetents, present the problem that parents or guardians of other incompetents must balance these different components of the child's interests, and must balance them with attention to the fact that decisions made for children will have effects over the rest of the child's life. Kagan's example of the businessman draws attention to the tension between a child's wishes, and what would be good for the child's life, both of which contribute to the child's interests. The distinction is often unrecognised¹⁰⁴. Another distinction within conceptions of interests is the extent to which achievements may contribute to an individual's interests. Wendler defends such a theory.

The Inclusion of Human Achievements as a Component of Well-Being

Wendler explicitly distinguished welfare from interests "...our interests go beyond our welfare to include the nature of our lives." [Wendler, 2010: 136]. Wendler's claim is

¹⁰⁴ Montgomery describes a similar situation involving children's health care "...a girl of 14 who belonged to the Jehovah's Witness faith...The girl accepted the advice of her doctors that the blood transfusion was necessary to save her life but still refused it...Sir Stephen Brown P held that she was not '*Gillick* competent' to refuse it...assessment of incompetence on two bases. The first was that the girl did not appreciate how distressing her death would be if she did not receive treatment...the reason that she did not appreciate this aspect of the situation was that she had not been told the details. In fact it is the refusal of the adults to allow her to be informed that rendered her incompetent, not her ability to comprehend." [Montgomery, 2003: 292].

that a life including worthwhile achievements is a better life, and claims that this is in a person's interests. In alluding to a better life Wendler draws a similar distinction to that drawn by Kagan, but Wendler's argument focuses on human achievements.

Wendler's typology of children's interests separates five (overlapping) groups of interests: biological needs; experiential preferences; meaningful relationships; personal goals and human achievements. Wendler argues that satisfying biological needs is in "almost all cases" [ibid130] in our interests¹⁰⁵. Wendler's second group is experiential preferences, 'certain experiences or states of mind'. These are not always distinct from biological needs (pain-relief is one example crossing the boundary between the first two groups). Wendler's third group is meaningful relationships which can be with persons, animals or projects (his example is of playing in an orchestra). The fourth group is that of personal goals "...a better life involves achievement of (more of) one's worthwhile goals...achieving goals that are not worthwhile does not further one's interests and often sets them back" [ibid p131].¹⁰⁶. Wendler's fifth group is of human achievements "...accomplishments and contributions that are valuable for us given the kinds of being we are" [p 133 ibid]. In limiting personal goals to *worthwhile* personal goals there is an overlap between

¹⁰⁵ But not always. Firstly, satisfaction of the biological need of a person in a coma may not be in his interests. Secondly, he cites Raz in noting that satisfying a biological need may not be in a person's interests "...but rather only provides the necessary conditions for one to pursue one's well-being." [Wendler, 2010: 310]. In many cases satisfying biological needs does directly improve a person's well-being (by relieving hunger or thirst or pain or whatever).

¹⁰⁶ In general, achieving personal goals matters to a person, it is in a person's interests, but Wendler limits goals to 'worthwhile' personal goals. Wendler does not make his caveat of 'worthwhile' much clearer, his discussion is limited "First, struggling for ends that are of no value is not a route to a better or more valuable life. We should not hope for and would not wish on those for whom we care, a life of pushing boulders up hills to no end, no matter how challenging the task might be. The ends matter in the sense of it being (more) valuable to pursue valuable ends...Second... Working for a good cause is valuable not only because it is valuable to have a good end in sight while one struggles and because striving for worthwhile causes puts one in contact with things of fundamental value, but because there is value in achieving or realizing valuable ends." [Wendler, 2010: 132]. Wendler does not clarify what 'worthwhile' means, nor who should judge worthwhileness. Although one may be uneasy about some personal goals (Griffin's example is of a brilliant mathematician who chooses to waste his talents counting grass), Wendler's limit that only worthwhile personal goals contribute to interests contradicts the claim that interests are what matter to the individual. It can be valuable to achieve goals that others (and perhaps even the individual themselves) would accept are not worthwhile. So I may want to try gliding or diving, even though having done it I say "thanks, but no thanks". However, had I not tried it for myself, I may always have a longing to do it.

Wendler's fourth and fifth groups. Wendler's first four categories of interests account for welfare but (Wendler argues) interests are made up of human achievements as well as welfare, so achievements contribute to a person's interests "...what is of value or what is preferable *for an individual* is not necessarily exhausted by what the individual values, what she prefers and what she wants to accomplish... We also want them to have valuable goals and to achieve them (at least to some extent)...having a life that includes more valuable achievements makes for a better life overall..." [p133 *ibid* Wendler's italics]. Wendler's claim is broad: "...even if one never experiences the realization of the achievement and moreover one does not have the realization of that achievement as a personal goal...making contributions to significant human achievements makes for a better life overall." [ibid 134-4]¹⁰⁷.

A challenging part of Wendler's theory is the claim that "Our interests, what is preferable or good for us, goes beyond our welfare to include the nature of our lives" [ibid 136]. In contrast to theories that emphasise personal validation of the values that comprise a person's interests, Wendler argues that a person's own assessment of their interests is correctable (by others) in two ways. Firstly, by limiting the contribution of personal goals only to those goals that are 'worthwhile'. And secondly, by including as components of the person's interests even those human achievements that are not endorsed by the individual. How does Wendler justify this? Firstly, he adopts flourishing as the correct characterisation of interests, quoting Harmon approvingly "...to flourish is to lead the sort of life it is good to lead...the sort of life you want

¹⁰⁷ Wendler's group of human achievements is troubling. Human achievements are part of a person's interests "...even if one never experiences the realization of the achievement and moreover one does not have the realization of that achievement as a personal goal...making contributions to significant human achievements makes for a better life overall." [Wendler, 2010: 134-5]. Firstly, Wendler cites Griffin's example of Bertrand Russell's campaign for nuclear disarmament which came to fruition only after Russell's death. Wendler agrees that the success of disarmament would have been in Russell's interests "...one of the things that is in our interests is to realize our personal goals...some of the more worthwhile ones cannot be realized in the span of a single lifetime." [ibid 135]. The concept of interests persisting after death, is metaphysically troubling. A second problem is that the achievements need not be a goal for the person, which is at odds with the claim that interests are what matters to the person. Wendler's conception seems more perfectionist. There are clear examples of great human achievements that were not in the interests of the individuals concerned. The Egyptian pyramids are staggering human achievements but did not contribute to the interests of the slaves who constructed them. Similarly, from the other end of history, the feat of the Allied soldiers who built the Burma Railway (fictionalised in the film *Bridge over the River Kwai*) great achievement though it was, was not in the soldiers' interests.

your children to lead, as well as the sort of life you want to lead yourself” [Harmon quoted in Wendler, 2010: 115]. Secondly, Wendler’s firmly rejects accounts of interests that depend on personal choice or preference, arguing that “...certain things are of value to individuals independent of what they happen to want or care about.” [ibid 125]. He argues particularly for children that parent’s decisions must be shaped by a general theory of value “...because some lives are better overall *for the individual.*” [ibid 126 Wendler’s italics]. That there are valuable human achievements gives a clear guide to parents for decisions that they must make for their children.

The claim that non-endorsed achievements contribute to an individual’s interests encourages paternalism. Wendler suggest that his typology of interests is not limited to incompetents in stating “...it will be useful to develop a general typology of our interests in which different claims regarding one’s interests can be located.” [ibid 129] and his arguments reinforce concerns of paternalism: “...not everyone cares about making valuable human achievements. Not everyone cares about making the world a better place...the question is roughly whether we should try to adapt such people to our theory to the existence of such people or try to adapt such people to our theory of what is in their interests.” [ibid 137-138]. If Wendler restricts non-endorsed achievements’ contribution to interests to those who are not competent, the paternalistic objection loses force. But, it is unlikely that those who are incompetent will (or should) play a large part in an achievement of sufficient magnitude to be called a human achievement. And if they do they are likely to be involved only passively (that is being directed by others)¹⁰⁸. If this is so, we should take care that the human achievement component of interests does not overwhelm the other components of the child’s interests. A better way to understand the category of human achievement for children would be as a developmental category so that children would (when they become adults) be able to participate in human achievements. Wendler states that a general theory of value is needed so that parents have a guide “The parent tries to direct the child toward certain lives and away from others on the assumption that some lives are better *overall for the individual.*” [ibid 126] and this may be where the category of human achievement fits, in enabling the child to become an adult with the prospect of

¹⁰⁸ Wendler’s typology of interests is used to justify the participation of children in non-therapeutic research of minimal risk.

human achievements. One broad division of interests that is missing is a category of developmental interests. As Wendler's understanding of a good life is summarised in terms of the concept of flourishing this is surprising. It may be that an adult's developmental interests are recognised in his fourth category of personal goals, but this category does not recognise the future-orientated developmental interests of young children, who have yet to formulate personal goals and may be incapable of imagining some of these goals. Slightly older children may have formulated personal goals but these may be immature goals that the child may later renounce as they mature. The interests that are recognized in Wendler's human achievement category may be better recognised as developmental interests.

In conclusion, Wendler's inclusion of human achievements as a component of interests is problematic and should not be accepted. It is again clear that different authors have differing conceptions of interests. This must be recognised when interests are invoked. Wendler's arguments reinforce the distinction between an individual and his life, both of which contribute to a person's interests.

The First and Third Person Perspective

The distinction in perspective between the first person viewpoint and the third person viewpoint was introduced in Kagan's example. Kagan contrasts being well-off (in the first person, how the life is for the person living it) with having a good life (assessed by those around the businessman). Darwall reverses these in judging welfare from the third person, welfare is "...when, in caring for someone, we attempt to work out what is good for her... a perspective we attempt to take *on* the person, whereas the person's own values are what seems good to her from *her* point of view." [Darwall, 2002: 2, his italics]. Welfare, for Darwall, is defined backwards from what follows when a person cares for another, though usually it is recognised that in caring a person acts out of concern for another's welfare. Darwall's description of welfare is close to what Kagan characterises as the businessman's life, which Kagan contrasted with the businessman's well-offness¹⁰⁹.

¹⁰⁹ Others follow Darwall's perspective "We might say that welfare is the type of value that a loving parent has in mind when she looks into the crib at her newborn innocent child..." [Feldman, 2010: 163]. And Scanlon's second conception of well-being is "...what a concerned benefactor such as a friend or parent has reason to promote..." [Scanlon, 1998: 108].

Scanlon recognises that the first person sense of wellbeing is not needed. He argues that the use of the term well-being in the first person perspective as a "...basis for the decisions of a single rational individual, at least for those decisions in which a person alone is concerned..." is unimportant. It has "...surprisingly little role to play in the thinking of the rational individual whose life is in question...in regard to their own lives they have little need to use the concept of well-being itself, either in giving justifications or in drawing distinctions." [Scanlon, 1998:109-110]. An individual just works out what would be best. "...an individual has no need for a theory of well-being that would, for example, clarify the boundaries of this concept." [ibid 111].

A competent person makes decisions about well-being from the first person perspective, (whether or not they use the concept) but when choices are made about the interests of a young child, the third person perspective must be adopted. Although older children's opinion can be taken into account, the determination of the older child's interests is also necessarily from the third person perspective. Obviously, the two perspectives are not entirely distinct: a parent can seek the views of a child when making choices for them, and a competent person may take advice from their friends or others around them. But the two perspectives are distinct in assessing interests. The concern is that in adopting a third person perspective external achievements, and so a good life, will be prioritised over the person's (internal, mental) perspective. The external components of a good life are more apparent to the person who makes the decisions, than is the incompetent's assessment of their own well-being. An incompetent's own internal assessment of her well-being is always subject to review – she is an incompetent. As a person's interests describe what matters to the person, when others decide those who choose must remember that this is the core sense of a person's interests, and if necessary justify their choices.

The importance of the difference between the two perspectives demonstrates that different people have different conceptions of interests or well-being, and that the differences in conceptions may not be appreciated by those using the terms.

Intrinsic and Instrumental Value

An intrinsic good is something that is good for a person just because it is good for the person: it needs no further justification. Instrumental goods are components that are good for a person because they lead (perhaps eventually, not necessarily directly), to an intrinsic good. Instrumental goods provide the means to a valuable end (an intrinsic good) and are valuable because of the eventual intrinsic gain. A medical example is that, being pain free is an intrinsic good (it just is good for the child), whereas receiving a pain-killing infusion to prevent pain after surgery is instrumentally good (in producing the intrinsic good of analgesia).

Kraut argues that well-being (which he equates with welfare) includes only intrinsic, non-instrumental, goods: “When one claims that well-being consists in X...one cannot justify that claim by holding that X is an effective means to something else...it must be non-instrumentally valuable...” [Kraut, 2007: 6]. ‘Interests’ includes both instrumental and intrinsic goods. Because intrinsic goods are directly valuable, they may be more easily justified than are instrumental goods as intrinsic goods can be more directly traced to the child’s interests than those that are only instrumentally good for a child. Instrumental components of a person’s interests may be more open to dispute, but they remain important components of a person’s interests.

The Scope of Things That Can Have Interests

That different authors have different senses of interests is reinforced by the disagreement over the scope of things that can have interests. Sumner asks the question whether a single conception of welfare will apply to all that we can “...speak of the welfare of women and men, children and adults, human beings and animals, without any consciousness of ambiguity or equivocation. But none of this evidence is sufficient to defeat the rival hypothesis that welfare is somehow different in its nature for its different varieties or occasions or categories of subjects. The assumption of welfare must therefore remain just that: an unproven regulatory hypothesis...” [Sumner, 1996: 17].

Wendler’s has a narrow account of interests, applying only to normal, healthy, human beings: “...one can assume that the account endorsed here is an account of human interests...The question of whether the present account of interests applies to dolphins

is not settled in the negative by citing the fact that they are of a different species; the question of whether the present account applies to humans whose brains are profoundly and permanently different from ours is not answered in the affirmative by pointing out that they are of the same species”¹¹⁰ [Wendler, 2010: 123]. Without clear boundaries to his theory, the application of his theory is problematic. Some of the more intractable problems of medical ethics deal with very abnormal people (Tony Bland, or Ashley are examples I have given already). Do discussions about their treatment need a different approach to interests? An account of interests that does not extend to these situations is less useful than one that applies to all. Worse than this, the limits to Wendler’s theory are unclear.

In contrast, Kraut recognises a very broad conception of well-being “To understand the human good, we are asking about a certain property – goodness...it is one and the same relation whether it is entered into by humans, animals, plants or artifacts.” [Kraut, 2009: 3]. Using the argument that well-being is ‘good for’ Kraut argues that there is one conception of well-being but the ‘for’ in good for means that the good is specific to the context in which it is applied, and so well-being is instantiated differently in different contexts.

My concern is that in having very different groups of beings to which their theories apply, these different authors have had different conceptions of interests. The approach that I will use should be applicable to all humans. I see no reason to believe that it will not apply to conscious animals. Again the concern is that these authors understand interests or well-being very differently.

Conclusions

In this brief review I have described that there are multiple terms used synonymously with interests. Sometimes they have been used interchangeably. Sometimes they seem to have different meanings or nuances. Sometimes it is clear that different authors have different conceptions of interests, though this is not always made explicit. A starting point in a discussion of interests must be a stipulation of what interests are taken to be. I will take interests to be what is good *for* someone and this is understood

¹¹⁰ In excluding abnormal humans he errs in calling it an account of ‘human interests’.

from that individual's perspective. Because I am interested in those who are incompetent to choose, the assessment of interests that must be adopted is not the person living the life, it is another person who must make decisions. Despite this the judgment must be (or attempted to be) made from the perspective of the person living the life. What matters is for interests is - in Griffin's succinct phrase - 'life's being valuable solely to the person who lives it'.

There are at least two broad components to a person's interests. The first is that the person should have an experientially good life (Kagan's sense of being well off). The second is that it should be a life that seems good, or (at the least) justifiable from the perspective of a third-person - a 'concerned benefactor' or parent and also from the perspective of the person living the life. Or (reversing the order) there needs to be some external recognition that a person's life is going well and secondly that the person themselves believes that their life goes well (or as we are dealing with children, it is foreseeable that the person will believe their life is going well). Both are important components of a person's welfare. Neither, on their own, is sufficient¹¹¹. One extreme - a life that goes well - with success, respect, and possessions - and yet poor well-being, my belief that *my* life is wasted, is not in my interests. Perhaps I wanted to be an author but am stuck in the wrong path as an (even if successful) accountant. It seems to others that my life goes well, but it does not seem that way to me. The other extreme is a life that the person believes goes well, but which others believe is not 'all a life could be'¹¹². A person's interests involve combining both components: adults assess both their well-being and their lives, and if dissatisfied with either can attempt to change. They can attempt to change their life (by changing job, moving house, undertaking training), or they can attempt to change their assessment of their life (by talking to their friends, talking to counsellors or talking therapies or by taking mood-altering drugs). A competent person determines the balance between these two components of their interests. Those who are responsible for children (and others

¹¹¹ Darwall clearly identifies this conception of welfare: "The normative claim I shall defend is that the best life for a person (in terms of welfare) is one involving activities that bring her into an appreciative rapport with various forms of agent-neutral value such as beauty, the worth of living beings and so on." [p 17 Darwall].

¹¹² Griffin's example, which he uses to argue against informed-desire theories of well-being, is a person who chooses to count blades of grass, regarding this as his life's calling. Though there is no apparent reason for his chosen activity other than his own desires. It is clear Griffin regards the grass-counter's life as poor.

incompetent to make their own decisions) have to balance these components in making decisions.

I will take it that components that are instrumentally valuable contribute to a child's interests, I will not adopt Kraut's approach. I take it that human achievements are not a component of a child's interests, but that they have an interest in developing their abilities so that when mature they will be able to play a role in human achievements.

Before I consider the use of an interests-based standard in making medical decisions for children, I will consider three meta-ethical concerns. Firstly, although there are different meta-ethical approaches to understanding well-being, all have clearly defined problems and none are completely convincing. Secondly although interests are what matters to the person living a life, for children, the person - in a philosophical sense - does not exist, and is to a certain extent under construction. I will discuss the particular difficulties that this causes for children's interests. The final problem that I will discuss is that although much work claims that standards of interests must be subjective, for children, there are strong arguments that approaches to interests must be objective.

4.3 META-ETHICAL THEORIES OF WELL-BEING

An extensive range of academic work in philosophy addresses how well-being (or welfare or interests) should be conceptualised. I can do no more than offer an inadequate summary. Broadly, approaches to well-being have been divided into three groups, none of which are agreed to be satisfactory. Parfit (and others) have classified these as hedonistic theories, desire-fulfillment theories and objective list theories. Although other authors may alter the names of the groups the allocations are broadly the same [Parfit, 1984: 493-502; Sumner, 1996; Griffin, 1986; Crisp 2006]. However, others dispute the classification of meta-ethical theories into these groups [Kagan, 1992: 60; Degrazia, 1995]

Hedonism

Hedonism (or mental statism) has it that a person's well-being is determined by their overall happiness. Some forms of hedonism suggest that pleasure and pain run on a single scale so an overall level of happiness can be generated by a 'felicific calculus'.

There are many objections to hedonism (as classical utilitarianism). Firstly, no single feature unites all the pleasures and pains that a person can experience. Consider the satisfaction of a hard days achievement digging the garden, laughing at slapstick comedy, the pride in a child's achievements, the disappointment of failing an exam, the pain of toothache and the dread of the imminent death of a close relative and then devise a single scale that makes them comparable: there isn't one. One response to this problem is preference-hedonism. Recognising that there isn't a common scale that unites all experiences in terms of pleasure and pain, preference-hedonism adds desire (and its opposite, avoidance) for these conscious states. The experiences that I choose are good, and those I avoid are bad. Those experiences that are avoided more strenuously are worse than those that I make less effort to avoid. Importantly, what is preferred (or avoided) is conscious experience. A person's wellbeing then depends on the balance of good (chosen) and bad (avoided) experiences.

A second objection to hedonism is that there is more to well-being than conscious experience of life. Achievement, for example, may contribute to well-being over and above the pleasure of the achievement. Nozick imagined an experience machine where "super duper neuropsychologists could stimulate your brain so that you would think and feel you were writing a great novel, or making a friend, or reading an interesting book. All the time you would be floating in a tank." [Nozick, 1974: 42]. You choose the experiences that you want. Nozick allowed that you would emerge to reprogram the machine intermittently, but whilst in the machine your experiences are your reality. He asked whether we would choose a life like this, but answered that we would side with him in declining it. He argued that this is because we want to *do* certain things, we want to *be* a certain way and we want contact with a deeper level of reality, not just a man-made pseudo-reality. The conclusion is that "...something matters to us in addition to experience" and that this refutes hedonism [ibid 44].

These arguments suggest that hedonism is at least an incomplete theory of well-being. There are some aspects apart from conscious experience that contribute to a person's well-being, most persuasively, achievements. Hedonism is particularly unsuitable for children. At least some of a child's time is devoted to education (and more if education is understood in a broad sense). The aim of education in the child's interests is to train, develop and teach the child skills or abilities, not primarily to make children happy.

And if so, then hedonism is an unsuitable theory of well-being for children. One response to this objection to hedonism is that although prioritising a child's education is not justified in the short term by hedonism, over the course of a life, an educated child will have a happier life, than one with less education. This is an empirical claim, and would be difficult to prove, and perhaps difficult even to conceive of how the question could be answered. Furthermore, education and training (again in a broad sense) aim at achievement not at happiness. And by developing desires for achievement, education develops a sense of discontent, if not of unhappiness, at least of dissatisfaction. It makes children strive towards the solution to academic problems, or implants the competitive desire to win sporting competitions. If the hedonists answer is that happiness comes from achievement, then this may be true, but the solution to one academic problem generates another: the dissatisfaction remains. And in sports competitions there is only one winner. The other competitors will be (to at least some extent) dissatisfied and unhappy. And even the winner may be dissatisfied if they feel that they competed badly or let themselves down.

Hedonism has one thing right for children: that their conscious experience matters. In past times, the happiness or unhappiness of children was often discounted. The stage of childhood was seen only as a time of preparation for being an adult perhaps best summed up by the response 'it's character-forming' in response to a child's complaints about unpleasant experiences. Childhood's concerns were development, not enjoyment. As hedonism recognises that the experiential quality of the child's life matters, it may correct this bias. However, overall hedonism is an unsatisfactory theory of well-being, particularly for children.

Desire-fulfilment

Desire-fulfilment theories are a second group of theories of well-being. Fulfilled desires contribute to well-being, unfulfilled desires detract from well-being. As desires and their fulfilment are measurable by behaviour in markets and by questioning, this approach appeals to those seeking to measure well-being and have found favour with economists¹¹³. An important difference of desire-fulfilment theories from hedonism is

¹¹³ A medical application of the desire-fulfilment approach is given by Mazor who, in attempting to assess whether circumcision was in a boy's interests asked "One way to

that desire-fulfilment theories depend on whether or not the desires have been fulfilled in real life, not whether the person believes that their desires are fulfilled. Desire fulfilment theories may be developed in different ways to account for some of the criticism to which they are subject.

There are several problems with desire-fulfilment approaches. Firstly, unless the desires contributing to well-being are restricted in some ways, then the theory is intuitively wrong. Parfit gives the example of a traveller, meeting an unwell stranger. The traveller forms the desire that the stranger be cured. Although they never meet again, and many years later, the stranger is indeed cured, without the traveller's knowledge. The stranger's cure fulfils a desire, but it cannot be argued that this contributes to the traveller's well-being. Parfit's solution is that our preferences about our *own* lives should be considered in assessing well-being, calling this the Success Theory. Parfit acknowledges that the limits that this places on desires relevant to well-being are unclear. Parfit recognises that most parents desire that their children's lives will go well, but gives two examples that stand in stark contrast. Firstly, he considers an example that a child dies in an avalanche unbeknown to the child's parent, arguing that this does not affect the parent's well-being. He contrasts this with an example in which a child is mentally unstable or unemployable as a consequence of the schooling the parent arranged intending that the child would have a good start in life. In this case although the parent is also unaware of the misfortunes, Parfit argues that the parent's well-being is worsened. The difference (for Parfit) between the cases is that in the first case although "I might claim that I want to live the life of someone whose children's lives go well...this is not really a desire about my own life." [Parfit, 1984: 494]. In the

approach this question is by looking at the percentage of men who are not circumcised as children and who voluntarily choose to become circumcised as adults." [Mazor]. Here Mazor is relying on a desire fulfilment conception of best interests. He does (correctly) discard this approach to determine the relationship between circumcision and well-being. However, even if a desire satisfaction based approach was correct there are many differences between men and boys so that the satisfaction of an adult's desires need not indicate the correct course for a boy. It may be that the complications of circumcision if delayed to maturity are less than when the operation is performed on a boy, and if so it would be reasonable for an adult to choose be circumcised and yet say 'I was glad that I was not circumcised when I was younger'. Against this, it is often claimed that circumcision is best done in babies as nerve growth is incomplete and so babies feel less pain. I do not intend to argue the best age for circumcision. My argument is that even if a desire satisfaction approach is correct, the satisfaction of an adult's desires do not necessarily indicate where a child's well-being lies. Desire satisfaction theories are unsuitable for children.

second case “...these failure in my children’s lives would be judged on the Success Theory to be bad for me. One of my strongest desires was to be a successful parent...this desire is not fulfilled. My life failed in one of the ways in which I most wanted it to succeed.” [ibid 495]. I disagree with Parfit that there is a difference in parental well-being between these cases. From the parent’s perspective the parent’s desires are neither fulfilled nor unfulfilled to the same extent - they are unaware of their child’s misfortune. From the perspective of the external world, the children in both examples are faring badly. The difference that he may have intended to draw attention to relates to parental intentions. The avalanche-death was an accident: it just happened, it was unrelated to the life-plans that the parents had made for their child. This can be contrasted with the failure of the carefully-planned education: that the other child be well educated was a core concern of the parent, who had devoted time, energy and resources to their child’s education and so the child’s educational failure is a fact about the parent’s failure in their own life. This is not so for the death of their child in an avalanche.

If this was the point that Parfit intended to draw out, it is wrong. If a child is unsuccessful, a parent will reproach themselves for choices that they made, but this is much less important than the fact that the child is unsuccessful. And if a parent whose child was unsuccessful was to concentrate on the choices that they (the parent) had made, rather than attending to the child and her troubles, the parent is, and would be seen as, selfish and self-obsessed. Either way, the important point that I want to make is that it is clear that one problem with desire-fulfilment theories is in the restrictions that must be placed on the desires that count towards well-being. Some limit must be placed on the desires that contribute to well-being in a desire-fulfilment theory.

A second objection is that a person’s desires may be wrong. Fulfilment of a desire need not enhance a person’s well-being¹¹⁴. Sometimes, when a desire is fulfilled we do not like what we get: whatever was ‘desired’ was not really desired. Desires can go wrong at several levels. There may be a factual error: plastic strawberries look real, but taste awful, however much you may desire them. There may be an error of

¹¹⁴ “There is no more melancholy state than the disillusionment that comes from getting what we wanted and finding it disappointing.” [Feinberg, 1984: 84].

reasoning: I thought that I had left plenty of time to get to the meeting, but had forgotten it was rush hour, so I arrived late and flustered and the meeting was a disaster. Another way in which desire fulfilment may fail is if my desire (for a particular sort of coffee, or film) has changed so that when my desire is fulfilled it is a desire that I recognise I no longer hold.

A third problem is that desire fulfilment theory gets the relationship between well-being and desire the wrong way round: desire does not determine whether things will contribute to my wellbeing, my desires depend on the fact that I like and want that which is desired. What is desired will contribute to my well-being. To claim that a successful life is one where desires are fulfilled is an error. Instead of looking at things that are desired we can look (as in objective list theories) for things or experiences or achievements that are good in themselves (these are the things that we desire). A life is successful in so far as we achieve valued ends or things that are themselves valuable, not because we desired and then achieved them. The relationship between value and desire may be still more complex as Griffin explores in *Value Judgement*, 1998.

Adaptive preferences cause a further problem for desire-fulfilment theories. Griffin notes that "...our desires are shaped by our expectations which are shaped by our circumstances" [Griffin, 1986: 47]. Nussbaum described women in India whose expectations have been stunted by pervasive sex discrimination and poverty [Nussbaum, 2000]. Women are treated less well than men in some parts of India, perhaps best demonstrated by the demonstration of 'missing' women [Sen 1990]. The problem for desire-fulfilment theories of well-being is that individuals who have low expectations generated by their circumstances will have a life that is not all that it could be, and yet the individual's (limited) desires will have been fulfilled. When assessed by desire-fulfilment theories, the person's well-being will be judged incorrectly.

More troubling is the way that when children of smokers grow to adulthood, they are more likely in their turn to become smokers [Chassin]. Has the child who becomes a smoker been harmed by his parents just because he becomes a smoker? In one sense parents whose choices make it more likely that a child becomes a smoker have harmed their child. Objectively, smokers die younger, and will suffer more illness in their

shortened life than a non-smoker¹¹⁵ [ASH]. But for a desire satisfaction theorist, the child has not been harmed. Providing the child's desires to smoke are fulfilled, then the child (and the adult she becomes) has benefited (she has more desires that are fulfilled). Perversely, she is harmed only if she develops strong desires to stop smoking, but is unable to do so because she is addicted. She is also harmed if she is stopped from smoking (for example by legal restrictions) even though her health will improve; her well-being is reduced because she has more unfulfilled desires¹¹⁶.

A further problem for desire-fulfilment theories is that desires can change. This presents a particular difficulty for children whose desires change as they mature. Fulfilment of some desires may contribute to a child's sense of well-being both at the time and as they mature ('...I'm glad that I went to the Spice Girls concert even though I no longer like their music...') but the fulfilment of some desires may have only a transient effect on well-being and as desires mature may be seen to be against a person's interests, ('...now I can see that it was a stupid thing to do. I wish I hadn't got the tattoos, I wish I could have them removed but it'll be painful and expensive...'). That an adult's desires change through the course of their adult life is not often discussed, but this is a significant problem for an attempt to hang a theory of well-being on desire fulfilment, and it is a particularly important problem for children.

For all these reasons, desire-fulfilment theories of well-being are ultimately unsatisfactory as theories of well-being. Children cause particular problems for desire-fulfilment theories. Children's desires can be overruled by their parents, and if so are not a reliable guide to where the child's interests lie. An adult's sustained desires are, if not determinative of their interests, at least a strong indicator of where the adult's interests lie. Buchanan and Brock state "...any standard of individual well-being that does not ultimately rest on an individual's own informed preferences is both problematic in theory and subject to intolerable abuse in practice" [Buchanan & Brock, 1986: 33], but children are completely different. Children are immature, with desires that are either unformed (a baby has no desire about the sort of education she

¹¹⁵ Polemically: "Each pack of cigarettes shortens a life by 28 minutes" [Medical News Today].

¹¹⁶ Parfit, 1984 has a similar example.

should have), inexpressible, or for older children at least correctable (the desires of older children may be overridden by their parents and other adults in authority). Even the most heartfelt desire of a child may be dismissed as a mere childish whim. Although it is recognised that adult's desires *may* be incorrect, and there is much discussion of the extent to which desires may be corrected within desire-fulfillment theories, all of a child's desires are taken to be correctable: there is an assumption that a child's desires are correctable (and can be corrected), just because they are children. A child's desires do not offer a clear indication of where their well-being lies.

Objective Lists

A third approach to well-being is to argue that certain things are intrinsically good or intrinsically bad for a person – some things will make a person's – any person's – life go better. And some aspects will make any person worse off. For example any of us will benefit from good health. These theories are named objective list or ideal theories. As with the other approaches, these objective list theories may be developed in different ways. A start can be made from the goods that are needed for healthy survival. Griffin characterises basic needs as "...what we need to survive, to be healthy, to avoid harm to function properly." [Griffin, 1986: 42]. But this does not take us very far. Survival is not enough for a good life, more must be needed on an objective list for well-being¹¹⁷. But as components beyond those needed for survival are added, the presence of some, but not other, components on the list will be questioned. A justification of specific constituents of the list may depend on a broader theory such as Aristotelian flourishing, Hurka's perfectionism [Hurka, 1993] or the capabilities approach developed by Nussbaum and Sen [Nussbaum, 2000, 2011].

It is likely that there will be several different domains to an objective list, for example both personal achievement and happiness are likely to be on any list. More than one

¹¹⁷ And survival may not even be sufficient for a well-being. People make choices that do not prioritise survival, recognising that their life is better albeit shorter if they make certain choices. Examples of this include the choice to smoke, and as a particular example of those who prioritise achievement over longevity Captain Scott's wife (Scott of the Antarctic) wrote to him "...if there is a danger for you or another man to face, it will be you who face it, just as much as before you met Doodles [their son Peter] and me. Because man dear we can do without you please know for sure we can...I want you to know that it wouldn't be your physical life that would profit me and Doodles most. If there's anything worth doing at the cost of your life - do it. We shall only be glad." [Scott, 2013].

sort of component brings the problem of comparability in balancing different components on the list, and with more items the problem becomes more awkward. How (as examples) are friendship, knowledge, happiness and achievement to be balanced one against another?

A further objection to this sort of approach is that it may become elitist: it seems wrong that something (an item on the list) can benefit a person who would, herself, make a different choice. So although a good diet is an important aspect of health which must be on any objective list, someone may scavenge food eating only a little so that she fulfils another goal that is more important to her, saving for a purchase she desperately desires. Her life is better when she eventually purchases her prize even though her health has been harmed and according to the objective list theorist her well-being is reduced. The objection runs that as well-being is necessarily subjective (it means what is good for the person), it cannot depend on an objective list, it must depend on the person's choices in some way. This objection, however, has no traction for children. Others can, and do, override a child's choice justified by the claim that it would be better for the child if the child's decision were overridden.

An objective list seems the most promising approach to take for children's interests. Firstly, the general biological and developmental requirements for a child of any age are more important than any needs that are particular to an individual child¹¹⁸. But, this is not the complete story. As well as these general interests, a child may have particular interests and these fall into two sorts. Firstly, there are particular interests that any child in similar circumstances would share. Examples of these particular interests of a child are those generated by particular biological or developmental needs of an individual child. A diabetic child needs insulin, and a dyslexic child needs a particular approach to literacy education. This group of particular interests is close to the general biological and developmental needs of the child in so far as they are particular needs to function as other children function. The other group of particular interests that children may have are 'subjective' interests generated by the child's

¹¹⁸ "A child's good is more fully determined by the developmental needs of children generally at that age than by his or her current but predictably transient goals and preferences." [Buchanan and Brock, 1990: 228].

parents (or the broader family) and include interests in a religious upbringing, and education or training for a particular achievement in life (that the child should go to university or that the child be a football player). The child's carers and family may generate these particular interests when the child is young, persuading the child that they are important. As the child grows and develops the child may come to endorse these particular interests, but the child need not. One of the problems for children's interests lies in teasing out the way in which this second sort of particular interests can count towards the child's interests. How much authority should be given to a parent's preferences regarding a child?

Conclusion

None of the approaches has universal support: all have significant objections to overcome. It may be that a hybrid theory will be successful.

I will not attempt to solve this problem here but just note that the failure to agree on a theory of well-being undermines the claim that we have a secure grasp on an objective notion of best interests. In the absence of agreement at a meta-ethical level on how to approach well-being, agreement on a normative conception of best interests may not be forthcoming. Degrazia applied the three broad approaches to well-being in two clinical scenarios where decisions are made in the best interests of the patient. Firstly, he considered neonates who have overwhelmingly severe disease such that "survival may not be in their interest" concluding "...objective list accounts can diverge not only from mental statism and desire accounts, but also from each other." [Degrazia, 1995: 58]. The second clinical situation was patients with persistent vegetative state (PVS). He argued that if hedonism is true, a permanently unconscious patient has no interests at all, so decisions must be based on reasons other than the patient's interests, including economic reasons, or the family's choices. In applying desire-fulfilment theories, he argued that the experience requirement must be abandoned to argue for an interest-based approach for clinical decisions for patients with PVS, and if the experience requirement is abandoned, this approach leads to decisions based on a substituted judgement. And finally in considering objective list accounts for patients with PVS he concludes "What is striking here is how differently these objective list approaches might interpret a PVS patient's best interests, without any of them being clearly unreasonable." [ibid 60]. Degrazia's analysis points to problems at two levels, firstly differences between the three broad approaches lead to different conceptions of

interests. Secondly, different versions of each of the broad approaches (as Degrazia notes is particularly true for objective accounts) may lead to different assessments of patient's interests and so lead to different courses of action. If his analysis is correct, then at least some disagreements about the best interests of children may remain intractable.

Therefore, although disagreement at a meta-ethical level may seem a long way from clinical practice, unless there is agreement at this level, then agreement at a normative level and then agreement in clinical practice may not be achievable. And importantly the source of disagreement may not be acknowledged. Neither side in a dispute appreciates that the disagreement is in what they believe interests to be, and although both believe that they are arguing about an individual's best interests (or even Best Interests) they are focused on different conceptions of interests. And if this is not recognised, then the disagreement stands no chance of resolution. However, if the nature of the dispute is recognised it may be possible to agree how the child's interests are best represented and understood.

4.4 THE PERSON

If Griffin's characterisation of well-being as "...the narrower notion of a life's being valuable solely to the person who lives it." [Griffin, 1986: 21] is accepted, it generates the difficulty that for some young children, and certainly for babies, there isn't a person (in at least one philosophical sense) whose well-being is to be considered. The *person* is being constructed or developed or is developing. And this means that what will be in a person's interests will depend (to at least some extent) on how the child is treated as they develop. Treating children in one or another way may determine the interests of the child (and later the adult the child becomes)¹¹⁹.

This problem is different from the extensively discussed problem of the harms that may (or may not) be inflicted on children selected by the application of novel

¹¹⁹ Brody argued that best interests could not inform the choices that must be made for babies in arguing "Once we move beyond very basic needs...we cannot know what is in someone's interests without knowing a good deal about that person's individual plans and desires. But a newborn infant is much more a promise of preferences and plans to come than it is the sort of entity for whom those things could be known in advance" [Brody, 1988: 38].

reproductive technologies. A claim in IVF cases is that children¹²⁰ who are born following the selection of particular traits as gametes or as early embryos have not been harmed unless their lives become so awful that that they would be better off if they had never existed¹²¹. If it was not for antenatal selection, a different child, and so a different individual, would have been born. The child that is born (even with disease or disability) is genetically determined to have the disease. Regardless of the success or not of this argument, the problem here is different. There is a recognisable individual who is not yet a person, and in the course of that child's upbringing that recognisable individual can be harmed or benefited. The further problem with children is that the way the individual is treated will determine (in uncertain ways) the person the child will become and the interests the child comes to have.

¹²⁰ Talk is always of designer babies or children, and not of designer people or designer, or designed, adults. As examples of this: Jonathon Glover's book *Choosing Children*, Stephen Wilkinson's *Choosing Tomorrow's Children*, John Robertson's *Children of Choice: Freedom and the New Reproductive Technologies*. Perhaps this is for different reasons. Firstly, it may be humility: a parent chooses to bring a child up in certain ways to develop particular values, but may recognise that the values they seek may not develop in the child. In the same way selecting for certain traits may fail to generate those traits. Secondly, it may be that one particular meaning of 'child' is used. This is 'child' understood not as young human being, but in the sense that even when she is 45 my daughter remains my child. Would the sense and concerns be different if the titles were *Choosing People* or *Choosing Tomorrow's Citizens*? I believe that the arguments are different when adults, not children, are considered. For example, Savulescu, argues for procreative autonomy "...value judgment should not be imposed on couples who must bear and rear the child. Nor should the value judgment of doctors, politicians, or the state be imposed directly or indirectly (through the denial of services) on them. The Nazi eugenic programme imposed a blueprint of perfection on couples seeking to have children by forcing sterilisation of the 'unfit', thereby removing their reproductive freedom. There are good reasons to engage people in dialogue about their decisions, to try to persuade them with arguments, but in the end we should respect their decisions about their own lives." [Savulescu, 2002: 772]. The last sentence of Savulescu's argument indicates that he sees the parental reproductive decisions as being solely about the parents' own lives. It is true that the decisions are about the parents' lives, but they are not decisions *solely* about the parents' lives, there are important effects on the lives of the children and the adults the children will become. And in recognising that other lives are altered, the consequences are not limited to the parent's life and so are subject to scrutiny that decisions that affect only the parent's lives would not be. Although those who argue for reproductive freedom do so on the basis that an individual cannot have been harmed by her parent's procreative choices (unless their life is so awful that they would have been better not born), harm is only one component of our moral lexicon. If the best that we could say of parents was that they had not harmed their child, they would be poor parents.

¹²¹ In general it is accepted that being alive is good, although in *Better never to have been: the harm of coming into existence*, Benatar argues that "...coming into existence, far from ever constituting a net benefit, always constitutes a net harm." [Benatar, 2006: 1]. This is a minority view.

There are some approaches that may be clearly in a child's interests, and others that are clearly against them. For example, a 'healthy' diet that ensures optimal physiological growth is in a child's interests. Similarly, 'appropriate' education ensures that the child is emotionally and intellectually appropriate for their developmental progression and will become equipped for adult life. Disturbance to either of these so that the child is physically or emotionally stunted is clearly against a child's interests. There are other aspects of upbringing where the benefits and harms for a child are contested. A clear example of a contentious case is male religious circumcision. Some argue that circumcision is in the child's interests, others the opposite. To take the first position, a boy benefits from circumcision as they may fully take part in their parent's religion and culture. And having grown, to maturity as an active member of the socio-religious community, the man now endorses the fact that he was circumcised, recognising that it was firmly in his interests to have been circumcised, along with all the other commitments to religion that were made by his parents which were also subsequently validated by the grown child's choices to become a full and active member of that religious community. However, the 'same' child born to less religious parents, who remains uncircumcised at birth and is brought up in less devout circumstances may be equally happy with his existence, relishing his freedom from religious indoctrination. And similarly when grown to maturity he delights in his multi-cultural existence, interacting with many friends from different backgrounds, exposed to a richer variety of opinions, food and cultural experiences. A retrospective evaluation by the adult the child becomes is an inadequate justification for the claim that the interests that have been inculcated in the child were in the child's best interests. Retrospective endorsement (or criticism) of parental choices based on the mature child's judgement need not mean that the decisions that a parent made was in the child's interests.

This problem is sometimes characterised as one involving the limits to the extent of parental authority to make decisions for children. Feinberg argued for limits to parental freedom to choose religious education bounded by the child's 'right to an open future' [Feinberg 1980]. Feinberg phrased his argument in terms of children's rights, though he noted particular problems with children's rights. Not all children's rights pose problems; some (A-C rights) are common to adults and children, (the right not to be mistreated or to be stolen from). The second group of rights listed by

Feinberg belong only to adults (A-rights) and include "...rights to vote, to imbibe, to stay out all night..." [ibid 125]. The third class of rights is characteristic of children (C-rights) and has two subclasses. First, dependency-rights derive from children's needs for the essentials of life. The second class of C-rights is rights-in-trust. These rights resemble adults' autonomy rights but as a child cannot exercise autonomy rights, these are "...rights that are to be *saved* for the child until he is an adult, but which can be violated 'in advance,' so to speak, before the child is even in a position to exercise them...His right while he is still a child is to have these future options kept open until he is a fully formed self-determining adult capable of deciding among them...rights-in-trust can be summed up as the single 'right to an open future'..." [ibid 125-6].

In Feinberg's analysis, children's rights are justified by the child's interests. A-C rights protect current interests "...the child's good *qua* child right now." [ibid 127]. The child's interests for the future "...those that he will in fact come to have in the future and also those he will never acquire, depending on the directions of his growth." are protected by the child's rights-in-trust. As the child's right to an open future can conflict with other rights "Respect for the child's future autonomy, as an adult, often requires preventing his free choice now." [ibid 127]. As well as this, a child's C-right-in-trust can conflict with a parent's A-right of authority (the parents' "...right to control their child's upbringing, or to determine their own general style of life, or to practice their own religion free of outside interference." [ibid 128]). He illustrates the conflict with examples of religious education, where an upbringing chosen by parents may constrain the opportunities available to the child once they have grown up. Feinberg argues for an education that "...should send him out into the adult world with as many open opportunities as possible, thus maximizing his chances for self-fulfillment." [ibid 135]. This is the child's right to an open future, a summary right of the child's C rights¹²².

¹²² Nussbaum arrives at a similar position albeit by a different route. In the 'capability approach' Nussbaum argues that although adults should have the capability to function in certain ways, that reflect what it is to be human, they should not be obliged to exercise their capabilities (they need not, for example, vote, though they should have the abilities that underlie voting and so the capability to vote). However, for children Nussbaum argues "If we aim to produce adults who have all the capabilities on the list, this will frequently mean requiring certain types of functioning in children, since, as I have argued, exercising a function in childhood is frequently necessary to produce a mature human capability...functioning in

Feinberg addressed the problem that the child's dispositions, habits and tastes develop through childhood and depend on the child's environment, which is at least partly determined by parental choices. So the child's parents determine (at least partly) the characteristics the child develops and so the adult the child will become. As Feinberg sets the scene: "If the grown-up offspring is to determine his own life and be at least in part the product of his own 'self-determination' he must already have a self fully formed and capable of doing the determining. But he cannot very well have determined *that* self on his own, because he would already have to have been a formed self to do that, and so on, *ad infinitum*." [ibid 148, Feinberg's italics]. Feinberg described this as a paradox, either of self-fulfilment (which he takes as the best description of welfare) or of self-determination. Having described the paradox, he argues that the paradox he describes does not exist, describing that the child's character is not 'wholly unformed' nor are his traits and dispositions 'entirely plastic'. Feinberg suggests that the child plays a part in a process of gradual and continuous development allowing that a "...loving upbringing and a human social environment in the earliest years will be like water added to dehydrated food filling it out and actualizing its stored-in tendencies...At a time so early that questions of how to socialize and educate the child have not even arisen yet, the twig will be bent in a certain definite direction. From then on, the parents in promoting the child's eventual autonomy and well-being will have to respect that initial bias from heredity and early environment." [ibid 149]. In this way, because the child will determine the course of his upbringing, Feinberg can escape from the paradox of child development that he has posed.

There are problems with Feinberg's escape-route from his paradox. Firstly, it depends on parents espousing the core liberal value of self-determination, and as well as this the child's parents must be committed to providing the child-centred upbringing that Feinberg describes. This need not be so "Parents beget, bear and raise children to fulfil certain aims, sometimes eccentric or personal." [Ruddick, 1979: 125], being a

childhood is necessary for capability in adulthood. The state's interest in adult capabilities gives it a very strong interest in any treatment children that has a long-term impact on these capabilities' [Nussbaum, 2000: 90].

parent is not just about the child. Some parents may have fixed goals for their children, perhaps that they play football for England, or that they worship one particular God. These parents do not hold self-determination to be valuable (or they may value self-determination, but only within their limits. It is self-determination ‘up to a point’). Self-determination is not a core value for all parents. As an example of this, Chao describes the clear distinction between the parenting of Chinese–American culture described by Chinese-American mothers reporting the importance of “...the value and honor of the whole family...” [Chao, 1996: 412] which Chao distinguishes from the child-centred parenting which she finds in American parents, whose dominant sentiment was that education should be enjoyable. If parents do not value self-determination, then the open future that Feinberg cherishes is not guaranteed.

A more fundamental criticism is that it is not clear that a right to an open future is coherent. There are several different objections that can be made. Firstly what does an open future mean? Does a more complete sporting education so that a child is able to choose between several different professional sports careers offer a more open future than an education that enables a child to play only one sport but to choose between life as a physician or sportsman? The first child has more options and the second child has only two options, but the two options encompass much broader life-styles.

And what does it mean to say that an option is open or closed? Most choices that are available to individuals are more or less possible, not open or closed. And this leads on to the problem that any choice that is made for a child will make some options more likely but others less so. Any choice that is made for a child limits options “...it is simply impossible to keep our options open: They close every day, as we make choices to spend our time this way rather than that, to pursue *x* rather than *y*.” [Mills, 2003: 500]. So consider the example of a promising child gymnast. At some stage in his early teens to progress as a gymnast he needs to train for longer periods and this will constrain his time at school, limiting his academic achievements. And if he does not train for these longer times, he will not be a world-class gymnast. But if he does train more diligently, he will not achieve the academic standard he would if he attended school full time (and these are achievements he may need if his gymnastic career fails, or he becomes injured). And if both options are kept ‘open’ by missing some school, but not enough to train as hard as he could, he will not achieve what he is

capable of, neither in scholastic ability nor in gymnastics. For all these reasons, the right to an open future is unhelpful.

Much of the discussion of the right to an open future involves children's education and particularly religious education, but there are several medical examples of the problems in attempting to keep the future open for a child. I will give two. The management of children with intersex genitalia (now named disorders of sex development, DSD) is one example. The traditional approach was early gender assignment and early surgery [Crawford et al, 2009], but this has been criticised, because some who have undergone the traditional approach believe that they have been assigned to the wrong sex. The proposal is that gender assignment should be delayed: "Any surgery should be deferred until the individual has developed a narrative sense of self that incorporates a sexual identity."¹²³ [Baker, 2013: 322]. This may well not be possible because some surgery is needed in some children in a timely fashion to prevent damage to kidney function. This approach protects the child's right to an open future, but is not an untroubled approach as sex (or gender) is an important part of a person's identity. The first response to the announcement of the birth of a baby is usually '...ooh boy or girl?' And if a straightforward answer cannot be given then all involved find it difficult. From birth, children are gendered (blue for boys and pink – sometimes lots and lots of pink – for girls) and as children grow they adopt gender roles, these roles become more strictly defined as the child grows (a father could take his two year old daughter into the male changing rooms at the swimming pool, but not his twelve year old daughter). There are two reasons why an open future is difficult. Firstly, sexual identity is such an important part of identity, that just to be a member of society, a child has to be male or female: it is required in social interactions. The second reason is that children learn how to be a boy or girl, through being a boy or a girl. They develop by participating in play or work or sport or whatever as a male or female, not by trying either role and choosing one that suits¹²⁴. Children learn progressively to be female or male, building on what they have learned

¹²³ An approach that has also been reported for a child without DSD, where parents attempted to raise a gender neutral child, though their attempt ceased at primary school entry [Alleyne, 2012].

¹²⁴ Schapiro regards the 'work' of children as the trying on and development of their selves: "By engaging in play, children more or less deliberately 'try on' selves to be and worlds to be in." [Schapiro, 1999: 732].

at earlier stages, through their own development growing older until they eventually adopt mature adult gendered roles (recognising that these roles may be of many kinds and are varied and that the adult roles themselves may change as adults themselves mature, and as they and societies change). Male and female roles are so complex and multifaceted that it would not be possible for a child to develop both roles, male and female, and then choose one or the other. Furthermore, because the roles develop by interacting with others *as a boy* or *as a girl*, a child develops as a girl, to be an adult woman, by being a girl. The claim that a child could be brought up with an open gender assignment is problematic.

Deafness gives another example of the difficulty of maintaining that there is a right to an open future. Recently the Deaf (with a capital D) have asserted that they are different, not disabled (there is an analogy with the claims for Black culture). Deaf culture has flourished and the Deaf are proud of their abilities in communication in particular ways. Two broad strategies for deaf children have developed and are now in competition. Firstly (and traditionally) oralism encourages the use of spoken language. Hearing aids (and now cochlear implants) maximise the child's ability to hear, and are combined with intensive speech therapy (the time commitment to speech training may compromise other aspects of education so that often educational achievement is limited). In some cases, to encourage children to interact with spoken language, signing is banned. Some deaf children, particularly those with some hearing achieve success with this route, but others, especially those with profound deafness don't. The second strategy is to embrace Deaf culture. This involves encouraging signing and rejecting attempts at spoken language. In Deaf culture, oral communication is ignored or resisted. Deaf culture is celebrated and communication may be fundamentally different: think of poetry in sign language. As a result there are two separate paths for deaf children: oralism or Deaf culture. The earlier a person starts to sign, the better their signing becomes. And this is true also for speech and hearing, the earlier that training starts, the more able the child becomes. For example, the sooner that Cochlear implants are placed (preferably before the age of two), the better the child hears [Kral & O'Donoghue, 2010]. Compounding this, those who have some hearing or use verbal communication are not taken to be 'properly' deaf and may be excluded from the Deaf community and the reverse may be true in which those who sign are excluded from groups more comfortable with oral communication. Parents of deaf children have to

choose which approach to take when their children are young. On the one hand, taking deafness as a disability and embracing the hearing world will cause the child to be (at the least relatively) excluded from Deaf culture. Alternatively parents may embrace the Deaf culture turning to signing, but if so they limit their child's interactions with the hearing world¹²⁵. Deaf parents are at some advantage. They have their own experiences, and knowing the possibility of inherited deafness they will have considered the options should a child be born deaf (and indeed some have chosen a deaf child¹²⁶). Their choices may be constrained as the deaf community may have expectations of the choices that deaf parents should make. Hearing parents are unlikely to be familiar with deafness and its management. As well as this, their recognition of their child's deafness is likely to be slower than the child of deaf parents. Parents of deaf children have very important choices to make at an early stage in their child's lives between two fundamentally different approaches. "Deaf people in the hearing world are always going to be at a disadvantage. So the question is whether people prefer to be marginal in a mainstream world, or mainstream in a marginal world and many people quite understandably prefer the latter." [Solomon, 2013: 107]. I don't want to argue which of these two courses are best for a child, what I do argue is that this example demonstrates that children have, at best, only a limited right to an open future. In the case of a baby who is profoundly deaf, parents have to choose one or other approach, if they aim to keep both options open - because of the child's right to an open future - neither will work well, the child will have poor verbal communication and poor signing communication.

These two examples emphasise clearly the choices that parents (and others) must make and undermine, to at least some extent, the notion of a child's right to an open future. In at least some situations, a claim for an open future cannot be correct, parents must choose one course or other course. Choosing one approach, excludes the other, and

¹²⁵ "Some deaf people choose only to interact with other deaf people...from my point of view the real world is the hearing world, and when you leave school you're not going to get a job working for an organization where everyone is deaf." Mat Gilbert, a 'profoundly' deaf rugby player [Ackford, 2014].

¹²⁶ "A deaf lesbian couple in the United States deliberately created a deaf child. Sharon Duchesneau and Candy McCullough used their own sperm donor, a deaf friend with five generations of deafness in his family, to ensure that their child would be deaf." [Savulescu, 2002: 771].

opting for the middle ground might be even worse. However, Feinberg's right to an open future is important in recognising that some decisions restrict a child's options, without opening other options, and these cannot be justified in terms of what matters to the child and to the adult the child becomes. The importance of Feinberg's right to an open future is that it encourages parents, and those in authority, to leave those decisions that can be left until the child is mature and so able to make their own decisions.

4.5 SUBJECTIVITY AND WELL-BEING

Introduction

Many conceptions of well-being depend on the assessment of the individual living the life, and so in one sense are subjective. This characterisation of well-being is broadly accepted and is required if well-being is taken to be what matters to the person living the life. It follows from this approach that well-being has to be subjective; that is, that it depends on an assessment by the person whose life it is. Against this, I will argue that subjective conceptions of well-being are inadequate for children. If this is true, and because children seamlessly develop into adults, it suggests that conceptions of well-being for adults must be objective too. I consider some objections to the claim that children's well-being is subjective, arguing that none are successful.

There are a number of examples of the way that many of those who written on well-being describe it as being subjective. For example, Feinberg states that "...a majority view that seems to me highly plausible would identify a person's good ultimately with his *self-fulfillment*...Self-fulfillment, so construed, is not the same as achievement and not to be confused with pleasure or contentment, though achievement is often highly fulfilling, and fulfillment is highly gratifying." [Feinberg 1980: 143 Feinberg's italics]. Raz writes "...people enjoy a good life to the extent that they succeed in the wholehearted pursuit of their *adopted* relationships and goals" [Raz, 2004: 279 my italics]. Scanlon writes of well-being that "...adequate criteria must allow for the fact of *individual variation* in taste and interest. (I leave aside for the moment consideration of the various ways in which this might be 'allowed for.')" [Scanlon, 1975: 655 my italics]. Sumner writes that "...well-being...requires that a *subject's endorsement* of the conditions of her life, or her experience of them as satisfying or fulfilling be authentic." [Sumner, 1996: 139 my italics]. Buchanan and Brock argue

“...any standard of individual well-being that does not ultimately rest on an *individual’s own informed preferences* is both problematic in theory and subject to intolerable abuse in practice” [Buchanan & Brock, 1986: 33 my italics] and “...on all three kinds of theories it makes perfectly good sense to speak of persons’ ...well-being as a subjective matter.” [Buchanan and Brock, 1990: 34]. The British Medical Association states it most explicitly, “Competent adults are allowed to define their own concept of ‘best interests’, even if their views are very different from those of the rest of society.” [Ethics Department BMA, 2003: 136]. And from the Royal College of Paediatrics and Child Health suggest that “Adults are usually presumed to have the ability to determine for themselves what their own (best) interests are” [Larcher, 2015: s10]. In a discussion of male circumcision, two German academics write “...in modern multicultural societies, what constitutes a ‘good’ life remains highly subjective and is usually accepted by the society” [Aurenque and Wiesing, 2015: 207]. And finally, “As rational people, we should all form our own ideas about what is the best life. But to know what is the good life and impose this on others is at best overconfidence—at worst, arrogance.” [Savulescu, 2002: 773]¹²⁷. Although the authors use different approaches and express it in different ways, what links them is that in all these examples well-being depends on the individual’s point of the view. Their conceptions of well-being are subject-dependent.

Subjectivity

Even if it accepted that commentators on well-being generally defend the subjectivity of well-being, it is clear that ‘subjective’ (and its contrasting term, objective) have unsettled and contentious meanings¹²⁸. And in their common use, although subjective

¹²⁷ Overwhelmingly, the approach taken in discussions of well-being is that a person’s well-being is subjective, but some commentators disagree so for Darwall “...a person’s good is a different thing from what she holds good, either actually or rationally, even from her own point of view.” [p1 Darwall, 2002: 1]. And Brighouse and Swift state “Well-being is objective, not subjective; things can be good or bad for people without their realising it” [Brighouse and Swift, 2014: 52].

¹²⁸ Wiggins offers this example of the problem: “A paradigmatic instance of the objective would be the question of the outdoor temperature at Kew Gardens on May 20th, 1993 at noon G.M.T.. A representative instance of the subjective would be the fairness or otherwise of the scales operative on that day for the remuneration of the grades of gardener employed there on that day... The right reply is to ask what it is that the first instance is meant to be paradigmatic of and what the second instance is meant to be representative of. Until we know that, examples can scarcely clarify the distinction that purports to be introduced here. Is the objector’s

and objective are taken to be jointly exhaustive and mutually exclusive, unless they are carefully defined, this is unlikely to be true. Sumner writes "...the concept of the subjective is one of the most treacherous in the philosopher's lexicon ...subjective has been delineated by means of a number of features: privacy, immediacy, incorrigibility, unverifiability, unquantifiability, relativity, arbitrariness, reliance on judgement or intuition, and immunity to rational arbitration. Since each of these features is logically distinct from all the others, each would draw a different boundary between the subjective and the objective." [Sumner, 1996: 27]. For ease of discussion, I will use Sumner's definition of subjectivity and objectivity. The boundary that Sumner draws is that subjectivity depends "...at least in part, on some (actual or hypothetical) attitude on the part of the welfare subject...Objective theories deny this dependency. On an objective theory, therefore, something can be (directly and immediately) good for me even though I do not regard it favourably...objective theories do not merely deny the sufficiency of a reference to my attitudes in an analysis of my well-being, for most subjective theories would join in this denial. The crucial differentiating question is the necessity of such a reference" [Sumner, 1996: 38]¹²⁹.

Having characterised the distinction between objective and subjective theories of welfare, Sumner argues that there is no "...prospect of constructing a descriptively adequate objective theory of welfare." [Sumner, 1996: 80] and so for Sumner theories of welfare *must* be subjective: welfare is prudential, objective theories are necessarily perfectionist and do not describe what matters to the person living the life. Having explored subjectivity, and how I will understand it, I now turn to children's welfare.

distinction of objective and subjective intended to sort things into two mutually exclusive kinds? (In which case more needs to be said about whether there are degrees of objectivity and more needs to be said about why the second example cannot aspire to any degree of objectivity.) Or is it a distinction that sorts into two only presumptively non-overlapping kinds? (In which case more needs to be said to argue the non-overlap of their extensions.) Or is it a distinction like that between being an animal and a mouse, where the things distinguished are indeed distinct but being a mouse is simply a special case of being an animal? (There are other possibilities again.)" [Wiggins, 1994: 248].

¹²⁹ Wendler develops a conception of interests and writes "I will argue for an account of human interests situated in the conceptual space between fully subjective accounts, according to which one's interests are fully determined by or dependent in some strong sense on one's individual mental states, and thorough going objective accounts, according to which our interests are facts...Our interests in many cases are influenced by, but are not determined fully by our preferences, by what we want and desire." [Wendler, 2010: 112]. For Sumner, Wendler's theory is subjective.

Children's Welfare

Young children are unable to express preferences about their interests, and although the views of older children can be heard to "...assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child" [United Nations 1959] even here the preferences of older children are not determinative of what is taken to be a child's interests (as an adult's choice would be). Whoever is choosing for the child, must incorporate the child's views (if, or as, they are able to express them) in an assessment of the child's interests, giving due weight to the child's views¹³⁰. But regardless of this, the child's interests must be determined by someone else. A parent or other adult determines the child's interests. As Hester phrased it "...whatever Best Interests is supposed to amount to must be imported from sources other than the individual patient" [Hester, 2007: 358]. The challenge, then, is to reconcile the claim that theories of welfare are necessarily subjective and yet they cannot be for children because young children cannot 'take an attitude' to the components of their welfare and the attitude that older children take to components of their welfare is subject to review by their parents. So for children, either we must accept an objective standard of well-being, or we must allow that the 'adoption of pursuits' is adoption of pursuits by someone other than the individual whose well-being it is. The individual variation in taste, is not the variation in the individual's taste but the tastes of their parents or the relevant adult making the decision.

When decisions are made for children, the standard that is usually advocated is that the decisions should be in the child's interests or the child's best interests. If welfare is

¹³⁰ The weight given to the child's views will be proportionate to several factors. Firstly, the maturity of the child: a more mature child's opinions will carry more weight. Secondly, there is a variable relationship between the child's views and the child's overall well-being: some beliefs may be at the core of a particular child's overall well-being, but others may be more peripheral. For example, a strongly academic child's participation in a particular sporting event is less central to the child's well-being than the participation of one with strong sporting potential but limited academic potential. A further factor is the depth of conviction. An opinion expressed passionately by a child particularly strongly about a topic should bear more weight. These factors are child-centred. Other facts, the parent's busyness, or concern for another child may also determine the extent to which the child's voice is heard.

necessarily subjective, and as parents usually make decisions for their children, there would be no reason to override a decision made by parents based on the parents' assessment of the child's interests. Parents could be reasoned with (perhaps to demonstrate to the parent that their reasoning was faulty) and perhaps the parents could agree that they had been wrong, and if so the choice that was made for the child would be changed. But if the parents maintained their decision about their child's interests, if interests are necessarily subjective there are no reasons why the parents' decision should be overridden. However, it is clear that parents can be wrong in the decisions that they make about their child's interests (as they can be wrong about their own interests). Some decisions that are made for children are clearly against the child's interests¹³¹. For this reason, children's interests cannot be subjective.

Responses

Firstly, one response is to reject the claim that welfare is subjective, relying on Sumner's characterisation of the subjective as "...some (actual or hypothetical) attitude...". The response is that a child's well-being can be subjective and that it is subjective because the standard can be justified by a *hypothetical* attitude. Sumner does not describe in any detail what he means by a hypothetical attitude and so what he means is unclear. What Sumner may have had in mind is the attitude that the mature child will come to adopt when he is able to. I have argued already that the attitude of a grown child cannot be used retrospectively to justify the choices that were made for an immature child and so this approach will not work.

Secondly, we can accept an objective conception of a child's welfare. This seems more plausible, and others have argued for this view¹³². Children need to develop and

¹³¹ Sometimes when decisions are made for children that are clearly not in the child's decisions, the parents have paid no attention to the child's interests or are acting against their child's interests (most clearly when parents have physically injured their children in non-accidental injury). Sometimes parents are considering the child's interests and make choices that are clearly wrong. An example of this would be when Jehovah's Witnesses' deny a blood transfusion to their infant.

¹³² Buchanan and Brock argue "A child's good is more fully determined by the developmental needs of children generally at that age than by his or her current but predictably transient goals and preferences...efforts to promote children's well-being focus prominently on fostering these abilities and opportunities so that as adults they will be able to choose, revise over time and pursue their own particular plans of life, or aims and values, now suited to the adults they have become" [Buchanan and Brock, 1990: 227-8] and their reasons are that "The general point is

grow physiologically, psychologically and emotionally amongst other ways. And there are ways in which a child's development can be normal and ways in which it can be abnormal. There is broad agreement on factors that are important for the survival, healthy growth and development of children (which should improve their well-being). There is a broad agreement on the factors that damage children's prospects for healthy development (and so damage their well-being). There may be a range over which a child's needs can be met, but there are clearly some aspects which lead towards healthy growth and development and some aspects which clearly harm children. This leans towards an objective conception of children's well-being.

This argument makes the case only that the welfare of children is objective. Is this also true for the welfare of adults? As children change gradually and seamlessly into adults, it would seem reasonable to accept that if there is an objective conception of welfare for children, this would also apply to adults. If there are to be two different conceptions of welfare, one for children and one for adults, there should be a reason for this. Sumner did not intend a different conception of interests for children and adult. He stated "...our welfare vocabulary applies just as readily to children and infants." [Sumner, 1996: 14]. One reason to reject an objective conception of well-being (at least for adults) is that it may lead to paternalism. If well-being is objective then others may know better than a person what is best for a person's well-being and so should intervene on the basis of that person's well-being. This is true if well-being is objective. It is widely recognised by those who defend desire-satisfaction theories, that some of our desires may be wrong (and uncontroversially wrong in the sense that the person themselves can recognise that the desire was wrong, perhaps as a consequence of faulty perception or reasoning) and so by analogy our assessment of our own well-being may, too, be wrong. However recognising that well-being is objective does not necessarily lead to paternalism. Firstly, we could accept an objective conception of well-being for children but deny that this is true for adults. This sets a major distinction between adults and children. I have argued that in the absence of good reasons to separate them, a similar conception of well-being should be used for both

that children's well-being depends less on their current individual preferences and more on the objective conditions necessary to foster their development and opportunities than does the well-being of adults." [ibid 228].

children and adults and so I do not believe that this is the correct response. Secondly, we can accept an objective conception of well-being but regard self-determination as an important value too. Concern for self-determination prevents coercive intervention by others on behalf of the well-being of an adult, but need not for children. In this way, recognising that well-being is objective does not necessarily lead to paternalism.

Thirdly, we can maintain the claim that interests are necessarily subjective, but claim that parents (and more widely adults or society more broadly) have to choose (to a certain extent) what is best for a child¹³³. To a certain extent in two ways. Firstly, there may be a mismatch between what parents intend in regard to a child's interests and what they produce: attempts to instil a love of the outdoors, by exposing the child to the hills and the sea may instead cause the adult the child becomes to prefer a good book by the fire. Secondly, it will be reasonable to place a limit on the choices that parents can make for their child, and the limits to how parents rear their children are justified in two ways. Firstly, one sort of justification is child-centred, recognising that certain abilities are needed to become an adult rights holder, or a person who acts with moral agency. And if so, children should be brought up in ways that make them able to become adult holders of human rights or able to act with moral agency, whichever skills are taken to characterise mature adults. The second justification depends on the abilities that are needed for an adult to function in society. A constraint on the way that children are reared is the need to create functional future members of society. If children are not brought up to be able to function as citizens, then society will be dysfunctional, which will impair the welfare of the adult that the child has become, and the other members of society. There will be a considerable overlap between these two justifications, one child-centred, the other society-centred.

¹³³ Savulescu claims a Millian justification for this freedom "Reproduction should be about having children who have the best prospects. But to discover what are the best prospects, we must give individual couples the freedom to act on their own value judgment of what constitutes a life of prospect. "Experiments in reproduction" are as important as "experiments in living" as long as they don't harm the children who are produced." [Savulescu, 2002:772]. Mill himself, however was less sanguine in writing, of parents "It still remains unrecognised, that to bring a child into existence without a fair prospect of being able, not only to provide food for its body, but instruction and training of its mind, is a moral crime, both against the unfortunate offspring and against society; and that if the parent does not fulfil this obligation, the State ought to see it fulfilled, at the charge, as far as possible, of the parent." [Mill, 2002: 109].

If it is true that there are limits to the ways that children are brought up then we have returned to an objective conception of well-being (albeit with a range of acceptable options), and so both of the responses to Sumner's characterisation of the subjective leads back to the claim that well-being, at least for children, is necessarily objective.

Conclusion

I have argued and demonstrated that subjective conceptions of well-being are widespread. I have argued that conceptions of children's well-being cannot be subjective, and that in the absence of a clear distinction in a conception of well-being between adults and children, this suggests that a subjective conception of well-being, even for adults, is incorrect. The latter is an argument that will not be easily resolved. However, it is important to recognise that the conception of children's well-being is objective, as I have argued, and if so there can be correct and incorrect conceptions of a child's well-being. And if this is true, decisions made for children (necessarily by others) may be wrong and should be corrected if they are wrong. The important component of objectivity here is corrigibility: wrong decisions regarding children can and should be corrected.

In this section have argued that although there are problems at an abstract or philosophical level with the use of a child's interests when making medical decisions, these can be overcome. I will now turn to some more practical problems which may be a concern when making medical decisions, using the child's best interests.

4.6 PRACTICAL CHALLENGES TO THE APPLICATION OF BEST INTERESTS IN MEDICINE

There are several practical problems that may be a concern when making medical decisions for children. These problems include that the child's interests are indeterminate, that they are unknowable, that a best interests standard is too demanding, and that decisions should be based on family interests. I will consider these in turn.

Indeterminate

In determining a child's medical treatment, a strong, robust, impersonal, notion of interests is needed, much more so than is required for adults. When medical treatment

is proposed for an adult, the dominant (Western) approach is to respect the adult's autonomous choice. And when dealing with an incompetent adult, decisions are made on the basis of what the adult would have chosen had they been competent. Buchanan and Brock can write "...there are deep and complex philosophical issues about the best or correct account of individual well-being...we can make no attempt to explore fully, much less settle, those issues here...Much of our account of...the principles guiding surrogate decision making does not presuppose one particular kind of theory." [Buchanan & Brock, 1990: 31]. And the reason that they can state this is because their account defends an account that prioritises autonomy over well-being. And even for those who are incompetent the decisions regarding their medical treatment are based on what the previously competent person would have chosen. Only rarely are they forced to fall back on an impersonal notion of best interests. Because their account of well-being relies on the autonomy of the previously competent person, they avoid the disagreement over an abstract, impersonal, conception of interests.

Only in two rare situations is an objective best interests assessments needed for an adult. The first is when the now-incompetent adult has never been competent; the second is where the adult was competent but there is insufficient evidence available to settle the decision. In most practical situations, decisions for incompetent adults are made on the basis of their prior choices. An adult may have made an advance directive, or have appointed a guardian to choose on their behalf or there may be clear evidence of the choices that they would have made. Regardless of the different ways in which the principle is instantiated, the point is that the adult's prior choice with regard to their treatment is respected, and so a clear objective conception of best interests is not needed. However, as children lack the ability to decide their own interests, a clear conception of interests is needed for them.

I have described the ways in which there is no meta-ethical agreement on a formal theory of well-being, nor even on an underlying approach to a theory of well-being. This may suggest that agreement at a normative level is unlikely to be achieved¹³⁴. It is

¹³⁴ Although some would see that meta-ethics is entirely distinct from normative ethics, Griffin wrote "We ought not, I think to treat meta-ethics as something that can be pursued for long independently of normative ethics." [Griffin, 1986: 4] which I believe to be correct for a variety of reasons. Similarly, Daniels describes the method of reflective equilibrium as

clear that there are deep divisions, even within individual western societies, about well-being¹³⁵. An example of the deep division was demonstrated by the legal dispute reaching even to the US Supreme Court over nasogastric tube feeding of Terri Schiavo (an American who developed persistent vegetative state following an out of hospital cardiac arrest). Terri's husband sought to withdraw tube feeding but Terri's parents thought it should continue. Their extensive legal battle is well-documented on the website of the Miami Ethics Programme [Miami Ethics Programme]. One reading is that the dispute was between those who valued biological life (as existence, as Terri's parents did) and those who valued life with meaning for the individual who lives it (a biographical life, as her husband did). Although it is possible that her parents thought that continued treatment may eventually reawaken Terri (though she had remained neurologically devastated for 15 years), others clearly value human life highly regardless of the conditions of the life. A clear statement of this position was made by the Pope (during, and perhaps in response to, Terri's case) "...I feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life. A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a 'vegetable' or an 'animal'. Even our brothers and sisters who find themselves in the clinical condition of a 'vegetative state' retain their human dignity in all its fullness. The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help." [John Paul II, 2004].

Another example is found in the case of MB. The doctors and nurses caring for MB and those appointed as expert witnesses all believed that withdrawal of treatment was in MB's best interests ("The experts all agreed that if only M's interests were being

"...working back and forth among our considered judgements (some say our 'intuitions') about particular instances or cases, the principles or rules that we believe govern them, and the theoretical considerations that we believe bear on accepting these considered judgments, principles or rules, revising any of the elements wherever necessary in order to achieve an acceptable coherence among them... seeking coherence among the widest set of beliefs, and revising and refining them at all levels when challenges to some arise from others." [Daniels 2011]. In the absence of agreement at meta-ethical level, support for widely different approaches to interests is available.

¹³⁵ An example of the recognition of this problem from academic ethics "...in any, even moderately, diverse community, no single agreed concept of the best possible life is going to be possible or desirable". [Parker, 2007: 281].

considered then this option would be in his best interests.” [*An NHS Trust v MB* [2006] paragraph 87]), as did the *guardian ad litem* appointed on MB’s behalf (“...it is the very strongly held view of the guardian that currently (even ignoring future deterioration) the burdens outweigh the benefits” [ibid paragraph 87]), and yet the judge decided that continued treatment was in MB’s interests. The disagreement between the experts and judge can be at two levels. One level is in the weighing of evidence, so Mr Justice Holman described that his disagreement with the *guardian ad litem* lay in their respective assessment of the evidence writing “A number of these benefits are expressed in the guardian’s list as “possible/probable” and it may be that doubts in the guardian’s mind as to whether he in fact gains these benefits is part of the difference between us.” [ibid paragraph 101]. But if so, it is interesting that the judge decided as he did, given that the guardian had visited MB: the judge relied only on testimony and a short video which had been made by MB’s parents. The disagreement may lie at the level of the assessment of the evidence of MB’s condition, but it may also (or instead) be that the guardian and judge have different conceptions of what is meant by interests, which led them to different decisions. And if this is true, it means that some situations will not be resolved precisely because the disagreement arises from different conceptions of interests. If it is recognised that there is not a shared meaning of interests by all who use the term, then some of the disagreements may be resolved. It may be that in other cases individuals will have different conceptions of interests and the differences are not able to be resolvable by reasonable discussion.

I have argued already at the beginning of this chapter that different authors have different conceptions of interests, and that one reason for a dispute about interests is when this is unrecognised. When interests are used in to determine medical decisions, what the child’s interests are taken to be should be explored and, if possible, agreed. The response to the claim that interests are indeterminate is to agree that this may be true, but only in particular circumstances. In other circumstances there is sufficient agreement to make decisions based on interest assessments.. There are many cases where it is clear where a child’s interests lie, even though others may make different choices and here the child’s interests offer clear guidance. An example of this is when

Jehovah's Witness parents refuse blood transfusion for a one year old who needs blood. This decision is clearly against the child's interests¹³⁶.

It is true that there are difficult cases in which it is not clear where a child's interests lie¹³⁷. And because these cases are difficult to resolve they attract more attention than those where resolution is straightforward. The discrepancy between the longevity of the conflict and the attention provoked by difficult cases contrasted with the more easily resolved cases exaggerates the problems with the disagreement over a child's interests. The more difficult cases are those that deal with the end of life (the themes explored in the discussion of Terri Schiavo and MB). In making an assessment of interests towards the end of life, some people object that the two options, being alive or being dead, are incomparable¹³⁸. However, we recognise that competent people can make their own choices, both to refuse life-saving treatment when they judge that the burdens of side-effects outweigh the gains of treatment¹³⁹ and (in the regions where it is permitted) to deliberately end their own lives. Both of these suggest that whilst choosing between alternate courses, one of which will result in immediate death, is hard and complex, it is not impossible. Although agreement on a conception of the child's interests in these cases may be difficult it is at least possible if reasons are

¹³⁶ Why is this so? Jehovah's Witnesses believe that the Bible (God's word) prohibits blood and so "Accepting a blood transfusion willingly and without regret is seen as a sin" and an adult "... would no longer be viewed as one of Jehovah's Witnesses because he no longer accepted and followed a core tenet of the faith - i.e. the act of accepting a blood transfusion stopped a person being a Witness, without any further action by the Church. If the Witness later changes their mind and repents of their action they can return to the Church." [Religions BBC] And so, partly because a one year old cannot 'willingly and regretlessly' accept a blood transfusion and partly because "Children who are transfused against their parents' wishes are not rejected or stigmatised in any way." [Religion BBC], transfusion is clearly in the child's interests (it will prolong their life and no sanctions will attach to transfusion) should they need it. Though it may also be true that the parents should refuse to agree to transfusion, because they know that the courts will order it and if parents do not voluntarily accept transfusion then no sanctions will be taken against the parents either.

¹³⁷ But it may also be that in some situations the child's interests are clear, but that sensitivity to parental emotions prevent courses of actions that would be in the child's interests. Here we have clearly moved away from the child's interests.

¹³⁸ "... we cannot make the comparison of life against nonlife demanded by the best-interests standard without foundering on conceptual incoherence." [Arras, 1984: 26].

¹³⁹ Demonstrated in the medico-legal case of Ms B, who was left paralysed and ventilator-dependent after a central nervous system haemorrhage. Her clinicians refused to withdraw ventilation (as she asked) because they believed further treatment was in her best interests. The court ordered that ventilation should be withdrawn (albeit in a different hospital) [*Ms B v An NHS Hospital Trust* [2002]].

given justifying what a child's interests are taken to be and why a particular course of action is held to be in that child's interests.

Uncertain prognosis

A second problem with the claim that decisions should be in a child's best interests is that even if there was agreement at a normative level as to what constituted best interests, best interests are 'unknowable': and they are unknowable in several different ways. They cannot be known because of statistical uncertainty; because there is an absence or a severe limitation of information about outcomes; because of an incomparability of different components of interests and because interest determinations are overwhelming complex.

Firstly, uncertainty is a problem for all decisions that depend on the statistical likelihood of future outcomes. A rational approach involves combining both the likelihood of an outcome and the quality of the outcome, so that the 'best' outcome (the highest quality) may not be sought if that outcome is prohibitively unlikely. In this case, a less good, but more likely outcome may be chosen as this approach is likelier to lead to a good (but perhaps not the best) outcome.

The problem of uncertainty is greater for children than adults for several reasons. Firstly, when decisions are made for a sixty year old the decision is based on outcomes that look 10-20 years into the future. But when outcomes are chosen for children these may be projected 50 or 60 years later. As well as this, a child's growth and development adds another layer of complexity to decisions about medical treatment that is absent from decisions for adults. And here, earlier correction may lead to normal growth and development, or conversely earlier intervention may produce scarring that impairs normal growth and development. As well as the development of the child, there may well be developments in therapies over time. Diseases which were untreatable, or which had treatments with unacceptable side effects 10 years ago, may now have safe and effective treatments (but also they may not. Stem cell therapies have been vaunted for a long time but have yet to come to fruition). For some conditions, therapies which had poor outcomes combined with a high risk of unacceptable side-effects, may improve through the time that the child undergoes treatment, changing from treatments that were barely, if at all, in the child's interests to treatments that are clearly in the child's interests.

A second problem comes when there is no, or very little, information about the outcomes of interventions. An example of this is the introduction of the arterial switch procedure, in a particular form of congenital cardiac disease (Transposition of the Great Arteries – TGA – where the pulmonary artery and the aorta arise from the wrong ventricles). In the mid 1980s the mainstream approach to TGA was a reasonably successful operation carried out when the child was around 10 months old (the Senning Procedure). However, following this operation, the chamber that usually pumps at low pressure to the lungs must work at higher pressure to pump blood round the body, which it can do for only so long before it starts to fail. Although the early results from the Senning Procedure were good, as children grew to teenage years, they commonly developed heart failure or heart rhythm problems, either of which was often fatal. In the late 1980s a newer approach - the arterial switch - anatomically corrected the heart so that the chambers pump as they are supposed to. The theory was that the switch would prevent the development of heart failure and dysrhythmia. However the switch procedure is a more complex operation and must be done within the first 10 days or so of life [Bull et al, 2000]. The difficulty of the operation (especially in the early days when the team of surgeons, doctors and nurses are learning the complexities of the procedure) meant that the complications, and probably the mortality at the time of operation, would be greater. So in the early days of the switch procedure, the choice lay between a proven operation, leading to significant problems in teenage years, or a newer operation likely to cause more complications around the time of operation (and likely a higher mortality) for probable but uncertain advantages when the child is older. The longer term advantages, are theoretical although the short term higher mortality is more reliably predicted by the more extensive operation, which needs to be performed on children of a younger age by practitioners learning a new procedure - ‘old dogs and new tricks’. The immediate disadvantages are more certain, and more immediately countable. Unless, and until, many children have had the switch procedure, whether the theoretical benefits translate into real benefits is unknown. And it is important to emphasise for all those who say that more information is needed (which is true), the information will not be available until long past the time when the decision has to be made for a particular child. Whichever decision is made for a particular child contributes to the information available for future children. The problem here is that although I have described that a

rational approach to uncertainty involves combining the chance and the quality of outcomes, both of these pieces of information are often lacking in situations where interest-based decisions based are made, and this is particularly true for children because of the longer time span over which the outcomes of medical decisions made for them must run.

A further way in which best interests are unknowable lies in the incomparability of different components of interests. Consider cytotoxic treatment regimes for childhood cancer. All chemotherapeutic agents kill normal human cells as well as cancerous ones. In doing so, the chemotherapy causes various problems amongst which the most likely is an increased susceptibility to infections. The optimal dose of chemotherapy kills all the malignant cells, but does not eradicate the child's immunity so that the risk of death from infection is not unduly increased. A higher dose of chemotherapy that is more likely to eliminate the cancer will increase mortality because it increases the risk of infection. Here, because the outcomes are the same (mortality), an optimal level of treatment, with the lowest overall mortality can be determined. However as well as this, chemotherapy is profoundly unpleasant, children feel awful, are unable to eat or drink because they vomit so much, they feel nauseous, their hair falls out alongside many other problems, some short term, and some more persistent. Some cytotoxic regimes are just too toxic and cannot be tolerated. The difficulty in assessing interests lies in balancing an increased probability of survival against the awfulness of the treatment which persists for quite some time. The problem lies in comparing two very different components of a person's interests.

A compelling example of the incomparability of different domains of interests are recent trials that studied the optimal amount of oxygen for prematurely born babies. It is known that the use of more oxygen contributes to an abnormal proliferation of blood vessels in the eye that, at its worst, causes blindness (retinopathy of prematurity, ROP). Following this, for some time clinicians have carefully controlled the amount of oxygen given to babies, but were uncertain as to the correct amount, so an experiment was conducted to determine the optimal amount of oxygen, by aiming at different levels of oxygenation in premature babies. Very unexpectedly, the researchers found that, although ROP was less, mortality was higher, in the group treated to lower oxygen levels: "...there is one additional death for approximately every two cases of

severe retinopathy that are prevented.” [SUPPORT Study Group, 2010: 1967]. This trade-off, one death to prevent two cases of ROP, is not acceptable, but there will be an acceptable or appropriate trade-off, perhaps one extra death to prevent one hundred cases of blindness and certainly one extra death to prevent the blinding of one million children. I do not intend to argue what the acceptable trade-off should be, just that the balancing of these different and incomparable domains provides a problem for a pluralist account of interests¹⁴⁰.

The final problem that I will discuss regarding the uncertainty of interests is the overwhelming complexity of some cases. As a child’s interests involves the rest of their life, which is potentially a long time, and extends over many different components, and as different individuals may weigh different components of their lives differently, there is enormous complexity to an overall interests determination. MB (the child ventilated with SMA) furnishes an example of why the best interests of a child may be unknowable because of complexity. In seeking MB’s interests, the benefits and burden were laid out in a table that was reproduced in the court judgement (an example of the list of benefits for only one of the proposed treatments is reproduced in Appendix 1). Although this seems a reasonable way to proceed, the ways in which the different components should be added or subtracted one from another to produce the child’s overall interests is unclear. And having listed the interests, there are so many interests and they are so broad a collection of interests, that to attempt to hold them in mind and then evaluate the different courses, one against another, and so choose rationally between different options is, effectively, impossible because of the complexity¹⁴¹. My claim is that the complexity of decisions

¹⁴⁰ Griffin’s example of the difficulty in balancing pluralist conceptions of interests is the example of the tree-lined roads in France. The beauty of the trees is offset by their effect to increase road accident mortality rates. The French Government balances human lives against aesthetics.

¹⁴¹ MB provides another example of the incomparability of different components or domains of interests. For example from MB’s list how much of the benefit of “Possibly/probably MB derives some comfort /pleasure from Barney the Dinosaur/Teddy” would be needed to balance the burden of “He is likely to be suffering some positional discomfort despite being repositioned by nursing staff.” [*An NHS Trust v MB* [2006]].

that must be made is sometimes overwhelming and in at least some cases renders an interests determination beyond computation¹⁴².

I started this section arguing that there are significant difficulties with knowing what a person's interests are, given the difficulty of with determining outcomes as a result of several problems: uncertainty, a lack of information, incomparability and complexity. These relate to problems with 'knowing' what will happen in the future. All of these are real concerns. However, none of these concerns are unique to medical decisions. At least some of them are present whenever we make decisions about our actions. Although the consequences of medical decisions may be greater than the consequences of other decisions, this is not always true. However recognising that there *may* be difficulties does not mean that there will be difficulties, and in many situations, there can be agreement on the course that will most likely produce the best balance of a person's interests. An approach that involves giving reasons for choosing between the importance of different interests, and not merely listing interests will be more likely to produce a justifiable assessment of a child's interests. A further difficulty with the use of the child's interests when making medical decisions is the objection that an individual child's best interests should not determine medical treatment for the child, because a child's interests are intertwined with others in the intimate family, and to concentrate only on the child is wrong.

Best Interests are too Individualistic for Children' Ethics

There are two 'individualistic' criticisms of the claim that a child's best interests should determine the medical decisions that are made. The first criticism lies in the conception and assessment of a child's interests. The concern is that in an intimate family, each individual's interests are so intertwined that the child's interests cannot be separated from those of his parents and other close relatives. The second objection

¹⁴² The table notes two burdens, amongst many, many, others, for MB: "MB has lost the ability to communicate his needs and wishes to others. This is permanent". This is followed by "MB has lost the ability to interact with others or his environment" [*An NHS Trust v MB* [2006]]. Given that these two burdens, describe a life of existence without meaning, it is difficult to understand the reasoning that leads to a decision that MB's extra-ordinarily isolated life is in his interests. He is unable to move and unable to communicate any of his wants or needs. Perhaps these very significant disadvantages to MB were lost in the large number of items on the list.

is that even if it were possible to determine an individual child's best interests, it is wrong that the best interests of one child should determine medical decisions, when the decisions have effects on others.

First, children, and people more generally, do not exist as lone individuals. Children are usually part of a family and this is exemplified by the fact that Lainie Friedman Ross' theory for children's medical decisions ('constrained parental authority') applies only to children in families "...I assume that children are members of intimate families. I realize that there are children who are not members of families (e.g. orphans) and that some children are members of families that are not intimate. Whether my proposal can be modified to accommodate such children or whether another decision-making model is necessary is a future project." [Ross, 1998: 5]. A challenge to the claim that medical decisions should be determined by the best interests of the child is that it is not possible to separate the interests of a child from the interests of their parents and others in an intimate family. That their child does well in life may be a major component of a parent's own well-being, and as a child (usually) grows to maturity within an intimate family, that their parents (and siblings) fare well may become a large part of the child's interests.

The first concern, that interests are incompletely separable in an intimate family, can be approached using Feinberg's categorisation of two sorts of other-regarding interests. Straightforwardly, "A may be dependent on the help of B for the advancement of his own (A's) interests, so that if B's fortunes should decline, B would be less likely to help A...It is therefore in A's interest that B's interest be advanced...B's good is, in effect, one of A's welfare interests." [Feinberg, 1984: 70]. This sort of other-regarding interest describes the way that children depend on their parents (and so the child's interests are setback when their parents' interests are setback, for example if a parent was to lose their job both the parents' and child's interests would be setback). Feinberg's second group of other-regarding interests is when

"...C has 'invested' a desire so strong, durable, and stable in D's well-being, that he comes to have a personal stake in it himself. It becomes, therefore, one of his ulterior interests or focal aims...he desires D's good not simply as a means to the promotion of the other ulterior aims that are components of his own good, but quite sincerely as an end in

itself. This should be contrasted with the more common phenomenon of spontaneous sympathy, pity or compassion which can be directed at total strangers...he desires D's good not simply as a means to the promotion of the other ulterior aims that are components of his own good, but quite sincerely as an end in itself. Such cases are, of course, rare but no rarer than disinterested love...Can anyone doubt that one harms a loving parent by maiming his or her child..." [ibid 70]¹⁴³.

The child's interests are a component of the parents' interests¹⁴⁴. The child's interests may be separable from their parents' interests, and so the child's interests can be identified, but the parents have such a concern for the interests of their child that it would be wrong to act on the interests of the child alone, without recognising the parents' legitimate interest in the decisions made for the child. Accepting that a child's welfare can be a component of the parents' interests is complicated by the fact that the parents' assessment of the child's interests may be modified by the parents' sense of what it would be for the child to do well (which may be different from what others believe would be in the child's interests). Arras described severely disabled children who lack "human capacities - for self-consciousness and relating to other people...the absence of fundamental human capacities can render a life valueless, both to its possessor and to others" though he continues to state "This is not to deny that families can derive great satisfactions from caring for such severely impaired children and may desire to keep them alive but this particular reason has nothing to do with the child's best interests." [Arras, 1984: 23]¹⁴⁵. And to confuse any claims that are made on the basis of the child's interests, there are many reasons why parents may claim authority in making decisions about their child's interests. Some parents may claim this as a

¹⁴³ Similarly, Mackie describes: "The happiness with which I am, inevitably, most concerned is my own, and next that of those who are in some way closely related to me. Indeed for any reasonably benevolent person these cannot be separated: he will find much of his own happiness in the happiness of those for whom he cares, or in what they and he do together, where the enjoyment of each contributes so essentially to that of the other(s) that it will be more natural to say 'We had a good...' (whatever it was) than to speak of a mere sum of individual enjoyments." [Mackie, 1977: 170].

¹⁴⁴ And as the child grows, the interests of other members of the intimate family and her friends' interests may become part of the child's interests.

¹⁴⁵ There are examples of brain dead children whose parents refuse to withdraw treatment. One child was ventilated at home for some months until she had a cardiac arrest [Siegel], another brain dead child was transferred ventilated to another institution [Durand, 2013]. Although surviving relatives may have an interest in the treatment of those who are brain dead, there are strong arguments that a brain dead person has no interests (and specifically if the brain dead individual is a young child and so can have had no thoughts about how they would wish to be treated after death, the arguments are even stronger).

parental right, other parents may claim that because they have known their children longer (and know them better than any other) that only the parents can judge the child's interests, other parents may claim to be more able to interpret their child's communication and so are more aware of their child's needs, wants and likes (or any or all of these combined). Although there are reasons why parents *may* be best placed to assess a child's interests, there are also reasons why parents may not. One reason why they may not be best placed to decide their child's interests is that parents may be so tightly bound to their children's wellbeing that they cannot be disinterested or dispassionate in their assessment of their child's interests. If an 'objective' assessment of a child is sought, a parent is the wrong person to ask¹⁴⁶. Regardless of the concerns over the correct assessment of a child's interests, the objection here is that medical decisions cannot be determined by the child's interests because child's interests are incompletely separable from the interests of the other members of an intimate family. The child's parents may have such concern for their child, that the child's interests have become a part of the parent's interests in Feinberg's second sense and so it would be wrong to base decisions solely on the child's interests.

Another example of the intermingling of the child's interests with others is that an older (though not yet competent) child can invest such concern in the welfare of another that it becomes a component of the child's interests. This is recognised to be so for an adult, though it cannot be true for a baby: children lie somewhere between the extremes. Older children may make significant compromises to their self-interest for friends or causes that they believe in. Buchanan and Brock state that the interests of others cannot be a component of an incompetent individual's interests, arguing "If there were sufficiently weighty evidence...to justify a decision that runs contrary to the patient's self-regarding interests, then this evidence would presumably be strong enough to justify the use of substituted judgement instead of the best interest principle...when decision-makers must rely on the best interest principle (rather than an advance directive or substituted judgment), the determination should focus on the

¹⁴⁶ A parent's assessment of the child's interests may be modified by the parent's sense of what it would be for the child to do well (what would be in the child's interests) as this may be different from what others believe would be in the child's interests. For some parents, that their child dies is such an unimaginable tragedy that they demand that their child survives regardless of the quality of life of their child.

individual's self-regarding interests, not upon his or her alleged interest in the good of others." [Buchanan & Brock, 1990: 133]. This discussion is not in the children's section and so it may concern only those who were previously competent (as is suggested by the reference to previous decision-making capacity). Against the restriction of their argument to previously competent individuals is that Buchanan and Brock mention court cases involving minors in their introduction to this argument. Taking the best interests approach, children are different from adults. An adult can donate an organ because it will benefit the recipient (be they a relative or even a total stranger) for altruistic reasons. However, the justification for organ donation by a child (or other incompetent) cannot be just a benefit to the recipient: there must also be a benefit to the child donor. Amongst the benefits may be that the organ-recipient is an important carer for the child, and so will be better able to care for the child or that the organ-recipient has a particularly strong bond with the child, and so when healthier will visit the child more or some such.

The injunction that the interests of others cannot be a component of an incompetent's interests has the advantage that it protects the incompetent person from being used to benefit another: the child cannot be used as a means to someone else's advantage. It is important to consider how Buchanan and Brock's arguments apply to children. Here, although children are not granted authority to decide to donate, some children will have their own opinions and those who make decision about donation should take the child's views into account. So for older children, although the decision is not a substituted judgement in the conventional sense of substituted judgement, the views expressed by a more mature child should be taken to hold some weight¹⁴⁷. Buchanan and Brock's claim that other's interests cannot be a component of an incompetent's interests is too restrictive. They recognise that "An important part of children's and adolescents interest in self-determination is not in their interest *qua* children in making

¹⁴⁷ Particularly because the law relating to donation sets the age for consent to donation at 18 in the UK, whereas a person can make decisions about their own treatment at 16 or younger. In England and Wales the Human Tissue Act defines that a child is under 18 years. A panel must consider any donation of a solid organ or part of a solid organ in those under 18 "Before any such procedure the approval of a court should be sought." [Human Tissue Act 2004]. A famous American court case adjudicated donation between 19 year old identical twins, as a 19 year old was (in law) a minor. The twins and the twin's parents were all in favour of donation [Masden v Harrison, 1957].

decisions for themselves but their interest in developing their capacities to be self-determining adults...developing capacities for self-determination requires that children's opportunities for decision making be continually expanded" [Buchanan & Brock, 1990: 232] and if so, the views expressed by more mature children must be taken into account in determining whether or not to donate (recognising that children are malleable and so a child's expressed views need not reflect their real feelings). I do not wish to settle the rules for organ donation by a minor, but just to give a further example of the way in which an attempt to separate out an individual child's interests are troubled.

I have argued that although a young child's interests can be separated from their parents' interests, a parent has a legitimate other-regarding interest in their child, in Feinberg's second sense of other-regarding interests. For this reason it would be wrong to determine medical decisions solely by the child's interests. As well as this, older children may have other-regarding interests in others' welfare too. In these situations it would also be wrong to determine medical decisions solely on the interests of the individual child.

The second individualistic objection is that even if we could isolate an individual child's interests, this is not the right way to make medical decisions. It is wrong to prioritise the interests of one member of an intimate family when several family members will be affected by medical decisions made for one member of the family. An individual child's best interests are important in making medical decisions, but are only one reason, amongst others and should not necessarily determine medical decisions. This second 'individualistic' objection lies, not in the conception of best interests itself, but in the use that the best interests assessment is put to. When best interests are used to decide for incompetent people, the choices that are made may have important effects on others. Salter argues that "Decisions about a child's course of treatment affect not only the life and welfare of that child, but they often involve very significant financial, relational, and emotional consequences for the rest of the family." [Salter, 2012: 4]. Ross provides the fictional example of Amy, a 9 year old with cerebral palsy, who will have better rehabilitation if her family relocate from their rural location to the city: the move would be in Amy's best interests. However, Amy has two sisters whose educational and emotional needs are better served in their rural

location and who would be compromised by the move. Ross argues "...Even if the Smiths are willing to ignore their own needs and interests, they are unable to satisfy maximally the needs and interests of all their children simultaneously." [Ross,1998: 21-22]. If Amy's best interests is considered the correct test for making a medical decision in this situation it would be unjust and unreasonable to other members of the family. Similarly, although Buchanan and Brock argue that decisions should be in the best interests of the child they argue although "...parents are rightly expected to make sacrifices for their children, they are not obliged to thwart their own most important interests whenever doing so would achieve some additional small increment of benefit for their child, no matter how small, no matter at what price and regardless of how well off the child already is." [Buchanan & Brock, 1990: 236] so they too deviate from a best interests standard. My argument here is the claim that an individual's best interests should not be determinative when medical decisions are made for that individual because this would be unfair to other members of an intimate family.

It is clear that an attempt to isolate an individual child's interests from the interests of others, will fail on at least some occasions. This means that decisions for a child based solely on the child's interests may be contentious. The resolution to this problem is to recognise that although a child's interests may not be separable as a distinct conception, reasons can be given for preferring one or other approach to the child's interests and reasons can be given for particular ways of balancing the interests of a child and having done that for balancing the interests of the child and others within the family justifying an appropriate course of action.

The 'Best' Interests Standard

The standard that is most often advocated to guide medical decisions for children is the child's *best* interests (I listed many example at the beginning of this chapter). However, although best interests would seem to be a clear standard, many of the defenders of a best interests standard describe approaches that are not best interests. In this section I will describe the confusion over the best interests standard. After this I will argue that it is not feasible to adhere to a best interests standard for several reasons (which may explain why others defend standards other than best interests). Following this I will consider other standards that could be applied to medical decisions for children, arguing that none are suitable.

At first sight, best interests has a clear meaning, it means what would be best for the child. However, it is clear that the phrase ‘best interests’ is understood in different ways, and even advocates of best interests recognise that the standard that they defend is not a literal best interests standard. Buchanan and Brock state “The best interest principle is to serve only as a regulative ideal, not as a strict and literal requirement...” [Buchanan and Brock, 1990: 236]. The Nuffield Report displays a similar retreat in writing “We leave aside some more subtle discussions about whether promoting someone’s best interests requires promoting *all* of their interests to *the highest degree*, or promoting only a *subset* such that a basic level of wellbeing is achieved [Nuffield Council, 2006: 15 their italics]. A basic level of well-being is very far from ‘best’ interests. Kopelman, in extensive writings justifying the best interests standard, distinguishes three different meanings of best interests. First it is a threshold for intervention by the state, secondly it is an ideal or goal to be aimed at, and thirdly it is a standard of reasonableness in court procedures. Together these three “...unite[s] under one standard different meanings and uses about how to make good or at least acceptable choices...” [Kopelman, 2007(b): 375]. These standards are clearly distinct (as Kopelman recognises) and yet Kopelman is content to call all ‘best interests’. She writes “Insofar as they are joined conceptually and historically, however, I believe that it is preferable to regard them as three uses of one standard” [Kopelman, 1997: 282]. Kopelman recognises that a strictly best interests standard cannot be defended stating “...judges try to assess the child’s best interests. But this cannot mean literally the best, since neither parent may be ideal. Rather it is a practical decision based upon available options. The best-interests standard, when used as a standard of reasonableness may be less than ideal but it is often better than a barely acceptable minimum.” [ibid 272]. And in a later work, Kopelman states “...the Best Interests Standard does not require one to do what is ideal for the individual, since this may be impossible...” [Kopelman, 2005: 347]. Kopelman’s impossible may mean very difficult to achieve, or very disruptive to others or perhaps a very unlikely (though not truly impossible) outcome. If an option is truly ‘impossible’ then it is not a real option: an impossible option cannot be in a person’s best interests and has to be excluded from consideration¹⁴⁸.

¹⁴⁸ But even ‘impossible’ can be disputed. At first mortality rates for childhood leukaemia were in excess of 90% and still worse, early treatments may have increased mortality [Simone,

Kopelman's example is: "A judge in a custody dispute must place a child somewhere and seeks what is best given the options, usually with one or the other parent or joint custody; it is rarely ideal and sometimes barely tolerable." [Kopelman, 2005: 347]. It is wrong to describe an approach that can produce an existence that is barely tolerable as 'best interests'. In Kopelman's example, if the child's existence living with her parents is barely tolerable and this cannot be improved by support for the parents, then the child should be fostered, adopted or placed in institutional care if this would be better for the child. And none of these would be impossible, though they may be difficult for the child (at least initially) and for her parents. Having described three different best interest standards and in so doing defended options that are 'barely tolerable' Kopelman continues to define clearly an approach that is defensible, but would be better called a rational or reasonable assessment of the child's interests in arguing

"First, decision makers should use the best available information to assess the incompetent or incapacitated person's immediate and long-term interests and set as their *prima facie* duty that option (or from among those options) that maximizes the person's overall or long term benefits and minimizes burdens...easy to use when informed people of good will agree about what information is salient, which goals and values are relevant, and how to rank potential benefits and risks...Second, decision-makers should make choices for the incompetent or incapacitated person that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable people of good will regard to be acceptable were they in the person's circumstances...Because guardians have considerable discretion, unless they abuse, neglect or endanger their ward, they can make decisions that take the interests of others into account...Third, decision makers should make choices compatible with duties to incompetent or incapacitated individuals (those unable to make decisions for themselves)...The meaning of the Best Interests

2008]. In the 1930's, a clinician who claimed to have cured leukaemia with a primitive drug and radiotherapy regime was dismissed from his job because leukaemia was universally fatal [Beutler, 2001]. Cure was 'impossible'. However trials of treatment continued and eventually childhood leukaemia mortality fell. Long term (5 year) survival after acute lymphoblastic leukaemia having been 9% in the 1960's was over 70% in the 1980's and is still higher nowadays [Rivera, 1993; Simone, 2003 2008]. At some stage, survival has changed from 'impossible' to routine, but this was gradual, there was not a step change. One reason why this happened was a refusal to accept that survival was impossible, If options are taken to be impossible they will be excluded, but if outcomes are believed to be possible they may become so.

Standard should be understood in relation to the context where it is used...medicine...law...” [Kopelman 2007(a)].

The standard that Kopelman defends is not best interests, but acting on a reasonable or a justifiable assessment of the child’s interests, as Kopelman describes it decision makers should “...focus on the child...pick the option that most informed, rational people of good will would regard as maximizing the child’s net benefits and minimizing the net harms to the child without ignoring the rights, needs, and interests of others.” [Kopelman, 1997: 279]. The standard for decisions for children that Kopelman defends then is a reasonable assessment of the child’s interests, taking others’ interests into account. It is not a best interests standard. I agree with the approach that Kopelman takes: my disagreement lies in the description of this approach as one that is in the child’s best interests. Salter dismissed best interests as the determinative factor when making medical decisions for children writing “...while the BIS [best interests standard] has potent rhetorical power, its invocation and application is actually quite inconsistent, and that ultimately, it should be rejected” [Salter, 2012: 180]. In doing so, Salter goes three better than Kopelman and finds six meanings of best interests¹⁴⁹, none of which he finds defensible. My concern here is that with several different standards described as best interests, defenders of the best interests standard are defending different approaches. And so the first problem that is faced by an advocate of a ‘best’ interests standard is in recognising that there is no single best interests standard, but multiple different approaches, all of which go under the name of best interests. I will argue that a reasonable assessment of a child’s interests (akin to that advocated by Kopelman) should determine how decisions are made for children, and this is because there are further objections to a best interests standard.

¹⁴⁹ Salter writes of a “...range of meanings of the best interests standard I would like to highlight six versions of the theory: Allen Buchanan and Dan Brock’s ‘best interests principle from the seminal decision making text *Deciding for Others*, Jeffrey Blustein’s priority thesis, the American Medical Association’s opinion on surrogate decision making, James Drane and Jack Coulehan’s biopsychosocial model of the BI [Best Interests], Loretta Koepelman’s ‘negative’ version of the BIS [Best Interests Standard], and Joseph Goldstein and colleagues’ best interests standard.” [Salter, 2012: 184]. For Salter, these theories all differ in ways that depend on the way that they deal with other-regarding interests, the sorts of self-regarding interests that are emphasised and their time orientation.

The first difficulty with a true best interests standard is that it is too demanding. With more than one child in a family or ward, it is likely that a course that is in one child's best interests will not be in another child's best interests. In a family with two (or more) children it will likely result in incompatible choices. If a decision is made considering the best interests of Angela, the choice that results will be different when the decision is made considering Boris' best interests. And if the requirement is to act in the best interests of each child, there is no way to choose between the two courses, resulting in decisional paralysis. A requirement that decisions should be in a child's best interests becomes a self-defeating standard when more than one child is involved. And if the requirement was changed so that it would be the children's best interests that are sought, this leaves the parents no time to consider their own interests. This is unjust. The best interests standard will not produce a definitive answer in many situations involving multiple members of an intimate family.

A further problem with the best interests standard is that qualifier 'best' implies only one solution. This produces two concerns. Firstly, any pluralistic conception of interests allows different domains of interests. It may well be that what is best when assessed in one domain is not best in another domain. And if different options are better in different domains it may be that there are incommensurable assessments of interests¹⁵⁰. For example, a curative therapy with better longer-term outcomes may have greater short-term costs in pain, unpleasantness or disruption to life than a palliative approach that offers a shorter but more pleasant life. This may mean that neither therapy is clearly better in at least some conditions. A child who is likely to have a longer life may be better treated with the curative approach, another, with a shorter expected life, may be better treated with the palliative approach. But there may be others where the options are incommensurable. What this means is that there may not be a 'best' interests in some cases, because there are several different and incommensurable options. The outcome of medical decisions may be that there are several reasonable approaches, and perhaps some that are unacceptable, but not one clear 'best' option.

As well as this difficulty, if a 'best' interests determination generates one course of action that is in the child's best interests, it undermines the idea of parental authority

¹⁵⁰ There is discussion of incommensurability in Griffin, 1986: chapter V.

and parental consent to treatment. Parental consent, where parents are offered only the one treatment that is in a child's best interests and the parents have to accept the single treatment offered (because it is in the child's best interests) is not consent, as consent is usually understood (a voluntary choice, in which options can be accepted or rejected). The only sense in which parents could legitimately refuse 'consent' would be to dispute that the treatment offered was in the child's interests. And the dispute would then be resolved not in terms of the parent's consent or authority but in terms of the child's interests. The parent's consent has authority only in so far as they are able to assess and defend their version of the child's interests. The clinical team's authority too is dependent on their version of the child's interests. The clinical team would be obliged to administer the treatment that was in the child's interests and the parents would be obliged to accept the treatment. This seems very far from what parental authority and parental consent are usually taken to be¹⁵¹.

These problems might seem unimportant in medical decisions. After all parents choose to consent, or decline to consent, to treatment offered by clinicians. This is true, but the clinical team is held to a best interest standard too, and so clinicians should not tolerate any deviation from the 'best' treatment for the child. However, if there are disagreements over the proposed treatment for a child, clinicians must decide how to proceed. For a wide variety of reasons, it is likely that a negotiated agreement between the family and treating clinical team will have a better outcome (and so be in the child's interests) even if the eventual treatment deviates somewhat from what would be the best medical treatment for a child. If so, the clinical team should always initially seek to negotiate an agreement with the family. But some compromises will have too many adverse effects on the child's treatment and so must be rejected. This may require court intervention. A recent example is a child with a brain tumour (Neon Roberts) whose parents were separated [*An NHS Trust and SR* [2012]]. Neon's mother, in particular, had concerns about the toxic effects of therapy and sought unconventional therapy for her son. Her prolonged negotiations with teams in two

¹⁵¹ Brazier recognises that consent for children is problematic, calling it proxy consent and that consent is only to procedures that are in the interests of the child: "In relation to my children, I am empowered to give a proxy consent while they are too young to decide for themselves, but only to treatments or procedures which at least do not violate their interests. I could not - for example, authorise surgery to alter my child's sex because I suddenly decided that I wanted a 'boy' not a girl" [Brazier, 2003: 30].

different hospitals culminated in her disappearance with her son for fear of compulsory treatment. Amongst other concerns, she sought to avoid brain radiotherapy for fear that it would alter Neon's character. Neon's mother may be prioritising the quality of his survival over the likelihood of survival - that her son should survive as Neon, and not that he should just survive as a damaged, or unrecognisable, Neon. Neon's mother's commitment to his treatment is important, both medically in ensuring that the treatment is delivered, and more broadly for her support for Neon through very unpleasant treatment. The clinical team must accept some compromise to what would be best treatment for Neon in order to maintain a relationship with Neon's mother. But at some stage the effects of compromising medical treatment on Neon's outcome outweighs his relationship with his mother.

For all these reasons, a best interests standard cannot determine medical decision-making for children (and other incompetents) and must be rejected. In moving away from a best interests standard what other standard should guide medical decisions? One response is to recognise that basing decisions on an individual child's interests is unsuccessful and that family interests should guide decisions (this will be considered in a later section). A different response is to consider one of the many possible other standards for an individual's interests, amongst which are that medical decisions for children should be in a child's interests, not against a child's interests¹⁵², reasonable¹⁵³, not unreasonable¹⁵⁴, good enough for the child¹⁵⁵, limited by some harm to the child¹⁵⁶, or limited by the threat of imminent serious harm¹⁵⁷.

The requirement that actions should be in a child's interests, but not the child's *best* interests, is the first step back when it is accepted that decisions cannot literally be in a child's best interests. It seems clear that sometimes actions should be taken which are

¹⁵² "Another standard is consent to an intervention that is 'not against the interests of the child'." [Spriggs, 2005: 342].

¹⁵³ "...reasonable and informed people of good will regard to be acceptable were they in the person's circumstances..." [Kopelman 2007(a)].

¹⁵⁴ "...offer the *not unreasonable* standard as a useful tool for addressing these difficult and complex moral responsibilities." [Rhodes & Holzman, 2004: 383 their italics].

¹⁵⁵ "...according to this view parents do not have a obligation to do what is best, but what is good enough, in a sense to be explained" [Blustein, 2012: 200].

¹⁵⁶ "...some harm to the child..." [Diekma, 2004: 250].

¹⁵⁷ "...be imminent requiring immediate action to prevent it', and 'significant risk of serious preventable harm' [Diekma, 2004: 258].

not in a particular child's best interests because there are sufficiently great advantages to another child or other members of an intimate family or group. For example, the siblings of children with chronic disease may not have their interests best served by their parent's devotion to an ill child¹⁵⁸. Furthermore it is clear that decisions are made that are not in a child's interests, for example parents may refuse vaccination, or refuse metabolic screening for their child, both of which are generally in the child's 'best' interests. Accepting that there are multiple potential standards, I will consider the least restrictive standard, that in making medical decisions for children, they should not be harmed (guided by the principle of non-maleficence).

The Harm Standard

Several authors defend the standard that parents' freedom to make decisions for children should be limited only when their choices harm a child. Ross developed the concept of basic needs from Rawls' conception of basic goods arguing that parents must provide (or make provision for) all of a child's basic needs. As parents have broad authority to make decisions for their children, parental authority should be accepted unless decisions compromise the child's basic interests and so would harm the child. Schoeman makes a similar claim for children "...a clear-and-present-danger criterion... must be met before coercive state intervention is permitted." [Schoeman, 1980: 10]. Lord Mackay (then Lord Chancellor, UK) described the underpinnings of the Children Act and stated "...unless there is evidence that a child is being or is likely to be positively harmed because of a failure in the family, the state, whether in the guise of a local authority, or a court, should not interfere." [MacKay]. And another argues, "Parents should be allowed to raise their child as they see fit, as long as they do not harm the child too severely: this is their 'right'." [Bigelow, 1988: 189]. These standards are all subtly different. For example, for Bigelow, parents may harm their children just 'not too severely' but for Lord Mackay children must not be 'positively harmed'. The positive suggests that the harm is intentional and excludes the harm of neglect. I will consider the claim that the appropriate standard for medical decisions is that the child should not be harmed, and will concentrate on Diekma's account, which is clearly described and considered in detail [Diekma, 2004].

¹⁵⁸ And similarly, parents may not best serve the interests of the siblings of a gifted child in developing the talents of the child.

Although the harm principle is familiar from JS Mill's liberalism¹⁵⁹, Mill argues for a constraint on how individuals within a liberal society should behave towards one another, not how members of an intimate family should. Mill did not discuss relationships within families (political philosophers rarely intrude on the family) but did comment on parental responsibilities. Here Mill is less liberal, and writes:

“Hardly any one indeed will deny that it is one of the most sacred duties of the parents (or, as law and usage now stand, the father), after summoning a human being into the world, to give to that being an education fitting him to perform his part well in life towards others and towards himself. But while this is unanimously declared to be the father's duty, scarcely anybody, in this country, will bear to hear of obliging him to perform it...It still remains unrecognised, that to bring a child into existence without a fair prospect of being able, not only to provide food for its body, but instruction and training of its mind, is a moral crime, both against the unfortunate offspring and against society; and that if the parent does not fulfil this obligation, the State ought to see it fulfilled, at the charge, as far as possible, of the parent.” [Mill, 2002: 109]

So when Diekma claims the harm principle as a threshold for state intervention for children, he uses a familiar principle, but in an unfamiliar context.

Diekma's claim is that “The characteristic of parental decision-making that justifies interference is...that the decision poses some harm to the child.” [Diekma, 2004: 250]. And this is because “...society has an obligation to ensure that the basic needs of its most vulnerable members are met. In general, parental decisions should be accepted except in those cases where the decision of a parent places a child at substantial risk of serious harm” [ibid 250]. Diekma's question is “Does the decision made by the parents significantly increase the risk of serious harm as compared to other options?” Parental decisions that do not significantly increase the likelihood of serious harm as compared to other options should be tolerated.” [ibid 252]. And in Diekma's list of eight conditions required to justify state intervention, there must be a “significant risk of serious harm” and the harm must be “imminent requiring immediate action to prevent it”. Amongst the other eight conditions are requirements that the intervention is necessary to prevent harm, that it is proven to be effective in preventing the harm, that

¹⁵⁹ “...the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral is not a sufficient warrant.” [Mill, 2002: 18].

there are no less-intrusive ways to prevent the harm and that most parents would agree that state intervention was reasonable¹⁶⁰.

In engaging with Diekma's claim, we need to be clear what is meant by harm. Feinberg, in considering the limits of criminal law, defined harm as a wrongful setback to interests. Feinberg's interests are "...all those things in which one has a stake...the harmonious advancement of all one's interests in plural...distinguishable components of a person's well-being: he flourishes or languishes as they flourish or languish." [Feinberg, 1984: 34]. And for Feinberg harm is specifically: "(1) A sets back B's interests and (2) A does this in such a manner as to violate B's rights (i.e. wrong him)" [ibid 65]. To recognise that a child has been harmed, an understanding of when a child's interests have been setback must be complemented by an explication of children's rights in relation to their parents. Although (as I argued in chapter 3) rights are not the best underpinning for relations within an intimate family, a rights violation here can be understood as a failure to provide that which parents owe their children, or what children are due from their parents. Feinberg's analysis was of criminal law and so Feinberg's work on harm may not apply to intimate families. However, as Diekma refers to Feinberg I will take it that Diekma had Feinberg's notion of harm in mind for his theory. The two aspects of harm that Feinberg picks out, firstly a set back of interests, and secondly that the setback of interests is *wrongful*, point towards the two major problems with Diekma's application of the harm principle to children. The first problem is in recognising when a child's interests have been set back: this can be hard to characterise because a child's interests are fluid. The second problem lies in understanding when a child's interests have been wrongfully setback. A child's interests may be setback, but if there are good reasons in the balancing of interests in an intimate family, then the child's interests may not have been wrongfully setback.

Diekma causes problems by developing his initial claim that the harm principle is invoked when 'some' harm is caused, to the final version where the harm principle is invoked only if there is an immediate risk of significant harm. That he uses many

¹⁶⁰ Note that 'parents' and not members of society more broadly are those who determine the reasonableness of the intervention [Diekma, 2004: 252].

different descriptions of what counts as harm is a problem in itself¹⁶¹. The final standard of harm makes the recognition of when a child has been harmed easy, but the cost is that as the harm to the child is serious and immediate, not all harms to children will be recognised and proscribed. The appeal of Diekma's harm principle may lie in the small step between a child's best interests and preventing *some* harm to the child. But there is a big step between a child's best interests and the risk of immediate and significant harm. As Diekma continues to refine his definition of harm to add serious and then significant, and lastly imminent, constraints on the way that children are treated to protect their well-being almost vanish.

A particular problem for children lies in the separation of 'harm' from 'failing to benefit'. Merely not harming a child (as may suffice for adults) is not enough: the child will grow up to be a severely stunted adult: "...avoiding harm to children is itself morally necessary, but not ultimately sufficient." [Hester, 2007: 362]. The interests of an adult are more easily characterised than the interests of a child, because an adult's abilities and interests are relatively static. Adults may develop new interests talents and skills, but children *have* to develop, and if children don't develop they will have been harmed (because, for example, they can't read). Children have a trajectory through life to achieve more or less in their lives. Two apparently identical one year olds may progress in very different ways depending both on their capabilities and the way that they are educated (both nature and nurture). If a child is not taught to play music at a young age then even if taught later on, they are unlikely to be as capable as a child who learned from a young age. But two children taught music from the same age may have very different abilities later on. Would we say an adult 'lacking' musical skills, who was not taught music as a child was harmed? And what of adult similarly lacking in musical ability, but who had been taught at an early stage? He has the same abilities but he has not been harmed (unless the claim is that he was harmed by his

¹⁶¹ Diekma describes harm variably as 'some harm' [Diekma, 2004: 250], 'substantial risk of serious harm' [ibid 250], 'significant risk of serious harm' [ibid 252], 'serious preventable harm' [ibid 253], '...be imminent requiring immediate action to prevent it', and 'significant risk of serious preventable harm' [ibid 258]. 'Some' usually means 'any amount of' and so is a demanding standard, not too far from a best interests standard placing a significant burden on those responsible for children to make sure that there is not even trivial harm to them. This standard that Diekma migrates to, that of imminent serious harm, is very different from some harm.

genes). Feinberg recognises the problems in assessing a child's interests, stating "It sounds innocuous enough to say that a child's welfare has priority even over a parent's right of custody; but this is no more than an empty platitude when the child's welfare is not objectively and unarguably at issue." [Feinberg, 1980: 140]. A child whose parents are able to commit resource to their child's education (in a broad sense) will be more able than one whose parents have not¹⁶². The first problem in characterising harm to a child lies in recognising when a child's interests have been set back, given the uncertainty that a child's progress involves.

The second problem lies in determining what is meant by a wrongful setback of the child's interest, as this must depend on what children are due from their parents. Some adults clearly and directly harm some children. This is well-described in the syndrome of non-accidental injury and in many official reports that describe the failure of the authorities to intervene when parents, and those entrusted with the care of children have harmed children [Laming, 2003; Haringey Local Safeguarding Children Board, 2009; Coventry Safeguarding Children Board, 2013]. Other children are harmed by neglect [Radford, 2011]. Although there may be cases where neglect is clear, the boundary between neglect and lax or liberal parenting is difficult to define and will be likely to vary over time¹⁶³. Some children clearly benefit from attentive and caring parents. The quality of care lies in a continuum from fatally harmful, inadequate, through adequate to beneficial, and perhaps in some cases adults who are too caring or

¹⁶² There are many contemporary examples from the UK. Firstly children of lower social economic status (SES) suffer more disease, have higher mortality than do their higher SES peers [Spencer]. Educationally, children of lower socioeconomic status fall behind their peers from less than 5 years of age. This is long lasting: university attendance is strongly related to parental SES [Goodman and Gregg].

¹⁶³ "Neglect is the persistent failure to meet a child's basic physical and/or psychological needs likely to result in serious impairment of the child's health and development... It may involve a parent or carer failing to provide adequate food, shelter and clothing, failing to protect a child from physical harm or danger, or the failure to ensure access to appropriate medical care or treatment. It may also include neglect of or unresponsiveness to a child's basic emotional needs." [Gardner, 2008: 15]. This is true, but the problem lies in deciding what this means. Are the parents who permit young children to cycle to school guilty of neglect or are they good parents encouraging their children to accept age-appropriate responsibility? "Oliver and Gillian Schonrock let their daughter, eight, and son, five, cycle a mile unsupervised from their home in Dulwich, south London, to Alleyn's junior school. They believe cycling to school is good for their children's independence and self-confidence. But other parents and the headmaster have said it is irresponsible. Last week the Schonrocks met the headmaster and said they were told that unless they supervised the journey in both directions they would be referred to children's services." [Savill, 2010].

protective¹⁶⁴. Where these points lie will depend on many factors and will likely vary through time, place and society. The problem for Diekma's account is that some setbacks of interests would be wrongful, but some would not be. Within an intimate family, children's (and adults') interests must be balanced against each other. One child's interests may be set back because of advantages to another. This may not be wrong, but it would be wrong (unjust), if one child was continually passed over for advantages to another child or adult. Or it would be wrong (unjust) if a minor interest of one child was prioritised over a major interest of another. The objection for Diekma's harm theory is that an account of when a setback of interests would be acceptable and when it would be wrong (ie harmful) has not been provided.

But even if Diekma was able to overcome the problems in defining harm, a further objection is that it is not enough that children are merely not *harmed*. Children who are not benefited will not grow and develop into healthy, flourishing adults. If adults merely do not harm children, both the child and society will be worse than they could or should be. During Ceausescu's regime in Romania, families were encouraged to produce more children, more 'citizens for the state', but through poverty, parents were often unable to care for their children. Many children were placed in state orphanages where, although they had the basics of life in shelter, food and clothing (and so imminent and significant harm were not present) the children lacked close relationships with consistent adults and also lacked the emotional and psychological stimuli to grow and develop. The role of neglect in damaging orphans was confirmed in an experiment comparing foster care with orphanage care. Children already in Romanian orphanages were randomly assigned to stay put, or to be fostered [Nelson CA 2013]. After some time, fostered children had higher IQs, better language development and were better able to form attachments to others. And even more worryingly (in that it suggests that the harm is irrevocable) neurophysiological changes are demonstrable between those fostered and those left in state orphanages [Nelson CA 2013, Chugani *et al*, 2001]. My claim is that 'harm' does not set the level

¹⁶⁴ Children can be cared for too much. There are two concerns, firstly, for others in society. Swift, argues that there are limits to legitimate parental partiality. The upper limit to acceptable parental partiality is "...if that leaves others unfairly worse off." [Swift, 2003: 79]. The second limit to care for children is with regard to the child themselves, where over attentive parenting may mean that the child cannot develop to become an independent adult.

of intervention high enough. Parents (and others) have an obligation to benefit children: it is not enough for children that they are not harmed (as may be acceptable for interactions with adults). And so instead of avoiding harm we should "...consider instead what 'imperfect obligations' adults and parents may have to children - obligations to do children good, or to seek to ensure that they may flourish..." [Prusak, 2008: 190].

Another problem with Diekma's theory lies in the wide variety of contexts in which state intervention may (or may not) be justified for children. State intervention may be justified at a different threshold for different sorts of intervention. Diekma limits his analysis to state intervention when parents refuse medical treatment. What is understood by medical treatment may be disputed (paralleling the discussion of what counts as health). Sometimes treatment is understood just as therapy for disease. In using vaccination as an example, Diekma understands medical treatment in a reasonably broad sense and the problem this brings, is that the more broadly medical treatment is understood, the less likely it is that the harm principle will function to justify or prohibit state intervention. Some state interventions may have important effects on the parent-child relationship (as examples, if a child is compelled to have treatment against parental refusal, or is taken into care so that treatment may be delivered), but some interventions have only trivial effects on the parent-child relationship (but may have dramatic effects on the health of the child). As an example of an intervention with a trivial effect on the parent-child relationship but potentially a significant effect on health: in the UK, it is proposed that mothers be paid (a limited amount, and in shopping vouchers) to breastfeed [BBC 2013]. This is clearly state intervention, and is justified in the medical interests of children¹⁶⁵ but is not justified by the threat of imminent serious harm to the child, nor is it ever likely to be. It may be that Diekma intends 'state intervention' only as forcible compulsion of the child's

¹⁶⁵ The benefits of breast-feeding are most clearly demonstrated in third world countries, but are also present in the developed world. In the third world "Breastfed children have at least six times greater chance of survival in the early months...non-breastfed children in industrialized countries are also at greater risk of dying – a recent study of post-neonatal mortality in the United states found a 25% increase in mortality among non-breastfed infants. In the UK Millennium Cohort Survey, six months of exclusive breast feeding was associated with a 53% decrease in hospital admissions for diarrhea and a 27% decrease in respiratory tract infections." [UNICEF nutrition].

treatment as he recognises that if the harm is not imminent, state intervention should be postponed whilst working “...with the child’s parents or guardians in a non-confrontative manner to resolve the issue” [Diekma, 2004: 253]. A broad range of interventions, such as those for public health in general are other examples of state intervention by clinicians that are unlikely to be justified by Diekma’s trigger of immediate harm: the harm is more distant in time.

I have argued that Diekma’s does not defend a clear ‘harm’ standard. And that even if Diekma could set a clear definition of harm, it would not be the appropriate level for intervention: children need more than just the avoidance of harm (however defined). I will rebut one of Diekma’s several applications of the harm principle to demonstrate these problems. He offers several examples, arguing that the harm principle justifies state intervention for blood transfusion of children of Jehovah’s Witness parents, and insulin administration to diabetic children but the harm principle does not justify intervention to require treatment for cancer with poor prospects of survival. His last example is that of parents who refuse vaccination. “Parents may refuse to immunize their children for a variety of reasons including religious proscriptions, naturopathic preferences and beliefs, or a rational calculation that remaining unvaccinated would be better for their children.” [Diekma, 2004: 257].

Vaccination refusal for Diekma is justified by the harm principle. Diekma gives two reasons. Firstly, because vaccine refusal may be in the child’s best interests “While most mandatory vaccines are effective and safe, a small possibility of adverse reactions exists...a parent might reasonably conclude that refusing the measles vaccine is in the best interests of a child living in a community with a high immunization rate.” [ibid 257]. It is true that vaccines may cause harm and that attention is paid to the balance between the risks of vaccination and the benefits of vaccination, which may change as the underlying rate of disease in the community changes¹⁶⁶. However, it is unlikely that a child’s parents are best placed to assess the best interests of the child. They are not experts. They do not have training in this field. They are unlikely to have

¹⁶⁶ As is demonstrated by the move from oral polio vaccine to inactivated polio vaccine as the incidence of polio reduced. Although the oral vaccine is more immunogenic, producing immunity where it is needed in the gut, cheaper and more easily delivered but it can occasionally cause become virulent and produce a form of polio [WHO 2003].

access to the scientific information about vaccination. Furthermore, they are not ‘disinterested’. They may feel more responsible for the consequences of acts rather than omissions. Parents may be easily swayed by media campaigns concentrating on the harms of vaccine programmes [Ditum, 2013]. For these reasons parents may not make a correct assessment of the child’s best interests. Parental rejection of measles vaccine in the UK as a consequence of the measles mumps and rubella (MMR) controversy has caused serious outbreaks resulting in epidemics, deaths and costly catch up vaccination programmes [Abertawe Bro Morgannwg University Health Board, 2013]. I disagree with Diekma’s claim that parents are well-placed to assess the effect of vaccination on a child’s interests, as parents are likely to be mistaken about whether vaccination is in their child’s interests for many different reasons.

But even if parents were able to assess the advantages and disadvantages of vaccination, there is an interesting question about the extent to which parents should give their children a free-ride. A free-ride describes what happens when all or most of a population are vaccinated such that significant disease transmission rates (epidemic or endemic) are unlikely and so there is less (or no) benefit to an individual from vaccination, though the risk of harm from vaccination (however small) remains the same. In these situations, and for some diseases, remaining unvaccinated may be in a child’s best medical interests¹⁶⁷. This strategy depends on sufficiently high vaccination rates, because if enough individuals avoid vaccination, then as vaccination rates fall, there will be increased risks of disease transmission and the risks of remaining unvaccinated increase. If sufficient people adopt the selfish strategy, there will be a point where it will be in the child’s interests to be vaccinated. There are two responses to this. Firstly, children should be taught to behave fairly towards other members of society as a part of education in its broad sense. Refusing vaccination is an example where the child would be taught to deal unfairly (selfishly) towards others¹⁶⁸. This is certainly troubling and seems wrong. The claim could be that although vaccine-

¹⁶⁷ Crisp describes a similar problem, albeit from a different part of a child’s life with the claim that teaching children to behave morally may not be in their best interests [Crisp, 2013].

¹⁶⁸ Diekma could respond that MMR vaccination is given to young children (in the UK at 12-13 months) and so that the child does not learn selfishness from this approach. However, there are subsequent doses when the child is older and the consequences of being unvaccinated require that the child and its medical attendants know of the child’s unvaccinated state and so the child will become aware of the parents’ choices.

avoidance is in the child's medical interests, overall it is not in the child's interests. A second response is to recognise the analogy between vaccination and other demands of life in society. Life in society requires that an individual does not always demand what would be best for them individually. There are many examples, including that a person gives up their time for jury service or that they accept that they will be taxed. It would be in any individual's best interests to avoid paying taxes, but tax avoidance is taken to be the wrong way to behave. And the rightness or wrongness of tax evasion is not a best interests calculation, that we make having compared the relative costs and likelihood of succeeding in tax evasion or being caught and punished. There is a strong sense in which tax evasion is just the wrong thing to do, not an action justified (or not) on consequentialist grounds. Analogously in refusing vaccination for selfish reasons, parents are behaving wrongly and are educating their children to behave wrongly. For all these reasons Diekma's first justification for parental refusal of vaccination in a child's interests does not work.

The second reason that Diekma gives for accepting parental refusal of vaccination is that the danger provoking intervention is not imminent. Imminent harm is present only for vaccination in epidemics, or in certain situations exemplified by a "...child lacking tetanus immunity who has sustained a deep and contaminated puncture wound." Tetanus vaccination is an important and effective vaccination. But to leave vaccination until there is this sort of wound will be unsuccessful because in tetanus infections, the "...portal of entry in approximately 80% of cases is an insignificant wound." [Feigin et al, 2004: 1769]. If vaccination is left until there is a tetanus prone wound, the opportunity to prevent more than 80% of cases of tetanus will be missed: children will develop tetanus when tetanus could have been prevented. The example demonstrates that vaccination, and many public health interventions more broadly, will not be justified by the threat of imminent harm. And as public health measures are responsible for enormous improvements in both the quality and length of life, Diekma is wrong. This response is specific to tetanus vaccine, but it reinforces my claim that experts in infectious disease, alongside others, are best placed to determine the value of vaccination, and that parents, may not be best placed to decide what would be in the child's interests. Parents, because they are not experts may make the same error that Diekma makes (although he is a medical doctor he is not an expert in the field of vaccination). A dispassionate assessment of the effect of the intervention on the

child's interests by experts is more likely to give a correct assessment of the child's interests. It may be that parents should be permitted to refuse vaccination for their children, but we should not pretend that this is in the child's interests, it is allowing parents authority over the way their children are brought up.

I have argued that the harm principle as advocated by Diekma is unsuitable as a standard for making medical decisions for children. This is for several reasons. Firstly, what counts as harm is not clearly defined by Diekma, nor will it be easy to define for children whose interests are more fluid than those of adults. Secondly, it is not enough merely not to harm children, both children and the society they will grow into need children to develop and flourish. Thirdly, there are occasions on which parents must act against the interests of a child determining when this is appropriate and when this is wrongful has not been clearly described by Diekma and so what counts as harm has not been clearly characterised. The appropriate standard for medical decisions for children should not and cannot depend on the harm principle alone. I have argued that neither a best interests standard nor a standard that depend on the harm principle will be appropriate to guide medical interventions in children.

4.7 FAMILY INTERESTS

One response to the problems in using the best interests standard to make medical decisions for children is to appeal to the concept of the family's interests. If so, when medical decisions are to be made for a child, they should be based not solely on the child's interests, but on "...what is best, all things considered, for the family." [Strong, 1984: 10]. The child's interests will be a component of the family's interests, but family interests go beyond the individual child's interests. Moving from an individual child's best interests to family interests may solve three problems in particular. Firstly, if a best interests standard is accepted as too demanding, the problems involved in developing an alternative standard of interests for the individual child can be sidestepped by appealing to the family's interests. Secondly, as children are usually brought up in a family consisting of several members, and as it is unlikely that a course of action that is in the best interests of a child will be in the best interests of all the individual members of the family, it is unjust to prioritise the interests of the child over other members of the family. In these cases, one approach is to consider some way of amalgamating the interests of family members as family interests. Thirdly, the

concept of family interests recognises the interests that parents (and grandparents [Draper, 2013] and other relatives) have in the lives of their children. As well as this, it recognises the voice of the parents in determining at least some aspects of the lives of their children. An approach that prioritises family interests recognises the parents and children as joint participants in an enterprise with family interests as an end [Bainham 1998; Inwald, 2008; Ross, 1997, 1998]. However, family interests are often brought in as a solution to the problems posed by the child's best interests without a clear description of what family interests are taken to be (see for example Inwald, 2008; Gopfert, McClelland and Wilson, 2010) and so family interests may repeat the problem of the child's best interests: it is a appealing approach, but is unclear and unhelpful when medical decisions must be made for children¹⁶⁹. In the absence of a clear conception of family interests, the claim that family interests will resolve the problem does not carry much weight, and may cause difficulties¹⁷⁰.

It is important to separate the claim that decisions for children should be based on family interests from the claim that parent's should make medical decisions for their children. The two ideas are separate.

In this section, I will consider whether families are the sorts of thing that can have interests. I argue that a weak 'collective' conception of family interests can be defended though a strong 'corporate' conception of family interests cannot. Despite this, I argue that family interests cannot and should not guide the medical decisions that must be made for children.

Is the family the Sort of Thing That Can Have Interests?

People have morally significant interests, however some things don't have interests and some things don't have morally significant interests. For example, a fridge can be

¹⁶⁹ Wilkinson, in arguing against a family veto over posthumous organ donation, makes a similar point "...if there is posthumous autonomy, I believe that it is more important that the autonomy of the family. But it is hard to defend this view in the absence of a detailed case for family autonomy. It is really up to someone who wishes to defend a significant role for the family to make this case." [Wilkinson T, 2007].

¹⁷⁰ "Family loyalties present two sources of potential conflict...and extra weight given to the promotion of the family either at the expense of those outside the family or even at the expense of those within" [Schoeman, 1985: 54].

treated in ways that will damage it or in ways that will preserve it, but damaging a fridge is not taken to be acting against the fridge's interests (though it may be against the fridge-owner's interests). Other things have interests. For example, it makes sense to talk of the interests of a seedling (in that it has an interest in being watered, being in a sunny spot, and being protected from slugs and snails etc), but these are not morally relevant interests or at least not morally important interests (it would not be wrong to sacrifice a seedling so that other seedlings could flourish in an overcrowded vegetable patch). Sometimes, whether or not something is the sort of thing that has interests is disputed. In the House of Lords when the lawfulness of discontinuing tube feeding for a young man in a persistent vegetative state was decided, Lord Mustill stated "...the proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind." [*Airedale NHS Trust and Bland* [1993] : 77]. Keown, a legal academic, disagreed, responding "...to state, as did Lord Mustill, that Bland had 'no best interests of any kind' is, with respect surely false. Would it not have been contrary to his interests to use him as, for example, a sideboard?" [Keown, 1997: 494]. Where do families sit in this hierarchy? People (or persons) uncontroversially have the highest moral standing, with goals, rights and morally significant interests. Families are made up of people, and so one straightforward position is that family interests describe the combined interests of the members of the family, and in this characterisation of family interests there is nothing more than the individual interests of the family members. This position was proposed by Sumner: "Any talk, therefore, of the welfare of groups, if it is not merely metaphorical, must be interpreted as referring to the aggregate of collective well-being of their members. Collectivities have no interests to be furthered beyond those of individuals." [Sumner, 1996: 179]. Buchanan and Brock described the claim for familial goals, perspective and objectives over and above the interests of the individuals in the family as '...dangerous reification.' [Buchanan & Brock, 1990: 236]. And this position is reinforced by others "...no approach we know suggests that group persons can have morally commanding interests such that a corporate good or benefit would determine what should be done, independently of the good or benefit to individuals... 'normative individualism' ...the view that something is good only if it is good for individual human beings or, more generally, sentient beings." [List & Pettit, 2011: 182] I will call this amalgamation of individuals' interests a weak conception of family interests.

There is a second, stronger, conception of family interests (hereafter strong conception of family interests) that families' interests go above and beyond the interests of individual members of the family¹⁷¹ [Ross, 1988; Schoeman, 1985; Nelson 1992; Taylor Sands 2010]. In the way that a school or a sports club may have aims or goals that are independent of the goals of the individuals who constitute the school or club, so too, some groups may thrive in a way that is not wholly dependent on the well-being of the individual members of the group (though nor is it completely independent of the well-being of individual members). In this characterisation, family interests describe the aspects which are a communal good for the whole family. In *Taking Families Seriously* the Nelsons state "Families aren't simply more or less efficient means to some independently specifiable good ends; they are also (at least oftentimes) valuable in themselves." [Nelson & Nelson, 1995: 7]. Either way, it is clear that in at least one, albeit weak, sense the notion of family interests holds water and that the important question is the second question: how should family interests be understood?

Much of the literature concentrates on the advantages of being a member of a functioning family. Families are often taken to be an undiluted good. As well as the Nelsons' comment above others write "...the important factor is that family members cherish each other simply for each other's sake, and that being devoted to 'the family' and its members is a source of deep meaning and value in our lives and the lives of those around us" [Crouch and Elliott, 1999: 283]. Although families are often a source of support, and material and emotional sustenance and of great value to the individual members of the family, this is not always true. Children and adults can be harmed physically and emotionally by other members of dysfunctional families [DeCourcy, 1980; van Eck, 2003; Haringey Local Safeguarding Children Board, 2009] and is the subject of much literature (amongst which are *Snowwhite*; *Oranges are not the only Fruit*, *Why be Happy When You Could be Normal?* and *the Goldfinch* as examples) and many films (*Mommie Dearest*; *the Sopranos* and *Shameless* are amongst many others). A theory that accounts for family interests also needs to recognise and account

¹⁷¹ Jones draws a similar distinction when considering group rights, naming what I describe 'weak' as collective and 'strong' as corporate conceptions of group rights "...*corporate* will be used here to describe...a right-holding group as a unitary entity. The term *collective* will be used to describe the conception of a group right as a shared or joint right, since it conceives a right-holding group as a 'collection' of individuals." [Jones, 2009: 12 Jones' italics].

for dysfunctional families. Families cannot be taken to be a source of unmitigated good.

Two Conceptions of Family Interests: A Weak Conception

The weak, collective, conception of family interests is that family interests are merely the combined interests of the individuals in the family. All members of a family may be affected by important decisions taken for, or by, other members of the family. Salter describes this clearly “Decisions about a child’s course of treatment affect not only the life and welfare of that child, but they often involve very significant financial, relational, and emotional consequences for the rest of the family.” [Salter, 2012: 4]. And it must be a requirement of justice that “...the interests of patients and family members are morally to be weighed equally” [Hardwig, 1990: 7]. Hardwig was reacting to the dominant approach that a patient’s autonomous choices should determine medical treatment for adults, claiming that an individual’s medical interests (as reflected by their autonomous choices) were only one, among many, interests that must be balanced by family members. Hardwig argued that it was wrong to regard a choice about medical treatment as being only one for the autonomous individual. Similar criticisms can be mounted against an approach that prioritises the best interests of a child. Family interests would “...replace the discreet and separable interests of family members with a more realistic view of the family, one that recognises the conflict, confluence and confusion of interests characteristic of life within a family.” [Crouch & Elliott, 1999: 284]. In considering the care of critically ill children towards the end of life, Inwald advanced a ‘family-based welfare approach’ because “...the interests of siblings are often ignored as the debate focuses on the parents and the child.” [Inwald, 2008 :250]. Using the family-based welfare approach would “...ensure that the interests of the child, the parents and the siblings are all properly considered and weighed”[ibid 250]. The meaning of the family-based welfare was not stated but, in describing the need to weigh the interests of all in the family, it need not rely on anything more than the interests of those in the family. Inwald’s approach was derived from Herring (a British legal academic) who sought to reconcile English Law (focusing on the child’s welfare) with Human Rights legislation. Herring’s approach (which he named relationship-based welfare) modified the child’s best interests by “two planks”: a recognition that in growing up the child must “...learn to suffer sacrifices as well as to claim benefits” and “...ensuring that the child’s relationships

with other family members are fair and just.” [Herring, 1999: 233]. Herring’s approach explicitly mentions only the parents. Herring’s concern stemmed from the legal focus on a child: UK law states “...the child’s welfare shall be the court’s paramount consideration.” [the Children Act 1989] and from the Convention on Children’s Rights “the best interests of the child shall be a primary consideration” [United Nations, 1989]. However, in families, others’ interests, rights or welfare must also be considered. Bainham (another British legal commentator) argued for a ‘collective family interest’:

“...children are not just individuals, with individual interests. They are also members of a family unit and have an interest which forms part of the collective interests of that unit...While, therefore, it may be a necessary condition for upholding children’s rights that children be accepted as individual persons with claims and interests which are independent of, and can conflict with, those of their parents, this is not the complete picture. There may also be a collective interest of the family (of which they are part) which needs to be taken into account...in some instances, the combined interests of the parents and the family taken as a whole may outweigh the interests of a particular child.” [Bainham, 1998: 99].

To resolve the conflicting interests within a family, Bainham developed the notion of primary and secondary interests “...the more fundamental the interest and the more serious the consequences of failing to uphold it, the more likely it would be that *that* interest would be regarded as the primary interest.” [Bainham, 1994: 173 his italics]. So in amalgamating interests, a primary interest (of either a parent or a child) counts more than a secondary interest of another, suggesting that Bainham takes family interests to be the aggregate of the individuals’ interests. However, as he continues to argue “...we might need to throw in the desirability of preserving the family unit and holding it together if at all possible.” reasoning that “...there are benefits in keeping all the children together, avoiding institutional care etc. and some weight should be given to this” [Bainham, 1998: 102] it may be that Bainham is arguing for family interests as being something over and above the aggregate of individual’s interests and this interpretation is suggested by his phrase ‘if at all possible’.

It is in an individual child’s interests to be a member of a functioning intimate family: a child will have a happier childhood and is more likely to grow to be a healthy (in its widest sense) adult as a member of a ‘healthy’ family. And so it is in any child’s interests that some particular interests of the child are setback for the good of others in

the family to maintain the integrity of the family. The important point is that the appeal to family interests is for the integrity of the family to benefit the child. It is not that the child's interests should be sacrificed to preserve the family, for the family's sake. The family's value is instrumental to the child (and presumably other family members) it is not that the family itself is intrinsically valuable. So even a weak conception of family interests (as the amalgamated interests of those in the family) justifies actions that compromise an individual child's interests for benefits to others in the family. And the concern is that a sufficiently great advantage to others in a family can demand a large sacrifice from an individual.

Although this weak conception of family interests as the aggregated interests of individuals may seem straightforward, important questions remain. Firstly, there needs to be, within it, a robust conception of an individual's interests which is, as yet, absent, as I argued above. A second problem is that the way that the interests of the individuals should be combined or aggregated to produce the 'collective' family's interests remains to be settled. Smith describes it as "Each family member should be accorded maximal benefits relevant to his or her individual characteristics and compatible with maximal benefits relevant to others." [Smith, 1993: 49]. It is unlikely that any particular course will offer each individual *maximal* benefits and so there needs to be a balancing or optimising of the interests of the individual members of the family. Hardwig argues for "...the presumption of equality: the interests of patients and family members are morally to be weighed equally; medical and nonmedical interests of the same magnitude deserve equal consideration in making treatment decisions." [Hardwig, 1990: 7] The balancing of interests is unlikely to be straightforward. Bainham described primary and secondary interests, reflecting the fact that some of our interests are more important than others, but there are more than two grades of interests. And even the same sorts of interests deserve different weights. For example frequent and regular meals are a more important interest for an infant than they are for an adult and so frequent regular access to food is a more important interest for a baby than a parent. Balancing interests between family members will be even more troubled because the balancing must run through time. A decision to prefer the interests of one child to another on a particular occasion need not be unfair, but if one child was consistently preferred to another, that would be unfair (without other reasons). Furthermore, as with the criticisms that have been made of maximising

consequentialism, other values such as achievement or equality within the family may be important too. Whatever form of aggregation of interests is used, it is unlikely to be simple addition. Veatch asks “Surely, all that is expected is that a reasonable balance of the conflicting interests be pursued” [Veatch, 1995: 7]. This is true, but the devil lies in the detail.

A third problem comes from the power imbalance within families: parents make decisions concerning the child and the family, and in particular will make the decisions that concern the family as a whole. This is trivially true for just-born babies who can play no part in making decisions but it is also true for families with older children (and in many cases for good reasons). In contentious decisions, the parents will make the final decision¹⁷². A longstanding feminist criticism of the family is of the power imbalance within the family that leads to the needs and interests of women taking a back seat. Similar concerns are present if family interests are taken to replace children’s interests. In the absence of an objective notion of interests, and in the absence of oversight of decisions, a claim for family interests can become a claim that parents should make decisions, with whatever conception of interests (and whatever conception of a fair distribution of interests) that the parents choose to use. If this is so then we should recognise that in arguing for family interests, without a clear characterisation of family interests, parents will have a broad latitude in determining family interests and so their children’s interests. Brazier alludes to this in discussing consent for organ retention in stating of parents “...they are the guardians of the family’s values, be they religious or cultural imperatives, or simply personal convictions...” [Brazier, 2003: 31]. A claim for family interests may become a claim for strong parental (or paternal) authority, though these are distinct claims.

Two Conceptions: A Strong Conception of Family Interests

The second conception of family interests is that the family itself is the sort of group that has interests. Lainie Freedman Ross states this position clearly “...families can have interests that are not reducible to the interests and needs of particular members...” [Ross, 1998: 43]. This echoes earlier writing by Schoeman “The relationship within a

¹⁷² And even if the decision is made democratically, the parents have decided to make the decision in that way. They could have made the decision to choose themselves.

family typically has an inner focus and an independent meaning...They are not typically concerned with the maximization of individual welfare or the promotion of social interests.” [Schoeman, 1985: 48-9] and “...the family is to be thought of as an intimate arrangement with its own goals and purposes”. [Schoeman, 1985: 50]. Nelson described the importance of families as “...these particularities constitute how families distinguish themselves, how they become more than simply units of economic transfer. They express what might be regarded as familial character, as those reasons for which people have the deep and abiding interest they do in forming and maintaining families. For instance, a family may encourage and support music lessons but not karate lessons...” [Nelson, 1992: 8]. Taylor-Sands follows this strong conception in claiming “Intimate families are inherently valuable for the collective endeavour they entail, which gives our life meaning” [Taylor-Sands, 2010: 12.7]. In writing of maternal mental health, Gopfert argues “...the whole of the family (like any cohesive group) is more than the sum of its coherent parts” [Gopfert, McClelland and Wilson, 2010]. The Irish Constitution expresses the strong conception:

“The State 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...guarantees to protect the Family in its constitution and authority, as the necessary basis of social order and as indispensable to the welfare of the Nation and the State.” [Constitution of Ireland, 1937: Article 41].

And Chao describes empirical work that suggests that in Chinese-American families the individual is seen only as a member of the family. Chinese-American mothers report “...the child’s personal academic achievement is the value and honor of the whole family. If you fail school, you bring embarrassment to the family and lose face. If you do good, you bring honor to the family...” [Chao, 1996: 412]. The strong conception suggests that the family in and of itself can thrive. It should be distinguished from the idea that people can thrive only in a family, that being in a family is instrumentally valuable to family-members. The stronger conception of family interests has the family as intrinsically valuable, over and above the benefits to individuals of being in an intimate family. The benefit of the family in delivering intimate relationships “...I want to get a clear account of the special moral value of intimacy squarely on the bio-ethical table” [Nelson, 1992: 7] is caught in the first, weak, conception of aggregate family interests – as the amalgamated interests of individuals. The second, strong, conception describes that families are intrinsically

valuable. “Seeing families and societies as institutions with independent ideals and as invested with meanings of their own is necessary to understanding what is so important about them...” [Schoeman, 1985: 56].

An example of such a strong conception may be that it can be used to make sense of talk about the interests or good of a group such as the British Royal Family. In the late 20th Century, when the heirs to the throne were divorcing and attracting media attention for assorted misbehaviours: Prince Charles, the immediate heir, was disengaged from the problems of the times, and other members of the family were engaged in shady financial deals or partying with unwholesome individuals, it might be said that the Royal family was not thriving. The Royal Family itself (and not just the individual members) was failing. More recently with handsome, photogenic heirs, spouses and babies, alongside members of the Royal Family who engage with the problems of our time (Prince Harry and his support for injured soldiers for example) and the Queen enjoying unrivalled popularity we could say that the Royal Family itself (regardless of the individuals themselves) is flourishing. The Royal Family is taken to represent a flourishing Britain, and to be successful in itself. It is in this sense that there may be a strong conception of family interests. Importantly, actions that are not in an individual child’s interests may be countenanced by either sense of family interests, but find a stronger justification in the strong, corporate conception of family interests.

There are several problems which would need to be overcome to develop the strong conception of family interests. I will concentrate on three in particular. Firstly, one question is whether the family is the sort of group that can have group interests¹⁷³. A second concern is that there would need to be a clear definition of what a family is. If there is to be a strong sense of family interests then there needs to be a defined group of ‘family’ that has interests. Families have undergone marked changes in recent years, and those who defend family interests have not been clear in characterising the family group that holds family interests. A final problem is that a strong conception of

¹⁷³ I’ve argued that the British Royal Family may have group interests, but this may be a particular case. It may be that families in general do not have group interests, but the British Royal Family has group interests as a ruling monarchy, not as a family.

family interests needs to recognise and account for the fact that some families harm some or all of the individuals in the family.

Group Interests

The first question for the strong conception of family interests is whether a family is the sort of thing that can have interests that are over and above the interests of the individual members of the family? Some groups are constituted so that the group as a whole seems to have interests. A sports team may have a sense of history, a personality (the Harlem Globetrotters), and common goals (to win at all costs, or to compete with style). But it doesn't make sense to talk of the interests of some other groups. The group of people waiting at a bus stop each have an interest in the bus taking them safely to their (different) destinations, but the group does not have a common interest over and above their individual interests in completing their journeys [Jones 2009]. Does a family share the group characteristics of a sports club or a bus stop queue?

There is considerable philosophical literature discussing the ways that some groups may share some characteristics of a person, which include agency or autonomy [List and Pettit, 2011; Wilkinson T, 2007], rights [Jones 1999; Jones 2009; Tollefsen 2015] and interests. The Stanford Encyclopaedia of Philosophy entry (on group rights) describes the ways in which different groups are constituted and conceptualised, but makes no mention of families [Jones 2009]. List and Pettit consider the conditions under which group agency is possible, but make no mention of family agency [List and Pettit]. That the family does not appear in discussions of group rights, group agency and group autonomy is surprising, because of the ubiquity of families and the widespread importance of families within society. This stands in stark contrast to the frequency with which those discussing families make references to these characteristics. I have given many examples of the use of family interests above and as well as this, Taylor-Sands argues for "...the collective nature of agency within the family..." [Taylor-Sands, 2010: 12.9]. Kon argues that "...one ought [to] consider the autonomy of the family unit..." [Kon, 2007: 455]. Ross writes "My own theory will have greater respect for family intimacy and family autonomy" [Ross, 1998: 28] and "...I have argued that when the family is intimate, parents should have wide discretion in pursuing family goals, goals which may compete and conflict with the goals of particular family members" [Ross, 1997: 43]. But in the absence of a clear

characterisation of ‘goals’ or ‘agency’ and in particular what this means when ‘family’ is attached to them, the claims could be treated as merely metaphorical claims. Should the family be treated as the sort of group for which a strong conception of interests is appropriate? I argue that it should not.

Some features of the family cause concern when claims for group interests are made. There is an imbalance of power within a family (and this is more obvious the younger that a child is) that is not found in many of the groups that can be considered to have group interests. If a claim is made for a strong conception of family interests, the decision must be made by those in the family. Those in the family are the ones who know what the family traditions, goals and focus are¹⁷⁴. As well as this, with the strong conception of family interests, there is the sense that the family *has* to decide the family interests (analogously to the way that an individual’s interests may have a large component of personal choice). Within a family, some members are more powerful than others, and so a claim for strong family interests may become indistinguishable from a claim for strong parental authority. Or if the family is construed as a wider group, decisions may be made by a more distant relative, for example a grandparent or uncle. The concern here is that if claims are made for family interests, then an individual’s interests may not be apportioned proper weight.

Ross rejects this particular criticism of the strong conception of family interests arguing that “...parents perceive themselves as representatives of the family’s interests, and this can be separated from their role as representatives of their own interests. As such parents can serve as both moderator and disputant in intimate family decisions.” [Ross, 1998: 32]¹⁷⁵. Ross’ claim that parents *can* stand above the family and take a more objective view of the decisions despite being both a party to and a judge of family decisions, does not mean that parents *will* act in this way, nor that they always

¹⁷⁴ This may not be a criticism of the weaker conception of family interests. If family interests are the aggregation of the interests of individuals within a family, then the perspective of those outside the family could be taken to determine what the family interests are. In a strong conception of family interests, where the traditions, heritage and beliefs of the family are important it is those within the family who are inculcated in the values of the family who must determine what the family interests are.

¹⁷⁵ Others make similar claims “Parents can be seen as representing the interests of the family as an integrated whole in addition to representing their own particular interests.” [Schoeman, 1980: 19].

will, even if they do on occasions. In situations where a parent has to decide as both ‘moderator and disputant’, it is difficult for the parent to be objective, to compensate, but not over-compensate, for the fact that they are not disinterested. The parent must be neither too hard, nor too soft, on their interests. In discussing medical treatment for those incompetent to make decisions for themselves, Buchanan and Brock describe situations that rebut the presumptive decision-making authority of the family. Their conditions include “...the especially vulnerable position of the incompetent patient, the momentousness of the consequences of the decision...and some treatment alternatives would impose great burdens on the surrogate...” [Buchanan and Brock, 1990: 142-3] recommending that there should be some sort of institutional review when cases fall into these groups. These conditions are true of all newborn children and many older children. It is clear from the text that Buchanan and Brock did not intend to refer to normal children, but as a normal newborn child must be counted amongst the most vulnerable of humans, or that bringing up even a normal child holds enormous burdens for the parents (alongside great rewards), their cautions emphasise the need for concern when claims for strong parental authority over interest-based decisions are made.

Ross’ second response to the imbalance of power within families is that it “...ignores the influence that children, even infants, have in eliciting responses in adults that can profoundly influence relationship and goals. Although parents have ultimate authority, their decisions are influenced by the needs and interests of children. Parental decisions can reflect a family decision.” [Ross, 1988: 33]. Ross’ second claim is that children *can* influence the family decision. Again the response to Ross is to agree that some children can, on some occasions, influence some parents. This does not mean that a child is guaranteed the consideration that they deserve, and there are many examples of situations where child have not been given due consideration. A parent’s response to a child’s needs may go awry in two ways. Firstly, parents may fail by neglecting their child’s needs (be they physical or emotional or in whichever domain) harming the child by neglect. However a second concern is that parents be over-attentive to their children. Parents can be too concerned and so over-protect their child. Cameron describes the spoilt children (Little Emperors) born into China’s one child regime who differ from the generation before them in that they are less trusting, less trustworthy and less conscientious [Cameron 2013].

I believe that these are good reasons why the claim that the family can be the sort of group that can hold group interests as anything other than the amalgamation of the interests of the individual members of the group should be dismissed. But even if not dismissed, the strong conception of family interests needs to be clearly characterised before being brought into the debate. A second problem with strong conceptions of family interests is that families are not clearly defined.

The Lack of a Clear Definition of a Family

The family, and conceptions of families, are not static. Nussbaum notes “...Family is itself a political institution that is defined and shaped in fundamental ways by laws and social institutions.” [Nussbaum, 2007: 105-6]. Recent years have seen marked changes in how families are constituted. Amongst many examples are the way that both single mothers and gay people can lead families, neither of which were possible in the recent past because of stigmatisation of these life-styles.

In recent times, single¹⁷⁶ mothers were stigmatised as ‘fallen women’ or ‘damaged goods’, and often coerced into allowing their children to be adopted, having been persuaded (or bullied) that adoption was best for both child and the mother. An Australian Government report into adoptions between 1950 to 1992 reported that “Attitudes towards the women reflected and sometimes accentuated or became the vehicle for the broader societal view of unmarried mothers, which resulted in feelings of shame, guilt and an unworthiness to raise their child.” [Kenny et al, 2012: 35]¹⁷⁷. These attitudes are widely reported around the world (for example in Ireland, [the Interdepartmental Committee chapter 3]; in Britain, [Paton, 2012]; in America, [Wilson-Buterbaugh,]). This contrasts with current day practice where women commonly lead single parent families: around 20% of NHS Trusts in the UK fund IVF treatment for single women who would not otherwise be able to have children

¹⁷⁶ Single is ‘single’ as never married, not single as a widow or divorced.

¹⁷⁷ Some examples of the mother’s experiences from the Australian national research study of past adoption practices “I was only 17 and society did not accept unwed mothers...I was told, being unmarried, I wasn’t fit to be a mother...Being locked up in an institution with no choice, no support, and treated like I was nothing.” [Kenny et al, 2012: 35].

[Adams, 2011]. Private IVF clinics target advertising specifically at single women¹⁷⁸. Single motherhood, once humiliating for the woman and her family, is now a deliberate choice. This dramatic change took place over a short time. Another example is that homosexuality was a crime until 1967 in England and Wales (1980 in Scotland). Single-sex civil partnerships were legalised in 2004 (the Civil Partnership Act) and single-sex marriage became recognised in 2014 [Marriage (Same Sex Couples) Act 2013]. Single-sex couples already have access to IVF. These examples demonstrate only some of the significant changes in family structure that have occurred in recent years. That there is not a single recognised stable family structure undermines the claim that there can be a strong conception of family interests, because there is not a single conception of the family.

As well as changes in family structure, there have been changes in conceptions of parenthood. This has partly been driven by increases in family breakdown, but advances in reproductive technology have also been important. In the past families consisted of two parents (apart from rare occurrences when one parent died) with the tacit acceptance that the parents were the biological progenitors of the children in the family (even when this was not actually true). With increasing family breakdown and remarriage, families are constituted of parents and children not all of whom are biologically related¹⁷⁹. As well as this, developments in reproductive technology exposed different roles to parenthood, allowing that a biological parent (the sperm or egg donor) need not be the parent who raises the child. More complexly, there may be more than two biological parents: modern reproductive technology allows for at least two biological mothers, an egg donor and a gestational (or womb donor) mother, alongside a mother who will rear the child. In the past, these roles were necessarily

¹⁷⁸ “The London Women’s Clinic has always been a popular centre for single women because of our large sperm bank and our welcoming attitude towards alternative families. The seminars focus on the various fertility treatments for single women...” [The London Women’s Clinic].

¹⁷⁹ An example of the challenge that these problems pose comes from the US courts: a 13 year old boy with leukaemia needed a bone marrow transplant. He shared a father with 3 year old twins (born to a different mother). The twins lived with their mother, not their father, and there had been infrequent contact between the 13 year old and the twins. Having failed to persuade the twin’s mother, their father sought a court order to compel testing and bone marrow donation if the twins were compatible [Curran v Bosze]. The court withheld permission. Although the court’s deliberation did not rest on the definition of a family, the case gives a clear example of the complexities of modern day families when trying to resolve ethical problems with the claim for family interests.

combined. Macklin describes several different conceptions of families, amongst which are those she names biological, legal, custom and subjective intentionality, but concludes “...there is no single, univocal concept of the family...” [Macklin, 1991: 11].

In the absence of a clear understanding of what a family is, those who argue for family interests could overcome the problem by stipulating a clear definition, but they don't. Ross, needs a conception of family as a cornerstone of her theory of constrained parental authority: “My conception of an intimate family is an intimate group in which the parent-child relationship and its attendant obligations are central. This conception includes some legal families and excludes others. It also includes many non-traditional, non-legally sanctioned families. The intimate family is a moral and not a biological or legally defined relationship.” [Ross, 1998: 6]. Another proponent of strong family interests, Schoeman, defines the family in a similarly nonspecific way “...‘family’ an intense continuing and intimate organization of at least one adult and child, wherein the child is extensively and profoundly dependent on the adult, in which the adult supplies the child with its emotional and material needs, and in which the parent is dependent on the child for a certain kind of intimacy. This relationship is to be understood as moral, not biological.” [Schoeman, 1980: 9-10]¹⁸⁰. The absence of a clear and consistent definition of a family renders an agreement on family interests difficult. In excluding both biological and legal relationships as the basis of a family, it becomes difficult to define the group that is a family. In excluding legal definitions of the family, family interests become impracticable for use in applied ethics because contentious decisions regarding family interests will go to law for resolution, and the law will use a legal definition of a family. Some characterisations of what it is to be a family are almost deliberately obscure, for example Nelson writes “...a difficulty that can be overcome by letting go of the idea that families *have* a defining essence...families as people configurations that have at least some of a rather wide array of characteristics, no one of which is definitive, but most of which will be present to one degree or another” [Nelson, 1995: 35]. And from another author

¹⁸⁰ Schoeman's definition is too restrictive and could be improved by dropping the requirement that there *be* a child, recognising that relationships where there are plans to have children or an attempt is being made to have children should be recognised as families. She also excludes families with adult children where the child no longer relies on the parents for material needs, and those where the child supplies the parent with material needs.

“...what is the ‘family’? As I will use it here, it will mean roughly ‘those who are close to the patient’...‘Family’ so defined will often include close friends and companions. It may also exclude some with blood or marriage ties to the patient.” [Hardwig, 1990; 5]. Here Hardwig conflates friends and family. This error is repeated by Kuczewski “...the family is described in terms of ‘closeness’ not biology” [p30 Kuczewski, 1996: 30]. Similarly, Taylor-Sands recognises the many different forms that families can take and settles on “...at the broadest level, a group of persons in a household who regard themselves as family.” [Taylor-Sands, 2010; 12.4]. There are certainly occasions in which a person is isolated from their family, but has close friends, but these are friends not family. Although sometimes friends should be recognised to be more knowledgeable about the values of a person than are distant family members, this does not mean that friends should be confused with family members. And it is not always true that current friends are better guardians of a person’s values than are family members even if the family are more distant at the time. Some people have been rescued from cults (such as the Moonies) where estranged family members take themselves to have a better knowledge of the ‘true’ values of the person than the person’s (cult) friends. Either way, the point is that family members can, and should be, distinguished from friends and that some of those who argue for a strong sense of family interests have reconceptualised the family to include friends and in doing so they exclude individuals who others would take to be family members. And through all of this there is no clear sense of ‘family’, which is needed for those who argue for a strong sense of family interests. If this criticism is true, then an inconsistent approach to families will produce an inconsistent conception of family interests.

A clear definition of the family is a more important requirement for the strong conception of family interests than for the weak conception of family interests. The weak conception recognises the members of the family as those whose interests are considered in the overall calculus. Although there may be some differences in the way that a person’s interests should be considered depending on whether or not they are taken to be a member of the family, all people deserve consideration, and a person is deserves to have their interests taken into account whether they are, or are not a member of the family. All people are owed some attention. Whether a particular individual is, or is not, a member of the family may have little effect on the

consequentialist calculation for the weak conception of family interests. However, if the strong conception of family interests is adopted, then the family is the family and people cannot choose whether or not they belong to the family. Individuals cannot choose who should be bound by the family traditions and goals. The strong conception of family interests requires a clearer definition and understanding of a family. In the absence of a clear definition, the weak conception of family interests is to be preferred.

Dysfunctional families

The problems for the strong conception of the family are compounded by the fact that some families are clearly dysfunctional and harm at least some of their members. There is likely to be a range of families, progressing from good families through average to dysfunctional families on to those severely dysfunctional families. There are clearly dysfunctional families as is demonstrated by the episodes in which children are injured or killed by non-accidental injury in families¹⁸¹, but also by families where children are neglected or emotionally abused [discussed by Gardner, 2008]. Adults too are harmed in some families and this is described by the over-arching term domestic violence¹⁸². Children are the most vulnerable people in dysfunctional families for a variety of reasons, but adults too may be harmed. Adults may be coerced by violence or threats of violence to behave in ways that they would not choose because of family honour [van Eck, 2003]. A weak sense of family interests, relying on the amalgamated interests of members, deals well with this problem. The strong conception of family interests does not. And if family interests, and in particular the strong conception is preferred, it will become more difficult for those outside the family to enquire into

¹⁸¹ In an 18 month period researchers covering the whole of Scotland state “We identified 19 cases of NAHI [Non-accidental head injury], 12 boys and seven girls, between July 1, 1998 and December 31, 1999. The annual incidence of NAHI was 24.6 per 100 000” [Barlow, 2000: 1571]. There are high profile tragic cases where children have been killed by their parents, or those their parents have entrusted their children to [Laming, 2003; Haringey Local Safeguarding Children Board, 2009; Coventry Safeguarding Children Board, 2013].

¹⁸² “One woman in four (and one man in six) in the UK will be a victim of domestic violence during their lifetime, according to research estimates. Two women a week are killed by a current or former male partner” [NHS Choices (b)].

situations in which children are being potentially mistreated or neglected¹⁸³. There seems no sense in which a dysfunctional, harmful, family should be a bearer of interests¹⁸⁴.

A reason to prefer the weak conception of family interests

On some occasions, parents must make decisions that are not in a particular child's interests, but are for the good of another, or others, in the family¹⁸⁵. These decisions cannot be justified when attention is focused on an individual's interests, and can only be justified by an appeal to family interests, or the interests of others. The weak conception of family interests justifies some actions that at first sight are against an individual person's interests, when the benefits of being in a family (of intimate relationships and shared goals and values) to the individual are included. Some actions that might have been taken to be harmful (in the absence of their effect on family relationships) may be justified by the effect on the individual's *overall* interests. As well as this, the weak conception of family interests allows the interests of others within the family to be brought into consideration in assessing an individual's interests and so act as another justification for decisions that are not in a particular child's interests. "To be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself." [Hardwig, 1990: 6]. This is true, but as Munoz-Darde argues "...justice requires us not to be concerned with family welfare or autonomy, but with each family member's demands for respect and well-being." [Munoz-Darde, 1999: 39]. These two can be reconciled in the weak conception of family interests by allowing that other family member's interests are brought into consideration when a medical decision

¹⁸³ Wilkinson, in arguing against the role of family veto in posthumous organ donation, writes "Many feminists rightly emphasize justice in the family...Medical staff should probably not be asking grieving families whether they are internally unjust." [Wilkinson T, 2007] If the strong conception of family is taken to be correct, these are the wrongs that children will not be protected from.

¹⁸⁴ Larkin expressed the concern that families (perhaps all families) are dysfunctional somewhat pessimistically "They fuck you up, your mum and dad. / They may not mean to, but they do. / They fill you with the faults they had / And add some extra, just for you." [Larkin].

¹⁸⁵ "Just as the interests of the interests of the infant limit parental authority, so the interests of the family limit what can be required of the family for the sake of an infant" [Strong, 1984: 15].

must be made for one child. However, the strong conception of family interests justifies choices that are not in an individual's interests 'for the good of the family'. The risk is that "...if we give moral standing to groups as such, we shall lose sight of individuals within the group" [Jones, 2014]. And this is a particular concern for children, because of their vulnerability and their difficulty in making their voice heard. Adults are the voice for young children and even older children may struggle to be heard. If the strong conception of family interests is defended the concern is that the stronger (usually adults) may enforce a course of action to the detriment of the weaker (usually the children). A strong conception of family interests may "...reinforce the power of conservative elites whose wishes and interests clash with those of others in the group. Typically an elite will want to use its power to maintain the traditions and integrity of the group and will be unwilling to tolerate dissent, deviance and demands for reform." [Jones 2014]. An example of the extreme end of the consequences of the strong conception of family interests is 'honour' killing of those who have offended against the family's honour, or place in society¹⁸⁶. The weaker conception of family interests (the amalgamated interests of individuals family members) is defensible as the individual members of the family are what are taken into account in coming to a decision about family interests: it is the interests of the individuals that are amalgamated for the family interests. This is not true of the strong conception of family interests.

Conclusion

I have argued that, there is not a clear understanding of family interests and that even those who use family interests have not made clear their conception of family interests. I have argued that only a weak conception of family interests (as the aggregate of the individual's interests) is defensible. The weaker conception justifies some actions that at first sight do not benefit an individual child, firstly for advantages

¹⁸⁶ Van Eck catalogues and describes honour killings in the Turkish community in the Netherlands attempting to understand the complex causes and interactions that can lead to honour killings of children, women and men. Killings are the most extreme way (the tip of the iceberg) that powerful family members coerce weaker members of a family. There are many other ways in which the less powerful in families may be 'persuaded': "Honour killing is the most extreme solution: it only becomes an option when the alternatives have failed and the question of honour escalates. The reason that honour killings do not occur more frequently is that people do their utmost to prevent questions of honour from arising" [van Eck, 2003: 185].

that accrue to the child herself in remaining in her family, and secondly for advantages to others in the family (because of justice). Recognising this, it is important to make sure that children's interests are protected even within the weak conception of family interests. There remains a tension between the individual child's interests and the interests of others in an intimate family and so medical decisions for children cannot be determined on the basis of the family's interests. As family interests are not helpful, I will consider a different approach to medical decisions based on a reasonable assessment of the child's interests, a development of the child's best interests modified by the criticisms that I have made so far in this chapter.

4.8 A PROPOSAL FOR CHILDREN'S INTERESTS

Introduction

I have argued that medical decisions for children should be based on the child's interests, but that the current approach, depending on the child's 'best interests' is flawed. A better approach is that the concept of interests is taken to offer a structure in which arguments for and against a particular medical course can be made. There can be reasoned argument to reasonable agreement both about what a child's interests are, and the effect that healthcare interventions will have on the balance of the child's interests. Interests can be balanced one against another through reasoned argument to achieve resolution. An analogy is that the framework of interests is a table top on which bargaining chips (interests) can be placed to be balanced against one another in deciding which course produces the biggest 'pay off' when assessed in the currency of the child's (and perhaps others') interests. This is a reasonable assessment of the child's interests.

The criticisms that I made of the child's best interests can be used in developing an alternative approach, a reasonable assessment of the child's interests. Firstly, because there is not a single accepted understanding of a child's interests, and there are multiple different uses of 'best interests', a part of the agreement must be to agree how the child's interests are understood. Furthermore, with agreement about the child's interests, it may be appropriate to acknowledge the interests of others when medical decisions are made for children. Decisions for an individual child cannot (in all

circumstances) rest on the interests of that child alone. The approach must allow that the parent's interests in their child's well-being can be included¹⁸⁷.

A child's interests are not a fact about a child that can be determined in the way that a child's weight or blood pressure can be determined. That this is believed is suggested by those who write of a child's Best Interests (with capital letters) which has spuriously authoritative or authoritarian overtones, suggesting a technically correct answer. The standard approach is that "...the 'best interest' standard...is used as if its meaning is self-evident and uncontroversial..." [de Vries et al, 2013: 1], but this is not true. de Vries' group interviewed parents, children and clinicians in a paediatric oncology unit finding that clinicians and parents have different conceptions of interests. As well as this their conceptions of interests changed through the course of the child's treatment. I have argued that there are good reasons why there may be disagreement about a person's interests. This means that reasoned argument is important in constructing or agreeing an explicit conception of interests to be used in making medical decisions for a child. There may be broad agreement about some aspects of interests, but there need not be, and importantly although a child's interests are taken to be self-evident they should be part of reasoned agreement.

The common point of these criticisms is that they recognise that what matters are interests, they modify the best interests approach, but remain interest-based. Others mount a different criticism, that an interests-based approach is incorrect, and require

¹⁸⁷ An example here is found in treatment towards the end of life when a family demands a treatment that they strongly believe to be indicated, though clinicians disagree. If the treatment does not harm the child it will likely be used. There are two interest-based approaches to justify this intervention. Firstly, in recognising that parents have a legitimate interest in the well-being of their child, when decisions are made for children, the parents' interests can be included. The parents' interests in their child are not determinative of decisions that should be made, but are one, among other, interests that are amalgamated in determining an appropriate course. An alternative approach is required if the claim is that medical decisions should be determined solely by the best interests of a child. The approach depends on the contentious claim of the persistence of interests after a person's death and one sense in which this may be true is the memories of the person that continue after the person's death. Those memories can be tainted (harmed) or embellished (benefited) and so affect the dead person's interests. The memories of the person are tainted by the family's belief that she was ill treated at the end of her life. Her family may then be unreconcilable with their child's death. The claim is that the parents may have been able to come to terms with their child's death had the child been treated differently.

that decision should be made by parents by right for example¹⁸⁸. These critics do not regard the child's interests as amongst the important components in medical decisions. The move away from interests is wrong, as it is clear that what matters in many cases is the child's interests. A further advantage of an interest based approach is that it offers grounds for reasoned argument and agreement.

An interests determination is best seen as a conceptual tool¹⁸⁹. Interests are a common currency or denominator allowing the different aspects of the child and her life to be considered one against another and amalgamated by reasoned agreement to produce an assessment of their effect on the child's overall interests. Decisions about medical interventions can be assessed in terms of the effect that the treatments will have on interests, but there is not a specific category of medical interests. Decisions about medical treatments may take priority over other aspects of a child's life (their schooling or whatever) but do not necessarily trump decisions which primarily concern other aspects of the child's life. And when medical decisions do take priority it will be because the decisions involve particularly pressing, important, or consequential interests, not because the decisions are about medical interests. As well as this, other people's interests may be included in the interests determination: the calculation need not, nor should, be limited to the child alone.

I have argued that medical decisions for children should be based on a reasonable conception of the child's interests. There are two parts to this. I will describe and argue for what I mean by 'reasonable'. As well as this, there must also be some agreement of what a person's interests are. If not it becomes all too easy, whatever process is used, to become confused about a person's interests¹⁹⁰.

¹⁸⁸ For example, "To hold that adults may be Christian Scientists but that if they are parents they may not raise their children according to Christian Scientist principles is to deny Christian Scientists the full right to the practice of their religion" [DeGeorge, 1995: 2].

¹⁸⁹ "The concept of best interests thus serves primarily as a conceptual tool, a focusing device, for our discussions, our thinking, and the processes by which we make decisions particularly about voiceless patients" [Bartholome, 1988: 40].

¹⁹⁰ An example comes from de Vries who, in empirical work on children's interests, asserts "...it is not easily determined whether it is in the best interest of a child to be vaccinated, circumcised or treated with complementary therapies...the notion of best interests is inherently a matter of balancing different values, and not just a matter for medical judgment." [de Vries et al, 2013: 2]. Taking one particular example, it is easily determined that vaccination of a baby with DPT vaccine (active against diphtheria, polio and tetanus) is clearly

A Substantive Conception of Interests

I have argued that there isn't a single agreed conception of interests, and that there are good reasons why it is unlikely that there will be one in the near future. Despite this, if interests are to be used when making medical decisions for children there needs to be some clear sense of what is meant by interests.

In criticising the Baby Doe rules in America, Arras argued that when faced with difficult cases, it is easier to resolve questions regarding the decision-making process (who should decide), than it is to decide what the right thing to do is. Arras' criticism is that we focus on the process of making decisions, to the exclusion of a "substantive standard based on the 'best interests' of the child" [Arras, 1984: 25]. And yet in the absence of a clear sense of what interests are, whatever process is in place will not necessarily settle on the child's interests. In the absence of a substantive standard, decisions need not reflect the child's interests and will be likely to be inconsistent. Concentrating on process alone will not solve the problem of how medical decisions should be made for children.

A child's interests must be understood widely, and so interests is an appropriate term. 'Interests' are plural, recognising that there is more than one component to an individual's well-being, and so encouraging a broad review of all the factors that may be good or bad for the individual. It also recognises that there are benefits and gains to each course, and that the benefits and gains may be in different domains of a person's life, and so these domains must be balanced one against the other. For example a treatment that is more likely to cure a child (a medical interest) may be more unpleasant, and so unpleasantness (and other emotional interests) must be balanced against a greater prospect of cure.

in a child's interests. It reduces the likelihood of death and disease. It is not a matter of values, unless some bizarre value system prioritises a shortened, diseased, life over a longer life with less morbidity. Vaccination is a single event that will not compromise the child's relationship with their parents. There may be particular cases where determination of the child's interests is difficult, but this is not true in all situations. We may choose to let parents make decisions that are not in a child's interests (for several reasons), but we should not pretend that the approach that is taken is in the child's interests.

In focusing on the child's interests, the decisions are centred on the child, what *does* matter and what *will* matter to the child. The child's interests are seen through the child's eyes. Others (children and adults) may have interests that need to be considered in so far as they are affected by the decisions that are made for the individual child, but all justifications or reasons must be traced back to that child. Any reasons that cannot be clearly traced back to the individual child's interests may be questioned. I have already discussed the ways in which a child's interests are intermingled with others in an intimate family. Another example of the importance of focusing on the child's interests is found in justifications for a child's participation in research. Traditional guidance was that research on a child was acceptable only if "...it is good practice and in the best interests of the child..." [Medical Research Council, 2004: 28]. More recently, this has been watered down so the European Directive relating to clinical drug trials requires that "...some direct benefit for the group of patients is obtained from the clinical trial..." [European Parliament, 2001: 8]. UK Law is slightly different: "Some direct benefit for the group of patients involved in the clinical trial is to be obtained from that trial" [Statutory Instrument, 2004: Part 4 Section 10]. The UK's text makes it clear that the 'group' is the group of children taking part in the trial. However, both of these standards are clearly different from the initial standard requiring that participation in the research project be in the participating child's best interests. Benefit to a group (however characterised) is a less stringent standard for research-participation than one that depends on the individual's interests. With the prospect of sufficiently great benefit to the group as a whole, significant harms are justified to a particular child. This is clearly wrong. My example is intended to demonstrate that although it may be reasonable to include the interests of others in deliberation, the focus should remain on the individual child's interests.

Although interests may be categorised into groups, as others have done (Wendler lists five groups [Wendler 2010]; Holman, 2006 describes at least four groups¹⁹¹; as does

¹⁹¹ "Best interests...include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations." [*An NHS Trust v MB* [2006] paragraph 16].

Gillon¹⁹²) the importance of grouping interests should not be exaggerated. Interests are not demarcated within boundaries, and there is not a clear distinction between medical interests and other interests. In the same way that health does not have a clear definition, neither do medical interests have clear limits. The WHO defines health as “...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” [Constitution of the World Health Organization, 1946]. Daniels responds “Health is not all there is to well-being or happiness, contrary to the famous World Health Definition (WHO) definition...The WHO definition risks turning all of social philosophy and social policy into health care.” [Daniels, 2008: 37]. These statements demonstrate that there is not a clear demarcation of ‘health’ nor ‘medical’. To take one particular example of groups of interests, Holman seeks to separate ‘emotional, sensory (pleasure, pain and suffering)’ considerations from medical interests, but the features Holman seeks to separate from medical interests are integral components of medical interests. Specialists in Psychology and Psychiatry focus on the emotional well-being of patients. Similarly specialists in Anaesthesia focus on relieving pain and suffering. Throughout medicine there are attempts to limit the ‘emotional, sensory (pleasure, pain and suffering)’ consequences of medical treatments. Medical treatments prolong (or shorten) life, improve (or impair) functioning, reduce (or cause) pain, initiate and cement (damage or break) relationships, and can improve (or impair) mental health amongst many other effects. The interests that Holman seeks to separate from medical interests cannot be so isolated as they are integral components of medicine.

Despite these concerns, grouping interests may have a role to ensure that aspects of a person’s interests are not ignored in focusing on one particular component of interests. To this end, I discern three broad groups of interests all of which overlap: biomedical interests; experiential interests (in taking pleasure from being alive); interests in achievements and development¹⁹³. These interests may be further subdivided into

¹⁹² Discussing confidentiality in genetic counseling Gillon argues that ethics should “...not permit transgression of medical confidences in order to serve the medical interests of third parties...” [Gillon, 1988: 172].

¹⁹³ One group that is often proposed is a group of interests in human relationships (see for example Buchanan and Brock, 1990: 247). I believe that what is important in human relationships is encompassed by the other groups of interests. The experiences of being in a good (or bad) relationship, and the effects on a child’s development are ways in which the

current interests and future interests. Future interests are likely to be more important for children than adults because of the longer future time spans of most children's lives and at least for young children, their interests are likely to be richer when they are older.

An individual's interests change as they grow and develop. A baby's interests are essentially biomedical, experiential and developmental. Babies' experiential interests are more simple than the experiential interests of an older child. A baby's experiential interests lie in being warm, but not too hot, in feeling satiated, in being comfortably positioned, and so on. As they age, a child's, or person's experiential interests become immensely more complex, and change: an older girl may not mind being uncomfortable or tired whilst watching her favourite band. Developmental interests change enormously too. A baby's developmental interests are not particular to that baby, but common to all babies of that age. Any particular interests at that stage are imposed by their parents or family. As a child matures, the child's developmental interests start to become particular to the individual child – less general to humans – as the child's aptitudes, abilities develop and they focus on certain activities (mathematics or football for example).

Biomedical Interests

I have argued that medical interests are not a specific subgroup that is clearly separable from other interests, but if biomedical interests are taken to be interests about medical matters, then they may be broadly understood as interests in being

effects of relationships are contained in the other groups of interests. A reason to include interests in relationships as a separate group may be to the emphasis the importance of relationships in a person's life. A life without substantial and meaningful relationships is impoverished. But the importance of relationships may be exaggerated if there is taken to be a group of relationship interests. I have drawn attention to the way that family relationships, are often taken to be a source of unmitigated good. Another example is the claimed importance of the relationship that genetic parents have with their child. There are claims of a strong 'biological' link, and that children who do not know their genetic origins will be missing essential qualities. These thoughts underpin the right of adopted children to see their original birth certificate once they are 18 years old (16 years in Scotland) and the right of children conceived through IVF to seek their genetic (or gametic) parents once they are 18 years old under the terms of the HFEA legislation. Whether or not this is important, or whether it only becomes important if we believe that biological relatedness is important, is not clear. There is at least some evidence to suggest that there is no particular importance to biological relationships [Golombok, 2006]. My concern is that if there is a group of 'relationship' interests, relationship interests will be assumed to be important without good evidence.

healthy and growing and developing in a healthy fashion. Biomedical interests are interests in normal physiological and psychological functioning (and in normal development). This may be part of what is described as flourishing, but flourishing goes beyond normal physiological and psychological function in two ways. Firstly, flourishing suggests above average, better than normal, functioning. Secondly, flourishing tends to suggest that a person is achieving well in more than just their psycho-physiological domains (perhaps that they are successful at work or school or in whatever way is important to them). There are many different meanings of normal in physiology and psychology. The sense that I use here is that of physiologically normal, or species normal functioning (which begs many questions about what is meant by normal). It indicates that disease is not present and the prospects for healthy development are what would be expected for the organism¹⁹⁴. An alternative meaning of normal is statistical normality. The concern with this approach is that disease becomes 'normal' if the majority of population are diseased. So in some parts of the under-developed world where the majority of the people have intestinal worm infestations, infestations become (statistically) normal. This is not the sense that I intend for normal functioning.

A problem with this definition of biomedical interests is that although medicine can cure or ameliorate many conditions, there are some children with chronic disease who may have no prospect of having close to normal functioning. However, what would be in the interests of someone with uncorrectable disease or disability is as near to normal functioning as is reasonable. There is a balance between the costs (to the child and perhaps other family members) of medical interventions to improve their medical problems, and the benefits produced by the intervention. As near normal as is justifiable indicates that the benefits to the child of the proposed further medical intervention no longer outweigh the disadvantages of intervention. This is not to claim that the interests of all chronically ill or disabled children are at a lower level than all 'normal' children. The assessment of interests is a within-life comparison (how the

¹⁹⁴ I accept that the dividing line between normal, healthy, and abnormal, unhealthy, is not clearly drawn. For example, a minor elevation of arterial blood pressure does not cause symptoms today, but predisposes to the development of heart disease or stroke in the future. In one sense these are healthy people (at least until they develop a complication of hypertension) but in another sense they are not as healthy as they could be (most of us would choose to take at least some steps to reduce the likelihood of a stroke or heart attack).

child will be with or without the treatment), not a between-lives comparison (how the child is compared to other children). For children with significant chronic disease an explicit, reasoned, agreement on what the child's interests are taken to be can be very important.

Medical interests may assume greater importance than other interests, but they need not. And if they do, it is not because they are *medical* interests, but because the interests are particularly important. One reason that medical interests may be prioritised is because they are sometimes about matters of life or death, or other outcomes with important consequences. If so then medical interests should be prioritised, but medical interests are not always about matters of life or death and if so, if there are good reasons, other interests may be prioritised¹⁹⁵. Another reason why medical interests may be prioritised is that there may be a technically correct answer. For example it is true that tetanus vaccination prevents (or reduces the likelihood of) tetanus infection. We are less sure about some other non-medical decisions that must be made for children, for example their schooling or diet, and there are difficulties in knowing how to assess these interventions and so because we can be more confident of the effect of medical interventions, an interests assessment is more straightforward for them.

Biomedical interests are a greater component of a young child's interests than an older child or an adult's interests. Firstly, as a young child has only limited other interests: they do not yet have personal goals or projects, there are fewer other interests to consider. There is a similar limitation to interests based on their relationships. A young child has not yet developed, nor is able to express, a subjective sense of what matters to them as individuals. And because the particular characteristics of individuals are less developed there is a much greater range over which some things are 'objectively' good (or bad) for young children and so are in that child's interest (or against the child's interests). This is an area where experts can substantially help determine what

¹⁹⁵ In medicine sometimes 'life-saving' treatments are prioritised over other procedures. There are no life-saving treatments, there are only death delaying treatments. Perhaps all treatments should be compared considering the change in the individual's well-being and the likely length of life resulting after the treatment. This is the philosophy that underlies the use of QALYs in the evaluation of interventions.

is in a child's interest. There are many examples; exposure to passive smoking is against a child's interests; being breast fed is in a child's interests (unless the mother has HIV); being fed cows milk is against a young child's interests and so on. A second reason why biomedical interests are more important for young children is because of the length of time over which disease or disability may reduce the quality of the child's life and the length of time over which treatment can benefit a child. A change in the quality of life is multiplied by the longer life that children are likely to have.

Experiential Interests

A child (and as do all of us) has an interest in enjoying our lives and in limiting the amount of pain or suffering we experience. This thought underlies the utilitarian approach to ethics¹⁹⁶. An important component in determining a child's interests is the balance between good and bad experiences. However, the contrasting sensations of pleasure and pain may not capture the diversity of good and bad experiences that underlies experiential interests, and it may be better expressed as the balance between enjoyable consciousness and contrasting aversive consciousness. But nor does enjoyment capture the sense of all good experiences and indeed some good experiences may not be enjoyed at the time (because the person is tired or frightened). However as interests describe what matters to the person, the child's experiential interests, both current and future, must have a prominent position in an overall assessment of interests.

An assessment of experiential interests can offer significant challenges in several different ways. The first challenge is in determining whether the experiences of young children who are unable to communicate verbally are good or bad experiences. There are many examples, babies often cry on nappy changing, but nappy changing should not be painful and it certainly does not distress toddlers who often enjoy the interaction with their parents. Nappy changing in toddlers only causes distress if there are particular reasons (when there is excoriated skin as a consequence of nappy rash for example). It is unlikely that nappy changing would be significantly distressing for

¹⁹⁶ "...all desirable things (which are as numerous in the utilitarian as in any other scheme) are desirable either for the pleasure inherent in themselves or as a means to the promotion of pleasure and the prevention of pain." [Mill, 2002: 239].

babies, but is not so for slightly older children. Another example is ‘colic’. It’s not clear what colic¹⁹⁷ is but babies with colic behave in a way that suggests that they are in pain. Babies can appear distressed and cry for prolonged periods, and then just settle down to sleep. There is no obvious cause for distress, and there is no intervention that overcomes or prevents the distress. There seem to be no adverse consequences from colic. The interventions that usually calm babies are ineffective. Both of these examples demonstrate the difficulty in assessing the experiential interests of babies.

A second problem is that it is difficult to assess the experiential interests of some older children. Ashley is a severe neurologically damaged child who has extremely limited abilities requiring full time care, with neither speech, mobility, nor the ability to feed herself: “Now nine years old, Ashley cannot keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way. We call her our Pillow Angel since she is so sweet and stays right where we place her—usually on a pillow.” [Ashley’s Mom and Dad, 2012]. Ashley’s parents write “She has a sweet demeanor and often smiles and expresses delight when we visit with her, we think she recognizes us but can’t be sure... We constantly feel the desire to visit her room” [ibid]. Ashley’s parents describe the particular problem in assessing the experiential interests of severely damaged children: ‘we can’t be sure’. Ashley’s parents report “Ashley enjoys our company and our voices; when we sweet talk to her she often radiates with a big smile. She enjoys rich music, walks outdoors, a swim on a warm day, the swing, etc. She is also very fragile; a sneeze can set her crying inconsolably for more than an hour.” [Ashley’s Parents, 2008]. Ashley may not be happy when she smiles, and may not be upset when she cries. That smiling indicates happiness and that crying indicates unhappiness may be a reasonable start, but if she cries for an hour after a sneeze, then

¹⁹⁷ “Colic is the medical term for excessive, frequent crying in a baby who appears to be otherwise healthy and well fed. It is a common yet poorly understood condition, affecting up to one in five babies... If your baby has colic, they may appear to be in distress. However, the crying outbursts are not harmful and your baby will continue to feed and gain weight normally. There is no clear evidence that colic has any long-term effects on a baby’s health” [NHS Choices (c)].

either her sneeze is very different from a usual sneeze, or her crying is not a manifestation of distress. And the problem is that there seems no way to find out¹⁹⁸.

Another reason why it can be difficult to assess the experiences of children with severe brain damage is because much of a child's development depends on their experiences as they interact with their world. Young babies take everything they grasp to their mouth, older children crawl to experience their immediate environment (even when their parents prefer that they would not) and so on. The experiences of a severely-disabled immobile child are completely different from the experiences of a normally-developing infant able to explore and interact with her environment and so too the development of an immobile severely damaged child is compromised still further. It can be difficult to assess the experiential interests of others and especially when they are very different from those assessing the interests, and we should be cautious in our interpretations. What could we say about Ashley's interests? From the outside, Ashley's life is devastated. Arras, having described a boy of similar abilities, imagines "...if, miraculously, he could survey his situation with the clarity of a competent person. 'It's certainly not much,' he might ruefully admit to himself, 'but it's better than nothing. They feed me, change me occasionally cuddle me. And I'm not in any pain to speak of. So why not just play out the meagre hand that I've been dealt?' " [Arras, 1984: 31]. Although Ashley's life may be one that none of us would choose (and in fact may be one that many of us would choose to avoid by making our thoughts known using an advance directive) it is the only life available to Ashley. If Ashley has more pleasure than pain overall, then even though she doesn't have much, it is all that she can have and it may be enough for her. She does not feel the absence of all the abilities that those who try to put themselves in Ashley's place do. Arras' response (having pointed out the absurdity of an attempt to put oneself in the position

¹⁹⁸ Functional magnetic resonance imaging (fMRI) is sometimes suggested as a way to demonstrate and differentiate between conscious states. fMRI shows that different parts of the brain are activated when doing different tasks. Researchers claim that specific fMRI changes can demonstrate conscious awareness in a limited number of adults who are permanently unconscious [Monti *et al*, 2012]. But fMRI does not show consciousness, fMRI shows brain activation. And the compounding problem when dealing with damage to young brains is that it is clear that other parts of the brain can adopt (to some extent) the function of the parts of the brain that were damaged, and so that even if there could be confidence in the findings of fMRI, the areas that are activated during certain tasks in those with brain damage suffered when young, may well be different from those without brain injury.

of a child such as Ashley¹⁹⁹) is that "...biological human life is only a relative good. In the absence of certain distinctly human capacities – for self-consciousness and relating to other people – the usual connection between biological life and our notion of the good is effectively severed...so the absence of fundamental human capacities can render a life valueless, both to its possessor and to others. (This is not to deny that families can derive great satisfactions from caring for such severely impaired children and may well desire to keep them alive. But this particular reason for sustaining their lives has nothing to do with the child's best interests.) Without these qualities, no distinctly human good can be achieved." [ibid 32].

A way in which the balance of benefits and harms of treatment are disturbed in children like Ashley is that because their enjoyment of life, their development and achievements are all stunted when contrasted with normal children, the benefits that they can derive from medical treatment are limited. If the harms of medical treatment, the fear, pain and unpleasantness are not similarly reduced, then the balance between the benefits and harms of therapy which in a 'normal' child would favour intervention, now does not favour intervention. These are complex decisions, given the difficulty of assessing the experiential interests of a child like Ashley. Furthermore, it is likely that some of the harms of treatment are reduced, for example it is unlikely that children like Ashley will have the fear of medical treatment that is demonstrated by many others. However, many children with underlying chronic disease are more susceptible to complications of treatment, and often take longer to recover, than do children who are otherwise healthy and so the balancing of the effect of an intervention on Ashley's interests is complicated still further.

Arras' response draws attention to the important role that parents have in caring for children, in particular children with long-standing disease, and the way that the other's interests in their child may dominate the child's interests. Parents are well placed to be a good judge of the child's interests, but parents are not disinterested - they care deeply for their children - and good parents have an interest in securing the best for their child. A parent's view of 'best' may be taken to have particular importance, partly because parents are usually well placed to judge the child's interests and partly

¹⁹⁹ "This eerie soliloquy, spoken by a child who will never speak..." [Arras, 1984: 31].

because of the importance of the child as a component of the parents interests. Ashley's parents express clearly that they have a particular role, arguing: "In our opinion, only parents and caregivers of Pillow Angels are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or her caregiver." [Ashley's Mom and Dad, 2012]. It is important to recognise the distinction between the interests of the child, and the parents' assessment of the child's interests (and to distinguish these two from the parents' interests in their child). And whilst recognising that parents have a significant legitimate interest in the well-being of their child, parents may be mistaken in their assessment of their child's interests. It is clear that people may be mistaken about what would be in their own interests, but there are more ways that a parent may be mistaken about their child's interests. For these reasons if there is dissent regarding a child's treatment as a consequence of dissent about the child's interests, the child's interests should be subject to reasoned argument which may lead to agreement. The mother of another pillow angel clearly recognised the conflict between her interests and her daughter's interests "While I would never want her to go through the discomfort she endured during her life, I would give all I have for one more snuggle, one more gaze from her radiant eyes." [quoted by Ashley's Mom and Dad, 2008].

Experiential interests are a prominent component of children's interests, but there are many problems in addressing experiential interests which are particular to children. Both parents' and clinical workers' claims about a child's interests should be subject to reasoned argument to secure agreement. Experiential interests must be balanced against other interests, amongst which are the interests that the child has in development, or achievement.

Interests in Development and Achievement

Children are, in some sense, a work in progress and have interests in healthy growth and development to become a healthy, functioning adult in society. Amongst the skills that children need to develop are those required to become a person who will have the abilities to interact with others as a human rights holder, exercise moral agency, use basic goods as a member of society and become a responsible citizen. These are similar to the abilities that are listed by Nussbaum in *the Frontiers of Justice*

[Nussbaum, 2007: 76-8]. Young children's development requires intervention from those around them. Older children, themselves, cannot choose the generic skills that are needed as they may be unaware of the requisite abilities that will be needed in the future, others must direct the development of children. But as children become older and develop specific interests (in football or ballet dancing) then the child themselves may choose, to at least some extent, the way that their abilities should develop. In this group of interests, the more plausible interest is not an interest in human achievement *per se* (as Wendler, 2010 argues) but in personal achievements. The initial personal achievements are generic developmental goals such as the ability to sit, and to talk and so on. These are achievements that are important *en route* to other goals. As the child becomes older their parents and then the child themselves may start to choose their own particular achievements or goals: to be chosen for the sports team, or to achieve academic excellence or whatever.

Conclusions

I have sketched out and argued for what I take a person's interests to be. I have not attempted to develop a complete theory of a person's interests, but this is not needed in all cases where there may be uncertainty or dispute regarding a child's interests. In at least some situations, the child's interests can be clearly established, and the disagreement lies in how best the child's interests may be achieved. An important part of what I take to be a reasonable assessment of the child's interests is that there should be explicit discussion and agreement on what any child's interests might be taken to be. This is needed because there is not a clear agreed conception of what a child's interests are. In some of the contested medical decisions about children, it is clear that the source of disagreement is about what interests are and which are relevant. It is important that the assessment of any interests is focused on the child. The interests of others may be considered, but the justification for the importance of such interests to the child must be explicit. Parents have a privileged position in assessing the child's interests for several reasons, but parents cannot be taken to have an incorrigible knowledge of their child's interests.

A Reasonable Process

I have argued that children's treatment should be determined by a reasonable assessment of the effects of the proposed medical treatment on the child's interests,

where the reasons for pursuing one or other course are based on the child's (and perhaps others) interests. A part of this may include reasoned agreement on what the child's interests are taken to be, but in all cases there should be explicit discussion of the child's interests. In many cases the child's interests may be clear, but in particular circumstances they may not (examples include towards the end of life, or in children with severe neurological disability). I will sketch out what I mean by a reasonable process. A full defence of a reasonable assessment would necessarily consider many objections, I will consider only two. A full version would also demand that the many practical problems in establishing the process are resolved. This goes beyond the aim of the current work.

'Reasonable' has many different meanings. One way it may be understood is as the behaviour of a reasonable man (Lord Reed explores the paradigmatic legal reasonable man on the Clapham omnibus [*Healthcare at Home Limited (Appellant) v The Common Services Agency (Respondent) (Scotland)*]. Trinity Term [2014]: 1]). Alternatively, and the approach that I advocate, is that it may be understood as a reasonable, rational and reliable process. O'Neill characterises this as "...an individual's reasons for action must presumably be coherent and intelligible, and should not reflect unwarranted beliefs...Moral justification arises from a process of offering, receiving, accepting and rejecting purported reasons for action" [O'Neill, 2003(b): 328-9]. Reasons for a course of action can be given and can be argued for. Reasons can be given why other interventions are inappropriate. The strengths and merits of different reasons can be compared and argued for and against. Reasons why other reasons are invalid may be given. Reasons are given as justification for one decision over another. What counts as a reason in one case counts as reason in another, unless reasons can be given to justify the inconsistency (in which case it is no longer an inconsistency). This approach describes what should happen in discussions between parents and the treating clinical team (and may include an older child) in agreeing a treatment that is in the child's interests. Reasons are given and agreed. The best way to resolve a disagreement between the parents and the treating team is by the use of reasoned argument. And it is through reasoned argument and negotiation that agreement may be reached. Without reasoned argument, there is likely to be a failure to reach an agreement. And if there is no agreement then the likely source of help to

resolve a disagreement (the ethics committees, and the law courts) should themselves depend on a reasoned justification for the proposed interventions.

An example of this sort of approach is advocated by Rawls as a means of finding principles in ethics²⁰⁰. Rawls' approach is to find 'reasonable principles' which will guide decisions, he does not consider the application of the principles to make ethical decisions in practice, and so his method is not directly applicable to clinical problems. There are other reasons why his approach is not directly applicable to clinical decisions. His starting point is with a competent moral judge, who must have several characteristics, amongst which are a reasonable degree of intelligence, a broad knowledge of the world, knowledge of the particular case under consideration, and an enquiring mind. Parents need not be competent moral judges, parents as a group are likely to be no better and no worse than the average man or woman. As the group of competent moral judges excludes some individuals, so too it will exclude some parents. Furthermore, although Rawls does not explicitly state that the moral judge should be impartial or disinterested, I believe that this is implicitly understood in Rawls' work. For example Rawls writes that "...he must not consider his own *de facto* preferences as the necessarily valid measure of the actual worth of those interests which come before him, but that he both be able and anxious to determine, by imaginative appreciation, what these interests mean to the persons who share them, and to consider them accordingly" [Rawls, 1951: 179]. And this indicates another reason why Rawls' reasonable approach is not directly applicable to clinical decisions. Parents have a particular position in their children's lives. For the same reasons that the informed choices of adults are respected, there is uneasiness when parents' choices for their children are overridden, because parents are not disinterested decision-makers for their children (as say the local authority or a court may be). Another reason to suspect that Rawls' approach is unsuitable for medical decisions for children is that

²⁰⁰ Rawls is seeking a decision procedure for ethics "...a judgment in a particular case is evidenced to be rational by showing that, given the facts and conflicting interests of the case, the judgment is capable of being explicated by a justifiable principle (or set of principles)." [Rawls, 1951: 187]. He sought "...a reasonable decision procedure which is sufficiently strong, at least in some cases, to determine the manner in which competing interests should be adjudicated, and, in instances of conflict, one interest given preference over another; and, further, can the existence of this procedure, as well as its reasonableness, be established by rational methods of enquiry?" [ibid 177].

Rawls recognises that the procedure will find principles that “seems to be acceptable to all, or nearly all competent judges” [ibid 188]. If a decision is acceptable to all but one of the people involved, but the dissenter is the child’s parent, there will not be reasoned agreement. It may be that a dissenting parent, can be reconciled with a different approach to medical treatment having seen the reasons that have led to the decision. Or they may not. Parents may believe that they have a particular knowledge of the child’s interests, which is accessible to the parents only (perhaps because they can interpret their child’s communication in ways that no one else can). Alternatively the parents may claim that they must make these decisions because they are the child’s parents. In these situations reasoned agreement may not be possible. In whatever way, parents have a privileged position in the agreement.

A different approach is advocated by Rhodes and Holzman, who follow Scanlon, in arguing that a surrogate’s decisions to refuse treatment should be accepted “...if a surrogate decision is *not unreasonable*, it should be allowed to govern what is done.” [Rhodes & Holzman, 2004: 377 their italics]²⁰¹. They separate out three groups of reasons: firstly those ‘no one would reasonably refuse’, secondly those that ‘reasonable people could prioritize differently’ and thirdly reasons ‘that other reasonable people could refuse’ [ibid 372]. Rhodes and Holzman’s claim is that “only decisions based on widely shared reasons are allowable for surrogate refusal of highly beneficial treatment” [ibid 367]. They propose a ‘three box model’ of medical choices. The first box is populated by decisions with ‘likely poor outcomes’ and the third box

²⁰¹ Rationality for Scanlon is the “...capacity to recognize, assess and be moved by reasons and hence to have judgment-sensitive attitudes...reflective capacities set us aside from creatures who, although they can act purposefully, as my cat does when she tries to get into the cabinet where the cat food is kept, cannot raise or answer the question whether a given purpose provides adequate reason for action.” [p23 Scanlon, 1998: 23]. Scanlon construes irrationality narrowly as a “...direct clash between the judgments a person makes and the judgments required by the attitudes her or she holds.” [ibid 25]. This is rationality as internal consistency. Scanlon recognises another (broader) sense of irrationality asking “Is it sometimes irrational to fail accept certain considerations as reasons?” [ibid 25]. This distinction is used in distinguishing ‘reasonableness’ from ‘rationality’. Reasonableness is “...relative to a specified body of information and a specified range of reasons, both of which may be less than complete” [ibid 32] and so “A claim about what it is reasonable for a person to do presupposes a certain body of information and a certain range of reasons which are taken to be relevant, and goes on to make a claim about what these reasons, properly understood, in fact support” [ibid 192]. And so someone would be unreasonable, albeit not irrational, if they fail to recognise the importance of some reason that others recognise as important in a particular situation.

has decisions with ‘likely good outcomes’. The middle box has ‘uncertain or not dramatically different outcomes’. If the outcome is likely to be poor, the physician should counsel the surrogate towards palliative care. At the opposite extreme, treatment is likely to benefit the patient, and surrogates should not have authority to refuse treatment (although a competent person would have the authority to refuse this sort of treatment). This is because the refusal of beneficial treatment is “...paradigmatically unreasonable absent some very personal and unusual consideration: they can only be justified by reasons from the outer domain of idiosyncratic (or group) reasons that other reasonable people can refuse to endorse. Although personal reasons are sufficient for guiding one’s own life...physicians...cannot accept a surrogate’s personal reasons for refusing significantly beneficial treatment when their choice violates universal values. Unless they have strong evidence for believing that those unusual reasons were shared by the patient...” [ibid 376]. Here Rhodes and Holzman move away from the patient’s interests towards what most would recognise as a substituted judgement. For those decisions without significant consequences or with uncertain outcomes, the surrogate’s decision should be accepted.

It might be argued that a not unreasonable standard is more liberal, more *laissez-faire* than a standard that depends on reasonable agreement, and in particular if the sense of ‘unreasonableness’ is construed narrowly, then fewer decisions will be rejected than if there is a broader sense of unreasonable. I have only sketched out an account of interests, and just note that although rational or reasonable are often taken to have settled meanings, it would be important to resolve some of these varying interpretations of what is ‘reasonable’ when specifying exactly how a reasonable interests account would work.

In practice when there is disagreement, the focus of discussion is on the dispute, the areas of disagreement. Whilst this is for a variety of reasons, it may lead to the disagreement itself being emphasised; and as a result disagreement may become entrenched and reasonable agreement is harder to find. The tendency to focus on disagreement is initially perhaps due to an attempt to *understand* that disagreement, gradually characterising the cause of the disagreement and then attempting to resolve the disagreement, by trying to explain why one party believes the other to be wrong.

And this may be successful in some situations, but if the disagreement cannot be squared away, it may still be possible to agree on medical treatment if the focus can move towards the areas of agreement. If the disagreement can take second place so that the parents and clinicians (or whoever is dissenting) agree on what they can agree on, then it may be that an approach to treatment that is acceptable to all can be found. This may result in what both parents and clinicians accepting what is taken to be a second best, but good enough, solution.

Those who argue for *best* interests seem to have sometimes actually had a reasonable approach in mind. Kopelman's strategy to find best interests is an example. She argues that

“...decision makers should use the best available information to assess the incompetent or incapacitated person's immediate and long-term interests and set as their *prima facie* duty that option (or from among those options) that maximizes the person's overall or long term benefits and minimizes burdens. (2) Second, decision-makers should make choices for the incompetent or incapacitated person that must at least meet a minimum threshold of acceptable care; what is at least good enough is usually judged in relation to what reasonable and informed persons of good will regard to be acceptable were they in the person's circumstances. (3) Third, decision makers should make choices compatible with duties to incompetent or incapacitated individuals (those unable to make decisions for themselves).”
[Kopelman 2007(b): 377]²⁰².

What Kopelman described is not best interests, but a standard where the choice is at least acceptable to reasonable people, complicated by including ‘minimal thresholds of care’ and the ‘duties’ that some have to those who are not competent.

Parents are well placed to make decisions about their child's interests for several reasons. Amongst the reasons is that parents are likely to know their child best, and have known them longest and their children are more likely to confide in their parents. For all these reasons, parents are best placed to know their child's interests. As well as this parents are best placed to recognise and balance the competing interests of

²⁰² This is the latest version. Elsewhere Kopelman has phrased this as “...presupposes a consensus among reasonable and informed persons of good will about what choices for the incompetent individual are, all things considered, not unacceptable...” [Kopelman, 2005: 346]. ‘Not unacceptable’ is further from best interests than ‘acceptable’ and is a move that mirrors Scanlon's “...an act is wrong if it would be disallowed by any principle that no one could reasonably reject.” [Scanlon, 1998: 197].

individual family members. Mr Justice Wilson (an English Judge) describes "...a rebuttable presumption that the united appraisal of both parents will be correct in identifying where the welfare of the child lies" [*re C (A Child)* (HIV Testing) [2000] paragraph 58]²⁰³. Although there are many reasons why parents are well-placed to make decisions about the interests of their children, there are also reasons why they may be mistaken about the child's interests (as I have argued above). So despite the reasons why parents are well-placed to make decisions about their child's interests, parents' decisions about their child's interests may be wrong and must be recognised to be subject to review.

I have argued for a reasonable approach to agreeing the course that would be in a child's interests when medical decisions are made. I have sketched out what I understand reasonable to mean, but am aware that there is disagreement about what 'reasonable' indicates: my approach is incomplete. I will consider two objections to the claim that a reasonable assessment of the child's interests can guide decisions about medical treatment.

Objections to a Reasonable Approach to a Child's Interests

Problems with the approach that a reasonable assessment of a child's interests should be used to determine medical treatment for the child may be found at (at least) two levels. Firstly in what the parents and the clinical team take to be important components of the child's interests, which reasons count in a discussion about a child's interests. For example does the injunction to avoid a blood transfusion offered by Jehovah's Witness' parents count as a reason when discussing a child's interests? A second objection to the claim that a reasonable assessment of a child's interests should guide medical treatment is that the reasons for the decisions about medical treatment do not matter, what matters are the consequences for the child, the decision that is

²⁰³ This is true, but there may be reasons why parents, although well placed to know their child's interests, may not know or may not act in their child's interests. The examples I have in mind are the parents who cannot believe that their child could be pregnant, or could have taken drugs, or could have been drinking and so do not act in their child's interests (by arranging appropriate therapy or support and so on). Another example is the parents who demand inappropriate treatment because they cannot accept that their child will die as a result of untreatable disease. On at least two occasions parents in America demanded continuing ventilation and full intensive care treatment for a child with a diagnosis of brain death [Siegel, 1997; Case No. 4:13-cv-05993-SBA].

made. For the child what matters is that the right treatment is chosen, the one with the best outcome, the reasons do not matter.

One way in which disagreement about medical treatment for a child can arise is when parents and the treating team have different conceptions of what is important. If there is to be agreement then the starting premises – the reasons that count - must be agreed. The analogy is that interests are counters or chips on the table-top. If those involved in reasonable agreement cannot agree which chips should be on the table, then reasoned agreement is not possible. With disagreement about the importance or existence of an interest, the reasoning can go back one stage to explain why this interest should be included, or excluded, and in this way there may (eventually) be reasoned agreement over the reasons that are used (the counters on the table). However, in a pluralist society with multiple conceptions of the good, there may be some points over which there cannot be reasoned agreement. Reasoned justification for one's beliefs can go back only so far. Jehovah's Witnesses' belief that (or something close to this) voluntary acceptance of a blood transfusion will cause eternal damnation²⁰⁴ is an overwhelming concern for Jehovah's Witnesses, but at best an inconvenience for others. Not everyone accepts that there is a God, and still fewer accept that there is one particular God who threatens damnation following blood transfusion. If the belief that eternal damnation followed voluntary acceptance of a blood transfusion were universal, there would be widespread agreement by reasonable people that blood transfusion is not in a person's interests. The dispute comes down to a deep disagreement about whether God exists, and if so, which of the many potential contenders occupies the role. But most people do not agree with the belief. And it is not that the belief is incorrect because most people disagree. A vote only gives the most popular answer, not necessarily the correct one. There seems to be no reasonable way to resolve the question of God's existence and if so no reasonable way to determine whether or not damnation counts as a component of a child's interests. Reasons that one side gives, the other side will deny and vice versa. At a very basic

²⁰⁴ From an American court case “We also directed Judge Bacon to ask the patient whether he believed that he would be deprived of the opportunity for ‘everlasting life’ if transfusion were ordered by the court. His response was, ‘Yes. In other words, it is between me and Jehovah; not the courts. . . . I’m willing to take my chances. My faith is that strong.’ He also stated, ‘I wish to live, but with no blood transfusions.’ ” [re *Osborne*, 1972].

level there is no agreement on whether or not God's existence should count as a reason in the argument. Nor does there even seem to be a way that reasonable people entering the discussion with good will could resolve the question. I have chosen a caricature of an example, but there are many other such cases of disagreement. One in particular is whether medical treatment to prolong the life of a severely neurological damaged individual, who has no conscious awareness, is in the person's interests. End of life decisions are a particularly fertile area for these deep disagreements. Again there seems no easy way that this disagreement can be resolved so it might be argued that the claim that the child's interests can be used with reasoning to resolve such disputes about a child's medical treatment must fail.

What options are available to deal with deep disagreements such as this? Reasonable people of good will may not be able to come to agreement over some matters, they may have to accept that the best they can do is to agree to disagree. Rawls recognises not all disagreements can be overcome by reasoning in stating that the principles should be "...acceptable to all, or nearly all competent judges" [Rawls, 1951: 188]. However, not all disputed medical decisions for children fall into this group. A less troubling example is presented by American Christian Scientists who hold that prayer is an acceptable equivalent to medical treatment and can replace the need for conventional therapy (described by May, 1995). Dealing with this example is easier, because good, scientific, reasons can be given for standard medical treatment. Science is "...our most reliable source of knowledge in a wide variety of areas" [Hansson, 2014]. In scientific medicine, there are interlocking areas of knowledge, complementing each other, involving both the underlying mechanisms of disease processes and therapies. Science tests the hypothesis that treatments that *ought* to work (from knowledge of underlying disease) *do* in fact work: reasons can be given at two levels (why the therapy should work and that the treatment does work). Medical treatments, by and large, have been subjected to scientific evaluation of their effectiveness. A scientific justification of the mechanism of the effect of Christian Science based treatment on biological processes is missing²⁰⁵. Furthermore

²⁰⁵ The method of healing is by prayer, and so is opaque, and even more so to those who are agnostic or atheist. Prayer itself has been subject to randomised controlled trials and a subsequent Cochrane meta-analysis which because of concern about the trials' methodology

epidemiological work suggests indirectly that Christian Science based treatment is ineffective²⁰⁶. The reasons that can be given to argue in favour of Christian Scientist treatments are less clear. The outcomes of Christian Science treatments are reported as a series of anecdotes in Christian Science journals, which are not subject to the usual scientific approaches of peer review and critical analysis. The reason that this example is less troubling is because good reasons can be given for choosing conventional treatment, and the reasons that Christian Scientists offer in justifying their therapies do not have the same authority. The reasons for rejecting blood transfusion given by Jehovah's Witnesses cannot be compared with the reasons for accepting transfusion. The response is that a reasonable assessment of interests will resolve some of the disputed medical decisions for children. It will not resolve all of the decisions.

The second objection to an approach that medical decisions should be based on a reasonable assessment of a child's interests is that reasons don't matter; all that matters is the outcome for the child. If this is so, all that matters is which medical treatment is chosen, not why the treatment was chosen. The reasons underlying the decision don't matter. Diekma in arguing that state intervention in medical decisions for children should be determined by the harm principle stated this clearly "A parent's reason for the decision should not be a factor in whether the state intervention is sought. Rather, the likely outcome of their decision is the only relevant factor: is it likely to result in serious harm to a child?" [Diekma, 2004: 254]. Is this true?

concluded "...it is only possible to state that intercessory prayer is neither significantly beneficial nor harmful for those who are sick" [Roberts, Ahmed, Davison, 2009: 2].

²⁰⁶ Although not directly relevant to paediatric medicine, two case series compare the survival of graduates from a Christian Science College, with similar students. In the first, the longevity of Christian Scientists graduating between 1934 and 1983 from a Christian Scientist University were compared with similar graduates from another university. Christian Scientists were found to have a significantly higher mortality. Given that alcohol and tobacco are prohibited in Christian Scientists, mortality would be expected to be lower than in the general population, but it is not. [Simpson, 1989]. In another similar study, graduates of a Christian Scientist College were compared with graduates of a Seventh-day Adventist affiliated college. Seventh-day Adventists share a similar life style (refusing alcohol, tobacco and some foods) to Christian Scientists but do not refuse conventional medical treatment. Mortality was higher in the Christian Scientists [Center for Disease Control, 1991]. Both cohort studies demonstrate a higher mortality in Christian Scientists. This is a reason to suggest that the Christian Scientists' rejection of conventional medical treatment is not in a child's interests.

Take the example of a child with severe burns whose parents refuse treatment because of the prolonged, painful and unpleasant treatment that is required and the overwhelming likelihood that the child will die. After prolonged and arduous deliberation, her parents decide that aggressive treatment should not continue, she should be palliated with symptomatic relief of pain and distress, allowing 'nature to take its course'. Her parents reason that the remote possibility of survival, and the unpleasantness and length of the treatment make the situation so bad that any possible benefit of treatment is more than offset by the harms of the treatment²⁰⁷. This is a reasonable decision to come to, and reflects a reasonable assessment of the child's interests. Contrast this with another similarly injured boy whose parents take a short time to reject treatment giving the reason that the arduous treatment will disrupt the rest of the family and in particular the time and attention that they are able to give to their favoured child, his sister. Or perhaps his parents give the reason that they cannot bear the thought that after treatment their child will be scarred and no longer the handsome child that they sought. His parents have made the decision that was taken to be right, but there is no sense in which the boy's parents have made a reasonable assessment of his interests, indeed their decision is not based on his interests at all, or if so on a flawed assessment of his interests that it seems unreasonable. Should the second decision stand?

There are several different answers to the objection. One is that the answer to many questions of ethics is found through a process of reasoning (as I have argued) and there is not a transcendent correct answer that stands above the real world. Or even if there is a correct transcendent answer, there is no way of discovering it apart from through reasoned argument. The generally agreed approach to resolving problems in ethics is through reasoning: reasons do matter. However, faulty reasoning is just generally unhelpful: just because an answer is produced through faulty reasoning does not mean that the answer is necessarily wrong. The answer may be correct or incorrect: it is determined by chance. The importance of legitimate reasoning is that it will lead to a correct answer, regardless of how others get to the answer and so

²⁰⁷ The sort of example that I have in mind is Donald (later Dax) Cowart who was severely burned, in a propane gas explosion. Having asked his first rescuer to kill him, he repeatedly asked, unsuccessfully, for his medical treatment to be withdrawn. He survived blind, with limb amputations and severe disability, repeatedly arguing that he should have been allowed to die [Burton, 1989].

providing the clinical team are confident in their reasoning about medical treatment and the child's interests, they can be confident that the treatment is in the child's interests.

Another response is that there are different sorts of reason. Lenman characterises reasons as those that explain, those that justify and those that are used in deliberation [Lenman]. The sort of reasons advanced by the parent of the badly burned boy are explanatory reasons: they explain and motivate the parents' choice. The sorts of reasons that should be involved in reasoning about a child's interests (the sort of interests used in arriving at the correct decision) depend on the child's interests and are justificatory reasons and deliberative reasons. And so providing there are reasons which justify the choices that are made and that these are based on the child's interests, the explanatory, or motivational, reasons of the boy's parents may be unimportant. The parents' reasons may be unimportant in justifying that particular choice for the child, but may have some importance in so far as they provide information about the parents' approach to parenting. The reasons the parents give may give cause for concern for the child's future care, or for the care of the child's siblings. That reasons may be important is clearly argued by Aurenque and Wiesing "For example, circumcising a child as a form of punishment is unacceptable, but that very same circumcision performed as part of a religious ritual is acceptable." [Aurenque and Wiesing, 2015: 210]

4.9 CONCLUSIONS

I have argued that there is confusion over what is meant by interests, welfare or well-being, but suggested that the core concept is "...a life's being valuable solely to the person who lives it." [Griffin, 1986: 21]. Although best interests are thought to determine the decision that should be made when medical decisions are made for children, I have suggested that there are several problems with this approach. Firstly, there is not, nor is there likely to be in the near future, agreement at a meta-ethical level about how to conceptualise a person's interests, and in a pluralistic society, it is unlikely that there will be agreement at a normative level and this is compounded by disagreement about the subjectivity of a person's interests. A second problem is that 'best' interests is too demanding a standard. Accepting this, it is not clear that any other standard of interests (determined by the consequences to the child - such as the

harm principle) can be defended. I have argued that concentrating solely on the interests of the child is wrong. It must be recognised that others' may have an interest in the child's well-being, and also that the child may have interests in the well-being of others.

I argued that the correct approach to making for medical decisions for incompetent children should rely on a reasonable assessment of the child's interests. For this approach to be effective, there needs to be a substantive conception of a person's interests and an understanding of what a reasonable procedure would be. I have sketched out a theory of both and have considered two objections.

CHAPTER 5: CONCLUSIONS

5.1 CONCLUSIONS

I have argued that children are largely ignored in medical ethics, and in ethics more generally, as the methods have been developed for adults, who are taken to be rational, to be able to contract, or to be virtuous or whichever other feature is taken to be important. Adults are consistently distinguished from children, (and young children in particular) because children lack the abilities or skills that are taken to be important in whichever ethical system is adopted. The thesis addresses the question of how medical decisions should be made for unquestionably incompetent children.

The commonest approach to medical ethics adopted in the West depends on respect for autonomy exemplified by the importance of informed consent. The dominance of this approach distorts medical ethics for children in two ways. Firstly, parental decisions may be taken to have the same authority that we accord the autonomous person making self-regarding decisions (through the authority of respect for autonomy). But they are not equivalent. The justification for parental authority is different from, and weaker than, the justification for respect for individual autonomy. The second way that the dominance of approaches based on autonomy distorts ethics for children is in our conception of interests or well-being. When well-being is considered, the focus is on the well-being of adults. The components of an adult's well-being are subject to validation, adoption or endorsement by the adult and there is a reluctance to develop an objective approach to well-being perhaps for fear that it will encourage paternalism. The common approach in Western medical ethics is the four principles approach, and because of this distortion, three of the four principles (respect for autonomy, beneficence and non-maleficence) are less helpful in considering children. This makes the four principles approach unsuitable for children. This is recognised because the commonly advocated approach for medical ethics for children is that decisions should be in the child's best interests. This leaves the problem that our conception of interests has been distorted by the autonomous choices of adults, impairing the development of an objective notion of interests that is needed in the case of young children.

I have argued that although children are clearly demarcated from adults in several ways, we do not have a clear understanding of what children are nor how we should treat them. Part of this is because children are very heterogeneous ranging from a freshly-born baby to an adolescent on the verge of competence. For children in medical ethics, the important distinction is that the decisions of a child may be overridden. This contrasts with medical ethics for adults, where similar sorts of decisions will not be overridden. The distinction between adults and children has become blurred, more recently, an example of this is the loose way in which terms such as 'young person' are used. Children differ in fundamental ways from others who are incompetent to make their own decisions.

Although some see that children's rights are a solution to the problem of the way that medical decisions should be made for children, I have argued that the justification for rights are problematic in general and that this is a more serious concern for children. At best, rights draw attention to children and children's interests, and so may be important in public health and in politics, but are not helpful in making clinical medical decisions for children. Defenders of children's rights justify rights in different ways. I argued that the best defence of children's rights available is an interests-theory of rights, where children's interests demand consideration. If this is so, we should consider children's interests directly. There are good reasons why rights are not the best way to make medical decisions for incompetent children.

The most promising approach to making medical decisions for children depends on their interests. For several reasons the best interests standard is not defensible. I argue that a reasoned, or reasonable, agreement upon the child's interests should determine medical treatment. Because there is not an agreed conception of interests, the child's interests may need to be a component of reasoned agreement, although a framework for a substantive approach to interests is needed. Neither the child's parents, nor the clinicians, can be taken to have an incorrigible grasp of the child's interests, all should be prepared to explain and justify the reasons for their choices.

5.2 FURTHER WORK

More research is needed on this subject. In particular the areas that need further work are in developing a reasonable approach, and a substantive framework for interests. The particular problem with a reasonable approach is when parents and the clinical team cannot achieve agreement because of what I have termed a deep dispute, one that is unlikely to be resolved by reasonable argument. This may involve philosophical medical ethics in developing ways to understand and resolve the dispute. It may involve empirical (psychological or sociological) work in attempting to understand the reasons why clinicians and parents cannot agree on treatment.

I have concentrated on the young, unquestionably incompetent, child. Although disease is less frequent in older children (both the incidence of disease and mortality) the way that the expressed views or wishes of the developing, but not yet competent, child and the competent (to make medical decisions) but not yet independent (or globally competent) child should be incorporated in making medical decisions for older children also deserves further consideration.

APPENDIX 1

GUARDIAN'S "BALANCE SHEET" 8.3.2006

The columns below deal with the benefits and burdens for MB, associated with ventilatory support continuing.

| BENEFITS | BURDENS |
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| <ul style="list-style-type: none"> • MB can see during those periods when he can open his eyes (but see note regarding visual clarity under burdens). • Possible/probable recognition of his parents and siblings & some pleasure/comfort in their presence (extent of ability to experience pleasure uncertain). • Possible/probable recognition of those caring for him & some pleasure/comfort in their presence (extent of his ability to experience pleasure uncertain). • Possibly/probably MB derives some comfort /pleasure from Barney the Dinosaur/Teddy. • He has the sensation of touch and can feel gentle strokes and his hand being held. • He can hear and it should be assumed for balancing purposes that MB may have the ability to enjoy listening to voices/a story/music now or in the future. | <ul style="list-style-type: none"> • MB cannot move his body, head, arms or legs, although has some very restricted "flickering" movement in his thumbs and some of his fingers and possibly foot. • He is therefore reliant on others to be moved periodically, at least 8 times a day to prevent skin soreness and discomfort. • He is likely to be suffering some positional discomfort despite being repositioned by nursing staff. • MB cannot open his eyes fully and his difficulty in raising his eyelids is likely to progress. • MB's is able to follow and see. However his clarity of vision is uncertain, as he has both vertical and horizontal jerky movements (nystagmus) and his ability to focus is likely to be diminished (his pupils do not constrict) • MB has lost his facial expression, except slight movement of his eyebrows. • MB has lost the ability to communicate his needs and wishes to others. This is permanent. • MB's limited ability to respond is not consistent and repeated and therefore cannot be relied upon as a means for communication as to his distress and pain levels, wishes and needs by the nurses and clinicians. • MB has lost the ability to interact with others or his environment. |

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| | <ul style="list-style-type: none">• He cannot swallow and is fed via a gastrostomy tube.• He cannot cough or clear his own secretions and he undergoes suctioning from his mouth, nose and throat day and night. At a time when MB was able to show physical and facial reactions it was clear this distressed him. Dr S described this as “profound discomfort”. He requires ET suctioning at least every 3-4 hours (6-8 times a day). Dr Jardine’s enquiries regarding frequency of deep suctioning 4-6 times daily [C7]. Dr Hughes: at least once a day.• MB has to be “bagged” when deep suctioning occurs. This is an unpleasant experience and one which distressed him in the past when he was able to react physically.• The clinicians and experts agree that the use of IV lines, blood sampling, deep suction, bagging and respiratory physiotherapy are likely to be distressing to MB. Thus they are kept to a minimum at present.• The combination of being handled numerous times a day and undergoing the routine intensive and now for MB mundane procedures, whilst being unable to voice his wishes are considered to be “intolerable” for MB (Dr S).• Whilst blood testing has been minimised as much as possible, MB has to undergo blood testing about monthly and whenever there is a deterioration, a likely desaturation and infection at which time he will undergo more frequent blood tests. It is not always possible to give effective pain relief for this.• He has lived all bar 7 weeks of his life in a high dependency unit or intensive care ward in hospital and is likely to have to remain in an intensive care environment.• There is uncertainty as to whether pain |
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| | <p>relief and sedation levels are sufficient. It is difficult for MB to be held and cuddled by his parents because of his condition and his necessary connection to life sustaining equipment.</p> <p>The Future</p> <ul style="list-style-type: none"> • He will continue to suffer from infections, which if treated with antibiotics will require venous access and blood testing. He is likely to suffer at least 3-4 chest infections a year. • Chest infections will involve increased secretions, more frequent deep suctioning, blood testing, IV access and increased ventilator pressures and “intensive chest physio” therefore pain and distress for MB who will require increased doses of pain killers and sedation. • Intravenous access is particularly difficult with MB and has required a number of attempts in the past. There are only a limited number of sites and gaining IV access is painful. In cases of urgency sedation/pain relief may not be possible. • MB has to be handled numerous times during the day and night for both non painful as well as painful and distressing procedures listed above. • If MB underwent a tracheostomy, he would have to undergo a general anaesthetic and the ordeal and stress of minor surgery in his weakened state. <p>If MB receives LTIV</p> <ul style="list-style-type: none"> • He will continue to need suctioning, including deep suctioning, bagging, physiotherapy, splints, repositioning – all of which are known to cause pain/discomfort. • There will be continuing neuro-muscular deterioration, he will lose the ability to open his eyelids within several months & |
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| | <p>his eyesight will deteriorate further.</p> <ul style="list-style-type: none">• He will lose the ability to lower his eyebrow – losing all ability to communicate any measure of pain, distress or upset.• His contractures will worsen and scoliosis will develop, both these will cause discomfort and pain.• There will be dysfunction of his autonomic system.• He will need increasing amounts of oxygen and ventilation pressure, which of itself can be uncomfortable.• MB would need high levels of sedation all the time because some of the procedures he will need are unpredictable and he cannot communicate his needs or distress adequately.• The increasing need for sedation will reduce his awareness of pain as well as those experiences which give him comfort at present.• CPR would cause pain and distress as well as possible injury. <p>Caroline Harry Thomas</p> <ul style="list-style-type: none">• 8 March 2006 |
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