The Participation Rights of Premature Babies

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Introduction

Is it appropriate or useful to phrase premature babies’ needs, welfare, or best interests in the language of babies’ rights? Can babies be rights-holders? This paper reviews the relevance of the UN 1989 Convention on the Rights of the Child (UNCRC), and particularly the so-called participation rights, to premature babies and their care. The review is illustrated with examples drawn from a study of four neonatal intensive care units, NICU. The first part of this paper presents the background on human and children’s rights, on research about childhood, babies and participation, and on the neonatal research study. Examples from the study illustrate how participation rights relate to premature babies. The paper concludes that respect for babies’ participation rights is feasible, immediate, integral and indispensable to adequate neonatal care, and that babies’ rights justify and validate high standards of care.

Rights

Rights are justified on two main grounds. First, they may be seen as universal, inalienable to all members of the human family (the UNCRC is ratified by all governments except in the USA and Somalia) and legal entitlements that defend and respect every citizen. Citizenship from birth entitles the child to a legal identity, and the right to expect certain services, protections and amenities from the state. Babies can easily be included in these concepts of rights. Secondly and alternatively, citizenship with its civil rights may be justified as a status that is gradually learned or earned or developed towards, and is granted...
by age, sex, or merit. Traditionally, English law has restricted children’s rights and regarded children up to 21 and more recently 18 years as legal “infants”, literally “not speaking”. Current English policy on citizenship education (QCA, 1998) slips uncertainly between education for future adult citizenship or the education of children who are citizens now. Traditional links between a set age of majority linked with citizens’ participation or civil rights and the key right to a voice and to freedom of self-expression were replaced during the 1980s by competence or maturity. English case law now respects the decisions of children who have the understanding and discretion to make informed and wise decisions in their own best interests Gillick [1985]. The UNCRC accords to children who are able to form and express their 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” (UNCRC, 1989: 12). Neither article 12 nor Gillick states a minimum age, and these standards lean towards Holt’s view (1976) that children should be able to exercise their rights when they become able and willing to do so. Does the ability-competence criterion open all children’s rights from the above second concept of age-based rights towards the first universal concept that embraces all members of the human family? And are even premature babies able to form and express their own views?

In Britain, the foetus is legally not “a person” (Montgomery, 1997:401) and has no rights throughout the 40 or more weeks of pregnancy, except for one right after 24 weeks: protection from termination of pregnancy. This right to life, however, is qualified in three ways. First, termination is allowed up to term if “serious handicap” is detected (1990 HFE Act). Secondly, in 2002 for example, although 2,753 abortions between the 20th and the 24th week were recorded, gestational ages may be under-estimated in records to allow abortions after 24 weeks (Times 8.9.03). Thirdly, practitioners are advised to respect women’s refusal of interventions during pregnancy and labour, including interventions intended to save the life of the foetus (RCOG, 1994).

In marked contrast, from birth children are entitled to legal personhood, partly denoted by the complex and comprehensive UNCRC rights. The UNCRC preamble recognises the importance of special care within the family for the immature child in “an atmosphere of happiness and love and understanding” although these cannot be rights because they cannot be willed or enforced. UNCRC rights are qualified in that the best interests of the child shall be a primary consideration” (3), taking account of the rights and duties of parents or other responsible persons “to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the [UNCRC] rights” (5).

Premature babies can easily be seen as benefiting from their UNCRC provision rights to services, to health care, education (of their parents and carers),