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Abstract
Premature babies are the same gestational age as the fetus that, in Britain, has no rights. However, our ethnographic neonatal study illustrates how the UN 1989 Convention on the Rights of the Child applies to premature babies. Parents and staff in neonatal units offered socially and culturally constructed versions of childhood relating to versions of citizenship, duties, responsibilities and rights. Far from denying or trivialising rights, attention to premature babies' rights and citizenship can illuminate how human rights are embodied, aesthetic, interactive, emotional, political, economic and socially contingent. The babies' resistances also illustrated the relevance of rights to them as sentient, active meaning makers, within the private family and the public neonatal units. We review advantages and disadvantages of conceptualising premature babies' needs as rights, and their status as citizens.

Introduction
In this paper, based on research in southern England (Alderson et al. 2004) Britain, citizens are people who are recognised by the state as rights-holding members of their society. Citizens' civil, political, social and economic rights are more comprehensive than those of non-citizens, such as tourists. The framework of citizen's rights is a useful indicator of the extent of practical respect for an individual's status as a citizen. It is therefore used in this paper to explore the edges of citizenship, and how far premature babies can be regarded and treated as citizens with rights.

Premature babies, born as early as 22 or 23 weeks gestation, are the same gestational age as the fetus that has no rights. The babies show when 'inalienable' rights such as the right to life, and provision rights such as access to services, begin from birth, and why they matter. We review how premature babies' rights can illuminate that human rights are:

embodied - and informed through sensing physical and aesthetic needs;
interactive - and given meaning and reality through their social and emotional context;
political and economic.

The babies' cooperation with or their resistance to adult programmes illustrate the relevance of rights to them, the newest members of society, as sentient, interacting meaning makers.

The paper begins by explaining our neonatal study. Then we review how in the UNCRC - UN Convention on the Rights of the Child (UN 1989) the *provision* rights to services and amenities such as health care, apply to premature babies and can be used as criteria for citizenship. We review rights to *protection* from abuse, neglect and discrimination, and babies' *participation* or civil rights elsewhere (Alderson forthcoming), although all three types of rights overlap. Governments that ratify the UNCRC (every country except the USA and Somalia) undertake to implement it in law, policy and practice, so that the Convention especially applies to state services such as British National Health Service neonatal units. We consider reasons for according or denying rights to babies, and show how parents and neonatal staff offer socially and culturally

constructed versions of childhood that relate to versions of citizenship assorted with agency, duties, responsibilities and rights. We review advantages and disadvantages of conceptualising premature babies' needs as rights, and their status as citizens.

Children's rights have strong opponents. Talk of 'babies' rights' might seem to add negative complications to these debates that could trivialise and undermine older children's contested rights to be citizens. However, this paper aims to show how rights are realistic and relevant to premature babies and, therefore, to all older children too.

Foretelling futures

Our ethnographic study observed four neonatal intensive care units (NICU) during 2002-2004. Semi-structured tape-recorded interviews were held with 40 neonatal staff, and with the parents of 80 babies in the units and in their homes. Babies who, definitely or possibly, had conditions that could affect their neuro-development, and whose parents agreed to join the study, were selected sequentially, although the purposive sampling also aimed to involve babies with a wide range of medical conditions and socio-economic and ethnic backgrounds. The research notes and transcripts were analysed for replies to the key research questions and for references to themes that were often mentioned by staff and parents (Weber 1990; Strauss and Corbin 1990). Beyond the spoken and observed reality, we examined realities that are 'below the surface' and are only observable in their surface effects, which they help to explain (Bhaskar 1989; Scambler 2001). We observed that the intentions behind all the countless activities in the NICU, to promote the babies' health, welfare and neurological development, were undermined by certain routines and structures. We consider how these contradictions might be explained partly by whether the babies are perceived and treated as persons, rights holders and citizens.

Our research investigated how relatively new neonatal treatments, for example, those that now enable smaller babies to survive, can further complicate long-standing neonatal ethical dilemmas, such as whether babies are persons. We also investigated how clinicians select the many neurologically-related types of knowledge, when making treatment plans and discussing these with parents and colleagues. We observed parents' and babies' experiences and responses in the NICU, and aimed to understand as far as possible the practitioners', parents' and the babies' perspectives.

A growing contribution to neonatal knowledge comes from neurobehavioural research and practice. All babies give cues about their feelings and seek for optimal conditions. For example, we saw babies looking relaxed and contented in soft fabric 'nests' that, like the uterus, help them to maintain a fetal curved position, limbs gathered together and hands close to the face, so that they can soothe themselves such as by sucking their fingers, or stroking their face if they have oral ventilator tubes. In some units, the babies' limbs hang over loose loops of rough toweling and they try to gather their splayed limbs together, and to wriggle into a corner of the cot that could contain them more firmly. Nurses may then move them back to the centre of the cot. The babies' subtle behaviours can be 'read' as their language to inform understanding about babies' preferences and best interests (Als 1997, 1999; Huddy *et al.* 2001; Murray and Andrews, 2000). The NBAS - Neonatal Behavioural Assessment Scale - systematically documents term babies' responses to aversive and non-aversive stimuli. The observer scores behaviours taking careful note of which of six states the baby is in, from deeply asleep, through quietly alert, to upset and crying. The babies' observed competencies obviously much depend on which state they are in. NBAS notes positive behaviours in babies born from 37 weeks gestation, their progress and functioning, and efforts at self-regulation (Brazelton and Nugent 1995).

NIDCAP - Newborn Individual Developmental Care and Assessment Programme – also aims to describe neuro-developmental behaviour and progress, to promote infant mental health and competence and positive parent-infant interactions (Symington and Pinelli 2000). Naturalistic observations of even the smallest most fragile preterm babies from the first week after birth record the baby's strengths and sensitivities (not deficits) and identify goals and recommendations for care. Here is a NIDCAP care plan for 'John' (research number 2.2). We quote the plan in some detail: to illustrate how the baby is perceived as a person and a major agent in providing his health care; to show the detailed observations and responses that link to article 12, the child's right to express views in all matter that affect the child; and to inform readers who may be unfamiliar with NICU and premature babies. John (2.2) was born at 26 weeks gestation, 14 weeks early. Six weeks later his care plan listed some of his competencies as:

- Initiating breathing movements much of the time;
- Smooth well organised movements to protect and calm himself;
- Making efforts to open his eyes in response to his mother's voice.
- Using strategies such as grasping and holding on, taking his hands to his face, putting his feet and hands together to calm himself.

Goals. From the observations today it appears that John's next steps are:

- Consistent efforts to breathe on his own;
- More time in restful sleep;
- Keeping firm muscle power with curled up posture;
- Being increasingly successful in calming himself.

Recommendations to help John 'achieve his goals' included continue to:

- work gently with John, respond to his signs of discomfort by pausing, soothing him with still hands and letting him settle before proceeding;
- support his efforts to grasp, to clasp his hands or feet together, by offering your fingers to hold, by cupping his hands and feet.

Consider:

- if it would be possible to position his bed where it is less light and busy;
- using bedding tucked around him and a stronger ridge around his feet to help him to find boundaries to push on and to help him contain some big tiring movements.

Care plans progressed so that at 35 weeks gestation the plan advised, 'Continue to offer his dummy if it looks as if he might want to suck and let him choose if he wishes to take it into his mouth.'

Some plans were specific to individual babies' needs. Oludayo (2.4), when she was older was thought to need more light, and also especial care when she was moved because her bones fractured so easily. Edward's care plan (2.7) recorded that when he was offered a bottle of milk by a nurse 'he smacked his lips then gagged slightly as he began to suck.' The teat was taken out until he was ready to take it. After a few sucks he gulped and the teat was taken out again. After a few minutes he went to sleep looking pale but taking bigger breaths, so the rest of the feed was given through a nose tube, 'pausing once or twice when he grimaced'. His mother gave him his next feed, which he took more comfortably. The care notes also recorded that Edward preferred to lie on his side on a pillow on his mother's lap 'making sure his head is raised and his back is supported in line with his head. He may like to face you so that he can look at you, and you can see how he is managing. Continue to pace feeding so that it is an enjoyable event for Edward. Slow the flow when he grimaces, gags, gulps or squirms.'

NBAS and NIDCAP programmes regard brain development as activity-dependant on the babies' care and environment (Fox et al., 1999). The units we observed ranged from

ones that are well known for using NBAS and/or NIDCAP to one where only one or two junior nurses use aspects of the programmes. The next sections review background concepts to children's rights, and then the relevance of the UNCRC provision rights to premature babies.

Background concepts to children's rights

The UNCRC Preamble (UN 1989) recognises 'the inherent dignity and…equal and inalienable rights of all members of the human family [as] the foundation of freedom, justice and peace in the world'. This suggests that respect from birth reinforces equal respect for all, that disrespecting babies can open the way to sanctioned inqualities and injustice, and ignores treaties such as the UNCRC, which agree that 'childhood is entitled to special care and assistance'. Macklin (2003) asserts that 'dignity' is a useless, meaningless, overworked term in health care ethics, However, the UNCRC articles define respect for the child's 'worth and dignity' in many practical inter-related ways.

The Preamble also recognises the family's part in the 'growth and well-being' of children, and the benefit to every child of 'an atmosphere of happiness, love and understanding'. These cannot be rights, as rights are quasi-legal concepts of entities that can be willed and enforced. Although love and happiness cannot be willed, they are acknowledged as important contexts for children's rights, together with 'the spirit of peace, dignity, tolerance, freedom, equality and solidarity'. British NICU tend to include staff and families from every continent, they aim to provide equal care for every child and, in the words of the Preamble, to take 'due account of the importance of the traditions and cultural values of each people for the protection and harmonious development of the child.'

Although the Preamble states that the child 'needs special safeguards and care, including appropriate legal protection, before as well as after birth', this is not asserted as a right, because states that allow legal abortion would reject the UNCRC. States can choose when childhood begins, and in Britain this is from birth. In all the UNCRC articles, the best interests of the child shall be a primary consideration (article 3), and with some articles, such as 9, 13-15, 'national security, public law and order, public health or morals or the rights and freedoms of others' must also be observed. The articles do not specify any ages, and all apply directly or indirectly to babies, sometimes especially so. We review the provision rights to education, adequate services, health care, periodic review when in care, and an adequate standard of living.

UNCRC provision rights

Education and adequate standards of care

Article 28 on education affects premature babies in promoting the standards of education essential to achieve the scientific research and training that support neonatal services. Education links to article 3: children's services 'shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision'. Neonatal intensive care is arguably the most challenging and exacting form of medical and nursing care, when babies hover between life and death and can so easily become infected or injured through the slightest mistake. Agreed standards are recorded in detailed protocols, intended to protect the babies and also the staff from undue pressures and accusations of negligence. One example is the standard that there should be one nurse per intensive care cot, one nurse for every two high dependency cots, and one nurse for every three or four special care cots. This standard could seldom be met because of the current shortage of trained NICU nurses.

Education rights 'ensure that school discipline is administered in a manner consistent with the child's human dignity and in conformity with' the UNCRC, and can refer to parents aged under 18 who are still at school and need flexible respectful arrangements for their schooling to fit with their own and their babies' needs. The UK has the highest rate of teenage pregnancies in Europe. Often young mothers in Britain are either expected to leave their babies all day, and continue their schooling as if they have not become parents, or else they receive no education.

Article 29 emphasises that humane education is directed to the development of the child's personality, talents and mental and physical abilities to their fullest potential, and respects the child's cultural identity (article 29), including children in minority groups (article 30). Learning and therefore education start from birth and, in most units, parents are encouraged to talk and sing to their baby and to bring in pictures, mobiles, music on tapes or compact discs to play very quietly so that only their baby can hear them, and story books to share with their child (article 31). Early 'cultural identity' is indicated by the prayer cards or religious icons placed in the incubators with the soft toys, or by the small football kit hung over the incubator. Some babies' lifetime is compressed into a few days or weeks. Although many parents say that at first they 'hang back' from becoming too involved and distressed by a life that may be very brief, they tend to come to want to engage in the relationship as fully as they can. Some babies stay for months in the unit, and parents appreciate therapists offering ideas and toys, chairs and mats to interest the babies who become bored with the unchanging setting. One mother said: 'We could put the mats on the floor so the boys could roll around, and they would do their physio. That was lovely and reassuring to know that your child was having some degree of normality' (1.20).

Health care and adequate standard of living

Article 24 advocates children's rights to 'the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health', ensuring 'that no child is deprived of his or her right of access to such health care services'. The article is unusual in listing detailed items, many of which especially apply to premature babies. These include: to diminish infant and child mortality; to ensure the provision of necessary medical assistance and health care to all children; to combat disease and malnutrition…through the provision of adequate nutritious foods and clean drinking water…taking into consideration the dangers and risks of environmental pollution; to ensure appropriate pre-natal and post-natal health care for mothers; to ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents; to develop preventive health care and education.'

The care of premature babies can provide clear indicators of the state and status of children's political and economic rights and how these rights are honoured or not. Prematurity is associated with poverty and inadequate maternal diet (Davey Smith *et al.* 1996), and babies from disadvantaged families are over-represented in the NICU. The more unequal the distribution of wealth across society, the more disadvantaged and unhealthy are the least advantaged groups; people on a similar low income fare better in more equal societies, and worse in unequal ones (Wilkinson and Kawachi 1998) with life-long effects (Marmot and Wadsworth 1997; Bartley *et al.* 1997, 1998). Although it is the fourth richest country in the world, the UK has the highest level of child poverty and the highest NICU admission rates in Europe, partly because of problems for the babies following incidents in inadequately staffed labour wards (Ashcroft *et al.* 2003). Three of the NICU we studied are in inner London where, at the time, 49 per cent of the children

were living in poverty – in households with an income of less than 60 per cent of the average wage (Hood 2002). Some parents were homeless, others described damp, cold, noisy flats, and worried about taking home babies with the lung problems that commonly follow very early birth or weeks on assisted ventilation. The NICU therefore illustrate the extreme needs of babies that, in some cases, arise when governments fail to respect children's 'economic, social and cultural rights to the maximum extent of their available resources' (UNCRC 1989 article 4), to provide social security in accordance with the family's need and national law (26), and to ensure a standard of living adequate for the child's physical, mental, spiritual, moral and social development particularly with regard to nutrition, clothing and housing (27). But, paradoxically, the NICUs also demonstrate the elaborate services that governments provide in attempts to meet and reduce extreme health care needs. The usually underprivileged babies of refugees and asylum seekers have equal rights with resident babies to NICU treatment (article 22), so that again the NICU illustrate the generous state on the one hand, but also the unsupportive state, when stressed and disadvantaged women give birth prematurely, or have inadequate obstetric care so that babies' need for NICU services increases.

Breastfeeding

The UNCRC carefully respects mothers' as well as babies' rights, in the fairly rare instance when these might conflict, by phrasing the mothers' decision about whether to breastfeed in terms of providing education and support for mothers about breastfeeding. This education would include knowledge of the vital physiological and emotional benefits of breastfeeding to the baby and mother, particularly after the distressing disruption of premature birth and admission to NICU. The breastfeeding rates vary greatly from time to time within and between units, indicating the importance of informed and sensitive support for mothers by the staff. Posts for specialists to support breastfeeding are not always filled.

Structures and routines within the units are very important in encouraging or discouraging breastfeeding. Good practice includes providing a pleasant comfortable room for expressing milk, enough breast pumps, and easy chairs in semi-private corners near the cots (especially important for Muslim mothers) where mothers and babies can relax together and enjoy skin-to-skin contact or 'kangaroo care'; water coolers and toilets near the hot dry nurseries. This contact is a helpful prelude to breastfeeding even when the baby is not yet strong enough to feed much or at all. One mother (4.14) described how 'at the beginning I was protecting myself so I didn't want to rush and have contact' but later the mother became used to giving 'kangaroo' care twice a day. 'We was getting really close, you know, it was lovely, and I felt that she was my baby and I could get to know her,' and that the baby's health and oxygen circulation were helped by these sessions. Breastfeeding works best when the healthy baby sets the pace and timing of feeds. When babies are too weak to do this, mothers may need to have great flexibility, patience and confidence in order to persist.

Many mothers are recovering from a difficult birth or surgery; some have needed intensive care themselves following, for example, severe prenatal pre-eclampsia. Mothers of Asian and African heritage contrasted the weeks of postnatal care that their families would have given them, with the way in Britain they were sent home a few hours or days after the birth, and expected them to manage difficult daily journeys to the NICU. So good practice includes providing comfortable areas for mothers to rest, nutritious food and fluids, several parents' double bedrooms, and practical and emotional support from the staff. The closer the mother can stay and have free access to the baby at all times, the more breast feeding is likely to succeed.

As already mentioned, the UNCRC repeatedly sets children's rights in the context of the loving supportive family that premature babies especially need (articles 3, 5, 7, 8, 9, 10, 16, 18, 22, 27, 30). Some NICU respect these needs and rights. Others do not. Nurses who encourage breastfeeding may have to work against and in spite of obstacles, and against colleagues who discourage breastfeeding by giving uninformed advice and promoting formula feeds. The barriers also include unhelpful protocols, such as that babies must be able to feed four-hourly and to have no recorded weight loss for days before they can go home. Parents described desperately trying to 'force' milk into the baby and resorting to top up bottles of formula milk, in order to be able to take the baby home. Many mothers give up persistent attempts to breastfeed. The obstacles could feel painful and frustrating, such as for the mother who recounted how she phoned the unit to say she was bringing in fresh breast milk so would the nurses not take any of her stored expressed milk out of the freezer. That evening, she found that a nurse had defrosted all her bottles of spare milk and these had to be thrown away. The mother felt the nurse did not apologise or seem concerned.

The premature babies highlight the potentially life-saving importance of breast milk, because it reduces their risk of acquiring bowel infection. Many babies become infected and some require surgery to remove sections of infected and necrotising (decaying) gut, and to insert and later remove stoma (temporary anus-type openings made in the abdomen wall to bypass damaged sections of bowel). The illness and treatment weaken the babies, delay their growth and progress, and lengthen their stay in the NICU, thus exposing them to further risk of infection. Doctors regard the bowel infection as systemic, affecting the whole body system, and linked, for example, to inflammation of the brain. They talk of the 'guts, lungs and brain' as the three parts of the baby most vulnerable to infection and injury. Directly or indirectly, attention in the NICU centres on the babies' brains in efforts to prevent neurological damage. Monitors constantly flicker recordings of the babies' bodily functioning, so that the staff can check these and adjust the support equipment appropriately. The aim is to avoid pressure and bleeding in the brain, and to ensure that the oxygen supply is sufficient for the body's needs, but not so high as to harm the baby's retina and vision.

All the work in the NICU can be seen as directed towards and culminating in this extremely sensitive continual balancing of the baby's differing needs, systems and supports, to aim at equilibrium in the baby's brain and whole body systems. And this aim of neurological equilibrium also entails and perhaps symbolises the overall social endeavour of the NICU: to balance the sometimes conflicting and competing needs, systems, aims and supports relating to the many adults in the unit, staff and parents.

The link between breast milk and the risk of bowel infection illustrates vital aspects of the NICU management and also of children's rights. The babies' holistic needs or rights are all inter-related, from the seemingly trivial (providing enough breast pumps, storing breast milk carefully) to the highly important (avoiding costly major surgery and potentially fatal illness). In contrast to cases when mothers prefer not to breastfeed, many of these mothers long to do so successfully, saying, 'It's the only thing that I can do for her and only I can do it,' and 'I hope it will bring us close together after all the problems of the early birth and then us having to be apart for so much time.' They devote many hours a day to this aim, so that their babies may be said to have a right to 'their' milk. This right is highly important to the whole NICU endeavour of promoting babies' healthy survival. However, at times it is disrespected, as we have shown, through routines or ignorance or indifference, or by default in the busy units.

Pollution

Throughout the UNCRC, even clauses that seem unrelated to babies may not only apply to premature babies but can have particular resonance with them. One example is the earlier mention of the dangers of environmental pollution (article 24c). Again, this right connects seemingly minor with major issues, and shows how certain baby's rights are taken very seriously in some NICU and less so in others. Babies who are extra sensitive to noise and light cannot sleep deeply in bright noisy units. This can adversely affect their energy, feeding, moods and self-soothing behaviours, which may undermine their weight gain and health. Petryshen *et al.* (1998), for example, compared the nursing costs for 60 preterm infants receiving conventional care versus 60 receiving developmental (NIDCAP) care, and found that an average of $4,340 was saved per infant during the first 35 days of life. The babies could move earlier into areas with less intensive nursing support. They needed less time on mechanical ventilation and moved earlier from tube feeding to full breast or bottle feeds. The emotional strains for the baby and parents could thus be reduced. So the NIDCAP care plans that identify a baby's extra need to be nursed in a quieter dimly lit area can lead to marked improvements in individual babies' well-being. The programmes also advocate general `baby-led' whole unit policies, such as to reduce noise and lighting 'pollution' levels in all the nurseries. These NICU then resemble more nearly the subdued sensory stimuli that the baby experiences before birth.

There is a noticeable difference in some units between how the baby would be treated at home or in the NICU. For example, visitors to a sick baby at home would talk and walk very softly, as the staff in some NICU also do, although the advocates of this policy say that they constantly have to remind people and persuade them to respect the policy. Yet in many units there is loud talking, laughing and calling across the echoing rooms. When a doctor wore loudly tapping shoes that set off desaturation monitors as she walked past the babies, denoting the babies' stress, parents who noticed this felt they could not mention it, whereas at home they would have had more control over their babies' environment. Lighting may be very bright, with babies lying supine, staring up at fluorescent bars or spotlights. Towels draped over incubators to reduce the glare may be left drawn aside, whereas some units had covers over the top and sides of incubators to protect the babies – though one mother felt these covers were rather like 'coffins' showing how decisions about the babies' best care are very personal. Staff in bright noisy units tend to dismiss research evidence about the discomfort to the babies, and to discuss the need to attract and retain staff by making the units friendly cheerful places for them to work in. This is an important argument, adequate staffing levels are vital for the welfare of the babies and staff, but it appears to assume that the babies' need and possibly right to a quiet dim environment conflicts with and is less important than reasonable working conditions for the staff. The quieter units show that the rights of the staff and of the babies could be compatible, and that many nurses gained much satisfaction from helping the babies to be calm.

Regular review

Children being cared for away from the family home have the right to periodic review (article 25). Parents valued a formal time, at least once a week, to raise questions with the neonatologists, and sometimes to be advocates for their baby. The units varied in how much doctors offered to talk with parents, or left the parents to request a meeting, also in how informal or formal, regular or infrequent their contact with parents was. Some medical teams encouraged parents to attend their rounds, others asked parents to leave the unit during rounds. Again major and minor details in the units could influence each other: parents who felt welcomed and respected, who were used to hearing medical conversations, and knew the doctors quite well, were more likely to be able to raise

serious questions and to share in making any decisions that might arise. Parents who felt relatively excluded and unwelcome tended to feel less prepared to take part in discussions, even if they were invited to do so.

Babies as persons or passive dependants: active expressive babies

Neonatal staff varied in their attitudes towards the babies, ranging along a spectrum that could be drawn from 'the baby as a person-citizen with rights', and 'the baby as a needy passive dependant and future person', to the baby as a 'work object' (Hall and Stacey 1976).

An example of the differing approaches concerns bathing the babies. One nurse would briskly bath the sometimes loudly protesting baby, while 'teaching' the watching mother. In another unit, if nurses demonstrated they would do so with a doll, so that babies were bathed by their parents. The parents would wrap their baby in a sheet at first, to prevent the startle movement, and gently dip the baby into the water, waiting until the baby seemed to enjoy the bath and was ready, before starting to unwrap the sheet. The occasion was one for shared enjoyment and interaction, with the adults following the baby's lead, as in John's NIDCAP care plan about offering a dummy and waiting to see if he wanted to suck it. Parents in some units were encouraged to talk about their babies' agency. For example, a mother described a book she was given that:

> really emphasised the fact that just sitting next to your child, your child knows that you're there, and it showed studies that...the oxygen saturation's gone up just from having a parent near by and stuff like that, and that was really good (1.8).

Parents also learned from their babies.

> Joe worked out who I was very early on…because there were times when there'd be people around him, doing things…and then I'd walk in the room and start talking and it was obvious that he looked towards my voice and would try and…work out where I was, and change and get a bit excited, get a bit jumpy maybe (1.12)

Beyond babies' seeming preferences and responses, at times adults were convinced that the baby had ultimate control over whether the neonatal treatment was successful.

> I think he definitely chose to live, because there were a couple of points where I would have exited. I have to say I would have left this life. He was incredibly ill. There were a couple of times when he was dying effectively, and the doctors were saying that, 'You know it's not good,' and I kind of got this feeling that he had decided, 'No actually I am not ready to go. I want to live,' because then he would come back in from his sort of dying, and he would be fine. Well not quite, but he would be different, and I feel that he chose to live…(1.20).

And some doctors agreed, such as this consultant neonatologist:

> I think it is remarkable. I have enormous respect for these little babies, and sometimes the way they cling on to life is extraordinary. I don't know.. this will to live somehow…he nearly died about three or four times. It was extraordinary how this little body, this little soul kept winning through…(1.23).

During one follow-up interview, William, then aged 9 months, gazed at his mother with an anxious look of arduous concentration that he had also shown in the NICU, as he struggled to breathe and to bottle feed. His mother said:

> …the will to live, I mean it's obviously not as conscious as that in a baby, but the life thing is so strong, they'll fight and fight and fight, and you start respecting them for that, you know, he's been much iller than I've ever been…but they kind of keep going and you end up feeling really quite in awe of that (3.15).

We review babies' autonomy elsewhere (Alderson forthcoming), but mention these observations here to show how the UNCRC provision and participation rights broadly overlap when babies participate in their health care.

Discussion

Concepts of rights

Many of the parents and neonatal staff we spoke with offered socially and culturally constructed versions of childhood that perceived the babies as agents who, to some extent, held control over the process and outcomes of their health care. These intimations of babies' agency implied or hinted at versions of babies' citizenship, in their rights to receive and take part in their medical care - as very sick adult patients do. Some babies' strenuous efforts to learn to breathe and to suck simultaneously were linked to an incipient sense of their duties and responsibilities. This is not to agree with adults in the units who described some babies as 'naughty', 'lazy' or 'greedy', as if they could make deliberate moral choices. But it is to respect the great efforts the babies made, and to see these as a beginning of the agency of making choices, to continue or to give up, instead of being wholly distinct from adult decision making. Even if the babies' efforts were not at all conscious ones, this partly overlaps with all human agency, since people of all ages can never be wholly consciously aware of reasons for their actions.

It was notable how some premature babies leaned against their mother, gazing at her while she talked to the researcher. Some babies seemed to have an intense personal relationship with their mother, and also to respond as if a vital part of the care they received was *their personal relationship with the adult giving that care*. Joe's mother's view of his excitement when she arrived (see above) was shared by other staff and parents. And babies appear to be more comfortable, for example, when a cloth of pad with their parents' odour is tucked into their incubator with them (Als 1999: 57). So we can question whether the giving and, in a sense, the responsibility for health care were one-way, from adults to babies, or if the babies felt some encouragement or reward or even incentive from their parents' joy when they made a tiny step forward and, if so, whether these interactions might be the beginnings of being an active contributing member of a community.

We suggest that, far from trivialising rights, attention to premature babies can increase understanding of rights and citizenship.

Babies remind us that human rights are *embodied* and closely connected to basic physical needs and desires. A primary way to respect rights is to allow or enable people to satisfy these. A primary way to violate rights is to constrain, punish or disrespect the person's body.

Babies remind us that rights are *aesthetic*, such as in our desires, however conscious or unconscious, to seek pleasing light, sound, scent, taste and touch stimuli, and to avoid ones that are sensed as noxious. Many adult patients cannot sleep in hospital,

because of constant light and noise. The experiences may be painless and even at times desired, such as in noisy happy parties or bright sunny days, but unwanted stimuli are commonly used to torture prisoners.

Differences between desired or imposed stimuli link to rights as *contingent* on the person's will, need, desire and power. Although the UNCRC usefully enshrines universal principles, these are realised flexibly through contingent experiences that depend on the circumstances and (UNCRC article 12 views) of the child in question.

Rights are *interactive* by occurring and taking meaning from relationships between two or more people, or between individuals and systems, such as NICU routines that support or undermine mothers' effort to breast feed their baby, whatever the professed aims and efforts of individual staff.

Rights are *personal and relational.* Adults described babies' preference for care by their parents or by sensitive nurses that the baby knew well; it was not only the techniques of care that necessarily mattered to the babies, as much as who gave that care and the quality of the relationship between that person and the baby. This point, which is more a question for future research than a definitive conclusion, could have great implications for health, education, welfare and social policy – that perhaps children deeply know the importance of mutually respectful and caring personal relationships over impersonal health, education and welfare services.

Rights can be *emotional* when the ways they are honoured or disrespected are experienced and interpreted personally by the people affected, such as by parents and possibly by babies who feel supported or uncomfortable and very uneasy in the NICU.

Rights then exist within *moral communities* when people harm or help one another, and this links to early experience of interactive *citizenship,* especially for premature babies who stay in the public NICU, cared for by dozens of adults, and dependent on public services.

Rights are inexorably *political and economic* whether the state does or does not support education and health care services and adequate standards of living for children.

The babies' share in promoting and sustained their basic health care, such as, with difficulty, breathing and feeding, could be taken as evidence of their incipient responsibilities to exercise some of their *inalienable* human rights to life and to be members of the human family.

Their *agency* as rights holders was interpreted during our interviews with parents and staff in the babies' positive responses and possible *'resistances'*: babies' crying out for care; wriggling into a comfortable position; pulling out tubes, sometimes prematurely and sometimes appropriately, 'self-extubated' was not uncommonly recorded in babies' notes. A few parents attributed their baby's survival to 'force of character' or 'obstinacy'.

Parents and staff explicitly or implicitly described babies as sentient, active meaning makers, such as when babies learned to cringe in anticipation of painful heel pricks and simultaneously to be calmer in response to a tender touch or soothing voice.

Advantages of reframing babies' needs in terms of rights and citizenship

Is anything gained by rephrasing babies' traditional needs, welfare and best interests in terms of citizens' rights? Rights language can irritate and alienate its opponents who dismiss claims that children have rights as empty slogans in search of a meaning. Rights and citizenship, especially of older children, may be denigrated and trivialised if applied to babies. Yet there are advantages in expanding concepts of rights and citizenship to include the earliest years of life and to see them as inalienable to all members of the human family.

As Woodhead (1997) commented, talk of 'needs' can support adults' claims to know as experts what is best for children. Of course, in many ways neonatal staff are such experts. However, part of being a rights-holder is to have some say in how one's rights are defined and respected. There is a transfer of some acknowledged expertise and authority to the child. The neonatal examples suggest that babies too can have unique insight into their best interests, and adults need to take account of these if their decisions about care are to be adequately informed and humane. Informed neonatal care is then an interdependent partnership, with the adults referring to the baby's contributions.

Needs and interests may be arbitrary, rights are principled and formally agreed entitlements and standards, as in the UNCRCR.

Rights further involve respect and dignity as well as care, when babies are perceived as rights holders, and to some extent as persons and citizens. The recognition entails listening seriously to baby's expressions of pain or pleasure and responding appropriately.

The negative side of rights is associated with selfish individualism, competing claims, and threats of litigation. However, the UNCRC proposes a different understanding of rights, that emphasises solidarity and community in equal respect for the worth and dignity of every child. The respect is not zero-sum, meaning the more one baby has, the less another has. The respect is not competed for, and cannot really be promoted through threats and sanctions. Instead the respect can be an ethos for the whole NICU that increases respect for all the babies individually and generally, promoting positive attitudes among the staff in the relationships with the babies, and also in the structures and routines of daily care.

During interviews, parents described their trust when leaving their baby with nurses who 'really cared' and their high anxiety about nurses whom the parents saw as rather careless or indifferent to the babies, Underlying these differences in staff attitudes were, we suggest, beliefs about the babies as either sensitive aware persons, or else as unaware pre-persons. So besides being a practical tool to help to raise standards of services and amenities for children, the UNCRC can increase awareness of all children as complicated sensitive aware persons with rights and views. The onus is then on people to justify depriving babies of these rights, instead of on people who advocate granting rights to babies. The UNCRC, by not stating any ages, challenges age-stage theories and assumptions that children acquire rights at certain ages. Instead of trivialising children's rights, concepts of babies as agents and aware meaning makers, and concepts of rights along a continuum of human life from cradle to grave, can help to increase respect and care for every person, including those who may be at the edges of citizenship.

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