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Biographical Information

Priscilla Alderson is Professor of Childhood Studies and has been at the Social Science Research Unit Institute of Education University of London since 1991. She researched children's consent at the Charing Cross and Westminster Medical School 1989-1991, and parents' consent at Goldsmiths College University of London 1984-1987. Her publications include many papers and books on consent and rights, on the ethics and methods of research with children, and more recently on how current economic and ecological changes affect younger generations. Recent books are, with Virginia Morrow, *Ethics, Research and Consulting with Children and Young People* (Barkingside: Barnardo's, 2004) and *Young Children's Rights* (London: Jessica Kingsley/Save the Children, 2008). Priscilla teaches on the MA course on the Sociology of Childhood and Children's Rights.

Introduction

In 1989, when I began the research for *Children's Consent to Surgery*, the United Nations adopted the *Convention on the Rights of the Child*. The new *Children Act* for England and Wales advised attention to children's 'wishes and feelings'. The wave of rebellions around the Soviet Union led to the fall of the Berlin Wall and, although protests were suppressed in Tiananmen Square, Nelson Mandela's freedom was imminent. It was a time of cracking open old ideas and constraints to advance new approaches and freedoms. That year, I attended a lecture in Canterbury about Hieronymous Bosch's *Garden of Earthly Delights*. The lecturer puzzled inconclusively over the eggshells, glass and other fragile forms in the garden, and then by chance I spoke afterwards to a woman who believed that they symbolise the necessary breaking-open if new life, delight and understanding are to emerge. 'Your pain is the breaking of the shell that encloses your understanding.'¹ That day symbolised the year for me in many ways, not all apparent at the time, and I'll review some of the ways later.

Questions for the book

In 1985, Lord Scarman in the *Gillick* case had pronounced that, in English law,
'the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to understand fully what is proposed [and also] sufficient discretion to enable him or her to make a wise choice in his or her best interests'.²

The 1969 *Family Law Reform Act* had accorded the right of consent to minors aged 16 and 17 years, but the law appeared to be silent on younger minors. Victoria Gillick, the Roman Catholic mother of ten children, had sought to close what seemed to be a loophole in the law, to ensure that her children could not access contraceptive advice or treatment without her knowledge or consent. Eventually she lost her case, and she lends her name to the policy summarised by Lord Scarman, and 'the *Gillick* competent child' with which she disagrees.

Yet the law still seemed inconclusive. 'Well if the age is not 18 or 16 what is it?' many doctors and particularly surgeons asked. By 1989 there was still, as today, much uncertainty, but

there had not yet been the 'backlash on *Gillick*' of the re R 1991 and re W 1992 court cases with Lord Donaldson's rulings on seemingly incompetent minors. From 1985, emancipatory legal commentaries were advising that *Gillick* could apply to other decisions by children besides healthcare ones. The Department of Health supported minors' rights to confidential medical treatment, for fear of rising sexually transmitted disease and unwanted pregnancy rates.

So my first questions for the research for my book were: At what age are children able to have the understanding and discretion to make wise decisions about consent to their healthcare? And which age group should I research? Twenty years ago I expected (mistakenly) that it would be impossible to conduct research interviews with anyone aged less than 8 years and, as *Gillick* was concerned with those aged under 16, my sample was 120 children aged 8-15 years. (After the book was published a paediatrician told me that, when asked to review my funding application, he advised rejection because it was impossible to interview anyone under 16. He had changed his mind after reading the book.)

What type of healthcare might be most relevant and revealing for the research about age and competence to consent? Elective surgery tends to involve the most explicit, detailed and formal discussion about informed consent, with ample opportunities for the researcher to observe and record and interview all concerned, children, parents and practitioners. I chose elective orthopaedic surgery because patients often wait weeks or months for their operation, allowing maximum time for information and decision making. Orthopaedics seldom involves embarrassing or mysterious inner organs, or saving lives, matters which might over-complicate interviews with young patients. Other advantages of orthopaedics soon became clear. The child who is, and is in, the body concerned has unique expertise. Orthopaedics mainly treats problems of mobility, pain and deformity, all most intensely experienced by the person concerned, not only physically but also socially in how their everyday experiences, relationships, opportunities, feelings, values and aspirations are affected. Amy aged 10 with achondroplasia was determined to have leg lengthening so that, among other reasons, shop assistants would no longer treat her as if she were 4 years old. Tina was equally determined to resist growth treatment. 'I'd rather stay like me'. Society and public attitudes should, she believed, adapt to respect and include disabled people. I decided to involve experienced expert young patients, and not a healthy or representative sample of young people who might know very little about surgery. On average the group had had four to five operations already, not always successful. One girl had had over 40.

Another vital question was: What questions and methods will produce reliable findings on children's competence? Questionnaires to collect standardised data, tests of knowledge, ability and satisfaction, vignettes for discussion - all these popular methods have the advantages of producing stats-friendly data that can quite quickly be collected from impressively large samples, and packaged into those neat grids and graphs favoured by policy makers, scientists and, well, by doctors. My research would probably have had much more impact if I had used these methods, and invented a definite convenient numerical age-stage formula to help practitioners rapidly assess or assign competence levels along with the diagnosis and prescription. However, as I expected and as quickly became clear, each child's condition, treatment history, background, knowledge, information-sharing with adults, and other characteristics varied too much to fit standardised questions. Any test of competence would have to depend on some arbitrary notion and norm of what the pass/fail level should be, and what details children aged 8, 10, 12 or 14 ought to know. Who would provide the notions? Possibly there could be separate tests for those having foot or knee, spine or arm surgery, with other tests for the children with learning difficulties. In trying to be fair, we might end up with dozens of tests and still more confusing and arbitrary results. I would fall into the trap that dooms most research purportedly about consent, which is actually about information and how it is recalled and recounted, often without reporting what patients were originally told, making the results even less useful. In contrast, consent is far more personal, subtle, interior: the weighing of information, hopes and fears in the light of personal values, reflecting,

forming, and then signifying a decision. Before describing my chosen methods I will recount how I came to be interested in children's consent.

Prelude to the book

During the 1970s, few hospitals 'allowed' parents to stay with their children. I was relieved to be able to stay with my son for weeks in a London hospital, whereas our small local hospital banned parents at most times. So I joined a group campaigning for family centred care for all children in hospital. This led on to learning about advocacy, health care provision and policies, and later to joining a three year working group to review the ethics and law of medical research with children.³ The group, which included the philosopher Richard Hare and the lawyer Ian Kennedy, offered me a daunting introduction to academic medical ethics. The paediatric cardiologist Elliot Shinebourne saw that while the group debated parents' consent to research in depth, no one had yet written about parents' consent to treatment. He suggested that I research this as a PhD in Sociology. As an English literature graduate and former schoolteacher, I had never read any sociology, stupidly believing that it was merely common sense wrapped up in jargon. With perhaps beginner's luck, I was immensely helped by the staff at Goldsmiths. David Silverman introduced me to sociology, to qualitative research, to Foucault's work, and to the problems, and indeed the existence, of positivism. I was surprised to find that I had been talking positivism as well as prose all my life. David helped me to get a research council grant. Caroline Ramazanoglu, the Marxist feminist, gave invaluable supervision. Victor Seidler taught me about critical theory, Kant and feminist ethics. The research ethics committees approved, and the staff and parents in the children's heart surgery units at the Royal Brompton and Great Ormond Street Children's Hospitals were most generous in sharing their time and thoughts and in teaching me about the children's heart conditions and treatment. I spent months observing the wards, clinics, intensive care, clinical meetings, nurse support groups, catheter labs and, once, an operation. Parents only occasionally said they were too busy or distracted to talk, and many asked to speak to me. The only person who withdrew was the surgeon who told me to burn the transcript of his painfully thoughtful interview.

To give an example of their kindness, a sister (as senior ward nurses were called) one evening let me help her to lay out a baby who had just died and whose parents did not want to be involved. I found this gentle ceremony therapeutic as years before I had hardly been 'allowed' to glimpse my own child who had died of a heart defect. While I did not mention my experience to parents, I think it helped me, not so much in daring to ask questions as in daring to go on listening while they spoke of suffering, risk and mortality. One in ten of the children died in the units. I had a sense that I had been where the parents were, and that somehow we could manage these interviews together. Was this ethical? I hoped that I was firmly doing research and not attempting to offer therapy. The American ethnographies of intensive care⁴ tend to take the viewpoint of the staff, whereas I tried to understand and report the different viewpoints of the staff and the parents, each in their own right. I hoped that my work was respectful and emancipatory. I did some surveys of parents' and nurses' views for the hospital management, and one report at least led to a change of policy. Parents became able to give comfort and support before surgery until their child lost consciousness in the anaesthetic room, no longer having to watch porters take their crying child away in the lift, which had been the final memory for many parents.

The staff and families taught me to watch, wait and listen - to do ethnography, which became the chosen method for the children's consent study. The parents' consent research, which resulted in *Choosing for Children*, was an essential prelude to the children's study in so many ways, and I will give five examples. First, I saw how crucial the social context was to consent: how families were more or less informed and supported; how they learned slowly through clinics and ward rounds and through the child's embodied experiences; how ethics is practical and not solely abstract; how parents could give informed consent only if they were physically able to be present with their child, able to stay overnight and to pay the train fares; and how greatly these practical

problems distracted them and added to their stress. A few senior nurses kept parents away, and when they tried to freeze me out too I felt at times like an Arctic explorer, wondering how much longer to keep on persevering. Second, for parents the personal relationships and their feelings about the doctors and nurses were central to the ethics of trust, respect, risk-sharing and voluntary consent. 'Seeing the world comprised of relationships rather than of people standing alone, a world that coheres through human connection rather than through a system of rules.'⁵

Third, I learned how 1980s medical ethics was unrealistic and overly rational. Consent was seen as reasoned calculation, and emotion as dangerously distorting and distracting. How then could shocked grieving parents who arrived with their newborn baby possibly give valid consent? Carol Gilligan's work on moral emotions enfranchised women as equal, though different, moral agents to men, and not as inferior. She enfranchised children too, drawing on deep interviews with 10 year olds.⁵ Some parents described their thinking-feeling emotional journey, from horrified rejection of heart surgery to gradual doubt, growing fear of the untreated condition, growing confidence and trust in the information and the clinical team, towards the hope and courage to agree to accept very high risks believing this was best for their child, within the inevitable limits of the medical skill and knowledge of the time. Parents were shocked *because* they understood. Instead of being a distraction, emotion is integral to real understanding, and the painful breaking through into new knowledge and into new moral emotions of courage with pity and compassion for their child and for other families. A father who was an actor, describing to me his fear that his daughters might die, quoted;

'For it so falls out

That what we have we prize not to the worth
Whiles we enjoy it, but being lack'd and lost,
Why then we rack the value, then we find,
The virtue that possession would not show us
Whiles it was ours.'⁶

Fourth, I found how vital and complicated trust and voluntariness were to the parents. Each has its own chapter in the parents' consent book.⁷ Despite the unavoidable pressures of illness and risky painful treatments, valid consent involves freedom from avoidable pressures 'of any element of force, fraud, deceit, duress, overreaching, or any ulterior form of constraint or coercion'.⁸ Leading ethicists Faden and Beauchamp, however, gave up on voluntariness and decided to

'avoid the word entirely. We substitute a conception of noncontrol that does not have the history and connotation that burdens [*sic*] the terms "freedom", "voluntariness" and "independence".⁹

Contrary to their analysis, voluntary consent *is* the sense of control and freedom as opposed to coercion and helpless fear. We must never forget the history, purpose and profound meanings of voluntary consent.⁸ Parents described their willing consent as involving faith in clinician's respect for the child's body and wellbeing. Later, in the children's study, the spine surgeons especially spoke of the vital importance of young children having some sense of control in knowing that there was some respect by adults for their independence. Whenever possible, surgeons waited until the child was ready to consent willingly, and had made the emotional journey from fear of the treatment to greater anxiety about the untreated condition. And fifth, I found that ethnography, observing over time and listening to narratives, seemed to be the only way to research the often invisible processes of parents gradually arriving at being able to give informed and voluntary consent.

Because the children having heart surgery had so much to cope with, and the parents' consent protocol and ethics approval did not include my talking with them, I hardly spoke with those children. But I kept wondering what their views were and that led to the children's study.

1989 onwards

To return to 1989, while I was planning the research on children's consent and also finishing the book on parents' consent, my son was ill for 9 months. It was ironic to write about the parents' vital care, while feeling that I kept letting William down badly in the tangle of delays. At last surgery was recommended: either to remove the spleen and gall bladder, which William aged just 15 favoured, 'I'm not going through this twice!'; or to remove only the spleen and to see if the gall bladder recovered, which I cautiously preferred. William's decision prevailed and eventually he recovered very well. Only a few months later how differently I would feel about anxiously and reluctantly 'letting him decide'.

With ethics approval and access to three hospitals in London, the children's consent project soon expanded to a fourth hospital in Liverpool, where an experienced family advocate Jill Siddle collected many very valuable examples. Besides extensive observations, we interviewed 120 children and young people before and after surgery, their parents, and 70 hospital staff. Almost everyone was very generous with their time and ideas, their examples and narratives. I have mentioned the problems of common standards, norms and tests of competence. Instead we asked all children and parents when they thought the particular child was, or would be able, to decide about the specific proposed surgery as competently as his or her parents could. The staff were asked at what age they had found some, maybe exceptional, children could begin to give competent consent/refusal, and to describe examples. Very soon, I was painfully shocked and amazed at how well informed, and how morally and physically courageous so many of the children were. They were often coping with intense pain and with one or more chronic disabilities. Many of them protected their parents from knowing how much they endured, as children in American cancer wards had done over 30 years ago.¹⁰ It was one of the greatest 'breaking open of the shell of my understanding' I have experienced: to see that children of various ages, backgrounds and abilities were so much more 'mature' complex people than I had realised before, and to know that I had to have new relationships with my own children, more authentically person-person, less falsely constructed adult-child, hard and complicated as that might be. That has been a major theme in my life and work since 1989, and the rewards have far outweighed the risks.

I wrote *Children's Consent to Surgery* for several reasons. The answer to the question, 'At what age are children able to have the understanding and discretion to make wise decisions about consent to their healthcare?' is that there is no single age. Too much depends on each complicated child and context. The children's accounts, which illustrate this finding, were too detailed and varied to be reduced simply into short papers, let alone into graphs although the book does have 18 numerical tables. The over 300 replies we received about an age of competence to consent often told us more about the speaker than about children's abilities. The replies ranged from 8 years or younger to 'never' from one surgeon. Books allow the space to show how our research method of listening reflects the ethical clinical practice we observed when the best practitioners listened to each child individually. Competence is not a fixed fact. Through dialogue and negotiation, both the child and the adults can become more informed. As they work together towards the best or the least harmful decision, the child's understanding and courage can grow. Competence is assessed not by tests of general ability but by discovering how much, with help, the child is able to understand and to share in making the decision, and how skilful, supportive and competent the adults can be. Although most children preferred to share responsibility for the decision, a minority from 8 years onwards said they chose to be 'the main decider' about proposed surgery, and their parents agreed. Book length also enabled me to analyse through inter-connected chapters the context of law and ethics, children's human and legal rights, new approaches to research with children and about concepts of childhood, the children's and adults' views about the harms and benefits of surgery, the giving, exchanging and understanding of information, the process of making a wise choice, and meanings of competence to consent.

The final part of creating the book was to choose the cover picture. In 1993, the National Gallery in London had a six room exhibition of Edvard Munch's paintings, with the well known

The Scream in the room on madness. In the room on illness and death, Munch, his brothers and his 3-year-old sister stand beside their mother as she dies of TB. In *The Sick Child*, Munch's sister aged nearly 16 is dying of TB, with her aunt sitting by. I had seen that image of the calm brave child beside the distraught adult in the hospital wards, and felt that it epitomised children's competence to cope with great difficulties. The publishers agreed to print the painting on the book cover if they did not have to pay a fee to the Munch museum in Oslo. The trustees very kindly agreed to waive the fee. Perhaps it helped, when I asked them, that I mentioned visiting Trondheim in 1992 to report my research and to discuss their plans for children with the new Norwegian National Bioethics Committee. That was during a seemingly hopeful week when Clinton had swept to power in the USA.

Instead of summarising *Children's consent to surgery* in these pages, I will simply hope that if you are interested in parents' and children's consent you might perhaps look at both this book and *Choosing for Children*. Although it was very well reviewed, and may still be the only book reporting a research study of parents' consent, without ever contacting me the publishers quickly remaindered *Choosing for Children*. That felt a little like another neonatal death, although today Amazon is a great resuscitator of out-of-print books. Maybe some of the leading bioethicists whom I criticised objected to the book. Maybe it was ahead of its time. Bioethics, respect for consent, and the sociology of the emotions have all changed greatly since then. So too has respect for the 1989 UN *Convention on the Rights of the Child*, which states that:

'recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world'.¹¹

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¹ Gibran K. *The Prophet*. London: John Hunt Publishing Ltd., 1923/2004.

² *Gillick v. W Norfolk & Wisbech AHA* [1985] 3 All ER 423

³ Reported in Nicholson R. (ed) *Medical Research with Children: Ethics, Law and Practice*. Oxford: Oxford University Press, 1986

⁴ For example, Frohock F. *Special Care: Medical Decisions at the Beginning of Life*. Chicago: University of Chicago, 1986; Zussman R. *Intensive Care: Medical Ethics and the Medical Profession*. Chicago: University of Chicago, 1992

⁵ Gilligan C. *In a Different Voice*. Cambridge MA: Harvard University Press, 1982

⁶ Shakespeare W. *Much Ado about Nothing*, iv i

⁷ Alderson P. *Choosing for Children: Parents' Consent to Surgery*. Oxford: Oxford University Press, 1990, chapters 7 and 8

⁸ *Nuremberg Code*. 1947. 1

⁹ Faden R, Beauchamp T. *A History and Theory of Informed Consent*. New York: Oxford University Press, 1986; 257

¹⁰ Bluebond-Langner M. *The Private Worlds of Dying Children*. Princeton NJ: Princeton University Press, 1978

¹¹ United Nations 1989 *Convention on the Rights of the Child*. New York: UNICEF; Preamble