Section 1

The Body

2

Reforms to Healthcare Systems and Policies: Influences from Children's Rights

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Countless people have shared in reforming healthcare systems and policies when they planned, provided, researched, used and reacted to the services. Two-year-old Laura, filmed by James Robertson in 1952, helped to transform national policies on children in hospital, as reviewed later. This chapter highlights just a few examples from the UK which have radically altered health services for children. Health here is defined broadly as children's physical, mental, emotional and social health, affected by their families' well-being, and their housing and neighbourhood – wealthy, average or deprived.

Reformers may have thought of children's welfare, needs and interests rather than their rights. Yet their work has generally supported rights to life, the highest attainable standards of health and healthcare, nutritious food and clean water, warmth and shelter, an adequate income, recreation, leisure and education (including the benefits of educated parents and professionals), and rights to protection from discrimination, abuse, neglect and cruel or degrading treatment. Freedoms of information, thought, association and assembly enable anyone in need to access and understand health services (United Nations, 1948, 1966, 1989). Legal rights within health services include patients' rights to privacy and family life, and to refuse or consent to treatment and bodily touching. Common law in many of the 54 British Commonwealth countries grants this right to "Gillick competent"[1] children (Brazier & Cave, 2011). Rights to due process of law helps to regulate services, maintain standards, process complaints and prevent abuses.

Most reforms have been initiated and achieved by people working within the health services: practitioners, managers and researchers. Some of these insiders have great difficulties, when they seem to criticise their colleagues by advocating new, different or better services. While very much respecting these reformers' hard work and immense achievements, this chapter is mainly concerned with people who, like Anne Smith, were relative outsiders.

The examples of contributors to children's healthcare systems reviewed in this chapter emphasise individuals and voluntary groups that worked mainly outside and/or in creative tension with state systems. They were usually outsiders, not medical or nursing experts but laypeople, and their personal experiences were often crucial in informing and motivating their work. They concentrated in new ways on the interests of children (and adults) as users of current or potential future services.

Although research is copiously reported, the work of connecting research to policy and practice is far less often written up. For this reason I have followed my own work and interests, and drawn on my personal experiences, shared with many other people who are trying to reform healthcare systems. I have grouped these selected activists into innovators, partners (provision), fundraisers, boat-rockers, partners (policy), betrayers and protestors. They will appear under the heading relating to their main concern, although many were active in more than one group. This chapter is mainly a historical review.

Innovators

Anne Smith's second contribution to this volume (see Chapter 3) on promoting international childhood studies was a welcome lecture at my place of work, the London Institute of Education, which is still dominated by child psychology. Her third contribution (see Chapter 8) was given as a lecture at the nearby Thomas Coram museum, the site of the Foundling Hospital, the first children's home in England. William Hogarth's portraits of the founder, sea Captain Coram, and his friends who helped to fund the hospital gazed down on us. They included George Frederick Handel. Major fundraising events from 1750 were the annual performances of the oratorio *Messiah,* directed by Handel and sung by the foundlings with leading professional musicians. The high expectations, which the children met, and the great social experience for all choirs who sing the *Messiah* reflect the definition of the World Health Organization (WHO): "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or i.nfirmity" (WHO, 1946). Innovations created with and for children to improve services for them and to promote their health have a long history.

Anne Smith's lectures in London reminded me of my somewhat similar experiences in England. We both had children who were born in 1970 and 1972, and who redirected our lives. Formerly a schoolteacher, I remember attending a course in 1974 about play. I learned explicitly to undo my teacher training and practice, which assumed that adults have to organise children's learning and that children learn mainly through being taught formally. The course emphasised what my children were teaching me: the amazing power of young children's self-organised learning; their happiness when they are busy experimenting; and their frustration when they are stopped from doing so.

The course on play was held at the Margaret McMillan Centre, near to where Margaret and Rachel McMillan had set up their pioneering open-air nursery school in 1914 in the London slums. Convinced that all young children need fresh air, gardens, good food, clean and warm clothes, midday rest in cosy beds and inspiring education, they worked for children's physical and mental all-round health and well-being. They criticised schools that prepared working-class children solely for unskilled, monotonous work.

Educators who attend only to children's minds differ from those who know that healthy minds and learning need healthy bodies (Mayall, 1996). The longest-running strike in the UK (1914–1939) was conducted by children in Burston village, in support of two teachers who were sacked for such enormities as lighting a fire in the damp school without permission – to dry the clothes of children who had walked three miles to school in the rain (Bertram, 1974). Until effective medical treatments were developed in the 1940s, tuberculosis (TB) and pneumonia exacerbated by damp clothing in freezing rooms killed thousands of children in the UK.

Damp clothing was serious for children who wore the same garments all week, and who were sewn into their underclothes all winter. Led by 14-year-old Violet Potter, the Burston children marched and sang, waving flags while the authorities sacked their teachers. They set up an alternative school on the village green, with great official opposition but equally great working-class public support. In 1917, when their new school building was opened, Violet declared: "With joy and thankfulness I declare this school open to be forever a School of Freedom."

During the 1930s, English state education policy promoted health by wavering between providing free school meals and "providing" fresh air through open windows in all weathers. Fresh air won in some areas, presumably because it is cheaper for taxpayers (Cooter, 1992). Today, public protests are renewed in England where "austerity" policies have brought food banks run by charities for the poor. One in every seven schoolchildren was deemed by teachers to be too hungry to be able to concentrate at school (Kelloggs, 2013). "Cost-effective" policies still undermine the health of the whole child, body, mind and spirit.

Although they are now largely preventable and curable, TB, pneumonia and diarrhoea continue to take their toll around the world,[2] despite remarkable global progress: an estimated 12 million children died in 1990, which was almost halved to 6.6 million in 2012.[3] Save the Children, founded in 1919 by Eglantine Jebb, has played a vital practical part with other NGOs in the global fight for children's health and life. Jebb was motivated by witnessing children who were starving and dying around Europe by the end of the First World War. Her *Declaration of the Rights of the Child* was adopted by the League of Nations in 1924. Its provision and protection rights, later expanded to include civil rights (UN, 1989), are basic to services that promote children's health and well-being.

Pioneering individuals, small groups and charities/NGOs have complicated partnerships with state systems, harmonious or conflictual, cooperative or competitive. Some pioneers have welcomed support and funding from the state. If their initially privately run and funded services, such as children's homes or nursery schools, become large and popular, and are eventually taken over by local authorities, this can be a welcome recognition of the success of their work. They have enlarged the views of the general public and the state about what ought to be basic, routine services, so that many more children could benefit from the initiatives. Save the Children piloted new ideas, such as playschemes for children in hospital, and intended, once their worth had been proved and high standards set, that local authorities would take them over and run them in every hospital.[4]

The leading innovators of the UK's National Health Service (NHS) were outside any health system, and that seems to have freed them in three vital ways. First, they could clearly see deep flaws in pre-NHS health services and the terrible experiences for people who could not afford essential healthcare. Second, they were free to imagine an amazing alternative – the NHS. And, third, they did not have the complicated constraints and loyalties that can prevent insiders from making great radical reforms. William Beveridge was an academic economist and social reformer, and Aneurin Bevan, then minister of health and housing, was a former miner. He really knew about poverty, and untreated illnesses and injuries. The NHS opened on 5 July 1948, at a time of extreme post-war national debt and austerity, to replace a patchwork of local authority, commercial and charitable health services. Some 2,688 hospitals were nationalised (Bevan, 1952).

Women and children were most likely to fall through the large holes in the pre-NHS patchwork, which mainly supported working men. Many doctors greatly welcomed the NHS. There are stories of a general practitioner (family doctor) prescribing cough medicine for a child on 4 July. The next day he visited the family home and heard severe coughing. “Did the medicine not work?” he asked. “Yes it did,” replied the mother, “but his brother has caught the cough and I cannot afford more medicine.” “You can now,” said the doctor, and happily explained the new NHS. The benefits for poor families included no longer having to worry about the cost of each item of healthcare, about which child could have essential treatment and which could not, and about whether doctors added on unnecessary tests and treatments to inflate the bill. They no longer felt forced to delay seeing a doctor until it might be too late, when treatment was likely to be less effective and more expensive, and when infections might have spread through families and schools. Earlier care and prevention are especially vital for younger children because they succumb more rapidly to illness. When they survive severe illness, whether recovered or impaired, their minds and bodies, their whole lifelong identity and learning, relationships and opportunities, can be affected more intensely, and over a longer period, than adults might be affected.

The new NHS provided secure funding for expanding children's health services. Insider innovators included growing numbers of paediatric doctors and nurses who developed the services through research translated into teaching, policy and practice. By the 1960s, neonatal units were opening with their specialist medical, nursing and technical staff, and gradually babies were kept alive after earlier and earlier premature birth. Many neonatal illnesses and impairments were prevented and cured. The NHS was designed as an integrated whole, with basic national standards in every area, however privileged or disadvantaged. Cooperation between services enabled patients with complex needs to be referred quickly between specialities, locally and regionally. A very premature baby, for example, might need specialist care for the lungs, heart, kidneys, liver, gut, brain, eyes, bones and skin.

Another vital service that expanded in the 1970s was children's heart surgery, so that "blue babies" no longer languished and died. Whereas adult cardiology treats failing but normal hearts, paediatric cardiology treats children who are born with abnormal hearts. New research-practitioners developed foetal and neonatal anatomy, morphology and physiology, ultrasound, surgery on babies' tiny organs, and interdisciplinary intensive care. The NHS promoted comprehensive, coordinated and continuing care, with the transfer of children in need to the few highly specialised children's heart surgery units. Another innovation was when specialists travelled out to hold clinics in the surrounding referring hospitals. Besides saving families the time, upheaval and cost of returning to the specialist hospitals for regular check-ups, the clinics helped local paediatricians to learn about detecting and managing children's heart problems. These and many other complex innovations contributed to children's survival and well-being.

Partners (provision)

Some innovators are independent partners with state systems, complementing them or filling in gaps. Since the 19th century, Barnardo's and the National Society for the Prevention of Cruelty to Children have worked to reduce and prevent child abuse in the UK. They provided models when statutory child protection services were later established and they still work alongside them now.

In the UK, palliative care (for comfort but not for cure) towards the end of someone's life is mainly provided by cancer and other charities, including hospices. The first children's hospice opened in 1982 in Oxford and there are now 40 children's hospices in England. There were doubts about the benefits of hospices for children. Most sick children prefer to stay at home and near to their friends, with the help of practical support and equipment, such as hoists and ventilators (Sudbury & Noyes, 1999). Success in treatments for childhood cancer, cystic fibrosis, muscular dystrophy and other life-threatening diseases means that many more children live into adulthood and even to middle age. Rather than being places solely for terminal care, children's hospices are therefore also respite homes for children with long-term illnesses or disability, who need nursing care. Their parents and sibling carers can have some rest and free time. Warm, loving relationships develop between the families and the hospice staff. Yet there can be problems when treating children with a life-limiting condition as if they are dying, although they might live for years to come. Some surviving adults regret never having planned ahead, gone to university or started an ambitious career because, in childhood, "I was always expected to die soon."

Although the government funds about a third of their costs, hospices may continue as charities because of the uncertain benefits and costs of determining when exactly people need terminal care. Hospices are very well supported by donations. Many hospice staff and supporters believe that the patients have specific emotional and spiritual needs, which huge, generic mainstream healthcare services that are dedicated to cure and recovery might be less certain to meet.

Other independent providers are numerous self-help and support groups for families with long-term sick and disabled children, usually having been started by affected parents: STEPS for foot and leg problems; MENCAP for learning disabilities; SCOPE for cerebral palsy; and so on. Contact a Family is a central referral charity that they all belong to. They provide information and practical support to families, advise about benefits and inform professionals about high standards of care. Some run schools and other services, and some try to change discriminatory public attitudes.

In England, the Preschool Playgroups Association (PPA) was also centrally concerned with child and family health. It began in 1962 when Belle Tutaev wrote a letter to the *Guardian* which evoked enthusiastic replies from mothers who felt isolated at home when few preschool services were available. Led by mothers, playgroups sprang up in low-rent church halls and community centres, and in people's own homes (Henderson, 2011). In Kent, a semirural county south of London, the PPA was the only option for local children, except for very expensive, formal, private nursery schools. I valued our playgroup because it was child-led and inclusive; disabled children, including my son, were welcomed without question. Fundraising and subsidies helped families from varied social backgrounds to attend, and volunteer support helped to keep down costs. Mothers and staff formed the organising and fundraising committee. Mothers could stay as long as their child wanted while settling in (some weeks for my first child), and they joined in with caring for other children, organising play and music sessions, making equipment and planning events. There was no marked divide between professional staff versus “lay” mothers, and many were friends and neighbours. Sessions were informal, often spontaneous, and the large garden was well used.

The PPA (changed to the Pre-School Learning Alliance in 1995) helped countless mothers who were actively involved in helping at sessions and made friends with other young families. Many mothers became more confident and went on to train for new, more rewarding careers. The PPA was markedly different from the chains of high-priced nurseries today with their mainly low-paid staff, and from the increasingly rule-governed state preschools. Governments of left and right are clear that they intend that preschools should, first, increase parental employment and, second, prepare children for success at school and for later employment (HM Treasury, 2003; Williams, 2014). The PPA’s aim, however, was to help children to enjoy being children, and parents to enjoy being parents – one version of health and well-being.

Years later, Alison Clark researched her mosaic multimethod work with children, consulting them about their views and choices (Clark & Moss, 2005). In one Kentish playgroup, she asked the children to draw, photograph, map and talk about their ideal play garden. The research funds left no time or money to implement the findings, but my daughter Juliet was chair of that playgroup committee and with friends she raised funds, and redesigned and remade the garden, developing the children’s ideas. The unpromising plot, with steep sides sloping down to a boggy grass and mud area, was transformed into a sensory activity garden to use in all weathers and all seasons. The staff noticed how an autistic boy first began to play outside and enjoy the outdoors, and how tensions eased inside when many more children played outside.

The PPA tradition of independent partnership alongside state services supported many such informal innovations, when children, parents and staff worked fairly equally together. Both voluntary and state services range from very good to very poor. State services are most likely to have highly qualified staff and generous resources, but the PPA had valuable traditions of mutual trust and equal respect between many of the staff, children and parents, all experts in their different ways.

Fundraisers

Although fundraising is vital work for all NGOs, some members/supporters and local groups work solely as fundraisers. Medical research charities and international aid NGOs that provide healthcare for children around the world are two examples. Along with the promotion of imaginative innovations and great benefits, problems can arise. Fundraisers may choose projects that are not priorities for the children and adults whom they hope to benefit, but appeal to donors. Charities spend growing amounts on administration, and some compete wastefully with one another (Polman, 2010). Donations can skew services and increase inequalities in provision when, for example, they overflow into cancer services for children, but not into their mental health services, where the need may be greater. Disabled people have argued that fundraising appeal posters, appealing to public pity, can be counterproductive and may increase their disabling social exclusion. They would prefer reliable, sustained state support as a dignified recognised right, rather than the unreliable, humiliating whim of passing donors.

Generous donations for certain services can tempt managers to cut state support for them, implying that commercial and NGO services are better, more efficient and more sensitive to local need than general state services. The provision partners described earlier also risk promoting this view. Charities raise another serious problem when they glamorise giving, and court a wealthy elite of celebrities and royalty, reinforcing beliefs that a film star's photo opportunity matters more than ill health among the poorest billion people. Instead of challenging the causes of disease, this can launder them by making extreme wealth and the pity of the rich seem moral and acceptable, and maskings how gross inequalities, poverty and disadvantage cause so much childhood disease, disabling hunger and death (Marmot et al., 2013; Wilkinson & Pickett, 2009).

Boat-rockers

Most charities primarily provide services and/or raise funds. Fewer act as protest groups that try to rock the boat of big systems, such as health services, to alter their policies in new directions. They tend to claim that they do uniquely important work, which only independent charities can carry out. They are whistle-blowers and pressure groups, they publicise gaps in public services and campaign for better standards through informing policy-makers, practitioners and the general public. They are usually emancipatory, supporting the weak against the strong. Examples in the UK include campaigns by Liberty on the abuse of human rights, or Shelter on housing scandals (which cause serious harm to children). Most protest movements are relatively small, underfunded and involve individuals with personal experiences who challenge social structures. This section describes two such movements that I have been involved with, campaigning on child welfare and research ethics.

The National Association for the Welfare of Children in Hospital

During the 1950s, child patients tended to stay for weeks or months in hospital, and parent visiting was limited to an hour or two each day, or once a week. Two-year-old Laura showed typical fear and distress when filmed in her hospital cot by James Robertson in 1952 (Robertson & Robertson, 1989). Some children's doctors and nurses, with parents and James and

Joyce Robertson, pressured the government, which commissioned the Platt Report, chaired by the president of the Royal College of Surgeons. Among 55 far-sighted recommendations, the report concluded that mothers should be able to stay in hospital with their young children. And "if she can play a full part in his [sic] care she can be a help rather than a hindrance to the hospital staff" (Platt, 1959, p. 38). About three hospitals had been doing this for years, but most took no notice. So a formal pressure group was convened, renamed the National Association for the Welfare of Children in Hospital (NAWCH) in 1961 after the Platt Report, *The Welfare of Children in Hospital*. About 50 local branches grew up around England and there were related associations in other countries. NAWCH volunteers campaigned for hospitals to conform to government policy, providing a telephone helpline, a mail-order service for publications, a library and information service, practical support for all local branches, advocacy, publicity and fundraising work, regular contacts with healthcare personnel, large conferences and other meetings and events, and a national executive.

I joined in 1974 after my son had spent weeks in a London hospital. I was thankful that I was allowed to stay with him, deeply upset at the frantic distress shown by some young children whose parents were not with them, and concerned that our local Kent hospitals practically banned parents. I formed a local branch and found it stressful when we visited Kent hospitals, spoke to obdurate nurses, and pleaded for parents to be allowed to visit and stay. "There is no room, no beds for parents, no tea-making things. It's bad for children, parents only upset them. The risk of infection is too high to allow visitors," we were told. The experts were on our side, with research showing that infection rates fall when children are nursed by their parents instead of nurses. We would provide folding beds, kettles, and leaflets and posters about the benefits when parents can stay in the wards, funded by our jumble sales. We also spoke to many parents' groups about their rights to visit and stay. I admired the mothers who simply sat next to their child's bed through the night refusing to move. Every few years, the NAWCH telephone survey of all hospitals in England that admitted children mapped the slow progress in permitted visiting times, beds for parents, qualified children's staffing, and children staying in adult and geriatric wards (Belson, 2004; Hales-Took, 1973).

I was fortunate to be involved in campaigning for hospital reforms during a time of such dramatic change, and to experience the pros and cons of both voluntary and the later professionally headed NGOs. Up to 1980, like many charities, NAWCH was mainly run by stay-at-home women volunteers. From around 1980, with expanding women's employment and rising house prices, these women were moving back into professional careers, such as becoming managers of the very health services that they had wanted to reform, or becoming well paid directors of charities instead of unpaid volunteers. Charities were being professionalised, and the gains included their growing expertise in information services, publicity, data-collecting, fundraising and lobbying. Paid staff may be more reliable, available and disciplined than volunteers, giving more time and continuity to their work, and becoming more expert through watching daily events, maintaining contacts and being at their desks.

However, the losses in NGOs today include over-high salaries and costs, which require too much energy to be spent on advertising and fundraising, while direct personal experience of the problems and commitment to the NGOs' main aims are ebbing away. When staff move around between charities, their skills are valued over dedication to aims and vision. This is not to romanticise the old days, because there are excellent NGO staff and volunteers today, and there were plenty of inefficiencies in the past. Yet maybe volunteers work so hard, and achieve so much with scarce resources, because they are so committed to their aim. For us, this was child- and family-centred care in hospitals.

Our national executive met every two months, and, although two or three volunteers still kept the office going with paid assistants, we could no longer have a well-informed, up-to-date management team. Volunteers' emotional commitment needs to be channelled and nurtured carefully to motivate them, and to prevent them from leaving. At the first big NAWCH meeting that I chaired, James and Joyce Robertson sat in the front row to insist that we must concentrate on children aged under five years. Nearby sat Peggy Jay, demanding that disabled children in long-stay hospitals should be our priority. She had chaired a government enquiry about them (Jay, 1979). Other members, concerned with other age groups and illness groups, became bored or irritated by this longstanding battle over priorities. Fortunately a friend had lent me a small book by the speaker of the House of Commons from around 1898 about how to chair formal meetings. One useful rule is that everyone may speak only once on each topic (item, motion or amendment), except for the proposer, who may speak twice. This quietens dominant, boring and argumentative people, and allows more time for everyone to have a say, and to progress debates towards votes and decisions. Discussions need to be broken down into many separate topics on carefully planned agendas, and the chair has to keep everyone to that point, to avoid rambling and repetition. The rules are invaluable to ensure that large contentious meetings work efficiently towards clearly agreed practical outcomes. Effective meetings are a small but vital part of the decades of complex efforts that boat-rocking groups may have to spend on retaining members and slowly achieving policy change.

In April 1980, when I became the chair, the national membership voted to appoint the first director. I implemented their decision, although privately I disagreed with it. We had had our first paid administrator for about three years, and I felt that we had treated her very badly. Some autocratic volunteer members were not ready for a director; others worried about the cost. The administrator had taken the brunt of personal tensions in the painful transition of power from volunteers to paid staff. That April she resigned, leaving only two part-time secretarial staff in the office, and no members had time to help. We were funded by the government's Department of Health and Social Security and we were in debt. The chief children's nurse called me to meet her, and I dreaded that more nails would be banged into NAWCH's coffin before its imminent demise. The chief nurse turned out to be a loyal supporter of our work, her office was decorated with our posters and she doubled the grant. By the autumn we appointed our first director, Jean Davis, who had the close, friendly ties that we needed with leading politicians, civil servants, journalists and paediatricians. By 1982 we had 16 staff, and we were well organised and solvent. The Plain English Campaign makes annual awards for clear writing, and our leaflet for parents promoting NAWCH's, *Your Child in Hospital*, won an award.

In 1983 I wrote a ten-point *Charter for Children in Hospital*, rephrasing the main Platt recommendations in terms of rights. Point 2 stated: "Children in hospital shall have the right to have their parents with them at all times." Rights, such as to family life (ECHR, 1950, Article 8), are most crucial when they are being violated. They are claims and tools for change in order to meet needs and remedy wrongs. I also drew on the UN Declaration of the Rights of the Child (UN, 1959), and US and Australian patients' bills of rights. Jean Davis arranged for the charter to be adopted and displayed by numerous official medical, nursing, policy and health authorities, hospitals and NGOs. Later it was translated and promoted around European countries where, after 1989, it was strengthened by being connected with UNCRC articles.[5] It was also adapted and promoted around Australasia.[6] With Jean Davis' leadership, and constant hard work by branch members with their local hospitals, and by the staff nationally, the defensive hostility that most children's hospital staff displayed to NAWCH had changed by the late 1980s into friendly partnerships. Far from banning parents, many children's nurses were encouraging them to stay in children's wards.

The dangers of separating babies from their parents for weeks after birth were well known (Klaus & Kennell, 1976). Whereas the large regional intensive care neonatal units in the UK tended to involve parents in their babies' care, local special care units, where the babies were less sick and frail, still largely excluded parents. During 1984, local branch members of NAWCH, of the National Childbirth Trust and the Twins and Multiple Birth Association ran six conferences around the UK. Leading neonatal experts advocated family-centred care, and staff from smaller units who attended were surprised to learn how open their regional units were. Besides organising the exciting large conferences and excellent lunches, the branch members followed up the conferences, visiting their local neonatal units, persuading staff to change their policies, and giving beds and kitchen equipment for parents.

There was a great wave of change around UK neonatal units through this joint national and local campaigning.

During 1984–1987 I researched for my PhD on parents' consent to surgery in two children's heart surgery units (Alderson, 1990). In 1989–1991 I studied children's consent in four hospitals (Alderson, 1993) and saw NAWCH's aims gradually being achieved. We changed from being boat-rockers to being supporters of the hospitals' family-centred care.

Consumers for Ethics in Research

Another boat rocking-group was Consumers for Ethics in Research (CERES) (1989–2006). Members came mainly from campaigning for child health, childbirth and infertility NGOs. We were concerned that people who were asked to take part in medical research were seldom given enough information to enable them to give their informed consent, so we published a leaflet for potential participants, *Medical Research and You*, about the questions to ask researchers. *Spreading the Word on Research* (Alderson, 1994) summarised from ethics law and guidance the basic information that researchers should give, and that Research Ethics Committees (RECs) should check for during their reviews.

We held regular meetings on the ethics of research about different illnesses or disabilities, each with three speakers: someone with the condition, a researcher and a practitioner. Many people with the condition were invited to attend, and meetings were reported in *CERES News*. It became clear that few people were aware of their rights or of informed consent to research. The many illness/disability charities raise millions of pounds for medical research through the efforts of affected people and their families and friends, yet they seldom thought that they could share in choosing the research topics and questions, leaving researchers to decide. Our meetings showed that many affected people wanted more research on social ways of coping and less on pure science.

Those years of the group's existence were times of great change in research ethics. Review by RECs was gradually becoming routine for medical research. Bioethics courses and conferences, books and journals were popular. From 2000, social and educational researchers were slowly accepting that their research should be reviewed by RECs. CERES played a small part in this large movement, alerting those people involved to standards for informed consent. Current guidance by the NHS National Research Ethics Service that organises researchers' applications to RECs, and the Association for Research Ethics, is based on CERES' publications.[7] Many people have become more democratically aware of ethics, choices and abuses in research. We also emphasised official guidance on the importance of informing all children who are asked to take part in research, as well as respecting their consent or refusal as much as possible.

Partners (policy)

Whereas boat-rockers are independent outsiders, volunteers can also change healthcare systems as partners (policy) in a semi-insider role. Two examples are Community Health Councils (CHCs) and RECs.

CHCs

During 1974–2003, each of the 200 or so district health authorities in England and Wales had a CHC, with about 30 members drawn from the local general authorities and NGOs. The health authorities had to report their plans, changes and routine reviews to CHCs, which were funded by the NHS (for staffing costs and voluntary members' expenses). Yet CHCs were also critical and independent, and represented "the patients" voices' in the NHS.

We had the right to visit all hospital services and talk with the staff during my time on a CHC (1976–1980). I was concerned that CHC inspections tended to give superficial approval to serious problems, and so I wrote *What is a Children's Ward?* (Alderson, 1978). This summarised the enlightened law and guidance from the government and other leading reports. I added probing questions for visiting CHC members to ask, and standards for them to expect. The booklet was quickly ordered by every CHC through their national network. A similar guide, *Special Care for Babies in Hospital*, followed (Alderson, 1983).

Visiting hours were still very limited in children's and adult wards in semirural Kent. Many visitors took lengthy bus journeys, with nowhere comfortable to wait between the visiting hours of 2.00–3.00 p.m. and 7.00–8.00 p.m. It took a long time, immense resistance from the hospitals, dire warnings of impending chaos and countless committee meetings before the visiting times were extended: open visiting for children and 2.00–8.00 p.m. for adults. Quite quickly almost everyone was satisfied with the new hours.

In one maternity unit, mothers could not see or touch their babies except at feeding time every four hours, after crescendos of cries from the nursery. In those days, mothers had to stay in hospital for at least ten days after the birth. Two of us on the CHC, while we were pregnant, did a survey of 75 mothers' views. All except one mother wanted to keep their baby with them all the time, feed on request and see their other children more often than only at weekends. Five (childless) midwives discussed our report with us in April 1978 and dismissed the mothers' views as nonsense: "they are just making a rod for their own backs and will spoil the babies". Five months later, on our routine CHC visit, a new senior midwife proudly told us about the babies staying in the mothers' rooms, flexible feeding and daily visiting times for siblings. She did not know about the CHC survey, and we did not tell her, believing that real progress consists in the staff owning the new policies themselves.

We regularly visited the desolate large children's residential wards and school in the local "sub-normality" hospital of 1,400 beds. Only recently had the government decided "no child is ineducable" and school places must be found for every child (DHSS, 1970). Maureen Oswin (1973) warned visitors not to be impressed by wards with pretty wallpaper but to look at the abandoned children,[8] their emotions, relationships, activities and suffering. They were often called "cabbages" and, as Maureen said, "Cabbages do not cry." Thanks to Maureen's books and Peggy Jay's (1979) report, the wards were soon to close. The children were moved into smaller family-unit homes, and parents received more support to care for their children at home.

CHCs varied in their effectiveness, but when they were closed in 2003, nothing similar replaced them. Great opportunities to pressure health authorities to improve the services and to maintain new and high standards were lost.

RECs – Research Ethics Committees

REC "lay" members play a similar vital insider-outsider role. In the past, medical researchers were advised to seek "consent" from the patient's doctor (British Medical Association, 1980). Doctors could decide for themselves whether to involve their patients in "therapeutic" research about treatment (Medical Research Council, 1962–1963) right up to until the guidance was revised (Medical Research Council, 1991). The Department of Health's guidance, that all medical research protocols should be reviewed by an REC, funded and supported within the NHS, initially evoked angry resistance. One turning point came when patients, and their representatives – including many members of healthcare charities – joined RECs and shared in reviewing protocols. Lay members emphasised patients' hopes for the potential benefits of research, but also their fear of the risks. Medical researchers were then forced to recognise the patients' viewpoints and experiences, and to admit that their work could be dangerous, harmful and sometimes useless. Researchers came to accept that RECs could protect patients from careless or abusive research, and protect researchers from costly litigation.[9] Slowly, informed, voluntary consent became far more respected by researchers and clinicians (Alderson, 1990, 1993).

Betrayers and protestors

To achieve a nationally cohesive service, the NHS of 1948 was based on four tenets:

- to be universal and open to everyone in need;
- to be free at the point of delivery and funded through taxes;
- to have the secretary of state for health responsible for providing the NHS and accountable to Parliament for its performance;
- to be an integrated, cooperating whole.

The earlier examples of premature babies and children needing heart surgery illustrated the vital need for these basic standards. All four standards were removed by Parliament (Davis & Tallis, 2013; Department of Health, 2012). Successive governments have eroded the original vision that everyone willingly pays taxes for health services and social security, knowing that they can all benefit those in need, as well as supporting a generally healthy, secure society in everyone's best interests.

Gordon Brown (former UK prime minister) and David Cameron (current UK prime minister) have both had children who died, and they have both thanked NHS staff for their marvellous care, assuring the nation that the NHS was "safe in their hands". Yet they have combined to destroy and privatise the NHS (Davis & Tallis, 2013). The main political parties and the mass media have either (fairly secretly) supported the destruction, and/or have been mainly silent, so that the general public still do not know what is happening. Healthcare charities' rising costs were mentioned earlier, and many of these organisations rely heavily on funds from pharmaceutical companies, which see big profits in a privatised NHS. Knowingly or not, the charities collude with the destruction by their frequent highly publicised complaints. They highlight poor standards of NHS care, mistakes, neglect and patients being denied very expensive (often still experimental) drugs. They call for "reform", which is code for "privatisation". Yet the present problems, largely resulting from underfunding and a lack of staff time, training and support, will become far worse in the coming privatised systems.

Plans to close our local hospital in 2013, in a deprived area of London, evoked huge public protest. Over 22,000 local people of all ages marched with banners fixed to pushchairs or carried by children, including triplets, proclaiming, "I was born at Lewisham Hospital", "Lewisham Hospital saved my life!"[10] Later the people held an inquiry[11] and then won their case in the High Court. The government changed the law, to defeat them in an amendment passed by the unelected House of Lords (more than 170 of the lords work with private health services) (Molloy, 2013). At the inquiry day, doctors reported how they had built up recognised centres of excellence for the neonatal and children's units, for training doctors, for treating the high incidence of sickle cell, and for safeguarding children. Over 30,000 children per year attended the children's accident and emergency departments. Hospitals in neighbouring boroughs are already overwhelmed by too many patients, and are reached by awkward, slow journeys along London's crowded streets. The closure plan was not to preserve or improve good services, but to destroy them in order to raise funds to pay massive debts that were incurred at three neighbouring hospitals. Private funding initiatives involve health authorities having to overpay billions of pounds to private companies for building and running their hospitals (Pollock, Kondilis & Price, 2013).

This is a time of back to basics, a return to the need to begin to inform the public and campaign, as innovators did in the 1950s for family-centred care in hospital, in the 1960s for preschool play provision, in the 1970s for the closure of subnormality hospitals, and in the 1980s for higher standards of research ethics. Now, however, the survival of the NHS is the question, amid general ignorance and seeming indifference, unless individuals directly experience their lack of rights and services. Reforms to children's healthcare systems and policies will, it seems, always need innovators, partners, fundraisers, boat-rockers and protestors aiming to promote children's rights.

Notes

1. Gillick v. Wisbech & W. Norfolk AHA, [1985], 3All ER 432, the court ruling that children aged under 16 can give legally valid consent to medical treatment. In Lord Scarman's ruling, if the doctor believes that the child is able to make an informed decision that is a "wise choice in his or her own interests", the doctor need not also request parental consent.
2. Each year an estimated 74,000 children still die of TB (http://www.who.int/tb/challenges/children/en/) and nearly 1.4 million children aged under five years die of pneumonia, nearly one in five child deaths globally (http://unicefinnovation.org/challenges/pneumonia-leading-cause-child-deaths).
3. http://www.savethechildren.org.uk/news-and-comment/news/2013-09/dramatic-global-reduction-child-deaths-announced.
4. http://nahps.org.uk/index.php?page=history.
5. http://www.each-for-sick-children.org/each-charter/charter-and-un-convention.html.
6. http://www.awch.org.au/pdfs/Charter-Children-Young%20People-Healthcare-Au-version-FINAL-210911b-web.pdf.
7. www.nres.nhs.uk; www.arec.org.uk.
8. Often with subtle force against their parents' wishes.
9. http://www.nres.nhs.uk/about-the-national-research-ethics-service/development-of-the-research-ethics-service/.
10. http://www.standard.co.uk/news/health/25000-protesters-march-over-crazy-lewisham-hospital-ae-plans-8468135.html.
11. Lewisham People's Commission of Inquiry, 29 June 2013, 9.30–5.30, chaired by Michael Mansfield QC with Mary Warnock, and teams of barristers and expert witnesses.