

## **Life and death: agency and dependency in young children's health care**

This paper has two very different though linked parts. Complications in the tensions and connections between agency and dependency in the everyday lives of young children and their families are explored in part one. Part two considers further complications in relation to the ages when children can begin to share in making health care choices, and in relation to medico-legal cases in England and New Zealand when families disagree with doctors.

### **Opposition and conflict**

This section reviews a few of the many contradictions within concepts of agency and dependency. They are frequently seen as opposites. Active agency is associated with strong independence whereas dependency, literally meaning hanging on, is linked to passivity, helplessness and reliance on others. The reliance may be physical, intellectual, emotional and/or financial. 'Social' dependency may be a combination of these factors, with additional widely assumed and enforced structural dependencies.

One of many influential models of structural dependency is that of the active parent and the dependent child. Yet an infirm parent may depend heavily on a strong competent young child, although the dyad may be treated by social services staff as if the child wholly depends on the parent's agency. Dependency then arises not from the child's needs or limitations or lack of agency, but rather from structural traditions and assumptions. .

Although personal agency is contrasted with social structures, structures determine, reflect and reinforce each person's position in society as agent or dependent (Bourdieu, 1993). People occupy conflicting positions such as when a 15 year old 'child' is an e-commerce tycoon. 'Status dependency' is ascribed to children generally because of their age regardless of their abilities or activities. Ascribed status dependency helps to protect immature, vulnerable children, but can restrict and conflict with children's agency, wishes and interests.

The more dependent people are, it is assumed, the less agency they have in being able to think, act and express themselves freely. Agency links to concepts of autonomy as being most fulfilled when the agent is free from relationships which could influence, pressure, or constrain agency, which is then seen as achieved when, for example, young people grow towards independence (Erikson, 1965). It is often assumed that the more agency, freedom and power one person has in a relationship, the fewer freedoms the other more dependent person can enjoy. There is also a negative view of dependency as a double oppression, such as when a child's dependence burdens the mother, constraining the agency of both people and their opportunities to live their 'own life', or have 'free time'.

Numerous examples illustrate the above assumptions about the potential harms and constraints of dependency. Dependents risk being exploited and abused, as well as confined and restrained. In contrast, the rights associated with agency are highly valued, such as freedom of speech and expression, freedom of information, of thought and conscience, of peaceful association and assembly, of respect for each person's worth and dignity, of the right to express their views in matters which affect them, and to have these views taken into account (UN 1989). Dependents may be unable to enjoy these freedoms, whether through their own incapacity or an ascribed or enforced dependency.

## Convergence and relationship

This section considers realistic ways to link agency and dependency. It is said that when two lovers are together there is always a third presence: love itself, with its mystery, poetry and power. Love colours all the interactions between the two so that they see depths in their conversations which might appear banal to other people. This notion of the third presence helps to illuminate agency and dependency, which are often discussed as if they are mainly characteristics within and integral to individual people, albeit partly varying with age and context. This section considers how agency and dependency are partly extrinsic to individuals and inhere instead in the relationship between them, which is like a third presence influencing their interactions. People also combine agency and dependency. Sometimes, the greater their dependency the greater their agency, as shown in the following examples (provided by my family and friends whose names have been changed) about health care of children's bodies and well-being.

Melanie (aged 24 months) finds a ball and runs to James.

James (aged 25 months): Oh ball, bat, bat, tennis.

He finds two bats, gives one to Melanie and tries to bat the ball to her.

James's aunt: Have a balloon, let's find a balloon.

They find two balloons, and his aunt throws them towards James and Melanie who bat them back skilfully, whereas they were unable to return the smaller and faster balls.

By organising their play, the adult appeared to increase the children's dependency. Yet she also increased their agency by adapting their game to suit their skill. The children went to a gym club where babies aged from six months delighted in extending their agency through the numerous skills they exercised in action songs and games and on the apparatus. The adults might seem subservient, in their maternal holding back as much as possible (Ruddick, 1990) while babies risked new skills, or when mothers gently helped them to crawl, climb, jump and balance. Everyone seemed to be willing agents in the shared enjoyment and aim of increasing the young children's agency, thus resolving exaggerated contradictions between agency as being an overly autonomous liberated end in oneself, versus dependency as being the means towards someone else's ends. Meanwhile, 8 week old May was enjoying the babies' 90 minute massage session. The session was long enough to enable the mothers to follow the babies' preferred pace, at any one time, nine of the ten babies might be resting or feeding. The mothers were encouraged to sense and follow the babies' wishes about when, where and how they were massaged. Babies pace their interactions from birth (Murray and Andrews, 2000).

Agency also links to imagination, innovation and initiative, as shown when James picked up and extended suggestions. Later back at home, he sat on a sofa behind his aunt and tried to push her off, holding a back and orange jersey and making grunting noises.

James: Uuugh, uughh.

Aunt: That looks like a tiger. Grrrr.

James: Grrrrrr, grrrrrr.

He pushes her with the jersey.

Aunt: Help, help a horrible tiger is eating me up.

James makes loud sucking and biting noises, dabbing with the jersey.

A common form of agency is to exert power over others.

James held two cars.

Aunt: James, show me your cars.

James: (pause) No.

Aunt: Oh please let me see them.

James. (pause) No.

A longer pause. James puts on a macho frown and squares his shoulders.

He looks round to see who is watching, then walks over, gives the cars to his aunt and smiles.

In many ways very dependent, James, who called himself Bubby, orchestrated the interactions with the watching group around him. He showed his agency in his words, body language, timing, emphasis on ownership of his cars, his decisions about dissenting or consenting to requests and, perhaps most of all, his absorbed attention to relationships and to creating dramatic mood changes. At times, James appeared to be in control through his superior strength. He enjoyed holding out clothes pegs shaped like sharks at arms length, and chasing his grandmother (aged 80) round the garden. She considered that James could run faster and push and pull harder than she could. Power is also exerted through methods such as persuasion.

James's cousins are eating crisps

James runs around: Bubby crisps too, Bubby crisps.

Cousins: Go and get a packet.

James puts on a dejected neglected look, hangs his head and goes to the kitchen saying pleadingly: Bubby crisps too.

He soon returns with a packet.

Other observers have noted how young children are at least as fascinated by relationships as by objects during their play (Saunders and Freeman, 1998). Yet adults often assume that manipulating objects is the children's primary concern, and assume see agency as skilful doing, rather than being and relating which are as important.

Adults' definitions of appropriate toys, which often have limited pre-set functions, can limit children's imaginative agency. However, when James spilt a bag of lentils, instead of being punished for clumsiness he spent a happy morning playing with lentils on the kitchen floor.

The gym club children were intrigued by agency and dependency in the forms of power and resistance. Their favourite song was 'Three bad monkeys jumping on the bed, one fell off and hurt his head, called for the doctor, doctor said, "No more monkeys jumping on the bed".'

They sang the final line emphatically, wagging an authoritative medical finger while continuing to jump vigorously, as if they relished simultaneously asserting or mimicking authority and rebelling against it.

Melanie showed further connections and contradictions between dependency and agency when she refused to use the gym apparatus and ran around, tripping over and crying loudly. Later, she screamed while two adults ineffectively tried to put her coat on her. Seemingly the most dependent member of the trio, Melanie was also the most active and controlling, although her visible strength was framed by structures of dependency and helplessness in her limited status and abilities as a young child. Paradoxically, the adults who let James share in deciding when to wear a coat avoided these battles; by seemingly dependent patience and even subservience, and by sharing power, they retained greater control and evoked less resistance, through respecting his agency, than by confronting and trying to overrule him.

Lukes (1974) identified the most overt power, such as Melanie's struggle with the coat, as the weakest form because people can contest power which they are conscious of. The second less visible level of power, such as withholding information, and the third level which becomes internalised as the person's own values, are far more coercive, because people are unaware of its pressures in numerous everyday structures.

One example is the seldom questioned predominance of car drivers, which limits children's freedom to walk and run, or to meet friends, and threatens their health through pollution and accidents. Debates about traffic are deeply trapped into assumptions about adults' rights and children's helpless dependence, as illustrated by a typical news report about a 7-year-old boy on a scooter who was killed in a collision with a taxi (Siedlecka, 2000). The driver's and the child's agency were not mentioned. The accident was entirely blamed on the adults who allowed the child to ride a scooter and called for scooters to be banned.

Debates about children's risks and rights seldom progress far when they founder on these underlying structural beliefs about childhood dependence on adult agency. The beliefs are taken as rock-hard unalterable facts, intrinsic to childhood, instead of being recognised as tenuous assumptions which vary widely between societies. These assumptions have to be the main topic of debate instead of its basis if children's rights are to be considered seriously.

Evidence of agency and dependency fades when agents and dependents share numerous activities (proposing, persuading), and intentions (to control, influence, gain advantage) and when dependency is expressed through dependents' own agency (compliance, resistance). The overlaps illustrate the shifting extrinsic nature of dependency and agency, especially when parents and children share in nurturing children's growing independence through complex give-and-take. Parents' emotional reliance on their child is shown, for example, by their anguish if their child dies. Some agents depend on the power and convenience of having dependents around them; conversely, dependents may have the greater knowledge and subtle control over the relationship.

Family relationships are better understood as interdependent, and the children demonstrated the care and concern integral to interdependency in numerous attitudes and activities.

James accidentally crushed a snail and repeatedly said sadly: Bubby trod on snail.

Aunt: Let's go to the big ponds with the fishing nets.

James: Yes, yes, fishing rods.

Aunt: We'll put the fish and the little bugs in jars to look at them.

Susan (aged 8, with the ecological concern of her generation): And then we'll put them back in the ponds, not bring them home.

This first section has described something of the complex inter-agency and inter-dependency within families when young children are co-agents in care. Agency and dependency are not fixed, one-sided attributes, intrinsic to certain individuals or age groups, or even to certain behaviours and interactions. Like a third presence, notions and structures of dependency varyingly influence adults' responsibility and children's compliance or resistance. However, agency is especially identified with making decisions, and the second section considers when children begin to be able to do this.

## Sharing health care decisions

Among the most complex and serious decisions are those concerning major medical treatment. Children and their parents and doctors usually all agree on the preferred treatment option, although children's active consent may be mistaken for dependent compliance. Occasionally the child and adults disagree. Agency then stands out as the courage to make and stand by an unpopular decision. There are four levels in decision-making (Alderson and Montgomery, 1996): 1) to be informed; 2) to express an informed view; 3) to have that view taken into account when decisions are made; 4) to be the main decision maker. The fourth level includes signifying the decision, acting on it and taking responsibility for it whatever the outcome. It is often argued that children cannot and should not make major decisions, for reasons linked to the levels listed above: 1) they cannot understand the relevant information; 2) they cannot evaluate information in the light of lasting personal values; 3) they cannot know their own best interests, so that adult agents must act for them; 4) if things go wrong, children do not yet have the courage and resolve to stand by a decision, and they need to blame other people instead of enduring risking guilt and blame themselves. All these arguments were used by doctors in the past to protect adult patients.

The UN Convention on the Rights of the Child recognises the first three levels as rights without any age barrier (articles 12 and 13). Children have the right to all kinds of useful information, and account should be taken of children's views as soon as they are old enough to form and express them. Information includes knowledge passed on from other people, and knowledge children gain through their own bodily feelings and experiences. From birth, healthy babies express their views in knowing how to establish breast feeding, which is most likely to succeed when the mother trusts the most active partner's views on the timing and pace of feeds. Toddlers share in feeding, dressing and washing themselves. Some 2-year-olds are able to make complex decisions about their health care, such as actively cooperating with taking unpleasant cancer treatments (Kendrick et al, 1986), or physiotherapy and diet to treat their cystic fibrosis. Children aged 4-years with diabetes can share in administering daily blood tests and insulin injections, and in managing their diet to control blood sugar levels, which requires the

child's informed commitment, such as refusing the sweet foods which their friends enjoy.

The fourth level, to be the main decider about proposed treatment if the child is both able and willing to do so, is not covered in the UN Convention, but is part of English and New Zealand law following the 1985 Gillick case. New Zealand law extends further respect for patients' informed consent in its legal Code of Health and Disability Services Consumer Rights 1996 (Wood and Tuohy, 2000). In England, the 1998 Human Rights Act, recent medical scandals, the uncertainty (shared with New Zealand) about the law on minors' consent, and a new medical code of good practice on consent to treatment for minors (BMA, 2000) all exert pressures towards greater formal respect for children's informed consent.

The Gillick case allows that children aged under 16 years can give legally valid consent, when in the view of the doctor treating them they can understand the relevant information and have the discretion to make a wise choice in their own interests. The judges did not state an age when children become agents rather than dependents in medical decision making. Research with 120 people aged 8 to 16 years having elective major surgery asked the age when they, their parents and hospital staff caring for them considered that they were or would become competent to 'be the main decider' when surgeons propose to operate. On average the young patients had already had four to five operations and most had serious long-term conditions. The replies covered a wide range of ages (Alderson, 1993). One surgeon thought 'never' whereas some adults and children gave ages such as 6 or 8 years. Much depended on the child, the family, the condition and the beliefs of each interviewee. Most of the children wanted to share decision making with their doctors and parents, a minority (not age-related) wanted others to decide for them or else to be 'the main decider' about proposed surgery. Nurses said that after years of working with children they respected them at younger ages. Children's understanding appeared to depend far more on their experience than their age.

### **Refusing treatment**

Competence is assessed much more seriously when people refuse treatment, especially

when life is threatened. These are like high water mark cases, rising above the tide that washes confusingly over children's and parents' everyday interdependency, and exposing each person's separate agency. These serious cases may seem unrelated to earlier minor matters of gym clubs, but they are linked by the common theme of parents' and children's inter-dependency which goes beyond words into shared intuitive knowledge, emotions and bodily feelings.

Most cases of withholding or withdrawing treatment intended to sustain a child's life occur with very young babies who have no say, although some people believe that much depends on the baby's apparent wish 'to go on fighting' or 'to give up' (Alderson, 1990). There is concern that parents give consent to continuing painful treatment, such as repeated chemotherapy or organ transplantation, which many adults would refuse for themselves. Probably, in many cases which do not go to court, adults gradually accept the child's wish to stop treatment, such as when 6-year-old Samantha refused a third liver transplant and died a few days later (Irwin, 1996).

John Caldwell (2000) compared legal cases in England and New Zealand when parents and doctors disagreed over the care of sick children. He wrote that if parents are distressed by a legal decision, they may be less able to care for their child during treatment, thus compounding the emotional suffering of the child, perhaps to the extent of 'rendering a treatment order contrary to the child's best interests.' The courts should take account of parents' potential shock or grief, the extra support needed by the child, and the added tensions of supporting children through major treatment during a 'failure of unity between doctors and parents'.

### **Recognising parent-child interdependency**

The final part of this paper suggests that legal public values and somewhat masculine concepts of independent agency differ from families' personal interdependency. Significantly, the senior judge in the re T case whom Caldwell quoted as considering his list of problems was, very unusually in England, a woman (Butler Sloss, 1997). Also, as far as I know, the re T case is the only reported English case which supported the parents' view; they refused a liver transplant for their young son. Judges usually rely on medical witnesses and not the 'lay' views of parents or children. T's parents, however, were exceptional in being seen as experts because they were intensive care nurses - from New Zealand.

Recent English cases show the extent to which judges overrule parents or children. During the summer of 1999, for example, they authorized doctors: 1) to proceed with a heart transplant before the 15 year old patient was ready to consent (Dyer, 1999a); 2) to withhold resuscitation treatment, should it be necessary, from 10 year old David Glass whose family stood by to resuscitate him in the hospital (Dyer, 1999b); and 3) to refuse to refer Katie Atkinson, aged 9, to be assessed for a possible heart transplantation. (David and Katie

have learning difficulties.)

For the conjoined twins (Jodie and Mary, 2000), the parents refused to consent to surgery to separate the twins which would kill Mary although, without surgery, in time both twins would die. The judges stated that whereas doctors cannot disregard parents' refusal, 'overriding control is vested in the court,' and to leave the parents to decide 'would be a total abdication of the duty which is imposed upon us.' One judge added, 'I cannot flinch from undertaking that evaluation, horrendously difficult though it is.' They all spoke of having truly agonised over this tragedy, and the judge who was also the father of identical twin daughters said that his heart bled for the parents. Genuinely moved though the judges were, the more they expressed their emotions and respectful listening to the parents, instead of concentrating entirely on cerebral legal matters, the more they claimed comprehensive expertise in their authority to overrule the parents' views. Yet what did the judges learn from their pity and empathy? They claimed to know the children's best interests, but how did they gain this knowledge, and what made them more expert than the parents? Repeatedly, judges evince outdated views about children (Henaghan and Tapp, 2000).

The twins case moves English law forward in permitting 'sacrificial' surgery which kills one person to benefit another. The judges emphasised that the case is too exceptional to set a precedent, and any similar cases will each require separate judgements. Yet court cases are extrapolated in numerous unforeseen ways which profoundly influence society, as the Gillick case illustrated. The judges ignored the links between this step forward and the current adversarial ethos, of seeing individuals as competing, threatening, exploiting or infringing one another's agency, which dominates Anglo-American medical law and ethics. Defensive individualism was implied when the judges contrasted their judicial weighing of the girls' interests against one another in the scales of justice, with The judges contrasted their own duty to be decisive, with the parents' dependent faith in God's will and mercy, saying that the parents could not consent 'because their girls are equal in their eyes and in their love.' It is invidious to think that a child's life should depend on the parents' word, and yet it is realistic and moral, when parents are intensely thinking and feeling for and with their children about the dilemma which has no clear medical solution, and when their children depend on their support through whatever happens.

The Judges' imperative to act differs from the 'holding' maternal agency described earlier, in two main trends. Judges deny the equal worth and rights to treatment of children with learning difficulties which the families value. And judges treat consent as an event, a somewhat passive, rapid response to medical agency. Consent is also a process as the patient-agent journeys from fearful rejection towards hopeful acceptance and courageous resolve. The courts' authorisation of treatment may speed up this acceptance, sometimes in time to save life. Yet judges under-estimate the invisible power, the third presence in health and healing, of the complex interdependencies of risk and trust within families and between patients and health practitioners. In many court cases, perhaps in the twins' case, children need to be defended against their parents' decisions. Yet in order to understand children's best interests, it is necessary to learn from their views, their bodily responses to illness and treatment, and their intuitive knowledge and agency as far as possible.

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