Alderson, P. (2010) Younger children's individual participation in matters that affect them, In Percy-Smith B, Thomas N. (eds) *Handbook of Children's Participation*. London: Routledge, 88-96.

Studies of children's participation frequently look at their shared activities in groups when children comment or make decisions about adult-led policies and services (as other chapters in this book illustrate). However, people may demonstrate and exercise their competence more fully in their individual personal life and relationships, when they are agents and contributors rather than service users or members of formal groups.

Individual child-adult participation can also offer greater scope for sustained, original, deep conversations than groups can, as differences between research interviews and focus groups usually show. Transcripts of 4-year-old girls' conversations vividly reveal how much more rich and complicated their talk is with their mothers in private everyday life at home, than in the more formal public space of pre-school services (Tizard and Hughes 1984). As agents, young children may alter relationships, decisions and the working of social assumptions or constraints (Mayall, 2002:21). The CRC speaks of the rights of 'all members of the human family' and understanding of children's aware consciousness obliges adults to value their views and participation and their present life now, besides their potential and future. This chapter therefore concentrates on individual two-way participation.

From the start, children appear to be intensely concerned with the quality of relationships and trust. I will give an example later of premature babies' responses to certain adults. I do not want to over-individualise participation; collective political engagement is vital. And yet strong groups recognise and respect every individual member, and this chapter considers the personal beginnings that can lay foundations for later political engagement, as well as showing that participation and rights involve personal agency and relationships set in families and communities.

In terms of Article 12 of the CRC, when does a child become 'capable of forming his or her own views', and so having 'the right to express those views freely in all matters affecting the child'? At what stage do adults give 'due weight' to children's views 'in accordance with the age and maturity of the child'? The CRC allows for national laws which 'are more conducive to the realization of the rights of the child' (Article 41). Case law in England and Wales arguably goes beyond Article 12 in allowing 'competent' children to be sole decision makers (note to delete some argue it is widely transferable), without a stated lower age bar (Gillick 1985).

'All matters affecting the child' may include the continuing complexities of everyday life, frequent informal choice making, formal decision making (more rare, but a usual topic in participation literature) and the innumerable concealed prior 'decisions' now set into habits and routines, customs and structures, which adults tend to assume but children often question or have to learn, such as how to stand in line at school (Waksler 1991).

This chapter aims to show how children's participation is broader and more varied, and begins at a younger age, than is usually acknowledged. The first section therefore reviews early informal participation at home. A second aim is to suggest that what

passes for formal 'participation' when groups of children are consulted is more often concerned with provision and protection than genuine participation, and so the second part of the chapter reviews these competing emphases in the context of public services.

Early participation at home

Participation begins in the less observed private world of the family. This section offers a few examples of children's early and often under-estimated participation. Widespread violence, abuse and neglect at home warn against taking idealised views of the family. However, children generally report having more respect and choice, free time and space at home away from the demands of formal care and education. Mayall (2002, 2007) reviews how parents tend to respect their very young children as individual persons, competent inter-actors and interesting, supportive and amusing companions. Parent-child relationships are complex intellectually and morally, and can involve the personal respect that children most value. Mayall considers this is because of the wide range of shared activities, experiences and responsibilities, shared events and relationships, shared social and cultural worlds including television, which they discuss, narrate and interpret together. Parents and siblings have time to listen to young children and to understand and encourage their earliest communication. Very young children can take part in family dramas as actor, victim and observer, and can understand different viewpoints (Dunn 2004). Family life mainly inhabits the present, which can connect to Kantian respect for children as ends in themselves, in contrast to instrumental future-orientated child-professional relationships, when children may be the means towards the ends of the school, service or government. In many homes, the aims, topics, methods, processes, values and outcomes of participation within child-parent and sibling relationships are framed around respect for children's agency.

Although many majority world parents may be stricter and *talk* less about autonomy, they may *allow* much more autonomous activity (Katz 2004; Penn 2004). Children aged five years may have far more freedom over their time, space, friendships and activities, when herding goats all day, than wealthy minority world children are allowed. Child workers who contribute in cash or kind to their family can have higher status than wholly dependent richer children. Poverty may force parents to respect their child's independence and autonomy, as when mothers in Peru agree that their young children will earn and learn more by working their own business than by helping with their mother's business (Invernizzi 2008).

Research reports tend to analyse brief extracts from transcripts, which can misleadingly imply that young children cannot engage in the kind of sustained talk shown in the next example. When aged 40 months, Robbie told me this story in the park (quoted with permission).

> There was a Baby and the Baby said, 'I don't want to go to school.' And the Mummy said, 'You've got to go.' And the Mummy took the Baby to school…and the Baby do reading…But the Baby said, 'I want to go to London.' And they went to London and the Baby runned away home and the Mummy said, 'Don't run away', and took him home. And the Mummy cooked the dinner, and the Baby said, 'I want pasta,' and the Baby wouldn't eat dinner

> [more details] and then the Mummy came to get the Baby and put him in a bin and the Baby cried, 'Waah, waah', and then the Baby died.

Robbie went on with a story about a little boy who

> weared all these clothes in bed…and ate all his porridge up in bed [gobble noises] and he ate everything – all the windows, the glass, and then all people's hair, and then the sky, and then his house, and he was this BIG [shows with finger and thumb] yum, yum, yum, yum, the things went down into his body and into his tummy and then kerching and kerching, waah, waah, and then he died and dropped dead. He was sick from his eating. Then the doctor made him better again.

The boy ate more surreal items including birds, his own eyes and mouth, and the book in which I was recording the story. Robbie illustrated a range of participation *activities* – conversing, communicating, story telling, entertaining, imagining, playing with plausible and implausible ideas, making connections, meanings and sense, mixing his own experiences with fantasy and notions from films and stories. There is also participation within his deeply loving parent-child *relationships* of care and conflict, freedom and control, adventure, danger and protection, rule making and breaking, power and resistance, and continuous healthcare.

In neonatal units, where the private family world combines with public health services, we observed premature babies react with excitement to their parents' voices, in preference to other adults' voices. Parents and staff noted how babies appeared to prefer and relax with and 'trust' some adults and to be wary and tense with other adults (Alderson et al. 2005). Als (1999) writes of premature babies' 'autonomy'; influenced by her work, a few neonatal units have 'baby-led' policies, with low lighting and noise, and attention to 'reading' each baby's 'language'.

Babies take part in 'cultural life and the arts' when they are first wrapped or clothed, hear a lullaby and their family language, and smell food cooking. Breastfeeding depends on the baby's expressed 'views' about setting the pace and timing and the 'demand' that builds up the supply. By proxy, babies enjoy their parents' rights to freedom of association and peaceful assembly, to information, thought, conscience and religion, and they suffer if these rights are denied through family poverty or persecution. Young children soon learn when they are cold enough to need a coat and tend to assert their autonomy and dignity through strenuous resistance to being strapped into a pushchair without warning or negotiation. At two years, Robbie refused to use his bike brakes, until his parents showed him exactly how and why they worked.

Many child patients have long-term conditions with repeated health care treatments, so they make chains of countless informal decisions, based on their former experiences and growing understanding. Children with serious conditions, such as diabetes, learn early responsibility. At three years, Maisie warned her mother when she was feeling hypo (shaky from low blood sugar). At four years, Ruby could be trusted not to eat chocolates when her friend did and no adults were nearby, and by five she could test her blood sugar level and decide how much cake she could eat at a birthday party (Alderson et al. 2006).

Participation rights in formal services and welfare: provision and protection.

Disappointingly, participation projects rarely lead on to real change and action (Willow *et al.* 2004). This chapter reviews how, and possibly why, children's formal 'participation' is mainly about adults protecting and providing for them rather than working for change.

For example, staff and researchers in education, play, community, youth and childcare services might say to children: 'I am going to consult you as a group so that the expert adults can know how to provide better services or policies for you. You will learn about cooperating, listening, speaking, sharing, collecting and discussing different views and choices, and about democracy, citizenship and social inclusion. You will gain new skills, self-esteem and consideration for others.' The main aims are to teach children, to improve their trust, compliance and involvement, and to provide better services. However, adults are primarily accountable to systems that manage, evaluate and fund the services, not to the children. The aims, topics, methods, processes, values and outcomes, child-adult relationships and 'participation' itself are all framed around provision and the smooth running of cost-effective services, which discourages disruption and change that may follow genuine consultation. Fielding (2008) criticises the aims of 'effectiveness' based policies and considers they displace person-centred participation. When participation primarily means 'sharing', children are encouraged to share rather than challenge group consensus and decisions.

In child protection, the literature implies that social workers will say, or think: 'I will listen to the child as part of supportive, semi-therapeutic, expert practice, to learn about the child's problems and ways I can help. I must balance my decisions about the child's best interests with those of other family members and within available resources. I will give information and support in order to help the child to trust me and accept my decision as effortlessly as possible. This may mean avoiding painful areas where I may not be able to help, to save the child (and myself) from unnecessary distress and false hopes. I may need to hold back some information and over-emphasise certain hopes or dangers to persuade the child and parents to comply. Child development research proves that it is not worthwhile to discuss much with children aged under 8 years' (paraphrased from Winter 2006 and in progress).

Here, the main aims include protecting the child's safety and welfare. The social worker is ultimately accountable, not to the child, but to line managers, the courts and the public, while balancing costly over-intrusion into family life against the risk of failing to prevent fatal injury to the child. The aims, topics, methods, processes, values and outcomes, child-adult relationships and 'participation' itself are framed around protection of the child, the practitioner and society. Growing tiers of management and inspection allow less autonomy to professionals and thereby restrict the children they work with even more.

The above can all be valuable activities, in which children take part at various levels. However, the examples, like cut flowers in a vase, are detached from the roots of 'participation', its origins, meaning and purpose, context and grounding, so that the participation literature mainly describes the equivalent of the varieties of flowers, vases, arrangements and settings but not the root and growth of participation.

The background to participation: autonomy and freedom rights

UNCRC participation rights originated in adults' autonomy rights, exemplified in the European Convention on Human Rights but reaching back to Locke and Paine : freedom of information and expression, thought, conscience and religion, association and peaceful assembly; rights to life and survival, to privacy and family life, to a legal identity, to cultural life and the arts, and due legal process; freedom from discrimination, violence, torture, cruel or degrading treatment, exploitation, and arbitrary punishment, arrest, detention or interference. The whole UNCRC is imbued with respect for the child's person, worth and dignity, and concerned with the social, economic and political means of promoting these within a 'free society'.

There is not space here to respond to the main objections to children having autonomy rights (Guggenheim 2005). Such objections echo centuries of debate when powerful groups resisted the assertion of their rights by commoners, ethnic minorities, women and others. Autonomy rights are essential defences against violent oppression, inequality, injustice and abuse of power. These politics may seem far too extreme to apply to child-adult relationships. It may appear obvious that adults are children's best and most loving providers and protectors; and yet each year countless young children suffer and die through violations of their human rights (UNICEF 2008). Besides love and care, conflict, power and risk are central to human relationships, as even very young children know.

Paradox is at the heart of autonomy rights, which break down and also build up barriers: the individual is freely integrated into society and community but also distinct from it, with strong non-interference rights over person, property and privacy. The common thread is the belief that each person is best placed to make informed personal decisions without interference, in public civic life and also in private life, although many people want to share their decision making with others. Pure Kantian autonomy rights are not advanced here as totally realisable or desirable. All rights are qualified by respect for others and for common interests, while relationships involve interdependence and intimacy. Yet if the term 'participation' implies only community, harmony and unity, it sidelines the vital counterpart of autonomy that is necessary when interests conflict. and the ultimate defence of privacy, along with the crucial freedom to choose whether, when and how to participate. Autonomy rights enshrine equal respect for the worth and dignity of every person, for her unique and essential knowledge about her own best interests, and for defence of her inviolable physical and mental integrity against assault.

Participation rights and autonomy in formal services and welfare: medical decisions

One type of child participation uniquely illustrates autonomy: medical and surgical decision-making. Unlike the professionals discussed earlier, doctors in effect say to the child and/or parents: 'This is the intervention I recommend to treat this problem. Treatment involves these hoped-for benefits, these methods and processes, risks and discomforts, and these alternatives. I must warn you of all the potential difficulties,

and not put any pressure on you, so that you can give your informed, voluntary, autonomous consent, or refusal'.

The aims, topics, methods, processes, values and outcomes, child-adult relationships and 'participation' itself are all organised around the patient's and/or parent's autonomy, qualified by concern for the child's 'best interests'. Why and how is this approach so different from the two earlier examples? The emphasis is on truth about risk, caution about benefit, respect for physical integrity, deference to the patient's and/or parents' decision, and concern with direct intended outcomes, but not with ulterior learning and benefits for the child. Trust is based on honesty not on protective paternalism. The medical decisions also affect not groups with mixed interests but one *individual* child most directly (and potentially dangerously).
whereas groups can have conflicting interests.

Frequently, the child knows most about the bodily problems, the needs and benefits of treatment, the risks and costs. A study of 120 experienced children aged 8-15 years having repeated major surgery found that 13 of them were the 'main decision-makers', in the view of the child and parents (Alderson 1993:164) and some surgeons respected children's preferences from around 8 years. With non-emergency surgery, practitioners have time to recognise and enhance children's informed decision making. If children were reluctant to have surgery, there were usually great efforts to inform and involve them, sort out misunderstandings, negotiate, and avoid imposing a decision on a fearful resisting child.

Practical medico-legal concerns have developed most of the research, law and guidance on children's competence and consent. Child patients share the status and long history of adult patients, including the trials about Nazi medical experiments, which produced the definitive statement on autonomous voluntary consent: 'Free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or any ulterior form of constraint or coercion' and sufficient information to be able to make 'an understanding and enlightened decision' (Nuremberg 1947). Human rights gradually emerged through resistance against oppression; patients' autonomy rights developed in reaction to scandals about abusive research and treatment (Beauchamp and Childress 2001; Alderson and Morrow 2004:25-34).

Unlike the other professionals above, health care practitioners cannot simply overrule the family if there is disagreement. Also uniquely, healthcare professionals are ultimately accountable to the courts and the public, not for making a correct decision themselves, but for ensuring that they enabled the patient/parent to make an informed voluntary decision. The doctor cannot claim that the child or parents were all incompetent to decide, whereas teachers and social workers may validate their decisions by presenting parents as incompetent. The doctor, however, who acted without consent would be tried for negligence or assault. Consent transfers responsibility for risk from the doctor on to the patient, and doctors have gradually accepted that codes of ethics and consent protect not only patients, but also doctors, researchers and high standards of treatment and research. Doctors accept that they can do immense harm as well as good, whereas other professionals tend not to acknowledge this - another possible reason why they favour managing 'participation' over respecting autonomy.

Learning from children about rights: some conclusions.

Human rights are not simply abstract theories. As even babies show, rights inhere in inalienable, practical, embodied human experiences and relationships, freely expressed through bodies, and often denied by confining or punishing bodies. The child who is, and is in, the body concerned may have unique and essential knowledge about human rights and participation generally (Alderson 2008).

The director of a children's rights centre involving disadvantaged 'school rejects' thought that they had such deep, broad, generic understanding of rights, 'Because they know what it means when your rights are denied'. Children's active participation covers innumerable experiences, activities and relationships, the 'all matters' in Article 12. It ranges far beyond formal adult-led consultations, from explicit choices and decisions into challenges to the innumerable concealed and assumed prior 'decisions' now set into routines, structures and interests that affect children, as mentioned earlier. Hence the importance of respect for everyone's integral autonomy rights, when even premature babies' 'views' can inform policies in neonatal units to promote their health and welfare.

Fielding (2008: 59) warns against the dominant, instrumental, impersonal, market model of education and participation, divorced from personal relationships, meaning, narrative, community and history, and he speaks of its 'deep dishonesty'. Fielding's 'person-centred' learning communities and services enable children to take part at higher levels of agency, beyond manipulation and tokenism (Hart 1992). Often unintentionally, however, participation projects with children may promise respect, listening and future changes, which cannot be achieved. To guard against this, adults need to be wary about the aims and sponsorship, the political and economic context of each project. Is it possible to achieve real participation within short-term relationships and working contracts? Might the consulting adults be used and abused as much as the children during a pretence of participation within rigid hierarchical contexts? How often is the hidden agenda during consultation a determination to improve the children but not the service?

These few examples illustrate young children's early capacities to form and express views freely, adults giving 'due weight' to children's views, . and the higher level of Gillick competence to weigh choices and make formal decisions, which is being increasingly recognised and respected in young children. Obviously the youngest children cannot form and express complex legally valid decisions, but I suggest that this competence does not involve a Piagetian step up to a new and different stage of life, but exists on a continuum from birth, while young children gradually acquire the language to analyse, reason and express complex experiences and decisions.

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P6 paraphrased from Winter 2006 and in progress).
UNCRC or CRC