

Forever a child: analysis of the Ashley case

Abstract

Concerned for her future, the care-givers of a profoundly disabled girl (Ashley) consented to her having growth attenuation using high dose oestrogen, a hysterectomy and breast bud removal. Parents of other children with similar disabilities have requested similar treatment for their children. In this article relevant developmental issues are explored with discussion of child protection measures and ethical concerns around children with profound physical and cognitive limitations like Ashley. Open discussion of all possible motivators and ethical concerns helps ensure robust decisions are reached. Children's nurses have an important role in acting as advocates for the child.

Louise Terry PhD,
PGCHE, LLB(Hons),
FIBMS, Senior Lecturer
in Law and Ethics,
London South Bank
University

Anne Campbell RN,
MSc, BA(Hons),
Dip Nurs, Lecturer,
Children's Nursing,
University of
Hertfordshire

Key words

- Children: development
- Children: disabilities
- Ethics
- Child protection

This article has been
subject to peer review.
To find related articles go
to the archive section of
www.paediatricnursing.co.uk

The issue of growth attenuation in children with profound developmental disability came to world attention following Gunther and Diekema's (2006) article in which they described what is now called 'the Ashley case'. According to the parents' website (<http://ashleytreatment.spaces.live.com/blog>) Ashley, now nine years old, failed to develop normal mental and motor abilities despite a normal pregnancy and birth. Other than static encephalopathy of unknown aetiology, no specific diagnosis exists. Ashley is unable to roll over, hold her head up, walk or hold toys; although she enjoys music and seems to have some sight she is unable to talk and rarely makes eye contact.

Ashley is cared for within the family home. All accounts recognise that she is much loved by her parents and two older siblings. Since the age of five Ashley has had a permanent gastrostomy tube. At six years old, precocious puberty commenced, with pubic hair, breast bud development and rapid growth. She was reaching the limits of her primary carers' (particularly her mother's and her two grandmothers') abilities to carry and move her. Fearing that eventually Ashley would become impossible to care for at home, the parents sought solutions. Following careful consideration by a full ethics committee, Seattle Children's Hospital agreed to carry out three treatments: growth attenuation using high-dose oestrogen; hysterectomy; and breast bud removal.

Gunther and Diekema (2006) make it clear that each treatment was considered separately in light of the benefits and burdens, although subsequently the parents' website and the world media have conflated them, referring simply to 'the Ashley treatment'. Growth attenuation using oestrogen without pre-treatment hysterectomy would lead to the onset of menses and the need for progesterone with an increased risk of deep vein thrombosis. Menses can

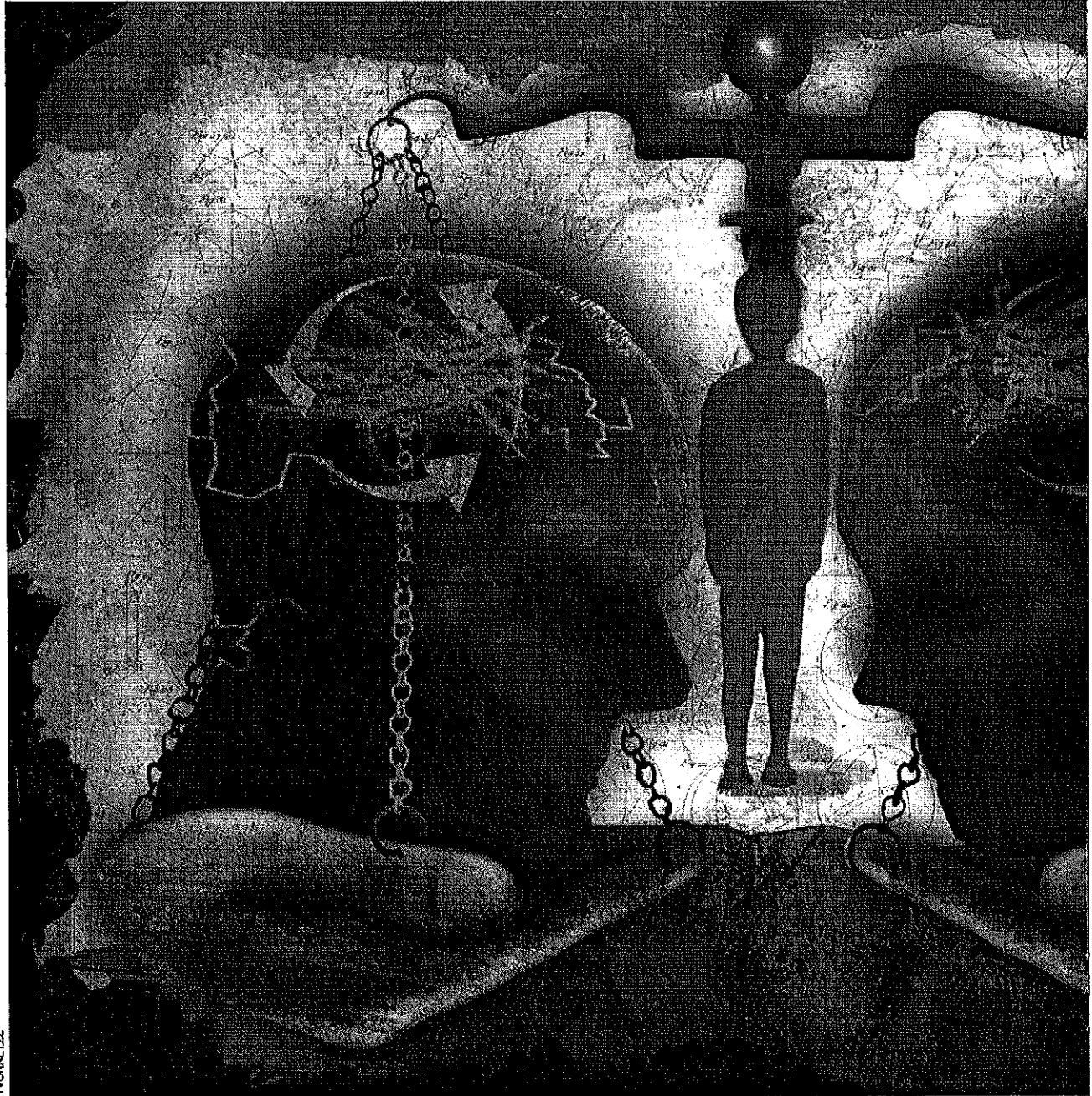
be uncomfortable (Ashley's family history includes painful periods). Pre-treatment hysterectomy meant oestrogen alone could be used. The family history of fibrocystic and very large breasts, along with the concern about large breasts reducing Ashley's chest expansion with an increased risk of chest infection, helped inform the discussion about breast bud removal. To sit up or be moved in a wheelchair requires the use of a chest strap which could be uncomfortable with large breasts; wearing a bra could distress Ashley who is upset by even a hair on her face and maintaining skin integrity under the breast could be difficult.

It later transpired that in Washington state judicial approval should have been obtained so Seattle Children's Hospital has implemented changes to ensure future compliance and the ethics committee will have a disability rights representative (Fisher 2006). Other children have similar disabilities to Ashley; some parents, including the mother of a 14-year-old British girl, have asked for similar treatment for their children (Thorpe 2007). This article explains relevant developmental issues prior to discussing child protection and the ethical issues relevant to children with profound physical and cognitive limitations like Ashley.

Developmental issues

Ashley's holistic development needs to be considered physically, cognitively and psychosocially. Physically, following treatment, it is expected that Ashley will reach a final height of four foot 5 inches tall and 75 pounds in weight (Gunther and Diekema 2006). This equates to the 50 percentile for a nine years six-month-old girl, and her weight on the 50 percentile at 75 pounds equates to that of a ten-year-old girl (<http://pediatrics.about.com/cs/growthcharts2/1/blgirltwo.htm>). This means that her anticipated height and weight should be in proportion. Using

ethics

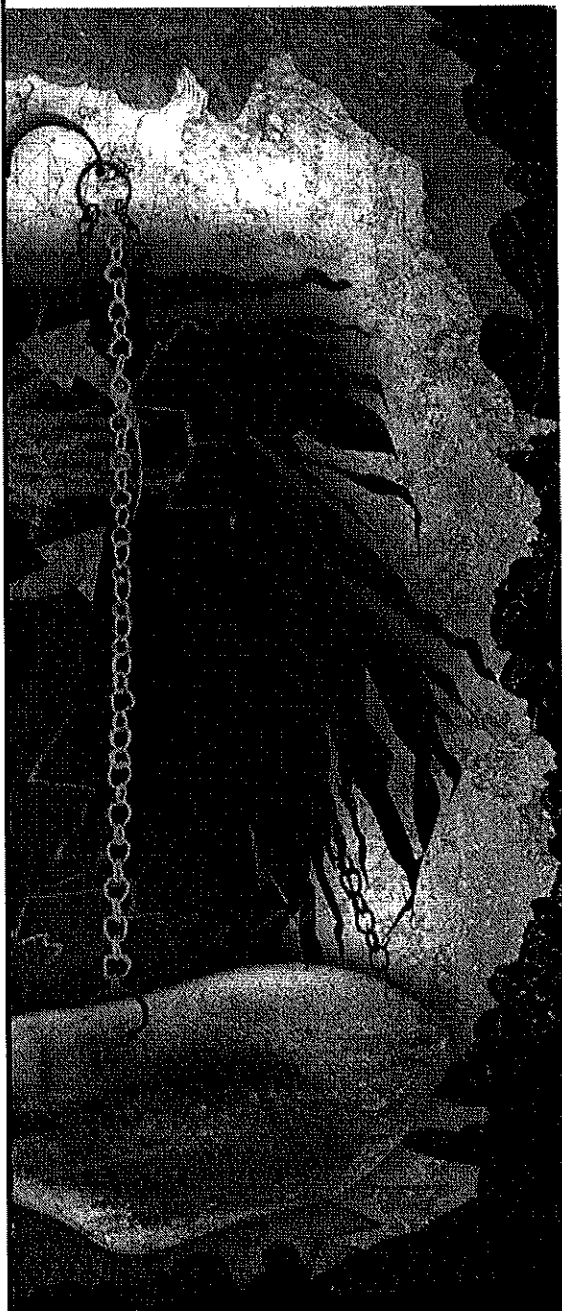


YVONNE LEE

'In both America and the UK, decisions about medical intervention must consider the best interests of the child; parents no longer have complete freedom'

the same chart, an average 18-year-old girl would weigh 125 pounds and be 5 feet and 5 inches in height. On-going physiotherapy will help maintain or improve gross and fine motor development.

Cognitively, Ashley could be judged using Piaget's sensori-motor substage (Piaget 1977). Her mental age was assessed at three months old with little prospect of improvement. She may be able to make interesting things happen with her body



eg thumb sucking and may also be able to tactually and partially visually, explore her immediate environment and people in it. Assessment of perceived cognitive ability should be viewed with caution in people unable to speak and she should be intermittently assessed to see if other forms of communication, for example, an alphabet board may reveal greater cognitive ability, as in the McDonald's case (2007). Ashley may lack the skills required to

undertake testing, so significantly disadvantaging her.

Psychologically and socially, attachment and bonding are crucial for a child whose mental age will probably remain at around three months. It is difficult to appreciate Ashley's view of the world or know if she can differentiate between her parents, siblings and grandparents but the presence of the pheromones secreted by family members may promote the bonding process as Ashley might recognise different but familiar individual smells, which may add to her sense of security and being loved. Ashley should experience fewer adolescent cyclical moods swings due to more consistent hormone levels. Maintaining a more even temperament should mean less emotional distress for both Ashley and her carers.

Child protection measures

In both America and the UK, decisions about medical intervention must consider the best interests of the child: parents no longer have complete freedom (Downie and Randall 1997). In the UK, to protect the child's rights, judicial scrutiny is a requirement when the treatment proposed is not clearly of therapeutic necessity or there is uncertainty over the determination of best interests. Individual cases are heard by a judge in the Family Division of the High Court. Appeals against decisions may go to the Appeal Court, with a further appeal possible to the House of Lords. As part of child protection, CAF/CASS (the Children and Family Court Advisory and Support Service) look after the interests of children in the family court system (<http://www.cafcass.gov.uk>).

CAF/CASS works with the child and family, trying to gain the child's views as well as the parents' and then advises the court on what it considers to be the child's best interests. Although many believe that loving parents should be the ones to decide, not judges, others believe such decisions should be made by doctors (Black 2007). However, doctors often disagree in such difficult cases (Brosco and Feudtner 2006).

In 2004, the UK government published *Every Child Matters: change for children*. This embraces the changes required by the Children Act 2004 such as, the duty of key agencies to safeguard and promote the welfare of children (HM Government 2004); health services are expected to deliver personalised care in line with the National Service Frameworks and the 25 aims within this (see Box 1).

Ethical analysis

Beauchamp and Childress (2001) hold that the ethical principles of autonomy (respect for bodily integrity and self-determination), beneficence (doing good), non-maleficence (avoiding harm) and justice (fairness) are central to medical treatment decisions. In cases such as Ashley's, medical intervention is chiefly being considered to resolve social care problems so a useful framework is the

Box 1

Aims from *Every Child Matters* (HM Government 2004)

Aims relevant to children with profound physical and cognitive disabilities include being:

- physically healthy
- mentally and emotionally healthy
- sexually healthy
- safe from maltreatment, neglect, violence and sexual exploitation
- safe from accidental injury and death
- safe from bullying and discrimination
- have security, stability and are cared for
- achieve personal and social development and enjoy recreation
- live in decent homes and sustainable communities
- have access to transport and material goods.

ethics

Clinical and Social Care Ethics Model designed by one of the authors of this article (LT) (Terry 2007). As set out below, this model modifies Jonsen *et al*'s (2006) well-validated model by incorporating social care factors. Decision-makers consider information relating to four categories: clinical and social care indicators; personal preferences; quality of life and contextual features, discussed as follows:

Clinical and social care indicators

Ashley's condition appears irreversible but her social care problems will increase. The model requires delineating actual and potential problems as accurately as possible and asks how do the social care and medical problems interact? This question has not been clearly articulated in discussions about Ashley. The model requires identifying the goals of treatment and care and likelihood of successfully meeting those goals and asks, 'In sum, how can this person be benefited by health and social care interventions and how can harm be avoided?' The main goals appear to be to ensure that Ashley can continue to be cared for by her family; any discomfort she might experience in future is minimised; and boredom avoided (<http://ashleytreatment.spaces.live.com/blog>).

Secondary goals include protection from abuse (including a potential risk of non-consensual sexual activity and pregnancy). Unarticulated goals include benefit to the parents in terms of making caring easier and reducing the institutionalisation of the home and the intrusiveness of having strangers often present.

Lobbyists argue that more assistance should be provided to enable disabled persons to remain in their family home: 'we hold as non-negotiable the principle that physical and personal autonomy of all people with disabilities be regarded as sacrosanct' (Disability Rights Education and Defence Fund 2007). However, they fail to acknowledge the burden that strangers and equipment place upon the family. In this respect, other family members have equal rights to privacy and family life. As Shannon and Savage, in support of the three treatments, argue most of the time 'families do the best they can and it is better than we, as professionals, could do', although sometimes professionals have to 'protect our patients in situations of abuse or neglect' (2007).

Limiting Ashley's size may be in her best interests, but Liao *et al* (2007) oppose hysterectomy and breast bud removal. These three male authors state: 'For starters, it is unclear how much discomfort women suffer from the menstrual cycle'; and suggest 'there are less invasive ways of avoiding pregnancy such as...contraceptive pills.' There is no discussion of difficulties anticipating or controlling menstrual pains or recognition of the inappropriateness of giving pills to someone with gag-reflex problems, nor that alternative injectable contraceptives have known side-effects of increased weight and bone fracture risk, even though the goal of Ashley's

treatment was to keep her weight and size manageable.

Personal preferences

The appropriate surrogate decision-maker needs to be identified if the person lacks capacity. However, the question of whether the surrogate has the necessary (US) legal power to make the treatment decision and whether appropriate standards of decision-making are being employed also have to be asked. In Ashley's case, the parents are decision-makers but, unrecognised at the time, lacked the necessary legal authority to consent to this treatment.

Ashley has limited ability to express preferences so most of the questions in the model are inapplicable. Discomfort is expressed through crying and she waves her hands to music she enjoys (<http://ashleytreatment.spaces.live.com/blog>). The interpretation of her needs as being to reduce discomfort and alleviate boredom seem accurate representations of her preferences. If Ashley had to be institutionalised, her preferences would have to be considered alongside others; for example, she might not hear the music she enjoys as frequently.

Quality of life

The model suggests questions including what are the prospects, with or without treatment or social care, for a return to the person's normal quality of life. For example, what are the biases that might prejudice the provider's evaluation of the person's quality of life and what plans exist for comfort care? Ashley's quality of life was likely to deteriorate as she grew larger, for the reasons already discussed, and her comfort and enjoyment of life therefore likely to decrease.

Lewis (1997) argues that developmental decisions should be based on the pragmatic needs of the present rather than gradual accumulated directional steps, especially as in this case, where prediction is specifically possible. It can be postulated that this pragmatism has been achieved through surgical intervention. As a parent of a child similar to Ashley describes: 'Every year, more doors close for her and no new ones open. As she grows, her life is being eroded... We regularly took her to theme parks...she's outgrown the rides.' (Thorpe 2007). Keeping such children small means they can continue to enjoy activities appropriate to their cognitive level which might also help develop latent cognitive or motor potential.

Contextual features

The model requires consideration of all issues that might impact upon the decision. First, whether there are family issues influencing health or social care decisions, as clearly there are in such cases. Using offensive analogies such as 'Dwarves...preferring to have short children' (p16) Liao *et al* (2007) challenge the contention that Ashley's parents sought to have her growth attenuated 'for our daughter's quality of

life and not to convenience her care-givers'.

In contrast, Shannon and Savage call for overt recognition that keeping Ashley small carries benefits for the parents (2007). Consistent family care is more likely to be managed if Ashley remains in her home setting. This may aid overall family cohesiveness, although it is acknowledged by McCubbin and Patterson (1983) that adjustment and adaptation will need to occur. Ashley is part of a family unit that includes two siblings: her parents have a moral, ethical and financial obligation to all of their children. Studies by Lavinge and Ryan (1979), Kazak (1986) and McKeever (1983) found higher levels of irritability and withdrawal among the siblings of disabled children than in a control group. The siblings' physiological and psychological health may be affected with sleep disturbance, recurrent abdominal pain and a preoccupation with their own health. Cirillo and Sorrentino (1986) discovered that healthy siblings were at risk for being assumed to function as autonomous adults, regardless of their maturity level. Each child deserves to have his or her own individual needs met, without unrealistic expectations. Clarke (1994), as well as Dobson and Middleton (1998) consider that having a child with complex health needs within a family can have a detrimental effect in relation to behavioural and educational issues. Some siblings experience feelings of neglect which is a matter for concern. In Ashley's case surgery means that care can be shared by older extended family members, freeing her parents to spend pleasurable periods with her siblings.

Issues that might affect health and social care providers' decisions need to be openly articulated: keeping disabled people within the family unit is often economically advantageous for the state. There may also be religious or cultural factors that have to be considered as well as legal and professional implications. In Ashley's case the professionalism of her doctors was challenged. Feminist Response in Disability Activism (2007) demanded that the American Medical Association issue a statement that where the person is not at risk of death, growth attenuation procedures such as 'the Ashley treatment' should be 'defined as a breach of medical ethics'.

Gender-based arguments include keeping her breasts so that Ashley can 'complete her gender identity' (Liao *et al* 2007, p18). They also claim that it is grotesque to have 'a full grown and fertile woman endowed with the mind of a baby' (p19), argue that her parents are 'in danger of blaming the victim for possible sexual abuse' (p18).

Conclusion

Open discussion of all possible motivators and ethical concerns helps ensure robust decisions are reached. Children's nurses have an important role acting as patient advocate, and, as accountable practitioners, need an understanding of relevant legal and ethical principles to ensure they are not responsible for carrying out or supporting poorly reasoned decisions. Ultimately, a loving, enabling and enabled family is the greatest resource of all for children like Ashley PN

References

- Beauchamp T, Childress J (2001) *Principles of Biomedical Ethics*. Oxford University Press, Oxford.
- Black C (2007) Children's hospital admits it broke state law with girl's surgery. *Seattle Post Intelligencer*, May 9, 2007 <http://seattlepi.nwsource.com>
- Brosco J, Feudtner C (2006) Growth attenuation. *Archives of Pediatrics and Adolescent Medicine*. 160, 1077-108.
- Clarke A (1994) Support for families with children with special needs. *Health Visitor*. 67, 10, 357.
- Cirillo S, Sorrentino A (1986) Handicap and rehabilitation: two types of information upsetting family organisation. *Family Process*. 24, 283-292.
- Disability Rights Education and Defence Fund (2007) Modify the system, not the person. <http://dredf.org/news/ashley.shtml> (Accessed: 7 January 2007)
- Dobson B, Middleton S (1998) *The Cost of Childhood Disability*. York Publishing Services, York.
- Downie R, Randall F (1997) Parenting and the best interests of minors. *Journal of Medicine & Philosophy*. 22, 3, 219-231.
- Fisher D (2006) Statement from Children's Hospital Medical Director. Growth Attenuation Press Conference, Seattle Children's Hospital. http://www.seattlechildrens.org/home/about_childrens/press_releases/2007/05/002039 (Accessed: 14 February 2008)
- Feminist Response in Disability Activism (2007) <http://fridanow.blogspot.com> (Accessed: 5 February 2008)
- Gunther D, Diekema D (2006) Attenuating growth in children with profound developmental disability. *Archives of Pediatrics and Adolescent Medicine*. 160, 1013-1017.
- HM Government (2004) *Every Child Matters: change for children*. Department for Education and Skills, Nottingham.
- Jonsen A *et al* (2006) *Clinical Ethics*. Sixth edition. McGraw Hill, New York.
- Kazak A (1986) Families with physically handicapped children: Social ecology and family systems. *Family Process*. 25, 265-281.
- Lavinge J, Ryan M (1979) Psychologic adjustment of siblings of children with chronic disease. *Pediatrics*. 63, 616-627.
- Lewis M (1997) *Altering Fate*. Guildford Press, New York.
- Liao S *et al* (2007) The Ashley Treatment: best interests, convenience and parental decision-making. *Hastings Center Report*. Mar-Apr, 16-20.
- McCubbin H, Patterson J (1983) Family transitions: adaptations to stress. In: McCubbin H, Figley C (eds) (1983) *Stress and the Family: coping with normative transitions*. Brunner/Mazel, New York.
- McDonald A (2007) The other story from a 'pillow angel': been there, done that, preferred to grow. *Seattle Post Intelligencer*, 17 June, 2007. http://seattlepi.nwsource.com/opinion/319702_noangel17.html
- McKeever P (1983) Siblings of chronically ill children. A literature review with implications for research and practice. *American Journal of Orthopsychiatry*. 53, 2, 281-289.
- Piaquet J (1977) The development of thought equilibration of cognitive structure. Viking Press, New York.
- Shannon S, Savage T (2007) The Ashley treatment: Two viewpoints. *Pediatric Nursing*. 33, 2, 175-178.
- Terry L (2007) Ethics and contemporary challenges in health and social care. In: Leathard A, McLaren S (eds) (2007) *Ethics: contemporary challenges in health and social care*. The Policy Press, Bristol.
- Thorpe A (2007) 'Why I want the same thing for my own daughter.' *Daily Mail*. January 6, 37.