# Chapter 3 Individually Directed Informed Consent and the Decline of the Family in the West

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## 3.1 Introduction

The traditional family-a husband and wife, together with their biological children-provides young children, adolescents, and adults with well-documented social, economic and adaptive advantages. Yet, in the West, this form of the family is in decline. A growing percentage of men and women choose not to be bound by the moral and social expectations of marriage and traditional family life and an ever more significant number of children are being born to single mothers. More than 40% of all births in the United States in 2011 were to unmarried women (Hamilton et al. 2012, Table 1). Such demographic shifts are associated with important changes in underlying taken-for-granted social and sexual mores. They also reflect public policies that instantiate a hermeneutic of suspicion against the traditional family. For example, the individualistic character of the social-democratic egalitarian ideology that underlies current dominant approaches to health care policy and medical decision-making in Western Europe and North America is associated with a decline in family stability (Akerlof and Yellin 1996, p. 21). Individually directed informed consent, for example, accents an unqualified affirmation of persons as the source of authority over themselves. This practice of informed consent tends to present persons outside of any social context in general and outside of their families in particular. The burden of proof is placed on the family to demonstrate that it acts with legitimate authority and in the best interests of individual members.

This paper critically engages moral and political pressures that have been brought to bear on the family, through such practices as individual-oriented informed consent. Whereas individual-oriented approaches to medical decision-making accent an ethos of personal autonomy, the family-oriented procedures typical of Hong Kong and China acknowledge the central social and moral reality of the family.

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Here, the family ought to be appreciated as more than simply a network of personal relations. It possesses a being that is social and moral, such that it realizes particular elements of the good and preserves necessary conditions for core areas of human flourishing. Moreover, the family and its core relationships are necessary for adequately appreciating the ways in which men and women come together to reproduce and the ways in which they successfully raise children. As Ruiping Fan, Xiaovang Chen and Yongfu Cao rightly note: "the family is the cardinal intermediate institution between the individual and the state. It is a biologically based community that produces children, nurtures and educates children, and tends to amass capital for its own purposes and goals" (2012, p. 509; see also Fan 2010). Family-oriented approaches to informed consent for medical treatment acknowledge this foundational social and moral reality. The family is appreciated as properly possessing more-orless significant authority over their members, as well as being the appropriate locus for determining their best interests. Consequently, from the perspective of family members, those who would interfere in the conduct of the family are judged as bearing the burden of proof, with a potentially very significant standard of proof, to impede family decisions. Throughout the analysis, I argue for the centrality of the family for human flourishing and, consequentially, for the importance of sustaining (or re-establishing) family-oriented understandings of informed consent to medical treatment.

#### 3.2 The Family and Human Flourishing

The family has traditionally been regarded as a normative form of social being, a morally regulative category of social life over and above a simple biological fact of the matter.<sup>1</sup> This core social reality, however, is evermore called into question. Even to refer to the traditional biological family as properly normative has become politically controversial. Yet, the family exists not simply as the creation of individuals or the state, but rather possesses a reality *sui generis* as a category of social existence. The dominant ways in which men and women create long-term social units for companionship, procreation and raising children, preserving and allocating resources, while also preferentially caring for and expending resources on their own biologically related children, elderly parents, and other close blood relatives, routinely document that humans are organized into families. The family is a key aspect of the fabric of social reality. The family's being discloses facts of the matter and normative commitments, including social and moral obligations, while

<sup>&</sup>lt;sup>1</sup> That the family is normative and central to human flourishing does not imply that family-based duties do not need to be carefully explicated. As Ilhak Lee notes: "filial duty has been (mis)understood as an unconditional, unlimited commitment and sacrifice, meaning children should do what, in the opinion of 'others,' is best for their parents, not what the parents prefer. It seems in this case children have little chance of demonstrating obedience, which is the proper understanding of filial duty. They also seem to have little chance for a discussion with their parents about the treatment they prefer, or what the parent would want" (2014).

sustaining the necessary conditions for central areas of human flourishing. Through the family one encounters and can know a domain of goods and virtues, as well as experiences of human flourishing, that are only understandable through its living reality. Appreciating the family in this fashion provides a foundational condition for the possibility of experiencing, conceptualizing, and appreciating a major domain of human experience and human good.

For example, the sociobiological empirical data demonstrates that traditional family structures and familial relationships are central to securing core areas of human flourishing. In part, family life permits persons as individuals better to achieve longer, more fulfilling lives. The high quality social relationships typical of traditional forms of family life, for example, are associated in significant ways with positive mental health, as well as with decreases in morbidity and early mortality.<sup>2</sup> Strong familial relations also increase social integration, social regulation and support, even reduce the risk of suicide (Kposowa 2009; see also Kunce and Anderson 2002; Neumayer 2003; Breault 1986). In part also, within the family, persons discover themselves as already sustained by and within a web of pre-existing responsibilities and moral obligations (see, e.g., Lee 2014a, b; Deng 2014; Yu 2014; Wong 2014). Parents and children are not isolated individuals. They are encountered as a social unity and must be appreciated in terms of their differing roles, duties and obligations within the family. As H. Tristram Engelhardt, Jr. concludes: "The obligations that connect parents and children are such to which they may never have committed themselves and to which they need never have consented in order for the obligations to have moral force" (Engelhardt 2010, p. 508).<sup>3</sup> In the absence of the intact traditional family central possibilities for mutual acknowledgment, social life, and human flourishing go unrealized (Engelhardt 2010, p. 508; Cherry, 2010).

Significant empirical evidence has accumulated, for example, that children who are raised in families with both biological parents present, have social, emotional, psychological and financial advantages over children raised in other types of environments. For example, children reared in single-parent households are statistically more likely to be impoverished, to engage in delinquency as adolescents and criminality as adults, to drop out of school, to get pregnant as a teenager, and to have poorer emotional and psychological health with concomitant difficulties in later

<sup>&</sup>lt;sup>2</sup> Julianne Holt-Lunstad, Timothy Smith and J. Bradley Layton, in a meta-analytic review across 148 studies with some 308,849 participants documented that strong traditional social relationships, such as the family, indicate a 50% or greater increased likelihood of survival across a wide range of causes of death. "Cumulative empirical evidence across 148 independent studies indicates that individuals' experiences within social relationships significantly predict mortality. The overall effect size corresponds with a 50% increase in odds of survival as a function of social relationships. Multidimensional assessments of social integration yielded an even stronger association: a 91% increase in odds of survival...Results also remained consistent across a number of factors, including age, sex, initial health status, follow-up period, and cause of death, suggesting that the association between social relationships and mortality may be generalized" (Holt-Lunstad et al. 2010, p. 9. See also House et al. 1988; Norval et al. 2009).

<sup>&</sup>lt;sup>3</sup> As Ana Iltis notes: "Families have particular interests both because they are stakeholders in family members' well-being and because they ordinarily want to protect the interests of individuals in the family (and of the family over all)" (2014). On this point see also Bishop (2014).

life.<sup>4</sup> Children from divorced families are more likely to end their own marriages in divorce, to attempt suicide as teenagers (Weisfeld et al. 1987), to misuse alcohol and narcotics (Norval et al. 2002; Weitoft et al. 2003; Defoe, 2003). Boys raised without a father are more likely to commit crimes or to be delinquent (Norva et al. 2002, p. 42). Girls raised in single parent families are twice as likely to give birth while a teenager and to drop out of high school (Rhoads 2004, p. 80).

The statistics on child abuse and neglect are significantly worse for children being raised in single parent homes or homes with stepparents or a non-spousal partner, such a boyfriend or girlfriend, over households in which children are raised by two biological parents. Consider, for example, the results of an empirical study conducted by Martin Daly and Margo Wilson, both professors of evolutionary psychology and former presidents of the Human Behavior and Evolution Society. When looking at child abuse data in the United States, Daly and Wilson were initially surprised by the over-representation of stepfamilies. Concerned that their data reflected an artifact, such as the under-reporting of child abuse by biological parents, they narrowed search criteria to the most unmistakable cases of abuse, such as those with fatal outcomes. They were forced to conclude:

But as we made our abuse criteria increasingly stringent and narrowed the sample down to the most unmistakable cases, the over-representation of stepfamilies did not diminish. Quite the contrary, in fact, by the time we had reduced the cases under consideration from the full file of 87,789 validated maltreatment reports to the 279 fatal child-abuse cases, the estimated rates in step-parent-plus-genetic-parent households had grown to approximately *one hundred times* greater than in two-genetic-parent households (Daly and Wilson 1999, p. 28).

Even when there is no abuse or neglect, stepparents statistically spend less time with their stepchildren than do biological parents who raise their own children.

Single mothers, who have never been married, produce statistically worse outcomes for children when compared to those reared by their married biological mother and father (Aronson and Huston 2004; Fomby and Cherlin 2007). As Charles Murray summarizes:

No matter what the outcome being examined—the quality of the mother-infant relationship, externalizing behavior in childhood (aggression, delinquency, and hyperactivity), delinquency in adolescence, criminality as adults, illness and injury in childhood, early mortality, sexual decision making in adolescence, school problems and dropping out, emotional health, or any other measure of how well or poorly children do in life—the family structure that produces the best outcomes for children, on average, are two biological parents who remain married. Divorced parents produce the next-best outcomes...Never-married women produce the worst outcomes (Murray 2012, p. 158).

Such empirical outcomes remain even after controlling for other family characteristics, such as parents' race, income, and socioeconomic status (Gallagher and Waite 2000, p. 125; see also Fagan and Rector 2000; Parcel and Dufur 2001; Rountree and

<sup>&</sup>lt;sup>4</sup> "Children raised in single-parent households are, on average, more likely to be poor, to have health problems and psychological disorders, to commit crimes and exhibit other conduct disorders, have somewhat poorer relationships with both family and peers, and as adults eventually get fewer years of education and enjoy less stable marriages and lower occupational statuses than children whose parents got and stayed married" (Gallagher and Waite 2000, p. 125).

Warner 1999; Cookston 1999; Osgood and Chambers 2000; Flanagan et al. 1999). More generally, children in single parent families: "… have negative life outcomes at two to three times the rate of children in married, two parent families" (Wilcox and Marquardt 2011, p. 87; see also Wilcox et al. 2011; Parke 2003).

Children raised outside of the biological family are more vulnerable to a wide range of social, psychological, and economic challenges. The transition from adolescence to adulthood, for example, can in the best of circumstances be traumatic.<sup>5</sup> Families typically nurture their teenage and young adult members, providing ongoing lifestyle and career guidance, financial support, and even the possibility of a temporary move back home with mom and dad if necessary. Children raised outside of the family environment are less likely to experience such advantages. Youths raised in non-family environments, such as state care and foster homes, typically must leave these settings once they become too old to be eligible for these types of social welfare services, even though the need for emotional and economic support continues.

Learning to function in the world as a responsible and effective adult can be a slow and arduous process. Children rely on their parents often well into their twenties for financial resources, a place to live, employment and educational assistance, emotional support and personal guidance. Unless children fully separate themselves from their families, this transitional period is most accurately described as taking place over a spectrum of semi-autonomy, during which the now adult child achieves additional autonomy, with significant assistance and guidance from parents and other family members.<sup>6</sup> Indeed, in functioning extended families, full independent autonomy may never be realized or sought. Access to the financial, intellectual, emotional and psychological resources of the family promotes positive outcomes while softening the consequences of the less than optimal judgments typical of early adulthood (Settersten and Ray 2010, p. 33). The roles that the male and female biological parents together play in the successful raising of their children cannot be adequately reproduced by third-parties, social institutions, such as group care settings, foster care, or governmental agencies. In short, the family helps to guide and smooth the transition from childhood to adulthood.<sup>7</sup>

<sup>&</sup>lt;sup>5</sup> "How an adolescent fares during the transition to adulthood has long-term repercussions. Earning a college degree leads to a higher-paying and more prestigious job, while early parenthood, unsuccessful marriage at a young age, and involvement in crime or problematic substance use all foretell difficulties in finances, family relationships, and beyond" (Osgood et al. 2010, p. 210).

<sup>&</sup>lt;sup>6</sup> Richard Settersten and Barbara Ray note, for example, that "both in the United States and in many European countries, the process of becoming an adult is more gradual and varied today than it was half a century ago. Social timetables that were widely observed in that era no longer seem relevant, and young people are taking longer to achieve economic and psychological autonomy than their counterparts did then" (Settersten and Ray 2010, p. 20).

<sup>&</sup>lt;sup>7</sup> "Even if the transition to adulthood had not become so demanding, members of these vulnerable groups [children raised in foster care or in a group care setting] would face exceptional challenges finding employment, attending college, and marrying and starting a family. Many struggle with emotional or behavioral problems; many have histories of problems in school and the community. Often their families are unable or unwilling to provide the support that most families provide to

Despite such advantages, demographics indicate a shift away from traditional family life. Individuals are becoming increasingly isolated from the rich and intimate social connections of the family.<sup>8</sup> Taken-for-granted background social mores and moral expectations have altered. Adults, for example, have become much less likely to marry than in past decades. This does not mean that they are choosing to remain chaste outside of the marriage of husband and wife. Rather, adults are much more likely to live unmarried with a sexual partner, or simply to live as sexually active singles (Wilcox and Marguardt 2009, pp. 69–70). In the United States, between 1960 and 2010, unmarried cohabitation, couples who live together as unmarried sexual partners, increased by more than a factor of seventeen (Wilcox and Marquardt 2011, p. 75). Some studies estimate that approximately 25% of unmarried women between the ages of 25 and 29 live with a sexual partner, and "an additional quarter have lived with a partner at some time in the past" (Wilcox and Marguardt 2011, p. 75). Moreover, greater than "... 60% of first marriages are now preceded by living together" (Wilcox and Marquardt 2011, p. 75) and over 40% of U.S. households with a co-habitating unmarried couple contain children (Wilcox and Marquardt 2011, p. 76).

Among the more predictable consequences of such a shift in sexual morality is that a growing percentage of children are born outside of marriage. In 2011, unmarried birth rates tracking the race of the mother in the United States were as follows: Black—72.3 %; Hispanic—53.3 %; American Indian or Alaska Native—66.2 %; White—29.1 %; Asian or Pacific Islander—17.2 % (Hamilton et al. 2011, Table 1). Such data ought to raise significant concern, since, as noted, children reared outside of the traditional family environment face real disadvantages. A number of studies have found that such disadvantages appear even when the biological father and biological mother cohabitate without getting married.<sup>9</sup> Despite well documented

<sup>8</sup> "Current evidence also indicates that the quantity and/or quality of social relationships in industrialized societies are decreasing. For instance, trends reveal reduced intergenerational living, greater social mobility, delayed marriage, dual-career families, increased single-residence households, and increased age-related disabilities. More specifically, over the last two decades there has been a three-fold increase in the number of Americans who report having no confidant-now the modal response. Such findings suggest that despite increases in technology and globalization that would presumably foster social connections, people are becoming increasingly more socially isolated" (Holt-Lunstad et al. 2010, p. 2; see also McPherson and Smith-Lovin 2006; Putnam 2000). <sup>9</sup> "The differences begin in infancy, when most of the cohabiting couples are still living together and the child has a two-parent family. Stacey Aronson and Aletha Huston used data from a study of early child care conducted by the National Institute of Child Health and Human Development to assess the mother-infant relationship and the home environment for children at ages 6 months and 15 months. On both measures and at both ages, the children of married couples did significantly better than the children of cohabiting parents, who in turn had scores that were only fractionally higher than the children of single mothers. ... The disadvantages of being born to cohabiting parents extend into childhood and adolescence, even when the cohabiting couple still consists of the two biological parents. Susan Brown used the 1999 cohort for the National Survey of America's Families to examine behavioral and emotional problems and school engagement among six- to eleven year-olds and twelve to seventeen-year-olds. Same story: Having two unmarried biological

their children during this transition—funding for college, child care that permits work or schooling for young parents, a place to live when times are hard" (Osgood et al. 2010, p. 211).

social, economic and adaptive advantages, however, an evermore significant number of couples find there to be little justification to be bound by the traditional expectations of marriage and so act in the light of their own particular agreements to live together, engage in sexual activity, and perhaps reproduce.<sup>10</sup>

## 3.3 Western Bioethics and the Undermining of the Family

By its very nature, the empirical data surveyed is statistical. As a result, not all particular cases will fit the statistical descriptions. Exceptions complicate but do not undermine statistical observations. The suggestion is neither that all traditional biological two-parent families are perfect, nor that all single mothers are poor parents. The character of the empirical data, however, strongly recommends taking seriously the cardinal role and reality of the traditional biological family and its life-world, for sustaining important elements of human flourishing. Such traditional family structures have a demonstrably positive impact on the successful raising of children. Demographic data routinely indicate that the negative impact on children of other types of living arrangements is far from negligible. Moreover, such family structures protect against poverty and provide a safety net for children, adults and the elderly.<sup>11</sup>

Consequently, one should be concerned when the character of public policy contributes to a decline in family integrity or to social shifts away from traditional family life. Here, a significant challenge is that liberal advocates often appreciate

parents was associated with worse outcomes than having two married biological parents, and the outcomes were rarely better than those for children living with a single parent or in a 'cohabiting stepparent family'" (Murray 2012, pp. 164–165, citing Aronson and Huston 2004; Brown 2004).

<sup>&</sup>lt;sup>10</sup> The prevalence of sexually transmitted disease has also increased. Roughly 16% of Americans between the ages of 14 and 49, for example, are infected with genital herpes, one of the most common sexually transmitted diseases. The infection rates are worst for African-American women (about 48%) and African-Americans generally (about 39%); for women (about 21%), than for men (about 11.5%). According to the Centers for Disease Control, treating sexually transmitted diseases costs the United States healthcare system some \$ 16 billion annually (see Allen 2010). The World Health Organization issued an alert in June 2012 expressing their concerns regarding new forms of antibiotic resistant gonorrhea (Shepherd 2012).

<sup>&</sup>lt;sup>11</sup> Perhaps, as Wenqing Zhao (2014), argues, it would be beneficial to turn to the family as a whole to help assure proper medical decision-making. Moreover, as Yaning Yang (2014), argues, family-based accounts of advanced directives would likely benefit the elderly. For insights into the situation in Taiwan see Lee (2014b, pp. 125–136), who notes that the goal in family-based decision making at the end of life in Taiwan is family consensus: "in actual practice, family consensus is the target. It is usually upheld by medical professionals. In many cases, the presentation of all the relevant family members, for example, in the decision for parent's medical treatment, the decisions of all brothers and sisters are usually requested. Even the spouse and elders were present, medical professionals would insist that other known family members be present before the final decision is made. In cases of not a matter of urgency, medical professionals usually ask the family members to hold meetings to arrive at a consensus decision before taking any further action."

the family as a major impediment to social implementation of their preferred conceptions of equality and social justice. To speak of the family as founded on the monogamous, heterosexual union of husband and wife, together with their biological children, clashes with the increasingly dominant political view of the family as fashioned around the equal partnership of free and equal men and women. For the progressive liberal, the idea of the family has become increasingly nominalistic; the family is seen as no more than a social construct, created through the particular agreements of its participants, with no independent reality of its own. Family members, of whichever sex, are presumed to be of equal authority and, as far as possible, as having interchangeable intra-familial social roles. Many feminists, homosexual activists, and other defenders of post-traditional social structures support just such a social-constructivist account of the family. The goal is to emancipate the family from what are judged to be the inappropriate and illiberal confines of traditional cultural, social and religious norms.

This progressive political vision recognizes itself as having an adversarial relationship with traditional family structures and forms of familial authority. The family as a foundational social institution is placed fully within a hermeneutic of suspicion. Elements of the feminist movement, for example, critically judge the family to be an institution of unequal power relationships and female subordination.<sup>12</sup> Susan Moller Okin, for example, disparagingly characterized "the sentimental family":

...the family had become characterized as entirely distinct from the outside world. Allegedly united in its affections and interests, this special sphere of life was held to depend for its health on the total dedication of women, suited for these special tasks on account of the very qualities that made them unsuited for the harsh world of commerce, learning, and power. Thus anyone who wished to register an objection to the subordinate position of women had now to take considerable care not to be branded as an enemy of that newly hallowed institution—the sentimental family (Okin 1982, p. 88; see also Okin 1994).

As Okin rightly perceives, the traditional family embodies particular understandings of proper family structures, including appropriate, albeit different, roles for men and for women. Such perceptions are among her reasons for concluding that traditional religious groups should not be permitted to nurture and educate their children within the religion itself. Okin decries such pedagogy as indoctrination (Okin 2002, pp. 218, 226). Securing her particular progressive vision requires decoupling morality and personal choice from cultural and religious viewpoints that recognize traditional family structures as presumptively authoritative.

The established American account of bioethics, similarly systematically seeks to limit the authority of families in medical decision making. As Beauchamp and Childress summarize their viewpoint: "...the authority of the family is not final or ultimate....Health care professionals should seek to disqualify any decision makers

<sup>&</sup>lt;sup>12</sup> "It was the contribution of the women's movement to attempt such a synthesis by placing the family in the center of social analysis. Feminists identified the family as a crucial institution in the reproduction of social relationships generally, and decisive for women's subordination. Hence, in theory and practice, the women's movement adopted a critical stance toward family life" (Breines et al. 1978, p. 43).

who ... have a conflict of interest. Serious conflicts of interest in the family may be more common than either physicians or the courts have generally appreciated" (2009, p. 188; see also 2012). The goal is a secular ethic that begins with the privileged presumption of the sovereignty of the individual. The dominant approaches to bioethics and health care law tend to support an unqualified affirmation of persons as the source of authority over themselves. Medical decision making, it is claimed, rightly rests with the individual patient (Beauchamp and Childress, 2009, p. 106). As a result, persons tend to appear as atomic individuals endowed with a right to determine their own futures (Applebaum et al. 1987; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1982). Individual liberty, conceptualized as autonomous self-determination, is assigned cardinal moral value. As rational moral beings, persons are to choose to be autonomous and self-determining individuals, who shape their moral values and perceptions of the good for themselves. Such an individualistic conception of personal autonomy is judged to be integral to human good and human flourishing.

Health care law, in turn, is framed to support individualistic consent, reflecting the centrality of the individual and ensuring adequate opportunity for persons to free themselves from traditional familial relationships. This individual-oriented practice of informed consent approaches patients as if they are not members of intact functioning families, unless there is good evidence to the contrary. Patients who wish to be treated as members of families, such as a parent who wishes to have his children make medical decisions on his behalf, are usually required explicitly to authorize the involvement of family members in the decision making process (Faden and Beauchamp 1986; Wear 1993). As Engelhardt marks this practice:

Those who regard autonomous individualism as the presumptively appropriate relation among persons would require any deviations to be established by explicit statement and agreement. For example, patients would be presumptively treated as autonomous individuals willing and committed to choosing on their own, unless they explicitly demanded to be regarded and treated within a traditional family structure (Engelhardt 2002, pp. 24–25).<sup>13</sup>

It is the individual, rather than the family, who is appreciated as possessing decisional authority.<sup>14</sup>

<sup>&</sup>lt;sup>13</sup> Engelhardt continues: "... consider the contrast between those who favor autonomous individualism and those who would give moral priority to family life. Those who regard autonomous individualism as the presumptively appropriate relation among persons would require any deviations to be established by explicit statement and agreement. For example, patients would be presumptively treated as autonomous individuals willing and committed to choosing on their own, unless they explicitly demanded to be regarded and treated within a traditional family structure... On the other hand, if one considered life within a traditional family structure as the presumptively appropriate relation among persons, the burden of proof shifts. Persons are approached as nested within the thick expectations of traditional family structures, unless they explicitly state that they wish to be regarded and treated as isolated individuals" (Engelhardt 2002, pp. 24–25).

<sup>&</sup>lt;sup>14</sup> For a detailed account of autonomy and family-based autonomy in the Korean medical context see Kyungsuk Choi who argues that "The individual (the self) and the family (a community) should be balanced. The family can be considered a community in a basic sense. From a traditional Eastern perspective, the family, rather than the individual, has been the basic unit for society and the state. However, it was not long before Korean society began to recognize an individual as

This progressive ethos similarly assumes individualistic approaches to patient confidentiality and access to medical information. For example, rather than being understood as united in marriage, spouses are treated as fully separate and separable individuals, with privacy rights vis-à-vis each other, and limited or no authority over the other. This legal circumstance has led to the limitation of spousal access to medical, financial, and educational records as well as limitations on the ability to grant permission on behalf of one's spouse for medical treatment or financial decisions. The United States Health Insurance Portability and Accountability Act (HIPPA), for example, restricts the sharing of medical information with spouses and children, unless the patient provides specific authorization. Such restrictions tend to be harmful to patients and destructive for family relationships:

Not only does HIPAA impose extravagant costs for exiguous benefits, HIPAA's sour assumptions about human nature work positive harm. For instance, HIPAA assumes people (1) want to keep information from their families ... HIPAA's rules are structured to serve patients who fit those assumptions. HIPPA's assumptions are wrong. Most people want their families involved in their medical care. ... Instead of having the few patients who fit HIPAA's assumptions to opt out of them. This burdens patients. Worse, most patients won't realize they need to act, and few will get around to it (Schneider 2006, p. 11).

Whereas consent in traditional cultures and religions is typically paternalistic and family oriented, Western bioethics seeks legal requirements for patient-oriented confidentiality and individual autonomous decision making, shielding personal information from spouses, children, parents, and other relatives.

With regard to children, emphasis is placed on protecting the child's "best interests"; such interests, in turn, are usually appreciated in terms of the child's liberty and equality interests. Children are to be nurtured towards equal liberty and personal autonomy as soon as possible.<sup>15</sup> Parental authority, in turn, is conceptualized as flowing from the state, which authorizes its proper structure and appropriate limits:

having autonomy. We cannot disvalue modernity. In this regard, the value of autonomy should continue to be emphasized, but it must be balanced with other traditional values" (2014).

<sup>&</sup>lt;sup>15</sup> See, e.g., Rawls 1999. Rawls urges that parents should not be appreciated as possessing moral status or moral authority in themselves, but only insofar as parents and the family function as the preferred social institution for raising children in a well-ordered and just society. "I shall assume that the basic structure of a well-ordered society includes the family in some form, and therefore that children are at first subject to the legitimate authority of their parents. Of course, in a broader inquiry the institution of the family might be questioned, and other arrangements might indeed prove to be preferable" (1999, p. 405). Left to itself, Rawls argues, the family makes it impossible "…in practice to secure equal chances of achievement and culture for those similarly endowed," which implies that for reasons of justice, "… we may want to adopt a principle which recognizes this fact and also mitigates the arbitrary effects of the natural lottery itself" (1999, p. 64). Insofar as families are the most appropriate social institution to integrate children, as they gradually acquire the proper sense of liberty, equality, and social justice, into a well-order society, so much the better; if not, then either the family ought to be regulated and reorganized or other more preferable arrangements found to raise children to become free and equal members of society.

Parents *are given* the ethical and legal responsibility to make decisions for children provided that they do so in the best interest of the child...Children are rights owners, even if they are not able to express their rights. Everyone dealing with such rights has the duty to promote them, to give voice to them and to become a true child advocate (Maria De Lourdes Levy, Victor Larcher, Ronald Kurz and the members of the Ethics Working Group of the CESP, 2003, p. 630).

Rather than recognizing the normative nature of the family, parental authority has been reconceptualized to give priority to the child's own self-determination, individual equality, and actual or potential autonomy. Emphasis is placed on the importance of developing children into self-possessed moral agents, who undertake their own moral decision-making as soon as possible and as far as feasible. As a result, Western bioethics frequently turns to children themselves to function as independent autonomous decision-makers (Cherry 2010).

For example, there is a growing commitment to augmenting the participation rights of children in medical decision-making, especially insofar as the minor child demonstrates intellectual understanding, affective grasp of the situation and reasonable maturity.<sup>16</sup> Here pediatric decision-making is sometimes appreciated in terms of a sliding scale, where the child's participation rights are given greater standing as the child demonstrates more individual maturity (see Ziner 1995; Kuther 2003; Dickens and Cook 2005). Children who physicians judge to be "mature minors" are appreciated as having rights to confidentiality, and to healthcare treatment in accordance with their own wishes, rather than in terms of what their parents' choose (Hickey 2007; Downie and Randall 1997; Zawistowski and Frader 2003). The Ethics Working Group of the Confederation of European Specialists in Paediatrics argued, for example, that:

Younger children may, according to laws of individual states, be able to consent to treatment especially if they have enough maturity and ability to understand the benefits and risks of the proposed treatment and its alternatives. The concept of a "mature minor" has been introduced by some authorities to include groups of children whose age ranges in most EU countries from 14–18 years and who are often regarded as being mature enough to give their own consent to treatment. In some countries the age at which children are considered to be potentially competent is even lower....doctors should always question themselves if the child is mature enough to give consent or assent (Lourdes Levy, Larcher, Kurz, and the members of the Ethics Working Group of the CESP 2003, p. 631).

In England, the "Gillick test" establishes a set of criteria for determining when children under 16 years-of-age have the capacity to consent.

In clinical practice, this means assessing whether the young person can understand and appraise the nature, purpose and implications of treatment; any risks there might be, any alternative courses of action and their consequences. In making the assessment, it is

<sup>&</sup>lt;sup>16</sup> For example, Unguru et al. (2010) argue that more should be done to educate children so that they can give meaningful assent to participate in oncology research. "Tools to assist investigators ascertain that children understand what they are agreeing to when they assent to research and to determine their preferences for inclusion in research may help make assent more meaningful" (e876; see also Unguru et al. 2010). Sinclair argues that adolescents should be permitted a significant role in deciding whether to undergo a life saving heart transplant, perhaps even permitting them to refuse a life saving transplant (Sinclair 2009).

necessary to consider emotional maturity, intellectual capacity and psychological state (Wright et al. 2009, p. 239).

The Canadian Pediatric Society supports a similar stance:

Once it is determined that children have the capacity to make decisions, which entails full understanding of a situation, and fully grasping the main purpose of interventions, the consequences of consent and the overall extent of what could occur, they should be the primary decision makers (Whitty-Rogers et al. 2009, p. 748; see also Canadian Pediatric Society 2004).

Many bioethicists urge that physicians should seek the "informed permission" of adolescents regarding the direction of their medical treatment (Zawistowski and Frader 2003; Zinner 1995); others conclude that adolescents should be able independently to consent to clinical trials (Ondrusek et al. 1998). Some advocates argue that even end-of-life decisions, such as refusing cancer treatment or a life-sustaining transplant, should be left up to the judgment of "sufficiently mature" minors (Lemmens 2009; Hickey 2007). Parents and physicians should work more-or-less as equals with the mature minor, who is appreciated as possessing the moral authority to make final treatment decisions.<sup>17</sup>

Children are often identified as independent of their parents even prior to having necessarily achieved maturity, especially regarding areas of life secular bioethics deems private. For example, parental consent to access birth control or sex education is not appreciated as necessary to protect the best interests of children (Cook et al. 2007). Controversial procedures, such as abortion, are routinely left up to the will of the child, often without even the requirement to inform her parents. For example, in Seattle, Washington, the health center at Ballard High School reportedly facilitated a 15-year-old girl's abortion during school hours. The young girl was evidently given a school pass, put into a waiting taxi and sent off to have an abortion, free of charge, without notifying her family. T.J. Cosgrove of the King County Health Department was quoted as stating: "At any age in the state of Washington, an individual can consent to a termination of pregnancy" (KOMO Staff 2010).<sup>18</sup>

<sup>&</sup>lt;sup>17</sup> As the Ethics Working Group of the Confederation of European Specialists in Paediatrics argued: "Firstly, seeking a person's consent/assent respects their basic right to self-determination (autonomy). Individuals are best placed to determine what is in their best interests and the only justification for infringing this right is to prevent harm to others. Secondly, obtaining consent/ assent involves treating others in a way in which we would expect to be treated ourselves. The universal need to obtain consent/assent also involves treating people justly. Thirdly, obtaining consent/assent protects patients from the physical and psychological harms which may occur as a result of illness or its treatment. Fourthly, obtaining consent/assent confers benefit by encouraging active participation of individuals in investigation and treatments which are intended to restore their health" (Levy et al. 2003, p. 630).

<sup>&</sup>lt;sup>18</sup> Similarly, current California law requires neither parental consent nor simple parental notification for a child to obtain an abortion. See Planned Parenthood Parental Consent and Notification Laws. Available: www.plannedparenthood.org/teen-talk/teen-pregnancy/parental-consent-notification-laws-25268.htm. See also California Health and Safety Code, Sect. 123420–123450. "Do I have to get my parent's permission to get an abortion? No. You do not need anyone's permission, and the law protects your privacy. No one else has the right to know or do anything about it—not your parents, your boyfriend or partner, or your husband. Even if you are married or under 18, the

"Sufficiently mature" minors, it is urged, should be permitted to decide on their own behalf regarding contraception, abortion and sexual practices with consenting others, and treatment for sexually transmitted diseases. Age thresholds have usually functioned as an established, if somewhat conventional, criterion for the capacity to make competent, mature, and responsible decisions. However, the focus has shifted away from any minimal age threshold to a particular medical professional's personal judgment regarding the child's "sufficient maturity."<sup>19</sup> In short, rather than being appreciated as within the authority of their parents, or other family members, minor children are anticipated as moving as quickly as feasible from giving assent to medical treatment, to giving independent consent and as having moral and legal standing independent of their parents.<sup>20</sup> Children are to exercise their own personal autonomy, to define their own conceptions of proper moral choice and life-style preferences, over against the authority of their parents and other family members, as soon as practicable.

As a result, familial authority is routinely assumed to reach no further than that of trustee of the individual member's best interests and, moreover, as always properly subject to significant state oversight and governmental intervention. As a result, core family relationships are evermore undermined and subject to legal restrictions designed to deflate the significance of, as well as to marginalize the family. Whereas spouses have usually been appreciated as possessing particular authority vis-a-vis each other, and parents have usually been regarded as the best judges for balancing costs and benefits for the family, for determining appropriate life-style choices for themselves, their children, and the family as a whole,<sup>21</sup> these positions have been radically brought into question. As demonstrated, pressure has been brought to bear on parents and families through law and institutional policy, focusing among other concerns on separating children from the sphere of parental and familial authority, as well as spouses from each other's authority. The examples of individually-oriented informed consent, personal privacy rights, and pediatric decision making, illustrate the ways in which the focus of much contemporary moral and political

decision is up to you." ACLU, "Your Health; Your Rights" [On-line.] Available: www.teensource. org.

<sup>&</sup>lt;sup>19</sup> Dickens and Cook argue that: "There is usually no chronological 'age of consent' for medical care, but a condition of consent, meaning capacity for understanding" (Dickens and Cook 2005, p. 179).

<sup>&</sup>lt;sup>20</sup> "Debates surrounding the rights of adolescents to receive confidential and private reproductive health services have centered around the potentiality conflicting interests of parents and their children. The desire of parents to guide and direct their children's health and development and make health-care decisions for their children is easily understandable. However, the health threat faced by adolescents exposes the tension between public or societal interests in maintaining a healthy population and private or parental interests in maintaining control over their children" (Ringheim 2007, p. 245).

<sup>&</sup>lt;sup>21</sup> For example, in his detailed Roman Catholic casuistry of parental decision making on behalf of their children, Edwin Healy (1956), argues that parents should and must make decisions regarding ordinary vs. extraordinary care on behalf of their children, including even determining when treatment is too expensive to be obligatory (Healy 1956, pp. 81–89, see especially page 82).

analysis has been to sunder the authority of the family over its members, and to undo the primary loyalty of family members to each other.<sup>22</sup>

## 3.4 Conclusion

Western accounts of bioethics routinely fail to appreciate the central role and reality of the family in human flourishing. Regardless of its advantages, defenders of posttraditional social structures seek to set aside traditional understandings of the social and moral obligations of family life, to dismiss or ignore the significant benefits of the traditional family, so as to liberate the family from the confines of traditional cultural or religious norms. Such disputes are often embedded in highly ideological frameworks, which give moral priority to secularity and individualism, to personal liberty as a positive entitlement to realize one's own understanding of the good. Such idealizations, however, ignore the actual choices of actual persons, trivializing the real connections between parents and children, among spouses and other family members, so as politically to achieve what is judged to be an ideally liberal, egalitarian, and progressive society. The liberal social-constructivist account of the family simply replaces traditional cultural or religious content with its own full-fledged political ideology. Consequently, such an anti-traditional ethos also contributes to the undermining of the family's nexus of key social relationships and, thereby, to the breakdown of the family.

A core challenge, however, is that this particular liberal ethos routinely conflicts with what would appear to be the long-term good of children as well as of the adults whom children and adolescents are destined to become. There is a considerable body of data, for example, demonstrating the positive impact of the more authorita-

<sup>&</sup>lt;sup>22</sup> Consider, for example, Susan Moller Okin who argues, "The liberal state ... should not only not give special rights or exemptions to cultural and religious groups that discriminate against or oppress women. It should also enforce individual rights against such groups when the opportunity arises and encourage all groups within its borders to cease such practices" (Okin 2002, pp. 229–230). Moreover, education policies, it is argued, should carefully restrict religiously-based education that might encourage children towards traditional sex roles. "If parents are permitted to educate their children in sheltered settings in which they are taught, by example, doctrine, and the content of their curriculum, that it is the will of an omnipotent and punitive God that women's proper role in life is to be an obedient wife and a full-time mother, how can the girls be said to be 'aware of ... alternatives' in any meaningful way, to be able to 'assess these alternatives' (or even to think it desirable to do so), or to be able to 'participate effectively' in other roles or ways of life?" (Okin 2002, p. 226) Children, it is asserted, should be educated in the public virtues of justice, equality and tolerance.

Amy Gutmann opines similarly: "Some kinds of social diversity ... are anathema to political liberalism. Civic education should educate all children to appreciate the public value of toleration" (1995, p. 559). Gutmann continues: "The basic principles of liberalism, those necessary to protect every person's basic liberties and opportunities, place substantial limits on social diversity. ... The limits on racial and gender discrimination, for example, enable many people to pursue ways of life that would otherwise be closed to them by discriminatory practices at the same time as they undermine or at least impede some traditional ways of life" (Gutmann 1995, p. 559).

tive parenting styles and boundary settings typical of traditional family structures on the development of effective, autonomous, decision making. The data support the conclusion that adolescents who grow up with parents who are authoritative, setting limits on the adolescent's behavior and choices, are more likely to become effective adult decision makers. Adolescents raised with permissive parents, in contrast, in which the child himself is treated as the authoritative decision maker, develop significantly poorer effective decision-making skills. Traditional authoritative parenting styles in general support, rather than undermine, the ability of the child to mature into a competent adult decision maker. Authoritative parenting is related to a wide range of positive cognitive and emotional outcomes, including better academic achievement (Dornbush et al. 1987; Weiss and Schwarz 1996; Wintre and Ben-Knaz 2000; Wintre and Yaffe 2000), less psychological distress, fewer adjustment and problem behaviors (Brown et al. 1993; Fuligni and Eccles 1993; Slicker 1998), and higher quality relationships with their peers, as well as greater levels of competence, self-esteem, personal reliance, and even individual autonomy (Baumrind 1991a, b; Buri et al. 1998). Authoritative parenting styles help provide adolescents with the ability to resist peer pressure, to avoid substance abuse and other potentially harmful circumstances (Weiss and Schwarz 1996; Adalbjarnardottir and Hafsteinsson 2001; Huver et al. 2007). As even the United States Supreme Court has come to recognize, the available scientific evidence supports the conclusion that adolescents are qualitatively different types of agents than adults (Cherry 2013).<sup>23</sup> Parents, by setting limits and giving direction, letting adolescents deliberate and choose within limited circumstances, while also withholding for the parents the right to veto adolescent decisions, protect children from the long-term consequences of poor choices. Moreover, as documented, the failure to sustain cardinal concerns focused on the family has lead to increased pregnancy outside of marriage and an ever greater percentage of children raised outside of traditional family life, which is significantly statistically correlated with a wide range of social, psychological and economic disadvantages. Such traditional family structures augment positive characteristics (cognitive, emotional, and adaptive) associated with becoming an effective adult.

In short, traditional forms of the family free people to live in ways that many (both men and women) judge to be central to human flourishing.<sup>24</sup> The family usually functions as the central locus of moral guidance for its members, but especially for the family's children. The empirical data surveyed supports the conclusion that

<sup>&</sup>lt;sup>23</sup> The Supreme Court has reasoned that, on balance, the available scientific evidence, including neuroimaging studies of the relative immaturity of the adolescent brain, does not support the conclusion that adolescents possess adult capacities for personal agency and rational mature choice. See *Roper v. Simmons* p. 541 US 551 (2005); *Graham v. Florida* p. 560 US (2010); and *Miller v. Alabama* p. 567 US (2012).

<sup>&</sup>lt;sup>24</sup> "'Less marriage means less income and more poverty" (Sawhill 2011, p. 42). reckons Isabel Sawhill, a senior fellow at the Brookings Institution. She and other researchers have linked as much as half of the income inequality in America to changes in family composition: single-parent families (mostly those with a high-school degree or less) are getting poorer while married couples (with educations and dual incomes) are increasingly well-off.

traditional understandings of parental authority benefit children, augment the quality of childhood decision making, helping them to avoid unnecessary risks and to develop into mature autonomous decision-makers. More generally, the rich social structures of traditional family life convey social stability and social integration and support, reducing morbidity and mortality, and offering protection from stressful life events. Given the centrality of the family for sustaining such key areas of human flourishing there are good grounds for sustaining (or re-establishing) more family-oriented understandings of informed consent to medical treatment and for rethinking rules regarding patient confidentiality that restrict access to information from spouses and other family members.

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