



CONCEPT OF INFORMED CONSENT IN THE CONTEXT OF RESEARCH WITH CHILDREN AND CHILD RIGHTS

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ABSTRACT

Children are beginning to be perceived as competent social actors, as a result of the United Nations 1989 Convention on the Rights of the Child. However, children's decision making capacity, and the concept of informed consent in research involving children has rarely been interrogated since the United Nations 1989 Convention on the Rights of the Child was signed. This article, therefore, discusses the concept of informed consent according to its elements and focuses on how to conduct ethical, lawful and scientific research with children.

Keywords: *informed consent, research with children, child rights, medical and social science research.*

1. INTRODUCTION, BACKGROUND AND PRELIMINARY ISSUES

Children's decision making capacity, and the concept of informed consent in research involving children has rarely been interrogated since the United Nations 1989 Convention on the Rights of the Child, which was ratified by the Turkish Grand National Assembly on 27 January 1995. According to Article 90 of the Turkish Constitution, the Convention is part of the domestic law which means that the provisions of the Convention are fundamental legal rules binding upon administrative authorities and other agencies and individuals. The Convention highlights the importance of listening to children and taking their views seriously in all matters affecting them.^[1] However, this rule has rarely been applied and interrogated in the context of research with children.

In this context, the literature on the ethics of research with children has largely been produced from within the field of medical and psychological research, and is mostly concerned with the risks that children are exposed to through participation in clinical studies.^[2] With respect to research involving children, the concept of informed consent is complex and, in the opinion of this author, confusing. In order to solve this complexity, we should draw a distinction between medical and social science research such as psychological, sociological and educational research. Within the field of social science research, 'informed consent has usually been seen as given as part of a "one-off" event at the outset, on the basis of the presentation of adequate information that provides sufficiently for the participants to "know" and "understand" what they are "getting themselves into"'^[3]. In the field of medical research many of the discussions have been related to issues either addressing when children become informed and wise enough to make a sensible decision about research, or, trying to establish rules specifying the age up to which parental consent is necessary, and from which children's own consent should be gained in addition to their parents'.^[4]

Research with children is, to a large extent, different from research with adults. However, there has been a tendency to perceive research with children as one of two extremes: just the same or entirely different from adults^[5]. Those

[1] The United Nations Convention on the Rights of the Child, Article 12

[2] Edwards, R. & Alldred, P. (1999) 'Children and Young people's views of social research: The case of research on home- school relations', *Childhood*, 6 (2), 261-281

[3] David, M., Edwards, R., & Alldred, P. (2001) 'Children and school-based research: 'informed consent' or 'educated consent'', *British Educational Journal*, 27 (3), 347-365, p.348

[4] Edwards & Alldred, op.cit., n.2

[5] Punch, S. (2002) 'Research with Children: The same or different from research with adults?', *Childhood*, 9 (3), 321-341, p.322

who consider that children are ‘essentially indistinguishable from adults’^[6] use the same methods as those used with adults, since they consider that children are basically the same as adults. Seen from this perspective, it is not necessary for the researcher to draw attention to any adult-child distinctions by treating them in any way other than as mature, competent people.^[7] Those who consider that children are entirely different from adults use ethnography as the most appropriate way to get close to understanding the child’s world.^[8] However, in the opinion of this author, none of those views mentioned above can fully address the evolving capacities of the child and their special vulnerability. Therefore, a method, which provides a balance between those two perceptions, should be devised and used. Otherwise, giving more weight to one of those views would be an inappropriate approach, which is inconsistent with the principle of respecting the evolving capacities of the child, set out by Article 5 of the UN Convention on the Rights of the Child. However, recently, James et al. (1998)^[9] point out that there is another perspective where researchers tend to use methods which are based on children’s skills, and develop innovative and adapted techniques such as pictures^[10], diaries^[11], writing^[12], sentence completion^[13] and drawings.^[14] In this perspective researchers perceive children to be similar to adults, but to possess different competencies. Clearly, this perspective and its methods can fully address the evolving capacities of the child and their special vulnerability.

Due to their special vulnerability and inherent inability to give a fully informed consent, the issue of informed consent must be considered to be the central difference between research with children, and research with adults. Research carried out without addressing the issue of informed consent and examining whether or not a child has sufficient capacity to fully understand the concept of the proposed research, has to be regarded as unethical, unlawful and inconsistent with the universally accepted basic principles of scientific research such as objectivity, and impartiality. In this context, ‘it is widely recognized that

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- [6] James, A., Jenks, C. & Prout, A. (1998) *Theorizing Childhood*, Cambridge: Polity Press, p.31
- [7] Alderson, P. (1995) *Listening to Children: Ethics and Social Research*, Ilford: Barnardo’s
- [8] Punch, op.cit., n.5
- [9] James et al. op.cit., n.6, p.189
- [10] Nesbitt, E. (2000) ‘Researching 8 to 13 years-olds’ perspectives on their experience of religion’, in *Researching Children’s Perspectives*, A, Lewis & G, Lindsay. (eds.), pp.135-149, Buckingham: Open University Press, David et al., 2001, op.cit.,n.3
- [11] Nesbitt, Ibid.
- [12] Morrow, V. (1999) ‘It’s Cool,...Cos You Can’t Give Us Detentions and Things, Can You? : Reflections on Researching Children’, in *Time to Listen to Children*, P, Milner & B, Carolin. (eds.), pp.203-215, London: Routledge
- [13] Ibid.
- [14] Ennew, J. & Morrow, V. (1994) ‘Out of the mouths of babes’, in *Children’s Rights: Monitoring Issues*, E.Verhelen & F.Spiess-Chaert (eds.), pp.61-84, Gent: MYS Breesch

in order to gain children's consent and involvement in research, one has to go via adult gatekeepers who are able to limit researchers' access to the children'.^[15]

Within medical research, gatekeepers from whom consent will be gained may be parents or guardians, who have parental responsibility for child. In the field of social science, the concept of gatekeepers is extended to those in loco parentis such as head teachers, school governors or social workers, who work and care for the children.^[16] Therefore, researchers, especially in school-based educational research, must obtain permission from the governing body of the school in addition to the child's consent and that of the parents; because the governing body of the school has the discretion to assess a research proposal, either as curricular or extra-curricular which requires permission from parents.^[17]

Thus, it is necessary that we should find answers to some questions arising out of the construction of the educational school-based research such as, 'is a head teacher's consent sufficient, or ought we to seek each child's consent in the school who might participate in research?' How do we do research with whole classes, if one or two children object?^[18]

Although, all these questions are still being debated, in the opinion of this author, research carried out solely by obtaining the consent from the head teacher or school governor, creates an impression that the research is 'just another form or piece of school work'^[19], which raises serious doubts over its validity and reliability, as it restricts the free will and choice of the child-participants, and disregards their autonomy and evolving decision making capacity. Moreover, such an approach would also be inconsistent with the essential components of informed consent, which require that consent must be given freely and voluntarily without any outside interference or any element of coercion.

[15] Punch, op.cit., n.5, p.323

[16] Croll, P. (1986) *Systematic Classroom Observation*, Sussex: The Falmer Press

[17] David et al. op.cit., n.3

[18] Alderson, P. (2004) 'Ethics', in *Doing research with children and young people*, Fraser, S., Lewis, V., Ding, S., & Kellett, M. (eds.), pp.97-112, London: Open University Press

[19] Denscombe, M. & Aubrook, L. (1992) 'It's just another piece of school work: the ethics of questionnaire research on pupils in schools', *British Educational Journal*, 18, 113-131; Pole, C., Mizen, P. & Bolton, A. (1999) 'Realizing Children's agency in research: partners and participants?', *International Journal of Social Research Methodology*, 2, 39-54, David et al. op.cit., n.2, p.352

2. FUNCTION OF INFORMED CONSENT AND THE ETHICAL STATUS OF CHILDREN IN RESEARCH

As mentioned before, in the field of social science research with children, the concept of informed consent and its function have usually been seen as an information process, by which adequate information concerning the objectives and nature of a particular research study is provided, in order that children can make choices about their participation.^[20]

From this perspective, the function of informed consent as a ‘form of information’^[21] is relatively unproblematic. However, the function of informed consent in the field of medical research can not simply be explained as an information process, by which the objectives and nature of the research are explained. In this context, the function of informed consent is quite problematic, and far beyond the form of information. We can give two reasons, which provide the foundations for this difference. Firstly, contrary to medical research, social science research is less physically dangerous. Secondly, while beneficence in medical research generally has a present-directed and individually oriented meaning, in the field of social science research, beneficence generally has a future-directed and society-oriented meaning.^[22] Thus, the Hippocratic tradition of medical ethics stipulates that:

‘Physicians have an obligation to seek their patients’ good, that is, to benefit them, and also a duty to refrain from harming them, or at least a duty not to add to the harms of their condition’^[23]

Because of the Hippocratic tradition and the differences mentioned above, the function of informed consent in medical research is not only an information process by which the objectives and nature of the research are explained, but also a legal process by which a legal justification for care, treatment or research is provided.^[24] Traditionally, consent from the patient or research subject is required prior to the physician initiating any form of treatment, research, operation or study,^[25] ‘without such consent, health professionals would commit a crime (battery) and a tort (trespass to the person) when they touch their patient.’^[26]

Although, this function of informed consent seems to provide a mechanism

[20] David et al, op.cit., n.3, Edwards & Alldred, op.cit., n.2

[21] David et al. Ibid., p.348

[22] King, M, P. & Churchill, R. L. (2000) ‘Ethical Principles Guiding Research on Child and Adolescent Subjects’, *Journal of Interpersonal Violence*, 15 (7), 710-724; Alderson, op.cit., n.18.

[23] King & Churchill, Ibid., p.714

[24] Montgomery, J. (1993) ‘Consent to health care for children’, *Child Law*, 5 (3), 117-124

[25] Kaufmann, C, L. (1983) ‘Informed consent and patient decision making: Two Decades of Research’, *Social Science & Medicine*, 17 (21), 1657-1664

[26] Montgomery, 1993, op.cit., n.24. p.117

for the protection of research subjects, the judiciary generally interprets and applies this mechanism in favor of health professionals by considering that the legal role of consent is primarily to provide a defense to actions against health professionals^[27] Consent is a necessary condition for the lawful and ethical conduct of any kind of medical or social science research. In this context, we should discuss one final point, which is closely linked to the ethical status given to children in research and the issue of research designs.

There are three main levels of involving children in research. These three terms or levels can show crucial power differences in children's status^[28] In the first level, children are assessed as active participants who willingly take part in research which have flexible methods, and are based on their skills such as writing, sentence completion, painting or maps created by them.

In the second level, children are assessed as aware subjects whose consent is sought to be questioned, observed, or take part in research that has inflexible methods such as questionnaire surveys, especially those designed and developed for adults.

Finally in the third level, children are assessed as unknowing objects of research who are not asked for their consent and may be unaware that they are being researched.^[29] This includes deceptive research 'such as when researchers ask one question but are really looking for answers to another, perhaps unspoken question'^[30], and covert participant observation ^[31] such as through two-way mirrors.

'In this type of research the researcher may undertake observation without informing his or her research subjects that the observation is taking place. This is justified (or otherwise) on the basis that, if the subjects are aware that they are being observed, they may change their behavior and thus the researcher would not gain a true and accurate picture of normal behavior. This is described as the Hawthorne effect'^[32]

In these two types of research (deceptive research and covert participant observation) the ethical status of the children is highly controversial, and they clearly raise concerns about informed consent and the autonomy of children. In this context, one can expect or arguably claim that these two types of research can be ethically and legally carried out either by obtaining proxy consent from parent/s or guardians prior to research, or by obtaining consent from a competent participant after carrying out the research. Such arguments and claims

[27] Ibid., p.122

[28] Alderson, op.cit., n.18.p.100

[29] Ibid.

[30] Ibid., p.100

[31] Greig, A. & Taylor, J. (1999) Doing research with children. London: Sage Publications, p.151

[32] Ibid.

are implausible and in breach of all codes of ethics. We can give two reasons for this. Firstly, consent has to be given prior to research. Secondly, as Lord Donaldson argued: “If the position in law is that upon the achievement of ‘Gillick competence’^[33] there is a transfer of the right of consent from parents to child and there can never be a concurrent right in both....”^[34], it naturally means that consent has to be given directly by the child-participant as long as he/she is competent. Therefore, as long as the child-participant is competent, consent has to be given directly by the child prior to research, and this right can not be used by the parent/s on behalf of a competent child.

3. THE AGE OF CONSENT AND CHILDREN’S COMPETENCE

3.1. Social science research

When do children become informed and wise enough to make a sensible decision about research? This is not a simple question to answer, because competence is not a standard of general ability and ‘there is no grey hinterland between competence and incompetence’^[35]. This term is used to determine whether a person is adequately equipped to perform a special task.^[36] Within social science research, it is generally accepted that children’s competence to consent to participate in research depends partly on each child’s own experience, education, the context and subject of the research and also partly on the skill with which the researchers talk with children and help them to make unpressured informed decisions^[37]. Therefore, children of compulsory school age can be easily assumed to be competent to participate in educational school-based research, or other social science research.

3.2. Medical research and treatment

With respect to medical treatment, children’s capacity to consent was examined by the House of Lords in the Gillick^[38] case. In this case, the House of

[33] Gillick v W Norfolk AHA [1985] 3All ER 402

[34] Re R [1991] 4 All ER 177 at p.185

[35] Montgomery, J. (2001) ‘Informed consent and clinical research with children’, in *Informed consent in medical research*, Doyal, L. & Tobias, S.J. (eds.), p.173-181, London: BMJ Books., p.176

[36] Ibid.

[37] Alderson op.cit., n.18, p.107, Morrow, V. & M, Richards. (1996) ‘The Ethics of Social Research with Children: An Overview’, *Children and Society*, 10, 90-105, p.95; Kirby, P. (2002) ‘Involving young people in research, in *The new handbook of children’s right: Comparative policy and practice* Franklin B. (ed.), pp.268-284, London: Routledge, p.272

[38] Gillick op.cit., n.33

Lords held that: ‘the test to be applied was whether the child had sufficient understanding and intelligence to enable him or her to understand fully what is proposed’^[39]. Despite the fact that the House of Lords did not make it clear exactly what is meant by ‘understand fully’, it can be concluded from discussions in the House of Lords that it requires an appreciation of the consequences of treatment, including possible side effects, and the anticipated consequences of a failure to treat. Although it was formulated in the context of family planning, the test of maturity set out in the Gillick case is now used as a test of general application, and children who satisfy this test for competence are described as ‘Gillick competent’. If it is accepted that Gillick competence extends beyond the context of treatment, then children who satisfy this test for competence can give a valid and legal consent to participate in medical research.^[40] However, the test of maturity set out in the Gillick case by the House of Lords should be assessed in respect of each individual child, and each separate medical procedure. Therefore, it is impossible to establish rules specifying the age up to which parental consent is necessary, and from which children’s own consent might be sufficient. Thus, King and Churchill report that children 12 years of age and older could qualify as mature minors for participation in child maltreatment research.^[41] Alderson and Montgomery suggest that children 5 years of age should be assumed to be competent to participate in medical research, and the onus would be on adults to demonstrate the child’s incompetence rather than for the child to pass tests of competence, which many adults might fail.^[42]

4. THE ELEMENTS OF INFORMED CONSENT

Informed consent has five essential elements.^[43] They can be described as choice, voluntariness, understanding, disclosure and finally competence, which the author has discussed above.

4.1. Choice and Voluntariness

When you say ‘I consent’, you mean that you freely agree to any proposal. This also includes an additional explanation that your consent to a certain study or research has been sought and granted without any outside interference, or any element of coercion.

[39] Montgomery, *op.cit.*, n.24, p.118

[40] Montgomery, *op.cit.*, n.24

[41] King & Churchill, *op.cit.*, n.22, p.721

[42] Alderson, P. & Montgomery, J. (1996) ‘What about me?’, *Health Services Journal*, 11, 22-24, p.24

[43] Faden, R. & Beauchamp, T. (1986) *A history and theory of informed consent*, New York: Oxford University Press; Hart, S. C. & Thong, Y. H. (1995) ‘Parental perceptions and attitudes about informed consent in clinical research involving children’, *Social Science Medicine*, 41 (12), 1647-1651

The possibility of acting under coercion and a child's degree of choice differ between social science research and clinical research. In this context, the design of the research and procedure used, have a significant impact on the reliability of the research. For example, Powel and Vacha refer specifically to psychological research, and point out that:

'It is possible that research projects can be designed to be "fun" and that the child will therefore enjoy participation. It is also possible that children will appreciate some type of concrete, post hoc reinforcement, like a pack of gum or an inexpensive toy, but it may be considered coercion if the child is informed prior to giving assent that he or she will receive a reward following participation' [44]

However, the difference between coercion and persuasion in clinical research is not at all simple and clear. We can say that 'persuasion aims to enlist the patient's reason by providing information and coercion aims to manipulate the patient's decision by influences which undermine independent reasoning.'^[45]

With respect to a child's degree of choice, we should discuss one final point, which is closely related to the designing of educational school-based research. The issue of children's degree of choice in the educational school-based research raises serious concerns, since there is a differential power relation between the child and the teacher in a school environment. As Denscombe and Aubrook^[46] and David et al.^[47] point out, the school context is inscribed by differential power relations, making it very difficult for children and young people to opt out of participating in research. They argue that the high pupil response rates achieved in school-based studies is rooted in this 'hidden pressure', and that researchers need to consider the ethics of their practice in this respect.^[48] Therefore, in order to avoid the risks of this hidden pressure, which confine the children's degree of choice; researchers make it clear that there will be no punishment if any child refuses to participate in research. The child's right to refuse must be respected,^[49] also researchers must take all necessary precautions to enable children to understand that the research is neither a part of education nor another piece of school work. Indeed, it is a voluntary and non-educational activity.^[50]

Continuing consent is another necessary condition for the ethical conduct of any research with children. Continuing consent during longer projects involves

[44] Powell, M, P. & Vacha, H, T. (1994) 'Issues related to research with children: What Counseling Psychologist Need to Know', *The Counseling Psychologist*, 22 (3), 444-453, p.450

[45] Gillett, G. R. (1989) 'Informed consent and moral integrity' *Journal of Medical Ethics*, 15 (3), 117-123, p.118

[46] Denscombe and Aubrook op.cit., n.19; David et al., op.cit. n.3

[47] David et al. op.cit., n.3

[48] Ibid., p.352

[49] Powell & Vacha, op.cit., n.44

[50] Denscombe and Aubrook op.cit., n.19; David et al. op.cit. n.3

checking that children are still willing to carry on. Sometimes children are afraid to refuse, and the researchers need to watch out for cues and gently check how they feel^[51]. In order to obtain free and continuing consent, researchers must provide children with the opportunity to withdraw from research whenever they wish. All of those rules have to be considered before setting any medical, or social science research with children, such as research with young offenders, sexually or physically abused children, otherwise research carried out without taking those rules into account- as mentioned before- has to be regarded as unethical, and inconsistent with the essential elements of informed consent.

4.2. Disclosure and Understanding

Disclosure and understanding are another two crucial elements of informed consent. No matter how intelligent they are, children can not fully understand the whole concept of the research without the aid of professionals who seek consent. Understanding disclosed information and granting a valid and free consent is totally dependent on forming a good and mutual communication with children.^[52] In order to do that, researchers should use simple language and methods which are based on children's skills, and develop innovative and adapted techniques such as pictures, drawings and sentence completion. Additionally, researchers must take special care to explain the purpose of the research, the length of time it will take, the procedures that will be used, a description of the potential benefits and risks, as well as the child's right to refuse to participate, in terms that the child will understand.^[53]

5. CONCLUSION

As mentioned before, children are beginning to be perceived as competent social actors, as a result of the United Nations 1989 Convention on the Rights of the Child. However, perceiving children as competent social actors does not necessarily mean that research should be conducted in the same way as with adults. Due to their special vulnerability and inherent inability to give a fully informed consent, the issue of informed consent must be considered to be the central difference between research with children, and research with adults. Research carried out without addressing the issue of informed consent and examining whether or not a child has sufficient capacity to fully understand the concept of the proposed research, has to be regarded as unethical, unlawful and inconsistent with the universally accepted basic principles of scientific research such as objectivity, and impartiality. Therefore, when doing research with

[51] Alderson, 2004, op.cit., n.18, p.107

[52] Faden & Beauchamp, op.cit., .n.43

[53] Powell & Vacha, op.cit., n.44, p.447

children and obtaining consent from them, researchers should always employ innovative and adapted techniques, and respect children's evolving capacities and autonomy. A method, which is consistent with the principle of respecting the evolving capacities of the child, set out by Article 5 of the UN Convention on the Rights of the Child, should be devised and used. Otherwise, we can not talk about a scientific research; in other words, addressing the concept of informed consent and children's evolving capacities and autonomy is sine qua non for conducting ethical, lawful and scientific research with children.

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