Annotated References

Conroy, H., & Harcourt, D. (2009). Informed agreement to participate: beginning the partnership with children in research. *Early Child Development and Care. 179,* (2), 157-165. doi: 10.1080/03004430802666973

This paper draws from the United Nations Convention on the Rights of the Child and the idea of a New sociology of childhood to discuss the notion of child assent in research. There is a particular focus on collaborative research.

Fisher, C. B. (2003a). A goodness-of-fit ethic for child assent to nonbeneficial research. *The American Journal Of Bioethics: AJOB, 3*(4), 27-28.

In this article, the author discusses parent permission and child assent within a goodness-of-fit framework. This framework recommends using consent procedures that fit to the research context and the child’s developmental capacities.

Fisher, C. B. (2003b). Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities. *Mental Retardation & Developmental Disabilities Research Reviews, 9*(1), 27-31. doi: 10.1002/mrdd.10052

Similar to the article above, this paper discusses a goodness-of-fit approach with research involving participants with cognitive disabilities.

Iacono, T., & Murray, B. (2003). Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*(1), 41.

This paper discusses the need for “supported decision-making” in regards to consent procedures involving those with cognitive disabilities. Supported decision-making involves the use of significant people in an individual’s life to provide support in evaluating the risks and benefits of research participation. Additionally this paper discusses the idea of reactive dynamics and the belief some researchers hold that we have created too restrictive ethical requirements.

Krugman, S., (1986). The Willowbrook hepatitis studies revisited: Ethical aspects. *Reviews of Infectious Diseases*. *8* (1). 157-162.

Is it ethical to give mentally disabled children hepatitis? Children were given no choice? Parents were given a consent form that would never pass standards today. Krugman revisited the idea and defends the ethics of the study. He says the children were likely going to develop the disease anyway. Based on the 1958 study, they did find a cure. The research improved over cohorts and became more ethical.

Lahman, M. K. E. (2008). Always othered: Ethical research with children. *Journal of* *Early Childhood Research. 6,* (3), 281-300.

Children are always othered. In cases where the child is a minority (race, SES, etc) they are doubly othered.

Levy, M. D., Larcher, V., Kurz, R. (2002). Informed consent/assent in children. Statement of the ethics working group of the confederation of European specialists in paediatrics (CESP). *European Journal of Pediatrics. 162*, 629 – 633. doi: 10.1007/s00431-003-1193-z

This paper gives criteria for determining the child’s ability and competence to give assent in medical procedures. Also, included is a list of relevant information that should be provided to the child in age appropriate language. This paper is focuses on medical research, but the principles can be applied to other types of research.

Lott, J. P. (2005). Module three: vulnerable/special participant populations. *Developing World Bioethics, 5*(1), 30-54.

Some individuals may have cognitive or intellectual challenges that limit their ability to understand complex abstract concepts, read or comprehend text or fully understand the implications of the research or decision-making process. This paper discusses these challenges and suggests ways to improve the consent process.

Moore, L. W., & Miller, M. (1999). Initiating research with doubly vulnerable populations. *Journal of Advanced Nursing. 30* (5). 1034 – 1040.

More information about undertaking research with children from otherwise vulnerable populations (minorities, cognitive diabilities, etc…)

Parr, M. (2010). Solving ethical dilemmas with children: Empowering classroom research. *Journal of Education, 45* (3), 451-461.

In the classroom there are multiple power roles (student, teacher, researcher). The researcher must balance the goals of the research with the needs of the child. When working in a classroom, research much be flexible as the day-to-day in school is apt to change.

Renold, E., Holland, S., Ross, N. J., & Hillman, A. (2008). ‘Becoming participant: Problematizing ‘informed consent’ in participatory research with your people in care. *Qualitative Social Work. 7,* 427 – 447. doi: 10.1177/1473325008097139

Rossi, W.C., Reynolds, W., Nelson, R. M. (2003). Child assent and parental permission in pediatric research. *Theoretical Medicine, 24,* 131-148

This paper uses a developmental continuum to discuss issues in obtaining consent from children in pediatric medical research.

Sudore, R. L., Landefeld, C. S., Williams, B. A., Barnes, D. E., Lindquist, K., & Schillinger, D. (2006). Use of a Modified Informed Consent Process among Vulnerable Patients. [Article]. *JGIM: Journal of General Internal Medicine, 21*(8), 867-873. doi: 10.1111/j.1525-1497.2006.00535.x

This paper examines the usefulness of a “teach-to-goal” informed consent strategy. The study required participants to take a comprehension quiz after being read a consent document. When an incorrect answer or “I don’t know” response was given, the researchers when back to that portion of the consent document and re-taught that portion of the document. Results showed that after 4 re-teachings 98% of the participants were able to provide accurate information about the consent form, research procedure, and participation requirements.

Wendler, D. (2005). Protecting subjects who cannot give consent: toward a better standard for "minimal" risks. *The Hastings Center Report, 35*(5), 37-43.

This paper discusses the current consent process for vulnerable populations and the risks involved in research participation. The author urges researchers to create a new standard for what constitutes “minimal” risk in order to more fully protect vulnerable populations.