



CENTRE FOR BIOETHICS

at Karolinska Institutet & Uppsala University



VIII Annual Symposium on Biomedicine, Ethics and Society: "Rethinking Informed Consent: The limits of autonomy"

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Autonomy's blind spots: Insights from child development and global health

What do a seven-year old boy in a Siberian orphanage, a young leukemia patient from Guinea, and a fifteen-year old Zambian girl who is now head of household have in common? Not one of these patients was autonomous in the strict sense and yet each made engaged, meaningful medical decisions with support. Contemporary bioethics continues to place a remarkable emphasis on individual patient autonomy over and above other values in health care decision-making: such as patient well-being, family harmony, or public health. With recent increased interest in public health ethics, especially issues involving global health, more attention is being given to areas of clinical decision-making typically overlooked by an autonomy-centered bioethics. Age, poverty, broken families, social and political chaos, the emotional stress of widespread illness in a community—all can undermine the possibility of autonomy and informed decision-making. I argue that this class of cases involving autonomy-failures represents, in fact, overlooked successes in ethical decision-making. Further, these successes point to a more promising model for ethically justified medical decision-making. Drawing on my work in pediatric decision-making in a Russian orphanage, recent data on child development, and data on decision-making in the context of HIV/AIDS in Sub-Saharan Africa, I argue that we should reject the dominant appeal to autonomy in favor of a more complex appeal to “agency”. To build the case for agency, I rely on a version of Amartya Sen’s model of basic human capabilities, revised in light of recent work in child development. In cases like those above, while the conditions of autonomy are absent or seriously curtailed, creative reliance on existing support and patient capabilities make engaged, meaningful choices possible. These insights can be generalized: Rethinking the goal of medical decision-making with patients, families, and communities as an activity aimed at promoting basic capabilities can better guide ethical choice in clinical encounters, and in a wider array of clinical encounters.