

4.H. Workshop: To be or not to be vulnerable: ethical challenges in taking children and young people seriously

Organised by: EUPHA section Ethics in public health
Contact: e.l.m.maeckelberghe@umcg.nl

Chairperson(s): Peter Schröder-Bäck - The Netherlands, Auke Wiegiersma - The Netherlands

Background

There is a general acceptance that children and young adults (YA) should be heard about their health needs. Internationally codes and guidelines have been drafted encouraging the development of autonomy of children/YA and protecting them in their vulnerabilities. However, many policies and discussions about health decisions and health management struggle granting children and YA their proper place. De Vries¹ for example identifies three pervasive dogmas: 1. Children/YA are a vulnerable population; 2. Children/YA are not able to give true consent; 3. Children/YA are genuinely heard and their opinions are taken into account. She argues we are still insufficiently clear about what children and YA can and cannot do.

Purpose

In this workshop we will explore the ethical challenges set to us. We need to address an agenda that includes the following issues: developing autonomy and its relation to dependency and vulnerability; development of life skills and assertiveness, as protective factors for health; involvement of young people in health programmes; dependency of disabled children on helpers, carers, but of course on their parents too.

Methods

We (a mother of an adolescent from the autistic spectrum and MA in psychology, the Head of Training for French school physicians, public health researchers and ethicists) will address the questions about vulnerability, dependency and autonomy of children and YA from a variety of areas: collaboration between children, families, educationalists and health professionals; participation of children/YA in trials; the necessity of statutory regulations for protection of children from food advertising. All presentations will critically address the so-called pervasive dogmas about the place and position of children and young adults.

Results

At the end of this workshop, a clearer understanding and framework for addressing ethical challenges regarding children and YA in (public) health will be presented.

Key messages:

- Public health researchers and professionals need to focus on a better understanding of children's and young adults' autonomy
- A serious collaboration between children/YA, families, researchers, and other professionals will provide an enriched notion of autonomy

The ethics of true collaboration between children with ASD, their families and education and health professionals

William Sherlaw

W Sherlaw, K McColl, A Ducros

Department of Human & Social Sciences and International Relations EHESP
School of Public Health, Rennes, France
Contact: William.Sherlaw@ehesp.fr

Background

The UN Convention on the Rights of Persons with Disabilities (2006) upholds 'the development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential'. Health may be defined as the capacity to carry out one's vital goals (Nordenfelt) and is related to educational achievement and development of autonomy. Achieving health for children thus is a shared responsibility by the school in partnership with families, school doctors, teachers and school assistants. Development of child autonomy occurs within a contradictory context. Adults' perceived responsibility to protect the child, contrasts with the child's desire to assume responsibility for developing their own autonomy. Every child deserves the right to develop autonomy in their own way, matching the degree of responsibility they feel ready to assume. This is particularly important for children with a disability or a health issue, who

need compensatory measures to offer them greater equality of opportunity to develop such capacity.

Methods

We will narrate the case of an adolescent with an Autistic Spectrum Disorder (ASD) within the French school system, from a family perspective, and how, in spite of substantial reform, the drafting of guidelines, allocation of resources and much goodwill, such compensatory measures fail to be applied.

Discussion

To respect ethically based decisions, it is necessary to achieve full investment of partners responsible for implementing the educational decisions. Insights gained from this case may promote understanding, discussion, investigation, research, and theoretical frameworks for policy revision. We must facilitate optimum development of all students. This involves transforming students with disabilities from being 'victims' of an imperfect system in which decisions are imposed upon them by others, into autonomous actors participating actively in their present and future.

Why young people participate in clinical trials

Els Maeckelberghe

M Luchtenberg¹, E Maeckelberghe¹, L Locock², L Powell², AA Eduard Verhage¹

¹University of Groningen, University Medical Center Groningen, Groningen, The Netherlands

²University of Oxford and Oxford NIHR Biomedical Research Centre, University of Oxford, Oxford, UK
Contact: e.l.m.maeckelberghe@umcg.nl

Background

Given the lack of knowledge about safety and efficacy of many treatments for children, pediatric clinical trials are important, but recruitment for pediatric research is difficult. Little is known about children's perspective on participating in trials. Purpose: To understand the experiences and motivations of young people who took part in clinical trials.

Methods

Qualitative interview study of 25 young people aged 10-23 invited to take part in clinical trials. Interviews were audio or video recorded and analyzed using framework analysis.

Results

Young peoples' motivations were both personal benefit and helping others. Both incentives appeared to be more complex than expected. We introduce the terms 'network of exchange' (a feeling of moral duty to others, i.e. other patients, parents, and doctors) and 'intergenerational solidarity' (acknowledgment of the contribution made by past generations) to describe these motivations.

Conclusions

To improve recruitment, professionals should be more open about research opportunities, provide better information, and give young people feedback after the trial has ended.

Discussion points for the workshop: The current information procedure (informed consent/informed assent) does not address the information needed for children participating in clinical trials. Information more directed at what children themselves value would be more adequate. In order to improve the assent procedure, we need to use the information young people themselves value. We want to discuss the much debated concepts of 'altruism' and 'benefits' from the perspective of 'networks of exchange' and 'intergenerational solidarity'.

A proposed European statutory regulation of unhealthy food advertising to protect children

Miguel Ángel Royo-Bordonada

MÁ Royo-Bordonada, A del Pino

National School of Public Health, Institute of Health Carlos III, Madrid, Spain
Contact: mroyo@isciii.es

Background

Food advertising targeted at children is associated with the development of unhealthy eating habits and childhood obesity. Children are an easily influenced and highly vulnerable population group vis-à-vis advertising. Until the age of 5-6, when eating habits are acquired, children are unable to identify advertising on television, until the age of 7-8 they are unable to discern the commercial aim of such advertising, and at the age of 12 the majority of them are still unaware of its persuasive intent.

Analysis

Up to this age, children lack the necessary cognitive maturity to be sceptical about commercial messages and the claims that these contain, which they judge to be true, fair, accurate and balanced, when in reality this is not always the case. Consequently, all advertising targeted at children under the 12 can be considered misleading per se. However, most European countries have opted for self-regulation of food advertising targeted at children, which many studies have shown to be ineffective.

Discussion points for the workshop

From this standpoint, it could be argued that the a statutory regulation to ban unhealthy food advertising targeted to children is not only legitimate but also constitutes a measure which the authorities are duty-bound to take, in order to protect children, a vulnerable segment of the population, from undue influence that affects their eating habits, with pernicious consequences for their present and future health.