



RESUSCITATION AND INTENSIVE CARE OF CHILDREN WITH SERIOUS INTELLECTUAL DISABILITIES

During autumn 2006 there was discussion in Finland about the care, principally resuscitation and intensive care, of children with serious disabilities and exclusion of children with serious intellectual disabilities from these treatments. The discussion was initiated by an article written by Docent Tuula Lönnqvist in the Finnish journal *Duodecim*: How to secure the right treatment of people with the most serious disabilities in intensive care? (*Duodecim* 2006;122:1940–1). The article is a part of the extensive theme 'intellectual disability' dealt with in that issue. The National Council on Disability (VANE) expressed its opinion on the issue (VANE's statement: [Vaikeavammaisen lapsen elvyttäminen \(resuscitation of children with serious disabilities\) \(22.12.2006\)](#), www.vane.to). Also the National Advisory Board on Health Care Ethics decided to discuss the issue. The Advisory Board heard Docent Tuula Lönnqvist from the Helsinki University Central Hospital, Hospital for Children and Adolescents, and Secretary-General for the National Council on Disability, Senior Officer Sari Loijas, at their meeting on 10 January 2007.

Among the many statutes regarding health care, the rights of patients resident in Finland are regulated, above all, by the Constitution of Finland (731/1999) and the Act on the Status and Rights of Patients (785/1992). According to them patients have the right to be treated fairly and equally in health care irrespective of, e.g., their health state, disabilities or other causes relating to their person, and they are entitled to quality health care and medical care.

Children with serious intellectual disabilities constitute a heterogeneous group of children. Children's development and disorders in it vary, and a handicap caused by a disability may be alleviated, remain unchanged or become more serious. Serious intellectual disability is often linked with structural deviations, other disabilities or chronic diseases for which the child gets various treatments and rehabilitation.

A significant number of children with intellectual disabilities are today living in their own homes. Families' everyday life is supported by special services, assistive devices and financially. In this way it is possible for many people with serious intellectual disabilities to live a meaningful life in their own homes. Only in particular situations, often when the child's health deteriorates, a child normally living in his or her home is admitted to a hospital. Some of the children with the most serious intellectual disabilities are placed in particular institutions for people with intellectual disabilities, either for respite care or on a permanent basis. Children in institutional care are cared for in mutual understanding and cooperation with the children's parents.

The prognosis for many children with serious intellectual disabilities has changed over the recent decades. For instance for children with an extra chromosome 21 (Down's syndrome) structural heart diseases (most often absence of the atrioventricular septum)



and other structural abnormalities are treated when it is possible from the medical point of view. Recovery of children with intellectual disabilities from an infection or treatment may take place more slowly than in case of a normally developed child, but if it can be expected that the child will recover so as to be able to take part in meaningful everyday life for the child and his or her family, the child must obtain treatment, and the treatment should be given at a similar intensity as to other children. In these situations it is not meaningful to limit intensive treatments in regard to either children with disabilities or other children.

If a child has a progressive brain disease, the treatment of the disease becomes more difficult with time. Then those involved will inevitably be faced with a situation when intensive care is considered to cause more harm than benefit. According to medical ethics, treatment that results in more harm than benefit may not be given. Treatment options must be sought among such treatments the benefits of which are anticipated to be greater than its harms. Refraining from intensive care may alleviate a child's condition more than intervention treatments. A patient may however not be left without care in any situation, and suffering and pain must always be treated by the best possible care methods.

It demands a great deal of professional skill to evaluate when a certain treatment or procedure would cause more harm than benefit. A decision on giving up intensive care or refraining from resuscitation must therefore be the responsibility of an experienced medical specialist. The decision must always be based on a comparison of benefits and harms. Intellectual disability as such is not a cause for refraining from resuscitation or intensive care.

Refraining from resuscitation and intensive care is an important care decision that must be based on intelligible information and that must be made in mutual understanding with the child's parent or other legal representative. It is important to record the care plan and decisions in the patient documents, in which case the care guidelines agreed upon jointly can be observed in emergency situations too.

It has been characteristic of the recent public discussion on the theme that many terms used in it have been vague, which is disturbing. In the discussion, the concepts 'serious intellectual disability' and 'serious disability', 'progressive brain disease' and 'stable condition' have been mixed up. Also the definition of procedures being part of resuscitation and intensive care has remained vague and terms have been used inconsistently. Then the different parties are talking different things. *Resuscitation* consists of assisting in breathing and restarting a stopped heart and, relating to it, support for respiration and circulation to maintain other vital functions. *Intensive care* involves monitoring, maintaining and supporting the vital functions of a seriously ill patient. Treatment is monitored by means of various devices and samples are taken at short intervals. It is characteristic of intensive care that it involves many procedures. It is justified in a highly dangerous situation that is considered to be passing when the benefit of the treatment is assumed to be greater than the harm caused by it. In certain situations, intensive care and resuscitation are the best possible care of a patient, while refraining from them is that in some other situations. Discussing those situations, their careful definition and a thorough weighing of different care options may reduce parents' concern, fears and suspiciousness towards the care staff.

In order to make some progress in the discussion, we need a clear, common language and terms. It is important that those involved in the discussion talk about the same things although the point of view would be different. Disability is not a ground for different treatment in health care. Children with serious intellectual disabilities are, in

accordance with the principle of equality, entitled to the best possible care in Finnish health care. It is vital to continue the discussion about what is the best possible care for each one.

On behalf of the Advisory Board

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