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## In this number

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### Disease "clustering"

Although there has been no formal correspondence for publication, a paper in the last number excited some controversy. It related to "clustering" of illnesses, and this number has several other papers in this general area although with different hypotheses and different illnesses. We do not believe that discerning readers will be disturbed by the airing of important problems even though the methods may be difficult and even arguable.

### Coronary heart disease

This remains a constant theme, including studies of and recommendations about diet – dietary fat in particular. Maintaining a European and worldwide perspective will no doubt help in extending our understanding of the public health implications of research in this area.

### Supplements

Readers should note that several supplements to the journal are planned for 1995; more information will be available soon.

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## Editorial

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# Quality of life for children and disabled children based on health as a resource concept

Over recent decades the quality of life (QoL) concept has been used increasingly, both in everyday language and in science. Public health and medicine have focussed on a health related QoL – that is, the measurement of perceived wellbeing in relation to functional status – but the concept has a much broader, interdisciplinary potential that needs to be addressed.

There is no commonly accepted definition of QoL, although the development of a broadly based concept that can be used to assess the QoL of vulnerable groups in society, such as the disabled or children, is important. QoL needs to be based on essential population resources – that is, the conditions that are necessary for people's development of positive experiences, relationships, and perspectives on their present and future lives and thus predict a better outcome in life.

### Defining the concept

Because the QoL concept is abstract and ill defined, it is a difficult area to research. It is, however, an excellent field for interdisciplinary study because of its complexity and because a broad understanding of the boundaries of disciplinary and professional relations is needed. The first task is to take an overview; to consider the ways in which various disciplines have approached the QoL concept and to analyse how QoL relates to health assets. Then a general QoL definition is formulated that describes the essential resources of life for an individual, a group, or a society in terms of both objective and perceived subjective conditions.

This definition then has to be operationalised in a general QoL model that encompasses four life spheres – the global sphere representing society and the macro environment, the external sphere representing socioeconomic conditions, the interpersonal sphere representing the structure and function of social support, and the personal sphere representing physical, mental, and spiritual conditions. This model may be said to have universal application.

### Developing a model

In public health this model can be used as an outcome measure and applied to health promotive or salutogenic mechanisms – that is, conditions that enhance positive development. The model is applied to children here. Studies of children place special demands on research because the child's cognition and perception of life are different from those of adults, and methods of studying children have therefore to be specially designed. This is particularly evident in the study of children's perceived QoL.

It is difficult to take an overview of modern society, its complexity, its mechanisms, and its structure. In QoL research on adult populations the global and external spheres are often used as background conditions and are therefore left out of studies. For a child global and external spheres are often far beyond comprehension and are thus taken for granted because the children are born into these circumstances. Therefore all four life spheres have to be integrated in children's QoL. The health promotive aspects are particularly important to children because they have a lifetime ahead of them. A corner stone is equity – the QoL, in its operationalisation, must serve the principle "in the best interests of the child". Equity also means that the QoL of children with disabilities comprises the same factors that are important to children without disabilities.

### A Nordic standard for QoL

In analysing children's QoL in the five Nordic countries (Denmark, Finland, Iceland, Norway, and Sweden) a normative approach was used. For each variable a base value was defined that took into consideration both the general level of development in the Nordic countries and the special requirements of children. Base values were determined by examining and analysing available research reports and statistics. The QoL resources, taken together, are considered to provide each child with sufficient to enjoy a reasonably good life in the Nordic countries. In this way a QoL standard for children was established. Because some conditions are considered similar in the Nordic countries

part of the global sphere was excluded in the comparison.

An overview of international research and statistics shows that the Nordic countries are among the most affluent in the world. The World Bank developed an index, the physical QoL index, that was intended to be a more relevant outcome measure of socioeconomic development than the GNP per capita:<sup>1</sup> four of the Nordic countries ranked highest in the world. Later an index of children's QoL was developed in which Iceland held top position in the world.<sup>1</sup> Vital statistics on life expectancy, perinatal and infant mortality, accident mortality and morbidity again put these countries among the foremost. They also have a relatively equal distribution of economic resources in the population, a measure that correlates strongly to infant mortality: Sweden holds the top position followed by Norway.<sup>1</sup>

Thus, the Nordic child is provided with one of the most favourable platforms for life. His or her possibility of surviving birth and leading a long life is statistically among the best in the world. In addition, the Nordic welfare states provide a substantial legal, social, and economic support system that sustains children's health, provides education, and protects their well-being.

On the other hand, there are factors that can be less favourable for children. The absolute and relative numbers of children in the Nordic populations are decreasing because of fewer births and longer life expectancy. Children have no direct economic or political rights, and therefore no economic and political influence. This issue has been discussed as a means of empowering children and improving the respect with which they are viewed by society and their position: the discussion is similar to that over women's rights at the turn of the last century.

In public policy the family is seen as a supportive setting for children which indirectly provides them with political and economic resources, but Nordic families have recently gone through several radical changes and have become more mobile, urbanised, smaller, less stable, and perhaps more isolated. Although more parents and grandparents are alive than ever before in history, the generations often live far apart and spend little time together. A fundamental change is the recent shift towards mothers working outside the home. This has, however, increased the education level and equity for women, which is positive for the children. Society has also partly responded by providing better child allowances and institutionalised services for child rearing.

To conclude, the children and their parents partly live in separate worlds. Negotiation and time management have become central issues in Nordic families.<sup>1</sup> Moreover, children have become more dependent on the welfare society's institutions in developing their knowledge and skills for life.

Most children in the Nordic countries had a good QoL – that is, nearly 70% exceeded the basic prerequisites of the Nordic standard for children's QoL. Furthermore, the differences were generally small between the countries. Children in Sweden, Denmark, and Norway had the best overall QoL, while that of Finnish children was slightly lower because of lower objective conditions, and Iceland had the lowest QoL, mainly because of low subjective conditions. Overall, Swedish children ranked slightly higher than the other children. They had the highest means in terms of overall objective and subjective conditions. In addition, the interpersonal and personal life conditions, which, according to Naess, correlate most closely to mental wellbeing,<sup>1</sup> were the highest in Sweden.

### Comparing children with disability

The QoL of children with two defined disabilities, cystic

fibrosis and myelomeningocele, was also examined using the normal population as a control. Surprisingly, the differences in QoL were quite small in terms of material well-being; a result that differs from most previous research, which claims that families with disabled children have fewer socioeconomic resources than the average families. Published reports generally claim that social support networks are less developed and family breakdowns more common in families with disabled children. This was partly repeated here but the differences were smaller than expected and the greatest differences occurred in the personal sphere. The self esteem of both groups of disabled children was rated much lower by the parents than that of the control group, and, furthermore, self esteem was lower the older the disabled children were. A high level of satisfaction (over 60%) with the various aspects of life was found in the control population.

The total QoL ratings in the study group suggest that children have a reasonable QoL in the Nordic countries. In addition some of the inequities regarding vulnerable children with disabilities have been reduced but the prerequisites for mental wellbeing were somewhat less advantageous.

An analysis of the relationship between QoL and children's reported health problems was also undertaken. This showed that the correlations between QoL and health problems were weak – that is, the QoL concept defined and used here to describe dimensions of life that are rather independent from disease – bringing new perspectives to public health.

### Achieving equity

The wellbeing of children, especially of those with disabilities, is a real challenge to any society. It is also arguably the most powerful arena for equity in health. Equity is a cornerstone of the Nordic welfare societies, it is the first of the 38 specific targets that WHO's member states have adopted in their Health for All strategy for the European region and is also supported by the UN Convention for the Rights of the Child. The model used here provides a vehicle for exploring the wellbeing of children with disabilities not only in terms of their health problems but also their QoL resources. Progress towards greater equity can therefore be assessed in terms of any success in ameliorating their health problems and in augmenting their personal resources, so that they have the same chance as people without such disabilities to lead satisfying, productive, and fulfilling lives, which is the ultimate health goal.

If anything this model will have even greater relevance to Health for All objectives in the future. In 1991 the Health for All targets were updated by the WHO Regional Committee for Europe. The emphasis on equity and prevention of chronic disease is retained. There is also a new target for children and young people, a sharper target for disability, targets for health promotion settings including the family and the school, and a new target on QoL. The need for strong models with explanatory and predictive power to explore the dimensions of QoL has never been more evident.

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<sup>1</sup> For review see: Lindström B. *The essence of existence – on the quality of life of children in the Nordic countries*. Göteborg: Nordic School of Public Health Report. 1994:3.