

Chapter 8

Quality of Life in the Polder: About Dutch and EU Policy and Practices in Quality of Life for People with Disabilities¹

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Introduction

Typical Dutch: Polder model

The Netherlands is probably best known for clogs, tulips, bikes and above all taming the water. Many parts of the Netherlands are below sea level, and with a dense population in a small country (17 million people on 41.500 km²), land was gained from the sea: the polders. These facts influenced the Dutch culture. For centuries the Dutch have had to fight the water. Landlords have had to negotiate with each other to build and maintain dikes around the polders. When in the 1990's the Dutch economy had better results than other EU countries, the explanation was found in the so called 'polder model'. In the political field no left or right wing were dominant, but a 'third way' of consensus after elaborate negotiating between parties was found (Wikipedia, 2008).

When describing Dutch policy and practice in the intellectual disabilities field, and more specifically in relation to quality of life (QoL), one should keep this so called polder model in mind. In striving for QoL in the disabilities field, the Dutch stakeholders negotiated about what and how QoL should have a place in the debate. In the following sections these developments will be described and discussed.

We will continue with a description of QoL as a sensitizing, organizing and reflecting concept. In the second section the Dutch health care system and relevant legislation is described, highlighting changing paradigms, changing roles of stakeholders, and at national level the QoL framework.

We will briefly refer to EU developments in this respect. How QoL is put into practice is described in the third section. We will give examples from perspectives of several stakeholders in the disabilities field. In the last section we conclude with the discussion.

Quality of Life

Aristotle defined quality of life, or 'eudaimonia' as the meaning and the purpose of life, the whole aim and end of human existence. Quality of life is a universal concept, of all places and times. As Aristotle stated, it is even the meaning of life. Searching the internet for QoL, you come up with millions of hits, indicating the widespread use of the concept.

Over the past decades, in the field of care and disabilities, the concept of QoL has received an international or global perspective, and been applied in several ways; as a *sensitizing, organizing* and *reflecting* concept (WHO, 1993, Brown & Schalock, 2006). Quality of life can be considered as a sensitizing concept that gives a general idea of what is important in life. The concept gives sense to several stakeholders in the disabilities field to be aware of 'what it is all about': people

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with and without disabilities want to live a quality life. As an organizing concept QoL (operationalized in dimensions and/or domains) provides a framework at several levels. For example, at a macro-level, the WHO uses the concept in describing poverty around the world (WHO, 1993). At a meso- and micro-level, domains of QoL are used in similar ways, as highlighted in the third section relating to the Dutch situation. QoL as a reflecting or evaluating concept gives a reference for evaluating performance, e.g. legislation or care provision. QoL has influenced Dutch policy on intellectual disabilities as a sensitizing, organizing and reflecting concept.

Policy

In the past few decades, mostly after deliberate debates and ‘poldering’, the Dutch health care system has changed. We will first provide a general overview of the Dutch health care system and the associated changes followed by a more specific discussion in relation to the disabilities field.

Health care system

The Dutch care system has significantly changed over the past decade. The *cost* system changed the *structure* and reflects the changing paradigm.

In the Netherlands we have an insurance based *cost system* in health care, similar to other European countries such as Germany, Austria and Belgium. Other EU-countries, like the UK and Sweden have a national health care system. In the Netherlands, the government does not participate directly in the actual provision of care. This is a task principally for private care providers: individual practitioners and care institutions.

In 2006 a new insurance system was introduced, following decades of debate about the escalating cost of the health care system. The Netherlands spends almost 10% of GDP on health care; the highest of any EU country (Ministry of HWS, 2006). With the expected change in demographics caused by an aging population it was feared the old health system would become unaffordable. Compared with the old system of standard insurance for all citizens, the new system is more market driven. It gives citizens the possibility to change insurance company, and for insurers and care providers to compete on cost and performance (Ministry of HWS, 2006). Chronic illness and disabilities are insured via the so called AWBZ, the General Act for Special Health Care Costs. The aforementioned principles apply to this act as well.

The new cost system changed the *structure* of Dutch health care, amongst other things, it meant changing roles for the stakeholders such as government, the insurance companies, the care providers and of course the citizens (as well care consumers as/or insurance payers). Citizens have more choice between insurance companies and care providers.

Other legislation defines more or less the roles of the different stakeholders and their relationships in the care system. Those acts apply in the disabilities field as well. The Quality Act obliges care providers to provide care that is at a high standard, effective, efficient and client centered. The care provider has to maintain a quality system. The Act on Individual Professions in Health Care aims for good professional practice through a process of registration, education and disciplinary rules. The Act on the Medical Intervention Agreement defines the relationship between the client and care provider by means of a formal agreement and informed consent. In the Act on Complaints of Clients in the Care Sector, clients have means of complaining about interventions or omissions of the (individual) care provider. Recently the Community Support

Act was adopted, followed by the introduction of a number of essential changes in the distribution of responsibility in respect of participation by vulnerable citizens. These acts all came into practice in the last decade, reflecting the *changing visions* in health care. Before elaborating on these changes we will first describe the disabilities field in the Netherlands.

People with intellectual disabilities: some facts and figures.

The number of people with intellectual disabilities (IQ<80) in the Netherlands is approximately 112,000. This number is estimated to remain stable until 2020 (SCP, Social and Cultural Planning Office of the Netherlands, 2005). The majority of people with intellectual disabilities need support to contribute to their quality of life. Support varies in intensity, complexity, continuity and labor-intensity and can change over time, depending on the individual's own development and changes in their social context. Informal and formal support can be distinguished. Informal support is provided by the social network such as family, relatives and neighbors. Whereas, formal support is provided by general and specific service providers, (Schippers, 2003). Professional support is provided to approximately 88,000 persons with intellectual disabilities (VGN, 2007). The above described General Act on Special Health Care Costs (AWBZ) and the Community Support Act entitle individuals to professional support, if required. In every region a person can choose from several professional care providers. These agencies, or sometimes individual professionals, provide all common types of support such as living and vocational support, respite care and 24-hour care. Allocation of resources differs at local level, but most people can choose from different providers, despite some waiting lists.

QoL as a sensitizing concept: changing paradigms

In the mid 1990's a paradigm shift took place in the disabilities field in Western Europe (including The Netherlands) and the majority of the Anglo Saxon countries. In the Netherlands, the perspective changed from viewing people with intellectual disabilities as patients, towards viewing them as citizens, and the support systems changed from institutional care towards community support (Van Gennep, 1994, 2000). Van Gennep (2000) pointed out a difference between a so-called scientific and civil paradigm shift. He stated that in the Netherlands the scientific and civil paradigm are not as congruent as in other parts of western society. In the Netherlands supporting people with intellectual disabilities is less influenced by scientific knowledge and is more influenced by social views. The physical- structural design dominates, not the content of the paradigm shift; e.g. 'community care' instead of 'inclusion'. Recently there have been some promising initiatives such as the Coalition for Inclusion (2008), an association of individuals dedicated to striving for the inclusion of people with disabilities, who are trying to influence policy and decision makers.

In contrary to The Netherlands, at an EU level science does influence policy. The EASPD, a NGO (non government organization) of European Service providers for Persons with Disabilities, produced a memorandum on a European Quality Principles Framework based on scientific insights (EASPD, European Association of Service Providers for Persons with Disabilities, 2006). This memorandum is aimed at improving the quality of services to improve the quality of life for people with (intellectual) disabilities. It is the result of "a fundamental shift" that has taken place from the medical model that stresses disability to a social and human rights model that aims at full citizenship; a paradigm shift from patient to citizen, from segregation to inclusion" (EASPD, European Association of Service Providers for Persons with Disabilities, 2006). The EASPD is proposing to adopt QoL principles as the defining values. "What such principles hold dear are elements such as equality, full participation, inclusion, empowerment,

creating opportunities, offering choices and supporting people with disabilities in shaping their own lives.” (EASPD, European Association of Service Providers for Persons with Disabilities, 2006).

QoL as an organizing concept: changing roles

In the same period that the paradigm shift took place (the 1990's), quality assurance became an important issue in the disabilities field. Quality assurance owed its rise to the same developments in the general health care field ('cure') and the service industry. Professional service providers took the lead in developing quality systems, driven by the idea that quality assurance was a means to be more (cost) effective. Influenced by the paradigm shift at least two developments took place in this so called 'quality decade'; both implied changing roles of stakeholders in the disabilities field.

First, in the early 1990's quality assurance and improvement of support was process driven. From the mid 1990's quality systems became more output and outcome driven, based on QoL. This change can be clearly illustrated by the increased emphasis on professional support plans as an important part of a quality system. This instrument, initially meant to monitor the professional process, also became an instrument for 'clients' to evaluate the support provided, reflecting the empowerment and citizenship of people with intellectual disabilities.

Second, the service providers developed quality systems, that were not only cost effective, but also improved their professionalism. Quality improvement was mainly internally focused. During the aforementioned structural changes to the Dutch health care system (in the first section), quality systems became more of an instrument to justify the provided support to several stakeholders, including clients, insurance companies and the government. Quality improvement became more externally focused, implying changes in quality assurance from processes to output and outcome. The concept of QoL proved to be useful in defining those outcomes.

QoL as a reflecting concept: reference framework

During the change towards a more outcomes focused system, the concept of QoL was not only used as an organizing concept, but also as a reflecting concept. The QoL paradigm is broadly used in The Netherlands. For instance, the Dutch Association of Care providers in Disabilities defined professional support in terms of the contribution of support to the QoL of people with disabilities (VGN, 2007).

A major effort is achieved by the development of a so called 'quality framework' (Kwaliteitskader Gehandicaptenzorg, 2007). All stakeholders of the disabilities field were involved in the development, including client organizations, care providers, professional organizations, Health Care Inspectorate, the Ministry of Health, Welfare & Sports and the Health Care Insurance organizations. The aim of this quality framework is to be transparent, evaluate, justify, optimize and enhance the level of quality of the support provided in the disabilities field. The two major principles of this framework are QoL and self direction. The principles are operationalized in the eight domains described by Schalock & Verdugo (2002) and four quality themes that are basic conditions for providing support. The quality domains and themes are the following: physical wellbeing, psychological wellbeing, interpersonal relationships, social integration, personal development, material wellbeing, self direction, rights, support arrangements & support plan, physical, social and emotional safety, quality of staff and

organization and consistency in support. The domains and themes will be further operationalized through indicators and implemented in the field. Some pilot studies have been conducted recently highlighting numerous applications and best practices in the field (Wijngaarden et al, 2008). We will focus on some of these pilot studies in the next section.

Practice

In applying the concept of QoL we find a parallel with the well known phases of change management: unfreezing, moving and freezing (Lewin, 1947). The first implication of using the concept of QoL is awareness and a sense of urgency to change, similarly with the unfreezing phase. In other words, QoL is a sensitizing concept. In the moving phase the awareness becomes action; things need to be changed. Similarly the sense of urgency to strive for QoL outcomes leads to action; QoL as an organizing concept. Finally, the concept of QoL is used in the freezing phase of internalization and evaluation; QoL as a reflecting concept. In this section we will clarify the three phases of the concept of QoL by describing some best practices, mostly from The Netherlands and some from the EU.

Applications in sensitizing

The concept of QoL leads to awareness. The ‘state of happiness’ is important on a personal level, but also on a meso level for organizations and on macro level for countries. Governments not only refer to QoL in, for instance, the fight against poverty and the war on terrorism, but also in recent disabilities policy, as highlighted in the previously mentioned example of the EU (macro level). A totally different example of sensitizing can be found in the recreation industry. A Dutch chain of holiday resorts brands itself with the slogan: ‘a State of Happiness’.

Many service providers in health care, including the disabilities field, mention QoL in their mission statements. Several good practices can be found at this meso level in the disabilities field. For example, one service provider which supports over 4,000 people with psychiatric or intellectual disabilities states in their mission statement that people with disabilities deserve support enabling them to live an inclusive life in which they experience optimal QoL (Pameyer, 2009). The service provider’s starting point is to support the client in directing his or her own life. At personal (or micro) level, one can find striving for a better QoL in personal support plans of people with disabilities (Schippers, 2003).

Another good practice is from the umbrella organization of clients associations, which mention in their website that they strive for participation in society and self direction (LFB, 2009). The umbrella organization of parents associations promotes that people with intellectual disabilities are part of our society and that they have to live their own lives and participate in their own way. Freedom of choice for all life domains is also promoted (Platform VG, 2009).

At an EU level, the Disability High Level Group, representing all the EU members states under the European Commission presidency, has drawn up a position paper on the “Quality of the Social Services of General Interest”. The purpose of this document is to “provide guidance and inspiration on how to promote quality social services addressing the particular needs of people with disabilities”. Guidance and inspiration is found in the QoL concept including the following key features: rights, person centred services, comprehensiveness and continuity, participation, partnerships, results orientation, and good governance (Disability HLG, 2007).

The examples of good practices in using the concept and domains of QoL in general information

is numerous throughout the disabilities field. The overall conclusion is that the concept of QoL played and is still playing an important role in ‘unfreezing’ the opinions on people with intellectual disabilities.

Applications in organizing

The new paradigm seems to have had an impact in the Dutch and EU disabilities field, but the proof of the pudding is always in the eating. Does the concept of QoL change services, programs, and interventions for people with intellectual disabilities? Implementations of the concept in practice show that this is the case.

A good example of using QoL as an organizing concept is given by a service provider in the south western part of the Netherlands, supporting approximately 600 people with intellectual disabilities. This service provider drew up a vision on living and working, formulated the objectives of the programs, and made them concrete. Essential in this process was that people with intellectual disabilities should be enabled to direct their lives themselves. This insight made it necessary to organize their services in a different way: the individual person became the smallest organizational unit, including the splitting up of supported home living and providing care. Specifically, the emancipation and self-determination of people with intellectual disabilities was the most important starting point for improving QoL (Van Loon & Van Hove, 2001). A focus on QoL was continued during the program changes. The concept of QoL was operationalized and implemented through eight domains of QoL (Schalock & Verdugo, 2002). From a large action research study, the service provider concluded that three out of those eight domains were important in the changes made; these being, inclusion, self-determination and personal development (Van Loon & Van Hove, 2001).

Another service provider in the north western part of The Netherlands focuses strongly on communication of core values in their program changes towards optimal QoL of their clients (approximately 2,500). QoL is operationalized in five elements: relations, respect, skills, participation, and choices. Staffing and recruitment policy does not specifically target experience or level of education but the person’s attitude and personal values. Both staff and clients are continuously and consistently coached. Personal initiatives, a flat organizational structure and a human face for organizational areas are critical in orientating the organization towards quality support. Staff members have the freedom to find their own ways, and are coached and stimulated to do so. Support planning is used to have a dialogue with clients and reflection is systematically organized on all levels (Van Dalen, 2007).

Applications in reflecting

Since the ‘quality decade’ in health care, described in section 2, assessment of products and services is not only process based, but more and more outcome based. This has led the way for using QoL as a reflecting concept.

A terrific example of using the concept of QoL in evaluating services is an EU study aimed at measuring QoL in programs on employment (QoL measures project, qol.euproject.org, 2009). This study needs to be mentioned for more than one reason. First, the emphasis in this study is on employment, one of the major issues in achieving QoL. There is not much research done on employment as a critical part of QoL (Schalock & Verdugo, 2002). Secondly the fact that both western and eastern European countries took part in the study, including Austria, Belgium, Croatia, Finland, Hungary, Ireland, The Netherlands, Portugal, and Sweden. Important indicators

that contribute to QoL in the workplace included working conditions, job characteristics and environment, job match, support, social interaction and integration at the worksite, positive effects of the job (e.g., wages), perceived role, and performance at work. One of the conclusions of this study is that specific employment indicators should be embedded in other QoL domains because the domains are interdependent. QoL at work should not be discussed in isolation from other life spheres. As this study was focused on instrument development, the country samples from the pilot studies were too limited to draw conclusions at (inter)national level (Astegger, 2008).

In a Dutch study on family-related QoL, the concept was used to interpret results from an action research model, aimed at developing partnerships to support nine families with a family member with an intellectual disability. The objective was to contribute to the experience of QoL, namely: ensuring personal needs were met, employment/satisfaction, personal meaning, positive self-image, social inclusion, and improved well-being (Brown & Brown, 2003). The development of various partnerships, for instance with employers, schools, relatives, support organizations and volunteers, led to a change in experienced QoL and improved well-being (Schippers & Van Boheemen, 2009).

These good practices show that the changes influenced by the concept of QoL are becoming internalized in the minds of policy makers and practitioners in the field of intellectual disabilities: they are becoming 'frozen'.

Discussion: chicken, egg or polder?

In conducting the above review of Dutch and EU examples of policy and practice in applying the concept of QoL, one can ask the question: 'Which came first, the chicken or the egg?' It appears that we may have a clue to the answer in that this chapter started with a description of Dutch health care system and legislation, followed by a description of changing paradigms in the field of intellectual disabilities. But this is not the case. It seemed so simple and straightforward, first giving an overview of the Dutch health care system and afterwards zooming in on the disabilities field, in the meantime illustrating some changing views. In describing those developments, it became ambiguous and the chicken and egg question arose. It appears that the developments were mutually influenced; as the changing paradigms in the field do not occur in isolation, but are influenced by changes in society in general. Moreover, in general Dutch legislation is following societal developments, rather than initiating them. In the EU, however, legislation is more often initiating or sometimes even forcing developments.

The time frame that is used to describe the Dutch and EU developments and practices covers the past few decades. In this time frame we described changes referring to Lewin's phases of change, unfreeze, move and freeze. However, by analogy with legislation that follows societal changes, developments in the practice of applying a QoL approach will change over time. Having said this, it would be a 'contradiction in terms' to state that a QoL approach involves 'freezing' good practices, meaning that the status quo will remain forever. Good practices will change over time, because a QoL framework changes over time. However, we are living in this decade and therefore it's important to have an actual focus on QoL outcomes for people with intellectual disabilities.

In the described examples and practices we could drain from a reservoir of practices on sensitizing practices, somewhat less organizing practices were available and little reflective practices. What matters in real-life for people with intellectual disabilities is not issues such as the chicken or egg question, but real QoL outcomes. The concept of QoL is definitely of use in

progressing towards a reflecting model; namely to justify policy and practice in contributing to and improving of the quality of life of people with intellectual disabilities.

The Dutch polder model is aimed at consensus, not necessarily at consistency. In the past the richest farmers mostly stipulated how and where the dikes were built. The ultimate objective for the future in the disabilities field is to strive not only for consensus, but consistency as well.

Consensus is reached in sensitizing, organizing and reflecting applications of the QoL concept; at least at macro level in The Netherlands and the EU. The described practices in this chapter look like separate flowers, not making a well arranged bunch of flowers – another famous Dutch export. If stakeholders at all levels become partners, a world could be won.

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