Social Inclusion
Dutch Perspectives

Factors for Success and Failure

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Introduction

Context

People with an intellectual disability in Europe

Schalock & Verdugo (2002) have shown that inclusion is a major aspect in the quality of life. However, the social position of those who have an intellectual disability in Europe generally, and particularly in the Netherlands, still leaves much to be desired as segregation and marginalization are often still found. Time and again, we are disturbed when we see shocking images of those who have an intellectual disability living in institutions under unacceptable circumstances, far from the rest of society. Frequently, the bare necessities are not even provided and their quality of life is seriously questioned. This concerns a social problem, one which has resulted from an age-old tradition of institutionalizing those who have a disability, and which is a problem that needs to be solved. Mansell et al. (2007) have indicated that more than 1.2 million people with a disability, including children and adolescents, still live in institutions in Europe. The quality of care provided in these institutions is often unacceptable and it is at odds with the international standards for human rights.

‘*The segregation of people with disabilities is in itself a violation of their human rights and is contrary to both national and European social inclusion policies. Despite this fact, too little action is being taken to develop alternatives to their institutionalization.*’

The European Commission has carried out research into ‘Disability and Social Participation’ (Eurostat, 2002). The results of their research study show that, in the fourteen European countries that were investigated, those who have a disability are greatly disadvantaged. The main question of the study was: What is the degree of participation in the main areas of life, such as marriage, family, education, work and social contacts of persons with disabilities? In responding to this question, data from the European Community Household Panel (ECHP) were used, which comprises some 60,000 households including more than 130,000 adults who are over sixteen years of age. The ECHP also asked questions regarding their state of health. Two questions here are particularly relevant, namely whether someone has a 'chronic physical or mental health problem, illness or disability', and to what extent they feel hindered in their daily activities. The responses to these questions allowed a comparison to be made between those who have a disability and those who do not. It can be concluded from the data that there is a significant difference between the social inclusion of those who have a disability and those who do not. Although one should be careful when viewing these conclusions, since the research entails quite a few methodological problems (cultural differences, definition differences, differences in educational systems and care, etc.), a number of problems are still evident. The report concludes that *'... this study provides valuable insights into inequalities in the social participation of Europeans with health problems and disabilities. In summary, compared to people who do not report a disability, those who do report a disability are less likely to be married and more likely to never have been married, have less chance of attaining the highest levels of education and are more likely not to complete their studies. They also have a lower probability of working and those who do work are less likely to work full time. They are more often in blue collar occupations and somewhat more often in agriculture. Their source of income is less likely to be earnings and more likely to be a pension or benefit, for example, sickness and disability benefit, but they are less likely to have no personal income. Finally, a much lower proportion of people reporting a disability report that they are in good health, a lower proportion is satisfied with their main activity and a higher proportion meets friends and relatives less than once a month.'*

Gradually, the notion seems to have prevailed that people who have an intellectual disability in Europe occupy a special position. The positive examples from the Scandinavian and the Anglo-Saxon countries, and especially from the United States, serve as a major source of inspiration here. In various passages of texts, interest organizations such as Disabled People International (DPI), Inclusion International, Inclusion Europe, the European Coalition for Community Living (ECCL), the European Union for Supported Employment (EUSE), the European Association of Service Providers for Persons with Disabilities (EASPD) and the 'Nederlandse Coalitie voor Inclusie' (Dutch Coalition for Inclusion) all plead for inclusion in society for those who have a disability. In this, they are supported by the United Nations which, in the Treaty regarding the rights of people with a handicap (2006), uses inclusion as the most important point of departure. This treaty compels each country concerned to ensure that those who have a (functional) disability can participate equally in society. In addition, the European Commission pleads for social inclusion in various policy documents, such as in 'Europe 2020: A strategy for smart, sustainable and inclusive growth' (2010). In this way, the quality of life for those who have a disability has been designated as top priority on the political agenda.

'Quality of life' is inextricably related to such concepts as participation in society, social participation, maintaining relationships, citizenship and inclusion. When the points of departure for the quality of life form the starting point for how the care and service is designed, this leads to drastic changes in the way the desired care is conceived. In this, we recognize the 'support paradigm' as opposed to the 'institute paradigm'. Working on quality of life takes place in the context of the support paradigm. In the institute paradigm, it is the expert who determines what is good for a person. The 'expert' care provider takes, as it were, total control over the lives of those who have disabilities. The role of professionals is a dominant one and there is hardly any freedom of choice for the individual who is disabled. The supporting organization takes an individual's potential and capacity into consideration when regarding those who have a disability. The responsibility should be placed on the very individual who has a disability and on his or her existing network; the individual and his expert knowledge form the point of departure concerning what should be done. This is supplemented by the expert knowledge provided by the network and possibly experts as well. Therefore, in the case of the 'institute paradigm' those who have a disability consult experts, whereas in the case of the 'support paradigm', the support is offered at home, at school, at work or when planning leisure time. A group approach is not what is offered, but instead individual care and support supplements the natural network.

It is a great challenge to achieve equality, to experience inclusion and to make choices for those who have a disability. In our opinion, three closely related strategies can be developed to that end: a strategy in which an active role is reserved, bottom up, for those with a disability, a strategy particularly aimed at politicians and legislation (top-down) and a strategy in which the (care) institutions play a major role in achieving the preconditions for inclusion (through the centre).

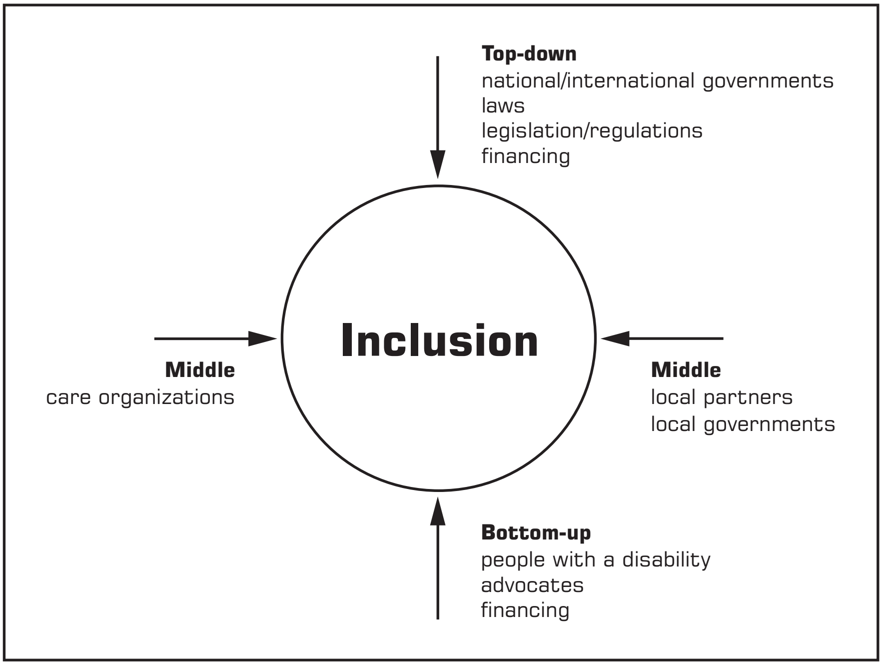

Fig.1 Three strategies for inclusion

Foreign studies (Meyer, 2004) show that the realization of the support paradigm and the realization of inclusion is an unyielding process. In Norway, for example, much has been achieved in the field of physical integration, but social integration has taken place gradually. This has involved a paradigmatic change of a complex nature, in which all 'business parameters' are at stake. From the care organization's perspective, it involves organizational factors (culture, structure, leadership), but it also has to do with the way in which the organization manages to involve the community (legislation, advocates, stakeholders) because inclusion can only be given shape with the help of society. There is a lack of insight into the success and failure factors (practice-based) which play an important role in this radical process of change – and the subsequent managerial tasks that follow. Up until now, not much research has been carried out in this field.

This book examines the role of care organizations and their contribution to inclusion. From the perspective of the care organization, the following questions were asked:
- To what extent does the history of the care have an obstructive effect on inclusion?
- Which roles do the government, advocates and stakeholders play?
- Which roles do the organizational characteristics, the employees and those who have an intellectual disability who are supported by a care organization play?
- Which implementation strategy would be the most appropriate when designing the changes?

According to Beltman (2001), the Dutch context, within which the research took place, shows evidence of an 'apartheid policy' in which those who have an intellectual disability were (and are) taken care of in special institutions. We are aware that the differences within Europe are great in regard to the approach taken, the legislation passed and the resources available for the care and the support offered to those with an intellectual disability. Nevertheless, we believe that important lessons can be learnt from the history of Dutch health care and the insights which have resulted from this research.

Purpose of the book

In writing this book, we would like to contribute to the subject by expanding on existing knowledge and by providing insight into how the quality of life can be improved for those who have an intellectual disability, particularly in the field of inclusion. Hereby, we would like to pay attention to the active components (factors of success and failure) that play a role when designing inclusion, as seen from the care organizations' perspectives (providers of care and service to those who have a disability). In this respect, we have made recommendations to care organizations, authorities, interest organizations and other parties involved in regard to promoting the inclusion of those who have a disability. Finally, we would like to explore what the implications of our findings are in regard to developing a theory in the area of disability studies, a new field of research and education.

We would like to thank Professor Dr. J. Katus for the comments he made and the suggestions that he offered while we were writing this book.

1 Socio-cultural context

The Netherlands

1.1 Not a trendsetter where inclusion is concerned

In the Netherlands, people with a disability often find that they are more on the outside of society than that they feel included. This often results in astonishment and criticism from foreign colleagues, such as in the case of Norwegian Professor Kristijana Kristiansen (2000) who has pleaded that a basic discussion on inclusion should take place. Traditionally, special provisions have been made for a number of differences that place people with a disability in an special position. Several authors have described this special position as the result of maintaining an 'apartheid policy' towards those who have a disability (Beltman, 2001). Baart (2004) mentions the Netherlands as a country that is a champion in confining people and the RMO (2002) calls the Netherlands a developing country when it comes to the position in society of people who have a disability. Internationally, we can see a trend in which the position of people who have a disability is being 'reassessed'. It is a movement that no longer treats people with a disability as being marginalized, second-rate citizens but as full-fledged participants in society. This is a trend that is also supported by legislation. Several noteworthy examples can be found in the United Nations (1994), in the United States (American Disability Act, 1990), in Australia, in New Zealand and in Scandinavian countries. In the former way of thinking, the handicap was, as it were, enlarged. Attention was not focused on the whole individual (1), but the focus was placed on the disability (2) and in so doing, the individual is reduced to a 'disabled person' (3) (Kröber & Van Dongen, 1996).

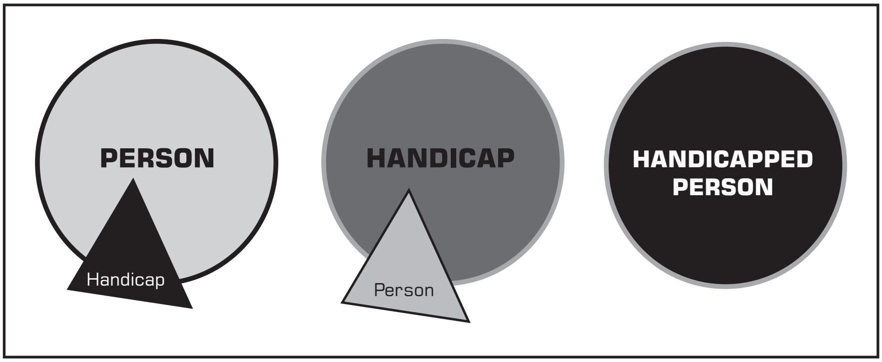

Fig. 1.1 From 'individual' to 'disabled'

1.2 Private initiative, limited influence of government

As is shown, among other things, in the comparative empirical study conducted by Kramer (1981), the private initiative – also called the social center field or civil society – plays a major role in countries such as the United States, England and the Netherlands during the institutionalization of the care for people with a disability. Particularly in the Netherlands, the care system reflects the history of compartmentalization. As it is, care institutions usually have a denominational background (for further reference see under 1.3). In contrast with numerous other countries, the Netherlands does not have any care institutions run by the government. However, when the welfare state developed, state intervention in the care institutions increased. This was manifested at first particularly in the subsidizing of care institutions, which then had to meet certain conditions.

As of the 1960's governments of a number of countries launched policies which were aimed at deinstitutionalization. For example, in the United States large state institutions were dismantled where sometimes thousands of people who had disabilities were housed under abominable conditions. The government's doings were critically monitored by well-organized interest organizations which consisted of people who had disabilities and their relatives. In Scandinavian countries we also witness substantial state intervention in the transformation of care.

This took place at a national level through legislation that enforced a phased deinstitutionalization, at lower levels of public management, by charging the local government with the policy/management and execution of care and support. A major distinction between the American and Dutch institutions was that in the Netherlands much was invested in the quality of housing and education, and in the training of professionals. As a result, the 'sense of urgency' in regard to initiating more fundamental changes was felt to be less urgent. The 'Raad voor Maatschappelijke Ontwikkeling' (Council for Social Development, 2002), a governmental counseling body, had drawn this conclusion as well. For some time the Netherlands had been seen as a pioneer where health care was concerned. Although with the development of the welfare state after the Second World War, the Dutch government gained more control over the developments (Health Act 1956; Exceptional Medical Expenses Act 1967), it did not opt for an 'inclusive' course. Despite the significantly increased state intervention, the role of the civil society in the field of care is of major importance. The providers of care have organized themselves in several branch organizations in order to protect the interests of their members in regard to the government. Care organizations in the Netherlands have joined the 'Vereniging Gehandicaptenzorg Nederland' (VGN, Association of Care for the Disabled) which has approximately 165 members and 146,000 employees who work for 146,000 clients. In certain fields, we can also see an increase in the (local) government's influence in, for example, a transfer of insured care (Exceptional Medical Expenses Act) towards municipalities (Social Support Act). In addition, legislation efforts have been made in order to strengthen the traditionally weak position of people who have disabilities in the 'care system' (Quality Act Care Institutions, 1996).

1.3 Compartmentalized structure and set-up of care

To a considerable degree, the strong role played by private initiative determines the development of the care in the Netherlands (compare Kramer, 1981), in which compartmentalization has also played a major role. The 'compartments' consisted of population groups classified by their philosophy of life, with their own organizational infrastructure in the field of politics, education, care and welfare, mass communi-