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A life of dignity for persons with developmental disabilities – a challenge to social pedagogical practice in the Nordic countries – essay

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## Introduction

Decades of efforts of normalising the conditions of life and including persons with developmental disabilities in society have been far from successful. This is not satisfactory. In this essay the member organisations of Nordisk Forum for Socialpædagoger (NFFS) will point to the fact that it is mandatory to change the focus of society's efforts. From an objective of normalisation to a new vision of citizenship - inclusion and participation.

"Social pedagogy is the teachings of how psychological, social and material circumstances and different concepts of value improve or obstruct the full development, growing, quality of life and well-being of the individual or the group". (NFFS: Socialpædagogik og socialpædagogisk praksis i Norden, 2001:10)

"A fundamental element of social pedagogical work is to create opportunities for integration and prevent marginalisation and social exclusion. This takes place through a process of social interaction aimed at supporting marginalised individuals and groups and contributing to the development of their personal resources in a changing society."

"A social educator is a reflective professional practitioner. A professional, who works with awareness and focus. Awareness meaning: Knowing the appropriate methods and their consequences. Focus meaning: Knowing what you want to achieve for yourself and others - in social pedagogy as well as humanly and politically."

This essay discusses the role and responsibility of the social educator in working with and for persons with developmental disabilities, while pointing to the facts that:

- · Ethical awareness, reflection and justified decision-making are crucial to the quality of the social pedagogical practice when persons with developmental disabilities are to experience living a life of dignity on equal terms with other
- · It is crucial to focus on the human rights of persons with developmental disabilities and, in continuation of this, ensuring that the UN convention on the rights of persons with disabilities becomes an active tool in the dialogue about the development of the target group's conditions of life and the social pedagogical practice.

The target group of this essay are the members of NFFS, students and other central agents who focus on the conditions of life for persons with developmental disabilities.

It is our hope that the essay will be used in debates about the development of the social pedagogical practice. Internally in the member organisations, at the educational institutions that educate future social educators and in matters of regional and social policy.

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## **Abstract**

The essay takes its initial point from the fact that despite decades of efforts of normalising and integrating persons with developmental disabilities this has not been accomplished in the Nordic countries. And we are far from the goal. Instead, it is necessary, in the societal and political debate, to articulate a changed vision: A vision about a life of dignity in citizenship through inclusion and participation.

The essay focuses on the social pedagogical practice, for and with persons with developmental disabilities, and the characteristics of this practice. We point to the fact that social educators have a number of irrefutable basic ethical values and principles. The characteristic of high quality in practice, and in the professional associations' articulation of the social pedagogical practice, is: Awareness, reflection and justifiable decision-making based on values.

In continuation of this, we want to highlight a number of articles in the UN convention on the rights of persons with disabilities and the consequences on the social pedagogical practice of those. We point out that there is a need to construct mental images of how the inclusive society can look like - on a societal as well as a political level, but also for the social educators and their professional associations and trade unions.

The roles of the social educators and their competencies are discussed in a perspective of inclusion. It is pointed out that when the social pedagogical practice is

to be executed in accordance with human rights and basic ethical values it must be administered with the aim of providing the individual person with developmental disabilities with as much control over his or her life as possible and, thereby, with the possibility to realize his or her personal rights through self-determination and participation.

The essay focuses on two central issues of the social pedagogical practice: The right of persons with developmental disabilities to have a home which they feel is their own and the use of force and coercion. It is pointed out that the right to have your own home requires a de-institutionalization of the homes and the everyday routines in the homes. Usual social pedagogical practice is challenged and new ways of practice are required. The use of force and coercion is discussed in the light of the Nordic countries' constitutional rights of the inviolability of the personal freedom. This is put into perspective by discussing care, neglect of care and forced care in the light of the basic ethical values and principles of social educators.

Finally, it is pointed out that the UN convention on the rights of persons with disabilities can be understood as a break from the usual thinking of "us" and "them". The convention challenges the social pedagogical practice and requires developing a practice with an anti-mythical perspective where non-discrimination, dignity and inclusion of persons with developmental disabilities are central.

### **Foreword**

In this chapter, the need to challenge and develop the principle of normalization and integration, which for decades has been the dominating objective of societal efforts, is pointed out. It is argued that this objective has not been reached. The conditions of life for persons with developmental disabilities continue to be, in many central aspects of life, very different from the conditions that other citizens in the Nordic countries experience. It is pointed out that there is a need for a new objective with the title "Citizenship - inclusion and participation". In this chapter, it is also explained why the term "developmental disability" is used although it is not an unequivocal concept.

# A challenge to the principle of normalization and integration

The Nordic countries have experienced a dramatic increase in the standard of living over the past 50 years. This goes for the population as a whole as well as for persons with developmental disabilities. In this period, also society's view upon persons with developmental disabilities has changed and developed. This has contributed to great changes in the ideological base for the shape of policies as well as the support and help to persons with developmental disabilities.

Today, it is mainly social educators who have the professional responsibility and purpose of supporting and helping persons with developmental disabilities in their everyday lives. A field of work, where the practice of social educators has been, and continues to be, changing and developing. There are differences the Nordic countries in between but in all of the countries social educators have been - more or less - affected by the same ideological changes.

Normalization and integration have, since the mid-1950s, been the leading principles for the societal and political objectives of the Nordic countries. When conditions of life, development and services for persons with developmental disabilities have been arranged, executed and evaluated the concepts of normalization and integration have been the founding base. Although the concepts are characterized by some uncertainty.

In any case, today, when the conditions of life of the target group are put on the agenda, the concepts of normalization and integration are what people talk about. Often without questioning these concepts, their exact meaning and consequences.

This essay argues that it is time to reformulate the societal and political objective and develop the principle of normalization and integration to be an objective of citizenship - inclusion and participation. The reasons for the need of such reformulation are plenty, so here are just some of the main arguments:

- The principle of normalization and integration can be criticized for often being practiced as efforts aimed at individuals rather than social contexts. Specifically, in the Nordic countries, this has often resulted in a practice aimed at changing persons with developmental disabilities rather than the social contexts they take part in.
- In the latter years, the general debate of society, about the relation between the individual citizen and his or her rights and duties, has increasingly focused on individual ways of life and diversity. This focus has not been realised in the debate about and efforts aimed at persons with developmental disabilities.
- Today, persons with developmental disabilities, in all
  the Nordic countries, have the same formal citizen's
  rights with the same rights and duties as everyone
  else, but real citizenship requires political, civic and
  social rights and the possibility to use them¹.
- Despite many years of striving towards normalization and integration, research in the Nordic countries shows that persons with developmental disabilities continue to have very unequal conditions of life. This goes for their standard of living, their homes, education, work and so on. They continue to live in parallel exclusion from the rest of society. They live in special homes, take special educations - if they have the possibility of education at all – and they work and perform their leisure activities in special locations.

# Conditions of life for persons with developmental disabilities

It varies greatly what is known about the conditions of life for persons with developmental disabilities in the Nordic countries. This is due to different degrees of investment in research of the field. Norway and Sweden have, over the past 10-15 years, had relatively big research programs, where as Denmark has only had sporadic research and a few evaluation programs. But despite the volume of research in each country it is necessary to produce more knowledge in all of the Nordic countries.

The following is an outline of what the research says: There is no doubt that the well-being of persons with developmental disabilities has improved. The greatest change has been in relation to their housing conditions. More of them are now living in private residences and experience greater room for self-determination. The contact with relatives has increased and there is possibly also more contact with friends, where as there has been a reduction of leisure activities<sup>2</sup>. It is, however, not everyone who has experienced significant improvements in their housing conditions. New research from Denmark<sup>3</sup>, points to the fact that there continues to be many who don't have a private bathroom and toilet, kitchen and main entrance door.

One thing is the standard of the residences, another thing is what possibilities of an active life each individual person with developmental disabilities has in his or her home. The residential services and the social pedagogical support are still characterized by being workplaces rather than homes for persons with developmental disabilities<sup>4</sup>.

Numerous studies<sup>5</sup> show that everyday life in the residences is planned and arranged by the professionals rather than the residents themselves. The daily life continues to be institutionalized and is characterized by discipline, force and coercion rather than being a private space for the individual and his or her self-determination<sup>6</sup>. A number of Nordic studies point to the fact that the degree of self-determination and participation, in the everyday lives of persons with developmental disabilities, is very small. It is mainly the professionals who make decisions on behalf of the individual<sup>7</sup>.

Regarding leisure and work activities, a study<sup>8</sup> shows that persons with developmental disabilities today take part in a range of leisure, social and work activities.

Their spare time is not as predictable and standardized as before and they tend to get relatively more and easier around in their local communities. However, at the same time it is argued that it is necessary to develop more variety and a range of different offers of activity within the general sector of leisure and employment.

#### **Terminology**

The aim of the essay is to describe the challenges a defined group of citizens pose to the organisations of social educators. Thus, it is necessary further to articulate and describe this group. However, this is not unproblematic since it also requires describing the group within certain type schemes.

In social interaction between people, we understand and see each other through different type schemes, which help us understand and find out who the other person is. You can distinguish between two different levels of social interaction where the type scheming becomes more anonymous the further away you are from face-to-face relations. The type schemes in face-to-face relations are more flexible because they can be examined and corrected during the course of the interaction. Type scheming which is detached from interacting with the other person is locked into certain images about behaviour, characteristics, personality and roles. Additionally, we also ascribe roles and specific characteristics to ourselves.

The concept of developmental disability is far from unequivocal and internationally there is no agreement of the content or definition of the concept. Thus, there are at least 3 understandings of the concept:

Developmental disability – persons with the need of self-help

Developmental disability – a condition of limited intelligence

Developmental disability – a social construction

The individual understanding of the concept will influence the aim and efforts prescribed as necessary in order to improve the conditions of life of the target group. If you focus on the need of help, the efforts will often be aimed at the individual rather than the contexts the person takes part in. If you focus on the lack of

intelligence, the efforts will often be aimed at regulating the person – medically or pedagogically. If you focus on the social construction the efforts will often be aimed at the individual but also at the social contexts of the individual.

In this essay we have chosen to use the term "persons with developmental disabilities" or just "citizen", when speaking about the target group. This was chosen because this is how the target group is referred to in the public debate in the Nordic countries. We acknowledge the fact that the UN convention on the rights of persons with disabilities refers the group as persons or people with physical or mental impairments and that it would be more correct to use these terms.

The terminology of the essay in regards to a proper term for the target group represents a pragmatic choice. At the same time, the choice reveals a dilemma which, for example, researchers and other social policy agents face when speaking on behalf of other people – a group with different needs and wants for their lives. By referring to them as a defined target group of specific activities and services the individual becomes one out of many and the group is ascribed certain well-defined characteristics. To diminish this dilemma we have chosen to add the term "person" to the term "developmental disability" to show that people who are ascribed the role of developmental disabled are much more than just this term, regardless of how the concept is defined. They are first and foremost persons, individual human beings, with the same dignity and rights as everyone else.

We use the term "people or persons with disabilities" when the whole target group of the UN convention is referred to. This term includes, apart from persons with developmental disabilities, persons with autism, mental illnesses or physical impairments.

Last, the term "persons with physical and/or mental impairments or social problems" or just "the individual" is used when we refer to the whole target group of the social pedagogical practice.

#### **Outline**

The essay is divided into 5 chapters with a number of sub-paragraphs.

In chapter 1 we focus on the basic ethical values and principles of the social pedagogical practice and central elements of the UN Convention on the Rights of Persons with Disabilities.

In chapter 2 we discuss the impact of the values and principles to society, the profession and the roles and competencies of the social educators.

Chapter 3 focuses on two central issues in social pedagogical practice: the right to a private home and force and coercion.

In chapter 4 we gather the main points of the essay and a new vision for the societal efforts is articulated as a break from thinking "us" and "them".

## **Chapter 1. Ethical values and principles**

In this chapter it is pointed out that ethics and focus on human rights can be understood as the lifeblood of social pedagogy, where the prerequisite of high quality, in practice and in the individual professional organization's articulation of practice, is knowledge and consideration of the importance of the basic ethical values and principles. Furthermore, a number of articles from the UN Convention on the Rights of persons with disabilities are highlighted. Articles that in future will have significant influence on the way the societal efforts aimed at persons with develop mental disabilities are understood and, thereby, also on social pedagogy and the roles and competences of social educators in the actual practice.

#### 1.a. Ethical values in social pedagogical practice

In the meeting between social educators and persons with developmental disabilities the basic ethical values have great significance on the course of the interaction. In this paragraph we will focus on the ethical values that a number of the member organizations of NFFS are obliged to follow through their membership of respectively the International Federation of Social Workers (IFSW) and the International Association of Social Educators (AIEJI).

#### **Basic ethical values**

From both IFSW's principal statement<sup>10</sup> and AIEJI's Common Platform<sup>11</sup> it appears that social pedagogical practice is based on human and democratic values, including respect of the principles of human rights.

Both documents state that the national member organizations are responsible of developing - and with suitable frequency updating - their own ethical values and guidelines, thereby accounting for the ethical and moral values they vouch for. It is different how the professional organizations in the Nordic countries manage this responsibility. Some have developed ethical rules, others an ethical base of values. Regardless of form, all existing documents point to the fact that the basic ethical values of social educators are about freedom and self-determination, justice and non-discrimination, dignity and integrity, compassion and good will<sup>12</sup>.

## Freedom and self-determination

Freedom is not only about being free from force and coercion. The principle implies a duality of both respect

and strength. Freedom is about the individual right to make decisions, as long as they don't limit others. At the same time, it is important to acknowledge that exercising freedom requires competences to do so in interaction with other people. Competences of the individual but also of the people close to the individual, who often, in this case, is the social educator.

In social pedagogical practice the concept of freedom has a new dimension because the citizen's self-determination is central in everyday life. The value of self-determination has, like the value of freedom, a duality of both respect and strength. Self-determination is about the individual's right to make decisions on his or her own behalf. But self-determination is not only about freedom from interference. Self-determination is also about the ability and possibility to make personal decisions regardless of physical and/or mental impairments or social problems. The individual person has this right whether he or she has developed competences to exercise it or not.

In this perspective, the social pedagogical practice aims at developing, building and supporting the personal decisions of the individual and his or her competences to make those decisions and, finally, respecting them (citizen competences).

#### Justice and non-discrimination

The value of justice is about fair treatment of all people. This implies that goods, whether economic goods, achievements or services, are distributed according to the needs of the citizens. The value implies positive special treatment aimed at insuring that the individual person, with the abilities he or she has, can influence and participate in activities of the community and society in general.

Non-discrimination is derived from the value of justice which for decades has been a leading value and principle in the Nordic countries in developing the services for persons with developmental disabilities. The principle of non-discrimination contains three elements: sector responsibility, solidarity and compensation. Sector responsibility means that the benefits, services and products of the public sector in principle are available to persons with disabilities.

Solidarity means that the strongest shoulders must carry the greatest burdens. This is expressed by the fact that the support of persons with developmental disabilities is financed through taxes. Compensation implies positive special treatment in order to ensure that the individual person with developmental disabilities has equal opportunities by considering and compensating for the individual background and condition of the person.

In this perspective, the main aim of the social pedagogical practice is to compensate for, and take into account, the impairments of the individual in order to ensure inclusion and participation. The individual social educator, and his or her organization, have the responsibility to point out when the necessary resources, material as well as immaterial, are absent (i.e. absent possibility of health treatment or violation of rights due to finances or lack of professional knowledge of the staff). It is from a perspective of non-discrimination and indignation of social injustice that social educators take part in the political debate about the conditions of life of persons with developmental disabilities when they see discrimination taking place.

### Dignity and integrity (intact/unharmed)

Dignity is a central value in social pedagogical practice and dignity and integrity are closely connected. Integrity means being whole or intact and you can distinguish between physical and mental integrity. Physical integrity is related to being bodily unharmed and mental integrity to being protected from emotional abuse and public exposure.

"Not to harm" is closely related to the ethical value of dignity and, thereby, respect of the personal integrity. At the same time, you can distinguish between active and passive violation of the physical as well as the mental integrity. Active physical violations can be beating and sexual abuse, and passive physical violations can be neglect of care. Active mental violations can be to ridicule, harrass or threatening, while passive mental violations can be ignoring and lack of stimulation.

In this understanding, social pedagogical practice aims at respecting the dignity and integrity of the individual citizen while also strengthening the dignity.

#### Compassion (good will)

Compassion (humanity) is a central ethical value in social pedagogical practice and can be understood as showing good will towards other people. To feel responsible of the well-being of other people, unbiased by religion, gender or political viewpoints, simply because the other person is a fellow human being. This responsibility is exercised without paying attention to or considering personal interests. Compassion is an example of active, out-warded love for other people.

From the value of compassion comes goodwill towards other people which is dependent on your own efforts. This value is of great significance in social pedagogical practice. However, at the same time, there is risk of the value being used as explanation for the social educator who, through his or her actions, takes to guardianship and violation of the other person, out of sheer goodwill.

#### Ethics are always at stake

In social pedagogical practice, ethics are always at stake when the aim is to ensure a life of dignity of persons with developmental disabilities. Behind the actions of social educators is an estimation of good and bad. In social pedagogical practice no actions are right. A given action in a specific situation can be in greater consideration of one ethical value than another. Ethical judgment is found by appropriate assessment and consideration of the different ethical values.

Social pedagogical practice is not a private matter. Social educators provide a societal service with the aim of ensuring that persons with developmental disabilities have the experience of living a life of dignity. It is therefore essential that social educators – as a competence - master evaluating their actions and decisions from an ethical point of view; assessing and evaluating social pedagogical actions through ethical considerations. The collective ethical reflections are a substantial aspect of quality to the social educators in the Nordic countries.

The focus on ethics and human rights can thus be understood as the lifeblood of social pedagogy. Reflection, values and assessment of these is the prerequisite of high quality in practice. At the same time, this focus can also be understood as an explanation of why the social pedagogical organizations are preoccupied with improving the conditions of life for persons with developmental disabilities.

# 1.b. The UN Convention on the Rights of Persons with disabilities - definitions and challenges

The UN agreed upon the *Convention on the Rights of Persons with disabilities* in December 2006. Although not all Nordic countries have signed the convention yet it will be a central element of the base of social educators in the dialogue about the development of the social pedagogical practice and their understanding of society's responsibility.

In this paragraph we will focus on central concepts and articles of the UN convention and its influence on social educators and social pedagogical practice in the Nordic countries. The convention is more than legal paragraphs that regulate the relation between the individual and the nation state of which the individual is a citizen. It concretizes and elaborates the ethical principles that we determined earlier to be the base of social pedagogical practice.

#### The objective of the convention

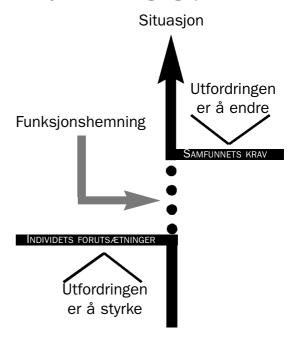
The UN Convention on the Rights of Persons with disabilities is built on principles of respect of the natural dignity of all human beings and personal autonomy, including the freedom to make personal choices. It is built on independence from other people, non-discrimination, full and effective participation and inclusion in society, respect of differences and acceptance of persons with disabilities as part of human diversity and humanity. It is an ethical argument that points to the fact that if persons with disabilities are not included in their respective nation states as equal citizens of the population those states and their citizens will lose a vital part of understanding what it means to be a human being.

## Disability/impairment

Konventionen omtaler funktionsnedsættelse/-hæmning på følgende måde i præambelens punkt 3: "Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

This understanding of disability/impairment focuses on the disproportion between the preconditions of the individual and the requirements of society. Disability/impairment can thus be illustrated by the Norwegian Gapmodel (reference: St.Meld. Nr. 40 (2002-2003) Nedbygging av funksjonshemmede barrierer. Strategier, mål og tiltak i politikken for for personer med nedsatt funktsjonsevne):

## Funksjonshemning - gap-modell



The Gap-model set high demands for political and social pedagogical agents. This understanding of disability challenges decision-makers in the Nordic countries to consider and plan for accessibility and availability on both a physical and mental level. People can have or acquire a disability/impairment. How disabled they are depends on the extent to which the environment compensates for and considers their disability/impairment.

When the conditions of life continue to be dissatisfactory for persons with developmental disabilities this, in the perspective of the Gap-model, can be understood accordingly: That the political decision-makers in the

Nordic countries have failed to meet their responsibility of ensuring the conditions of life of the target group. They have failed to accept the mandatory responsibility of society. The Nordic countries are, in other words, not inclusive societies<sup>13</sup>.

### **Central articles of the convention**

Here, we want to highlight some of the articles:

Article 12: Equal justice under law

From the article it appears that the signing nations confirm that persons with disabilities have the right everywhere to be acknowledged the same legal rights on equal basis with others in all aspects of life. The nation states are obliged to take appropriate measures to ensure the support, that persons with disabilities may need to execute their legal capacity, is available.

The article articulates the relationship between formal and real citizenship. According to the convention it is not enough, through law, to provide persons with disabilities with equal opportunities. Through support and guidance they must have a real opportunity to exercise their rights. This represents a challenge to social pedagogical practice as it involves supporting the individual person with disabilities in developing his or her competences as a citizen. But also local authorities and political decision-makers face a great challenge so words about equal rights and opportunities are turned into actual decisions that ensure persons with disabilities a real chance to exercise their citizenship, by implementing a number of political, civic and social rights.

#### Article 24: Education

From the article it appears that persons with disabilities have a right to education. To ensure this right, the signing nation states must ensure an inclusive educational system at all levels, while also ensuring lifelong learning. To realize this, all signing nations must provide education of professionals and staff at all levels in the educational system. Education which involves awareness of disability, knowledge of alternative ways of communication and educational methods and materials that support persons with disabilities.

Article 27: work and employment
From the article it appears that persons with disabilities

have a right to work on equal basis with others in, order to sustain their livelihood, through employment which they have chosen for themselves, in a job market and environment that is open, inclusive and accessible. It involves the right to fair and auspicious work conditions on equal basis with others as well as equal opportunities and compensation for work of equal value. It involves the possibility to take part in vocational training and training courses that improve their employment in both the private and public sector.

Implementing this article means that social pedagogical provisions of work and activities, which are the most common, must be finalized to greater extend. The objectives of the provisions must be amended so the overall aim is to ensure persons with disabilities a placement in the general job market. The professional support provided for persons with disabilities, through the provisions of work and activities, must be used to support them so their work life can be giving and meaningful.

Article 30: Participation in cultural life, recreational activities, sports and leisure

The article is related to the right of persons with disabilities to take part in cultural life on equal basis with others and obligates the signing nation states to take appropriate measures to ensure this right. This implies participating in recreational, leisure and sports activities at all levels in regards to both specific activities for persons with disabilities and general sports activities.

#### Additional rights of the convention

Additional rights of the convention are related to equal opportunities and non-discrimination, accessibility in a broad sense, the right to life, personal freedom and freedom of torture, cruel and humiliating treatment, freedom from exploitation, violence and abuse, protection of integrity, freedom of movement and the right to citizenship, the right to a life of independence and to inclusion, freedom of speech and access to information, the right to health services, habilitation and re-habilitation, a reasonable living standard and social protection, the right to participate in political and public life.

It is important to clarify that the convention does not grant new rights to persons with disabilities but merely confirms a number of rights they already have. What the convention does is to re-new the debate about the conditions of life of persons with disabilities in the Nordic countries and presents an opportunity:

- To reformulate the objective of the societal efforts aimed at persons with developmental disabilities,
- For the local authorities and municipal practice to take responsibility of all their citizens, including the conditions of life of persons with developmental disabilities and their participation in society,
- To revaluate and, if necessary, reformulate the objective of social pedagogical practice and social educators and initiate a change of the organization and planning of the practice.

#### Central concepts of the convention

Furthermore, article 2 of the convention gives a number of definitions of discrimination, reasonable adjustment, universal design and communication:

#### Discrimination due to disability:

"Means any differentiation, exclusion or limitation due to disability with the aim or effect of weakening or dissolving the equal acknowledgement, enjoyment or execution of all human rights and basic rights of freedom in the political, economic, social, cultural, civic or any other field. This includes all forms of discrimination, among these refusal of reasonable adjustment".

#### Reasonable adjustment:

Means necessary and suitable adjustments and adaptions that do not entail a disproportional or unnecessary burden, when necessary on specific occasions to ensure that persons with disabilities can enjoy and exercise all human rights and basic rights of freedom on equal basis with others.

#### Universal design:

Means design of products, environments, arrangements and services so they to greatest extent possible can be used by all people without need of adaption or specific design. Universal design does not exclude assistive tools to special groups of persons with disabilities when needed.

#### Communication is understood as:

Language, text display, Braille, tacit communication,

enhanced writing, accessible multimedia and writing, audio, clear speech, reading and enhancing and alternative ways of communication, means and formats, among these accessible information and communication technology.

#### Language is understood as:

Speech and sign language and other forms of non-verbal language.

The definitions have a number of consequences for the understanding of persons with developmental disabilities and the way their resources and limitations are referred to.

#### Discrimination in the spirit of the convention

In the spirit of the convention there are no people without language since all human actions can be ascribed meaning. This means the collective must take a significant part of the responsibility of ensuring inclusion and participation of the individual and the collective is, likewise, obliged to ensure as reasonable adjustment as possible. Anything else is discrimination.

Discussing the rights of persons with disabilities and force and coercion it is, in continuation of the convention, discrimination if:

- · Their rights are not respected
- It is questioned whether their self-determination has meaning and is competent
- The issue of whether it is neglect of care to let them make their own decisions is at the core of the discussion about the efforts

It can also be interpreted as discrimination, if they:

- Are not ensured the necessary resources (economically, professionally etc.) to compensate for their impairments
- Are not provided the possibility of developing their competences as citizens
- · Are forced to live under institutional circumstances

Finally, it can also be interpreted as discrimination if political awareness of their unequal conditions of life is not present.

## Chapter 2. The principles' consequences for social pedagogy

In this chapter we resume where we ended in the last chapter. The critical implications that the convention has on society, the profession of social educators, their role and competences, when the efforts of society and social pedagogical practice must be in accordance with the convention and the basic ethical values and principles, are highlighted.

#### 2.a. Konsekvenser for samfundet

If the basic principles are to influence the possibilities of life of the individual person with developmental disabilities it is necessary that the principles influence the development from a societal perspective. The principles imply radical changes of society. Professor Johans Sandvin<sup>14</sup> has pointed to the fact that a critical barrier of such changes is our own expectations to what is possible.

Are our mental images of how a society of full inclusion and participation looks like good enough? Or are we too restrained by historical and cultural images so this ideal becomes other than just an exercise of rhetoric?

If radical changes of society are to happen it is necessary with political will to act. It must imply priorities that favor a development of society with a focus on inclusion and participation for all. Until now, politicians in the Nordic countries, and other central and political decision-makers, have only had this focus to a very small extend. It is therefore necessary with a change of attitude.

An inclusive society requires that all levels of society focus on providing persons with developmental disabilities the option of realizing their citizenship. It requires real possibilities of participating in and influencing the societal political debate. It is about the option of expressing oneself and being heard in local as well as general political contexts. And, not least, about having access to social rights in the community and the same access to educational, work and leisure activities as other citizens.

A change of attitudes is necessary for both political authorities and other decision-makers as well as the rest of the population. Social educators are not excluded from this. It is paramount that also social educators can visualize an inclusive society.

#### 2.b. Implications to the profession

The objective of social pedagogical practice is to promote social change and solutions in human relations. The discussed principles will have implications to the professional development of social pedagogy. Ethics have always been central, but a new view on the implication of ethics is necessary. Social educators and their organizations must be able to justify actions both through ethics but also grounded in the UN convention on disability's perspective of rights.

As mentioned in the paragraph about the basic ethical values of social educators, social educators and their organizations take part in the political debate about the conditions of life of persons with developmental disabilities by, among other things, pointing out the discrimination that takes place. This has always been due to their indignation of social injustice. Radical changes of society require a general change of attitude in society but also within the professional organizations of the social educators. It is necessary that social educators and their professional organizations, to a greater extent, articulate what an inclusive society could look like.

This means that social educators and their organizations must initiate the debate and in general contribute to ensuring that the conditions of life of persons with developmental disabilities continues to be on the agenda, in the public debate but also as constructive critique of current social pedagogical practice.

Furthermore, it means that the organizations must ensure, in a more systematic way, that their members have on-going debates about the objective of social pedagogy. Both as a profession but also in discussions about the quality of practice and what characterizes constructive interaction between the individual social educator and the person with developmental disabilities. Development of knowledge and competences are on the agenda in the development of the profession.

#### 2.c. Implications to the role of social educators

Focusing on ethical values and principles will obviously also have implications on the practice of the individual social educator. When the values and principles are exercised in daily work it requires the social educator to take on the role as organiser and sparring partner.

The social educator must support and guide the person with developmental disabilities in making his or her own choices and implementing their decisions. A main task for the social educator is to lay out the possibilities and support the citizen in realizing his or her rights. Looking at the Gap-model<sup>15</sup>, it shows that the role of the social educator to a large extent is related to the preconditions of the individual and demands and barriers of society.

#### Mastering as a concept of reflection

Antonovsky's (2000) concept of mastering can be useful as a way to understanding the practice of social educators provided for persons with developmental disabilities. Antonovsky's concept of mastering has 3 elements: comprehensibility, manageability and meaningfulness. Those 3 elements are, according to Antonovsky, a prerequisite to mastering and significant to understanding a person's capability of change and development.

#### Comprehensibility:

 Means that the world is at order and seems coherent and structured. That we are able to redefine the stimuli (or problems) we face in such a way that they become informative and clear without seeming chaotic, random or inexplicable.

Improving the experience of comprehensibility means that the persons with developmental disabilities experience the things happening around them as comprehensible, that they experience life as predictable.

### Manageability:

Means that we feel we are in control and can influence a given situation. That we as people have the required resources to meet the demands we face.

Improving manageability means that persons with developmental disabilities experience having access to the resources they need. It is thus about how the social pedagogical practice entails that the individual person is in control and, by him or herself or in cooperation with others – i.e. a social educator – can handle the demands and challenges of life.

## Meaningfulness:

 Is about the meaning we ascribe to the stimuli or problems we face. Feelings are important in mastering because feelings effect our attitude towards and involvement in a given case. Meaningfulness is thus an indicator of how motivated we are to invest energy in the problems we meet.

Improving meaningfulness means that persons with developmental disabilities feel it is important and constructive to use energy on a given problem or challenge. Such a feeling cannot be transmitted instrumentally or cognitively by communicating a certain amount of knowledge through the social pedagogical practice. Motivation requires stimulation of participation and involvement.

Comprehensibility and manageability can be understood as competences which can be learned and developed, where as meaningfulness can be understood as a feeling. If social pedagogical practice solely focuses on developing the competences, without being preoccupied with the feelings this generates, we run the risk of social pedagogical practice, instead of improving the experience of living a life of dignity for persons with developmental disabilities, becomes a barrier to this.

#### The asymmetric relation of power

The concept of power is not an unequivocal concept. According to French philosopher Michel Foucault<sup>16</sup>, power is a force inherent within every social relation – which makes every relation a relation of power. Foucault sees power as a relation which causes, influences and changes. Therefore power cannot be seen as something unequivocally negative or destructive but rather as a productive force which is a basic element of social relations. Foucault's point is that power belongs to noone, it is always present and where power is exercised there is also opposing power.

In the interaction between the individual person with developmental disabilities and the social educator there is an asymmetric relation of power<sup>17</sup> characterized by the fact that the social educator earns his or her living by supporting the other person who is greatly dependent on this help and support.

When social pedagogical practice is to be exercised in accordance with human rights while considering the ethical values, social pedagogical practice must be administered with the aim of providing the individual person

with developmental disabilities with the opportunity to realize his or her rights and to be included in the community of society through self-determination and participation18.

It is therefore paramount for the quality of social pedagogical practice that social educators consider how the power is administered. The social educators must use their competences to ensure that the individual person with developmental disabilities has as much control over his or her own life as possible.

Social pedagogical practice is about ensuring that persons with developmental disabilities experience living a life of dignity on their own premises. This requires that social educators, through their practice, ensure that daily events and activities are comprehensible, that persons with developmental disabilities experience being in control of events and can handle the challenges of life and finally, that the daily activities are characterized by participation and involvement, cf. the concepts of Antonovsky.

But the participation of persons with developmental disabilities must go further than just the daily activities. The concept19 must also be understood as the citizen's influence on the community of society. The person must experience that he or she can contribute with something in many different contexts - in everyday life, in community and in general political contexts. In this perspective, it is the role of the social educator to support the individual person in having as much influence as possible while ensuring their representation and participation, for example by discussing possibilities of life and supporting them in networking.

Such a practice requires that the individual social educator masters a number of competences.

### 2.d. Implications to the social pedagogical competences

According to AIEJI, A common platform for social educators in Europe, social educators must in their practice

have a basic competence of action as well as a number of other competences. This stems from the fact that social pedagogical practice is a task exercised within the available provisions of society<sup>20</sup>. In the light of the basic ethical values and principles, among these the convention on disability, the competences that social educators must posses can be outlined as follows:

- 1. Competences of action mean that the social educators must initiate action face-to-face with the individual person with developmental disabilities while also principally taking action based on approval. They must plan actions, with the aim of ensuring that the individual person experiences living a life of dignity, and consider future co-actions. Finally, they must consider and evaluate their own actions and relate those considerations to the basic ethical values with the aim of professional evaluation and development in collaboration with colleagues and other professionals.
- 2. Additionally to competences of action, social educators must master system, relational, communication, development and learning competences as well as a range of other professional competences which are related to:
- The societal task and its legal basis
- Ethical awareness and reflection based on decisionmaking
- Competence of profession which is about the base of knowledge of the profession, among this central theories, concepts and methods - which can be justified and are coherent with the basic ethical values and principles of social educators
- Cultural competences in regards to both diversity, differences and development.

The two dimensions must go hand in hand in social pedagogical practice. It is not about a string of independent singular competences but basically, perhaps, two sets of complimentary competences that determine and are conditioned by one another.

## **Chapter 3. Focus on some central issues**

In social pedagogical practice in regards to persons with developmental disabilities there are certain themes which are often raised as specific issues. In this chapter, we want to focus on two issues - "the right to a private home" and "force and coercion".

In the paragraph about "the right to a private home" it is pointed out that the convention on disability sets a new agenda for residences and the social pedagogical support for persons with developmental disabilities by stating the right not to be institutionalized and, thereby, the right to make personal decisions about where and with whom you want to live. In continuation of this, it is pointed out that having a residence is not the same as having a home.

In the paragraph about "force and coercion" it is pointed out that it is necessary that social educators, through their practice, stand as guarantors to ensure the dignity and rights of persons with developmental disabilities. Further, it is pointed out that reflection upon and evaluation of the basic ethical values in future must have a more central place in the discussion about care – neglect of care and forced care.

#### 3.a. The right to a private home

In this paragraph we focus on the right of persons with developmental disabilities to not be institutionalized; their right to live among fellow citizens. At the same time it is pointed out that having a residence is not the same as having a home.

The term "institution" has at least two meanings which must be differentiated. In daily speech you can use the term institution about places like prisons or hospitals. In sociology, the term "institution" is used as a concept of a set of norms or rules related to a certain task or function of society. Both meanings are relevant when focusing on de-institutionalization of the life of persons with developmental disabilities.

# Articles about residence and home in the convention on disability

Article 19 of the convention on disability acknowledges the right of persons with disabilities to live as part of society with the same opportunities as others. The state must make effective and appropriate arrangements to

promote this right and ensure that persons with disabilities are fully included and participating in society by ensuring that they have:

- The option of choosing their place of living, where and with whom they want to live without being obliged to living under specific circumstances.
- Access to a range of support services in their homes and living area as well as other local support services.
- The required personal support in order to be able to live and be included in society and to prevent isolation and exclusion.
- Available access to society, services and facilities on equal basis with others.

Furthermore, from article 23, paragraph 1, it appears that no person with disability must be exposed to random and illegal intrusion of his or her private or family life, home, mail correspondence or other forms of communication, or to illegal assaults on his or her honour or reputation.

Article 19 and 23 set the agenda for a de-institutionalization of the support of persons with disabilities. Despite the fact that the concept of institutions was abolished in several Nordic countries, it continues to exist in practice. When developing new residences the institutional thought still exists and in existing residential offers the support of persons with disabilities is largely planned and provided within an institutional culture where the residence and service of support is one and same.

Simultaneously, there are still many outdated residences in several of the Nordic countries which are far from meeting current standards of living. It is the rule rather than exception that the social pedagogical support and residential offer are characterized by being a workplace, not the home of a person with disabilities<sup>21</sup>.

Discussing de-institutionalization it is important to focus partly on what we see as institutions and partly on the fact that having a residence is not the same as having a home.

Inspired by the descriptions of life in total institutions by sociologist E. Goffmans, institutionalized life is characterized by:

- · Isolation from environment
- · Categorising of residents
- · Standardising and predictability
- · Staff to whom the institution is a workplace

In a report from the EU22, an institution is defined as environments of living with more than 30 residents, of which at least 80 % are persons with disabilities.

In Sweden, the social government agency23 has contributed with a description of what a residence without institutional characteristics is.

Residences of persons with impairments cannot:

- · Be in close connection with other residences that are not regular residences
- · The residence must be separate from rooms with services of daily activities
- · Co-residences must not have more than 2-5 residents
- · Service residences must be integrated with regular living areas and the institutional environment must be
- · The residents' desires to the composition must be followed as widely as possible

In the perspective of the convention a de-institutionalization is still necessary.

- · New visions in regards to developing and decorating the residential environments
- · Focus on the professionally ethical debate
- · Focus on the distinction between a residential environment, a home and a workplace
- · A changed concept of professional social pedagogical support of persons with disabilities.

#### A residence is not the same as a home

The residence has influence on a person's options to fully enjoy a number of different human rights, for example the right to work, family life, private life, participating in cultural activities, developing and taking part in social relations, strengthening the person's feeling of security and health and experience of property rights.

But having a place to live is not necessarily the same as having a home and feeling at home. The experience of having a home is not only about the physical features of the residence but also about ensuring the creation of

identity, integrity, dignity and self-determination of the individual. Two central values are linked to the home<sup>24</sup>:

- Home is a place where you can make your own decisions, a platform for participation in the more public life and a place for privacy when needed.
- Home is a symbol of closeness and intimacy where we can be private. It represents security through a feeling of responsibility for one another amongst the residents and through receiving love, care and respect.

Furthermore, it can be pointed out<sup>25</sup> that the residence is closely related to having a private space which again is related to the experience of having a home. The prerequisite to the residence feeling like a home is that the home has several rooms with a number of functions:

- · A physical room which can be decorated according to personal taste through which process the individual takes ownership of the room.
- A private room to where you can withdraw from the public sphere and define your own rules, norms and values - a personal space of privacy.
- · A social room where identity, solidarity and meaning as well as social relations are created in a dialectic process.

When the residence is to be more than accommodation, be a home, a number of central values and preconditions must be met. But reality is different to persons with disabilities. A number of Nordic countries point to the fact that it is mainly the professionals who make choices on behalf of the individual<sup>26</sup>.

A realisation of the convention implies:

- · A break from package solutions
- That the residence and social pedagogical support are separated organisationally
- That support of the individual person with disabilities is provided in consideration of individual needs, conditions and background
- Individual access to support and help as needed in order to maintain a life of dignity in activity and participation
- That the range of residences and their variation are developed and integrated with regular residential environments

- that the individual person with disabilities decides for him or herself where and with whom he or she wants to live
- that the individual person can make personal choices about decoration, activities and routines, which will be part of the residence, and which activities he or she wants to participate in outside of the residence.

A separation of residence and organizing support obviously requires that the social educators have staff facilities, rooms and the possibility of professional evaluation and development of competences, other than in the residence. This also implies a break from the routines of practice of social educators, which often and easily are scheduled from a rationale of efficiency, and awareness of the principally opposing perspectives of time that practice is exercised within: that wage labour has a linear perspective of time, whereas everyday life is circular. Mental images, of how the support and help of persons with developmental disabilities can be provided in such a way so the characteristics of a home are not destroyed but rather strengthened and developed with regards to the individual person, are needed.

Finally, a realization of the convention implies a break from the thought of specific disability residences, prioritizing inclusive residences in all new developments and modernizing existing residences.

#### 3.b. Force and coercion

In this paragraph we will focus on force and coercion understood as intervention of the personal freedom and self-determination. It is pointed out that when considering intervention, where approval from the individual has been set aside, the rights of persons with developmental disabilities must be weighed substantially. Intervention which does not have a legal basis cannot be justified despite being done with good intentions.

## The inviolability of the personal freedom

It is of great importance, principally, in the professional environment and when working with the individual citizen, that we strive to agree upon what is meant by the use of force and coercion. Therefore, in social educational work, there must be an ongoing discussion. First, it must be discussed what we mean by force and coercion, then how we can prevent the use of force and coercion.

Last, we must also discuss in which situations force and coercion can be accepted, in which ways and under which circumstances.

In the process of assessing the use of force and coercion, the professional and ethical judgement of the social educator is continuously challenged. In the assessment of what is defined as force and coercion there must be a descriptive definition at the base. This means that all intervention and activities that a person opposes must be defined as force and be described according to what is happening in the actual situation. In this light, for example, it must be seen as use of force to hide medicine in the food that a person is eating because the person opposes to take vital medicine. In other situations, different types of actions and intervention can be seen as use of force and coercion, even if the person that the actions are directed at does not oppose. A descriptive definition of the use of force and coercion will contribute to the sensitivity needed towards the persons we are working with. Especially, when sometimes, it is judged to be necessary to use force and coercion.

The use of force and coercion can also be defined normatively. This means that actions that are seen as necessary and reasonable are not seen as force and coercion. In this light, it will be seen as legitimate to "lure" someone to take medicine since the intention of this act is steering to the content of the act. A normative view upon the use of force and coercion can result in acceptance of unethical actions. If the focus of the professional work is moved from the integrity of the individual, based upon thorough ethical and professional assessments, to mainly focusing on the result of the actions, the individual right to, for example, co-determination and participation be threatened.

Here is an example which can illustrate some of the dilemmas: Is it use of force and coercion to deny a person with developmental disabilities to spend his or her own money on buying alcohol? Is it use of force and coercion to deny the person to get drunk? The arguments, that it is of disadvantage and inappropriate for the person to spend money on alcohol, or to get drunk, can be fine. On the other hand, it is any person's right to decide how they want to spend their money, and alcohol

is a legal drink. If the intention behind the convention on disability is to be fulfilled, persons with developmental disabilities must enjoy the same rights as everyone else. This means, that if a social educator is to deny someone to spend their own money on certain things, this must be defined as use of force and coercion and the interventions that are needed must be authorized by law.

## Articles about force and coercion in the convention on disability

The objective of the convention is to "promote, protect and ensure persons with reduced functionality full and equal right to enjoy all human rights and basic freedoms, and to promote the respect of their inherent dignity". It is clear that in this light, any kind of force and coercion is problematic. Article 14-17 of the convention treats persons with developmental disabilities and their right to freedom and personal security, freedom from torture and cruelty, inhumane or humiliating treatment or punishment, freedom from exploitation, violence and abuse as well as the protection of the personal integrity.

In the discussion about how use of force and coercion can be defined, prevented and, perhaps, accomplished, the convention on disability is central to the necessary professional and ethical assessments. The convention is an important foundation and a good tool when working with alternative ways of understanding how to take care of the human dignity of persons with developmental disabilities, also when using force and coercion is seen as necessary.

Especially, the convention has significant meaning in the part of definition process which must be done together with the person whom it concerns and his or her environment. In social educational practice, the professional and ethical discussion, about how we promote self-determination and mastering, will be important seen against the issue of use of force and coercion.

## Force and coercion - neglect of care or forced care

Apart from situation of immediate emergency in terms of life and health, actions of force and coercion are often justified by the case that intervention in the personal freedom is necessary in order to ensure the individual dignity, or prevent neglect of care. However, neither explanation is unproblematic. The values of dignity and integrity are closely linked to the values of freedom and

self-determination. It is uncertain whether it is at all possible to ensure dignity by violating self-determination. But, if referring to individual dignity is not plausible, then what can be the explanation? The argument could be that it would be neglect of care not to take action. This argument, however, requires a clarification of the concept of care.

The concept of care comes from the value of good will, which means compassion. The concept has from a historical, cultural and societal point of view gone through changes and it is uncertain whether the concept can be clarified and defined<sup>27</sup>. When discussing whether it would be neglect of care not to take action, and therefore justifiable to use force and coercion, it is necessary also to include the values of equal opportunities, selfdetermination and dignity in the considerations. If this is not done, the use of force and coercion can lead to unjust, undignified and violating actions and be seen as forced care rather than neglect of care.

#### The inviolability of the personal freedom

The principle about the inviolability of the personal freedom is expressed through the central rule that this freedom can only in exceptional cases be intervened. The exception is applied if the person, through his or her actions, is of significant danger to him or herself or others. Intervention can only be accepted if it is authorized by law. In the Nordic countries the laws that regulate the social educational services towards persons with developmental disabilities are different, but common to all is that the possibilities of force and coercion are positively limited.

Conscious knowledge of the basic legal, ethical and professional principles is necessary in order to fulfill the intentions of the convention - especially in terms of the inviolability of the personal freedom. Social educational work must be organized so that the rights of the individuals are fulfilled the best possible way. Such a practice will also be a precautionary measure against force and coercion. It is the responsibility of the social educator and the professional community to ensure that the individual experiences:

- being able to make own decisions
- being able to have private time and room
- not to be exploited

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- to have a private life
- to have a reasonable standard of living and services, training and the option of education, socializing and activities
- being able to use his or her rights
- freedom from force

In the social educational work and assessment about the use of force and coercion, factors of sensitivity and resources must be considered. Factors of sensitivity point to the fact that something in the person, or his or hers environment, may create challenges in terms of development, learning and quality of life and his or her ability to take care of him or herself and own interests, immediately and in the long run.

Examples can be the professionals' lack of attention to the person's ways of expression, lack of meaningful activities in everyday life, the person's lack of ability to understand the environments and general ways of communication. Factors of resources are, on the other hand, things that are strengthening and supportive in the individual's life. The social educator's conscious knowledge about what hinders self-determination and participation, and which factors promote this, is important. This increases the possibility of good social educational work which will prevent the use of force and coercion and provide a greater experience of human dignity.

# Requirements to social educational practice and society

Taking the convention on disabilities seriously is a challenge to social educational practice. It is absolutely necessary that social educators stand as guarantors for the rights of persons with developmental disabilities not being violated. This requires that social educators have knowledge of and can ensure that national law on force and coercion are abided by. It requires respect of the individual right to self-determination and individual actions, even if these are not actions the social educator would personally have executed. It requires that social educators, through their work, continue to try and minimize the use of force and coercion as much as possible.

It also represents a challenge to public policies in the

field. It is crucial that the policy facilitates alternatives which will minimize the use of force and coercion as much as possible. This requires, among other things, adequate resources of staff with the right competences. It requires monitoring how the services are carried out in daily practice and it requires that economic considerations are not attached greater importance than professional and ethical considerations.

As an example of how law regulation on the use of force and coercion norway has developed new rules in their law on social services. The Definition of force and coercion is closely related to the basic views that are the foundation of the convention on disability. Chapter 4A-1 in the law on social services in Norway states: ".... to hinder that persons with developmental disabilities expose themselves to significant harm and prevent and limit the use of force and coercion. The service must be organized in respect of the individual's physical and mental integrity and as much as possible in accordance with the right to self-determination of the individual. No one should be treated in a degrading or humiliating manner".

Norwegian law defines use of force and coercion as actions that are opposed by the individual, or actions that are so intervening that - even without opposition – they must be counted as use of force and coercion. The law also states what needs to be done when social educators judge that the service they provide include or should include elements of force and coercion in regards to the intention of the law. An important principle is that alternative methods must always be sought in order to try and prevent the use of force and coercion. Professional competences are also required by the persons who execute and are responsible of the actions.

The field of work affected by the law and the practice that is a result of the law is still being debated in the professional circles and user organisations in Norway. The law, nevertheless, contributes to increased consciousness concerning persons with developmental disabilities and their right to self-determination and participation. So, the competences of social educators and other groups of professionals have hereby been increased and possibility of inclusion for persons with developmental disabilities can be realized.

## Chapter 4. A break from "us" and "them"

In this chapter it is pointed out that the societal efforts focusing on implementing the UN convention on disability can be understood as a break from thinking "us" and "them". It is necessary to establish a practice which builds upon an anti-symmetrical perspective on persons with developmental disabilities where the societal objectives of normalisation and integration are developed to become an objective of citizenship – inclusion and participation.

# The consequence of ethics and the principle of human rights

In this essay, a number of basic ethical values and principles in social pedagogical practice, with specific relation to persons with developmental disabilities, have been pointed out. The UN convention on disability has been highlighted as being central in this context. It has been pointed out that these values and principles will impact the societal efforts and, thereby, the social pedagogical practice at different levels as well as on the specific issues of the right to have a private home and the use of force and coercion. The most important message, however, is a break from the traditional distinction between "us" and "them".

Social pedagogical practice related to persons with developmental disabilities requires, from the perspective of the ethical values and the principles of the convention on disability, a break from the distinction between "we" and "them". This is a pivotal factor for the development of social pedagogy in terms of both the profession and the individual social pedagogical service.

Initially, the convention has a number of different perspectives upon the existence of human beings in this world. A legal perspective, which states that persons with disabilities have the same legal rights as everyone else, among these the right to democratic participation and non-discrimination. A psychological perspective, which focuses on the identity, communication and language of persons with disability. A sociological perspective, which among other things focuses on inclusion and participation, a pedagogical perspective with a focus on people's capability to learn and, finally, a philosophical perspective with a focus on dignity and integrity.

The overall perspective is that persons with disabilities are part of human diversity.

The German philosopher Bauman<sup>28</sup> points to the fact that when categorizing and classifying people we automatically distinguish between "us" and "them". The group of "us" belongs to those we feel we belong to and understand, while the group of "them" are the ones we can or will not belong to and understand and where the image of them is unclear and incomprehensible. The Swedish researcher of disability, Gustavsson<sup>29</sup>, points to the fact that a selective welfare society creates a gap between "us" and "them", between those who can take care of themselves and those who, like persons with developmental disabilities, are dependent on support and help.

The convention on disability can be understood as a break from the distinction between "us" and "them" where all human beings by the convention have their human rights confirmed, on equal basis with everyone else, and thereby become part of "us". This requires, however, more than ratification by each of the Nordic countries. The convention must be implemented in the social practice of all sectors of society and at all levels in the respective sectors.

#### Myths and anti-myths

Implementation of the convention requires a break from social practice which in many areas has a background of myths about persons with developmental disabilities<sup>30</sup>:

- that their actions and appearance are independent from surroundings and environment
- that it is justifiable to distinguish between the "good" and "bad", where the "bad" have no cognitive understanding, no language, no emotions and need help with everything
- that they are weak individuals who need help in all aspects
- that they can be described collectively as a defined group
- that they do not hold the same rights as ordinary people

The convention on disability requires establishing a different kind of practice. A practice built upon an antimythical perspective on persons with developmental disabilities:

 Human actions and appearance are dependent on the quality with which they are met by their surroundings and environment

- All human beings are of value and no-one is worse than others
- All humans have a language and can contribute to the collective community
- · All humans are unique and part of humanity
- It is only what we share collectively that can be described as collective
- · Everyone has the same rights

Non-discrimination, dignity and inclusion of persons with developmental disabilities do not appear automatically but require a revaluation of visions and aims of the field and a new understanding of what characterizes social pedagogical practice.

#### Citizenship - inclusion and participation

The convention on disability requires a social pedagogical practice established on a base of human rights where the main aim is to protect the inherent dignity and value of human beings.

The social pedagogical practice can be understood as a special effort of society with an independent field of practice which has developed authoritative answers to how children, juveniles and adults, who are subject to marginalisation and exclusion from society, can be integrated and become a true part of the collective community on conditions of modernity. This requires a more detailed description of the characteristics of the objective of practice, the definition of the target group of the practice and the base of knowledge which the actual practice is founded on. It is necessary to reformulate visions and aims. A challenge to the social pedagogical organisations in the Nordic countries is, increasingly, to develop and describe these characteristics in the perspective of democracy, ethics and human rights.

In the light of the basic ethical values and the convention on disability the objective is no longer normalization and integration. The objective of the social pedagogical practice and of political and societal efforts aimed at persons with developmental disabilities is:

A life of dignity through citizenship – inclusion and participation

This requires justice and distribution of the goods of society. It requires real possibilities to realise your rights

as a citizen. It is about having conditions of life comparable with others. Only on these conditions, persons with developmental disabilities will have the opportunity to live a life of dignity where they are genuinely accepted as part of human diversity.

#### **Questions for debate**

- 1. Discuss the basic ethical values and principles:
- How do you understand freedom/self-determination?
- How do you understand justice/equal opportunities?
- How do you understand dignity/integrity and non-harm?
- · How do you understand compassion/ good will?
- · How is this expressed in social pedagogical practice?
- Find examples of social pedagogical practice and discuss how the consideration of the importance of the different values is expressed in a given action/situation
- Find and discuss different articles of the UN convention on disability and how these can be implemented in society, the local authorities and in the interaction between you and the individual with developmental disabilities. Discuss the role and responsibility of the social educator in this context.
- Based upon your own thoughts about what a home is, discuss:
- How residences of persons with disabilities can become their homes?
- What prevents and improves the feeling of a residence being a home?
- · What can social educators do?
- 4. Discuss what can be done in order to include persons with developmental disabilities on the regular job market:
- · What type of support do they need?
- How can it be made possible for them to access the regular job market? How can existing offers of employment and social activities support this development?
- 5. Discuss your and your colleagues' understanding of the concepts of inclusion and participation:
- How can the inclusion and participation of persons with developmental disabilities be strengthened

through the social pedagogical practice?

- 6. When the aim of the social pedagogical practice is to ensure that persons with developmental disabilities live a life of dignity through citizenship – inclusion and participation:
- · Which roles and competences must the social

educator posses?

- 7. Which factors contribute to maintaining the dimension of we-them at your workplace?
- 8. What does an inclusive society look like?

## **Appendix**

#### Genesis of the essay

At a steering committee meeting in NFFS 2 May 2009, the participating organisations discussed the conditions of life for persons with developmental disabilities. The discussion was based upon a minute, produced by FO (Fellesor¬ganisasjonen i Norge), about "Conditions of life, legal rights and services of persons with developmental disabilities".

The minute described how the conditions of life, despite decades of efforts to normalise and include persons with developmental disabilities in community, continue to be dissatisfactory. Research in Norway shows a tendency towards increased segregation, institutionalisation of new residences, lack of respect of rights, including the right to self-determination, many breaches of law related to the use of force and coercion, lack of compensation of the individual impairment and also lack of political awareness.

The participants at the NFFS meeting confirmed that the described situation in Norway in many fields was

reflected and recognizable in the other Nordic countries. At the same time, the discussion showed the each country use a different set of concepts in order to articulate the conditions of life of persons with developmental disabilities.

It was therefore agreed to produce an essay for the further work of the steering committee. The essay should be based upon the UN convention on disability and elaborate the issues in regards to the conditions of life of persons with developmental disabilities. Additionally, it was agreed that the essay should be the base of a common Nordic publication. A common platform or common message from NFFS.

A first draft of the essay was introduced to the steering committee at a meeting on 2 October 2009 in Iceland. At the next meeting 14 March 2010 the content was agreed. After constructive debate about the challenges to social educational practice in the future, the steering committee decided to finish the document for publication and this was finally agreed 14 September 2010.

## **Footnotes**

- <sup>1</sup> Understanding of citizenship has in recent times been inspired particularly by the British sociologist T.H. Marshall. It was the requirement of no-one being deprived from participating in social and political life which caused him to develop the civic and political citizenship incorporating also the social rights.
- <sup>2</sup> Tøssebro (1996); Sandvin et al. (1998); Tøssebro and Lundeby (2002); Folkestad (2003)
- <sup>3</sup> Socialpædagogernes Landsforbund (2009)
- 4 Andersen and Sørensen (2006); Sørensen (2008 b); Socialpædagogerne (2009)
- <sup>5</sup> Sandvin et al 1998; Giske (2001); Sørensen (2005); Perlt m.fl. (2006)
- <sup>6</sup> See chapter 3 about the right to a private home
- <sup>7</sup> Rustad (1999); Sandvin et al (1998); Skov and Hansen Kermenoglou (2000); Giske (2001);
- 8 SUS (2002); Cowi A/S and SUS (2002)
- 9 Skov and Hansen Kermenoglou (2000); Rustad (1999); Sørensen (2003); Tideman (2000)
- <sup>10</sup> Etik i socialarbejde en principerklæring (2004)
- 11A common platform for social educators in Europe, AIEJI (2006)
- <sup>12</sup> Socialpædagogernes Landsforbund (2008): Dialog om etiske værdier, www.sl.dk/etik
- 13 Neuwiths (2009)
- <sup>14</sup> Sandvin (1998)
- 15 See chapter 1 about functional impairments/disabilities

- <sup>16</sup> Michel Foucault (1926-84) is a French filosopher. His concept of power kan be understood from his books, but is described intageably and ambiguously. A good introduction is given in a book by Dag Heede: Det tomme menneske, chapter 4. The book is published by Museum Tusculanum, Frederiksberg 1992
- <sup>17</sup>Sørensen (2006)
- <sup>18</sup> Honneth (2006) points to three forms of recognition: love, legal and social implementation which are all the condition of identity and human blossoming.
- 19 Sørensen (2006)
- <sup>20</sup>Inspired by AIEJI, A common platform for social educators in Europe (2006)
- <sup>21</sup>Andersen and Sørensen (2006); Sørensen (2008) b; Socialpædagogerne (2009)
- <sup>22</sup> Mansell m.fl. (2005)
- <sup>23</sup> Socialstyrelsen (2002)
- <sup>24</sup> Jensen (1997); Sandvin et al (1998)
- <sup>25</sup> Ivardsen and Andersen (2000)
- <sup>26</sup>Rustad 1999; Sandvin et al (1998); Skov and Hansen Kermenoglou (2000); Giske (2001); Stalsberg Mydland (2003)
- <sup>27</sup> Sørensen (2005)
- <sup>28</sup> Bauman (2004)
- <sup>29</sup> Gustavsson (2004)
- 30 Inspired by Kirkebæk and Sørensen (2008)

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