

**Working With Persons with
Developmental Disabilities
The Role of the Social Educator**

Discussion Paper



Working With Persons with Developmental Disabilities – The Role of the Social Educator

By: International Association of Social Educators (AIEJI)

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Foreword

The International Association of Social Educators, AIEJI, is a network of social educators from around the world. Following our publication "The professional competences of social educators – a conceptual framework (2009)" the board of AIEJI decided, within its current work strategy 2009 – 2013, to address the necessary competences of social educators in regard to working with persons with developmental disabilities.

A discussion paper was drafted based on the contribution by Nordic Forum For Social Educators (NFFS) and additional contributions from Italy and Spain. Subsequently, AIEJI held a seminar in September 2010 to discuss the content of the paper. This document encompasses the conclusions of the seminar. However, it is not meant as a final and absolute document, but rather as a discussion paper which, in the workplaces, can form the basis for further debate and reflection upon the role of the social educator and the development of our profession.

The basic debate about the role of the social educator

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 discussion paper the member organisations of AIEJI 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 education can be defined as: The theory about how psychological, social and material conditions and various value orientations encourage or prevent the general development and growth, life quality and welfare of the individual or the group. A fundamental element in social educational work is to facilitate integration and prevent marginalisation and social exclusion. This is done in a process of social interaction in order to support and help exposed individuals and groups at risk so that they can develop their own resources in a changing society". (AIEJI: The professional competencies of social educators, 2006)

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 education as well as humanly and politically.

This discussion paper discusses the role and responsibility of the social educator in working *with* and 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 educational practice when persons with developmental disabilities are to experience living a life of dignity on equal terms with other citizens.
- 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 educational practice.

The target group of this discussion paper are the members of AIEJI, students and other central agents who focus on the conditions of life for persons with developmental disabilities. It is our hope that the paper will be used in debates about the development of the social educational practice. Internally in the member organisations, at the educational institutions that educate future social educators and in matters of regional and social policy.

Benny Andersen

President of AIEJI, 2010

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Abstract

The discussion paper takes its initial point from the fact that despite decades of efforts of normalising and integrating persons with developmental disabilities there is still a long way to go. Therefore, it is necessary in the societal and political debate to articulate a changed vision: A vision about a life of dignity and citizenship through inclusion and participation.

The discussion paper focuses on the social educational practice aimed at 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 characteristics of high quality in practice, and in the professional associations' articulation of the social educational practice, are: 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 their consequences for the social educational practice. 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 discussion paper focuses on two central issues of the social educational 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 educational practice is challenged and new ways of practice are required. The use of force and coercion is discussed in the light of the constitutional right of the inviolability of the personal freedom prevalent in most democratic countries. 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.

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 educational practice and requires developing a practice with an anti-mythical perspective where non-discrimination, dignity and inclusion of persons with developmental disabilities are central.

Finally, the role and competencies of the social educator are discussed in a perspective of inclusion. It is pointed out that when the social educational 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.

Introduction

In this chapter, the need to challenge and develop the principle of normalization and integration, which for decades has been the dominating object 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 society 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 principles of normalization and integration

Globally, many 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 (see appendix 5 regarding the definition of "disease" vs. "disability"). 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.

Normalization and integration have been the leading principles for the societal and political objectives of many countries (see appendix 4 for an example from Italy). 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 discussion paper argues that it is time to reformulate the societal and political objectives 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. This has often led to a practice aimed at changing persons with developmental disabilities rather than changing 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 the services aimed at persons with developmental disabilities.
- Today, in most countries, persons with developmental disabilities 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 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 option 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.

There is no doubt that the well-being of persons with developmental disabilities has improved in many countries – for example in the Nordic countries. 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. It is, however, not everyone who has experienced improvements in their

¹ 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.

housing conditions and there are still many who don't have a private bathroom and toilet, kitchen and main entrance door.

One thing is the standard of the residence, another thing is what possibilities to an active lifestyle each person with developmental disabilities has in his or her home. The residential services and the social educational support programs are still characterized by being organized around workplaces rather than homes for persons with developmental disabilities.

Numerous studies show that everyday life in the residences is planned and arranged by the professionals rather than the residents. 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. The 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.

Today, persons with developmental disabilities take part in a range of leisure, social and work activities. Their spare time is not as predictable and standardized as before and it tends to be relatively easier for them to get out and about in their local communities – so they tend to do this more often. At the same time, it is argued that it is necessary to develop greater variety and a range of different activities within the general sector of leisure and employment (see appendix 4 for examples of activities).

Terminology

The aim of the discussion paper is to describe the challenges a defined group of citizens represent 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 that 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 ano-

nymous 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 is locked into certain images about behaviour, characteristics, personality and roles. On top of this, we also ascribe roles and specific characteristics to ourselves.

The concept of developmental disability is far from unequivocal and internationally there is no agreement on the 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 way disability is defined and understood has changed in the last decade. Disability was once assumed as a way to characterize a particular set of largely stable limitations. Now, the World Health Organization (WHO) has moved toward a new international classification system, the International Classification of Functioning, Disability and Health (ICF 2001). It emphasizes functional status over diagnoses. The new system is not just about people with traditionally acknowledged disabilities diagnostically categorized but about all people. For the first time, the ICF also calls for the elimination of distinctions, explicitly or implicitly, between health conditions that are 'mental' or 'physical' (see appendix 2 for WHO's definition).

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 discussion paper, 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 many countries. We acknowledge the fact that the UN Convention on the Rights of Persons with Disabilities refers to 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 discussion paper, in regard 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. In addition to persons with developmental disabilities, this term includes 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 educational practice.

Chapter 1. Ethical values and principles

In chapter 1, it is pointed out that ethics and focus on human rights can be understood as the lifeblood of social education, 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 the future will have significant influence on the way the societal efforts aimed at persons with developmental disabilities are understood and, thereby, also on social education and the roles and competences of social educators in practice.

1.a. Ethical values in social educational practice

In the interaction 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 AIEJI have agreed to follow through the Barcelona Declaration 2003 where it is stated that, the members of AIEJI will define ethical guidelines common to all social educators and that reflection on the practice and construction of the profession's conceptual framework is part of the competencies of social educators (see appendix 3 for the Barcelona Declaration).

Basic ethical values

From AIEJI's Professional Competencies², it appears that social educational practice is based on human and democratic values, including respect of the principles of human rights.

The document states that the national member organizations are responsible of developing - and with appropriate 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 represented in AIEJI manage this responsibility. Some have developed ethical rules, others an ethical code 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

² The Professional Competences of Social Educators – a conceptual framework, AIEJI (2009)

and compassion.

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 educational 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 educational 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.

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 ensuring that the individual person, with the abilities he or she has, can influence and participate in community activities and activities of society in general.

Non-discrimination is derived from the value of justice which for decades has been a leading value and principle in most countries in the development of 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, through considering and compensating for the individual background and condition of the person.

In this perspective, the main aim of the social educational 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/unharmd)

Dignity is a central value in social educational 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, harass or threaten, while passive mental violations can be ignoring and lack of stimulation.

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

Empathy

Empathy is a central ethical value in social educational 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. Empathy is an example of active, out-warded love for other people.

From the value of empathy comes goodwill towards other people which is dependent on your own efforts. This value is of great significance in social educational 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 educational 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 educational 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 educational 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 educational actions through ethical considerations. The collective ethical reflections are a substantial aspect of quality to the social educators.

The focus on ethics and human rights can thus be understood as the lifeblood of social education.

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 educational 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*³ in December 2006. Although not all countries represented by the members of AIEJI have signed the convention⁴ yet it will be a central element of social educators' foundation in the dialogue about the development of the social educational 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 educational practice. 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 foundation of social educational 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

The convention refers to disability/impairment in point 3 of the pre-ample in the following manner: "Recognizing that disability is an evolving concept and that disability

³ The United Nations (2006): Convention on the Rights of Persons with Disabilities
⁴ <http://www.un.org/disabilities/countries.asp?navid=17&pid=166#A>

results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on equal basis with others".

This understanding of disability/impairment focuses on the disproportion between the preconditions of the individual and the requirements of society and sets high demands for political and social educational agents (see appendix 4 for an additional definition of "disability"). It challenges the decision-makers 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 can be understood accordingly: That the political decision-makers 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. Thus, many countries fail, in effect, to be inclusive societies.

Core 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 educational 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 to turn words about equal rights and opportunities 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 the 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 the 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 educational provisions of work and activities, which are the most common, must be finalized to greater extent. 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, the right to sexuality, 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 rehabilitation, a reasonable living standard, social protection and 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 as it 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 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 reevaluate and, if necessary, reformulate the objective of social educational practice and social educators and initiate a change of the organising and planning of 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 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 appropriate adjustments and adaptation, when required in specific situations, that do not entail a disproportional or unnecessary burden, to ensure that persons with disabilities can enjoy and exercise all human 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 adaptation 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 adjustments 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. Focus on some central issues

In social educational practice related 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 educational support of 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 they 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 the future must have a more central place in the discussion about care, including neglect of care and forced care.

2.a. The right to a private home

In this paragraph we focus on the right of persons with developmental disabilities not to 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 home 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 disabilities 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 has been abolished in several 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 which are far from meeting current standards of living. It is the rule rather than exception that the social educational support and residential offer are characterized by being organized around workplaces rather than private homes of persons with disabilities.

When 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.

Institutionalized life is characterized by:

- Isolation from environment
- Categorisation of residents
- Standardisation and predictability
- Staff to whom the institution is a workplace

In a report from the EU⁵, 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 agency has contributed with a description of what a residence without institutional characteristics is. Residences of persons with impairments can not:

- 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 prevented
- 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 educational support of persons with disabilities.

A residence is not the same as 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.

There are two central values linked to the feeling of having home:

- Home is a place where you can make your own decisions, a platform for participation in 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.

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 a process where 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.

A realisation of the convention implies:

- A break from package solutions
- That the residence and social educational service are separated organizationally
- That support of the individual person with disabilities is provided in consideration of individual needs, conditions and background
- Individual access to services and assistance according to personal needs, in order to maintain a life of dignity characterized by 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 that are part of the residence, and in which activities he or she wants to participate outside of the residence.

⁵ Report on the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities. February 2009.

A separation of the residence and organizing the support and services 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 the general 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, where as everyday life is circular.

Mental images of how the support and assistance 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.

2.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 base, can not be justified despite being done with good intentions.

The inviolability of the personal freedom

When discussing the social educational efforts, the issues of force and coercion and how to prevent the use of this, keep coming back. The use of force and coercion in the services aimed at persons with developmental disabilities must be understood in the light of the constitutional principle of the inviolability of the personal freedom.

The principle is expressed through the overall rule that the personal freedom is inviolable and only on rare occasions can be exempted from. The exemption applies if the person, through his or her actions, is at significant risk of causing self-harm or harm to others. Intervention can happen only on a legal basis. The laws that regulate the social educational practice are different from country

to country but a common theme is that the option of using force and coercion is positively limited. It is explained in detail under which circumstances intervention can take place and which criteria must be met.

The principle of personal freedom, and the fact that intervention must have a legal basis, also mean that some actions can be so intervening so they, regardless of whether the person opposes or not, must be considered as force and coercion. Therefore, it is necessary to define force and coercion descriptively. That is, describe the specific action in relation to what actually happened.

Force and coercion – neglect of care or forced care

The use of force and coercion is often justified with the explanation that an intervention of the personal freedom is necessary in order to ensure the dignity of the individual or prevent neglect of care. Both explanations are, however, somewhat problematic. 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 goodwill, that is, 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. 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, self-determination 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.

This poses a challenge to the 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 ensu-

re, 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 poses a challenge to public authorities and their

related policies. 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 support is carried out in daily practice and it requires that economic considerations are not attached greater importance than professional and ethical considerations.

Chapter 3. Inclusion and citizenship

In chapter 3 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.

3.a. Consequences of ethics and the principle of human rights

In this discussion paper, a number of basic ethical values and principles in social educational 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 educational 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 educational 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 "us" and "them". This is a pivotal factor for the development of social education in terms of both the profession and the individual social educational effort.

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 disabilities. 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 points out 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 on disability, Gustavsson, points out 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 assistance.

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 everybody else, and thereby become part of "us". This requires, however, more than mere ratification of the convention. The convention must be implemented in the social practice of all sectors of society and at all levels in the respective sectors.

3.b. 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:

- 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 and no emotions
- That they are weak individuals who need assistance 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 anti-mythical perspective on persons with developmental disabilities:

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- 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 “less” 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
 - Everybody has the same rights

Non-discrimination, dignity and inclusion of persons with developmental disabilities do not appear automatically but require a reevaluation of visions and aims of the field and a new understanding of what characterizes social educational practice. It also implies that we think and speak of disabled people in a neutral way, as men and women with different abilities.

3.c. Citizenship – inclusion and participation

The convention on disability requires a social educational 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 educational 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 and the base of knowledge which practice is founded upon. It is therefore necessary to reformulate visions and aims. A challenge to organisations of social educators 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 educational 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 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 will persons with developmental disabilities have the opportunity to live a life of dignity and be genuinely accepted as part of human diversity.

Chapter 4. Consequences of the principles for social education

In chapter 4 we resume where we ended in the last chapter. The critical implications that the convention has on society, the profession of social educators, the role of the social educator and the competences of social educators, when the efforts of society and social educational practice must be in accordance with the convention and the basic ethical values and principles, are highlighted.

4.a. Implications to society

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 that radical changes in society must take place. 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 a political will to act. It must imply priorities that favour a development of society with a focus on inclusion and participation for all.

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 concerns the option of expressing oneself and being heard in local as well as general political contexts. And, not least, 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.

4.b. Implications to the profession

The objective of social educational practice is to promote social change and solutions in human relations. The discussed principles will have implications to the professional development of social education. 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 upon the UN convention on disability's perspective of rights.

4.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 (see appendix 4 for examples of functions of the social educator).

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. The role of the social educator is, to a large extent, related to the preconditions of the individual and demands and barriers of society.

Mastering as a concept of reflection

The concept of mastering can be useful as a way to understanding the practice of social educators provided for persons with developmental disabilities. The concept of mastering has 3 elements: comprehensibility, manageability and meaningfulness. Those 3 elements are 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.

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.

Meaningfulness:

- Concerns 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.

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 educational practice solely focuses on developing the competences, without being preoccupied with the feelings this generates, we run the risk of social educational practice, instead of improving persons with developmental disabilities' experience of living a life of dignity, it becomes a barrier to this.

The asymmetric relation of power

The concept of power is not an unequivocal concept. Power is a force inherent within every social relation – which makes every relation a relation of power. Power is therefore understood as a relation which causes, influences and changes and not something unequivocally negative or destructive but rather as a productive force which is a basic element of social relations. The point is that power belongs to no one, 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 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 educational practice is to be exercised in accordance with human rights, while considering the ethical values, social educational practice must be administered with the aim of providing the individual person with developmental disabilities the opportunity to realize his or her rights and to be included in the community of

society through self-determination and participation.

It is therefore paramount for the quality of social educational 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 educational practice is about ensuring that persons with developmental disabilities experience living a life of dignity on their own premises (see also appendix 4). 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.

But the participation of persons with developmental disabilities must go further than just the daily activities. The concept must also be understood as the citizen's influence on the community. 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.

4.d. Implications to the social educational competences

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 educational practice is a task exercised within the available provisions of society. In the light of the basic ethical values and principles, among these the convention on disability, the competences that social educators must possess can be outlined as follows:

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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 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.*

Chapter 5. The responsibility of social educators and their organisations

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 educational 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 education. 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 must be part of the agenda in the development of the profession.

It is for this purpose that this paper was written, to stimulate discussions in the various associations, organisations and work places of social educators.

Appendix 1. 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 educational practice?
 - Find examples of social educational practice and discuss how the consideration of the importance of the different values is expressed in a given action/situation
2. 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.
3. 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 educational practice?
6. When the aim of the social educational 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 possess?
7. Which factors contribute to maintaining the dimension of wethem at your workplace?
8. What does an inclusive society look like?

Appendix 2. WHO's definition of disability

The new ICF focuses on analyzing the relationship between capacity and performance. If capacity is greater than performance then that gap should be addressed through both removing barriers and identifying facilitators. The new WHO ICF specifically references Universal Design as a central concept that can serve to identify facilitators that can benefit all people.

The WHO defines disability as a contextual variable, dynamic over time and in relation to circumstances. One is more or less disabled based on the interaction between the person and the individual, institutional and social environments. The ICF also acknowledges that the prevalence of disability corresponds to social and economic status. The 2001 ICF provides a platform that supports Universal Design as an international priority for reducing the experience of disability and enhancing everyone's experience and performance.

The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual's functioning and disability occurs in a context, the ICF also includes a list of environmental factors.

The ICF is WHO's framework for measuring health and disability at both individual and population levels. The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001(resolution WHA 54.21). Unlike its predecessor, which was endorsed for field trial purposes only, the ICF was endorsed for use in Member States as the international standard to describe and measure health and disability.

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed, ICF allows to record the impact of the environment on the person's functioning.

Appendix 3. The Barcelona Declaration

Professional Associations of Social Educators/ Pedagogues met in Barcelona on 8th , 9th and 10th October 2003, to participate in the First European Symposium of Social Educators' Professional Associations called by the European Office of the International Association of Social Educators (AIEJI).

Declaration

The will to take part in the process of building a European Union that makes for easy professional mobility. The will to participate in the common construction of the European Social Educator's profession.

The will to contribute our knowledge in defining criteria for the professional recognition of Social Educators Professional Qualifications in Europe.

The will to define ethical guidelines common to all social Educators in Europe.

The need to have a specific training at level 4, as outlined in the European Directive 2002/0061(COD), for all social educators in Europe.

Considerations

The stated will and needs.

That our profession is based on socio educational practice.

That reflection on the practice and the construction of the profession's conceptual framework are part of the competencies of social educators.

The goal of building the European social educators common platform, in addition to other projects.

We agree

To work together for the recognition of the social educators' profession in Europe.

To define the set of professional qualifications criteria that provide a suitable level of competence to perform the profession. Develop a common ethical base that will guide social educators' practice in Europe.

To work for recognition at level 4, specific training at University or equivalent institutions, as specified in the European Directive 2002/0061 (COD), that involves theoretical and practical issues.

Appendix 4. Cognitive Consultation by ANEP, Italy

Introduction

This Italian contribution, produced exclusively for AIEJI, intends to make a survey on the role of social educators used in various services for people with disabilities. However, before focusing on the role of education it is necessary to introduce a brief reading of the context.

Italy, in the beginning of the '70s and following the closure and decentralization of large daycare organization facilities for people with disabilities (which included special schools with differential case classes and custody institutes), set up a gradual progressive network aiming at social integration services for people with disabilities. An integration which was also supported by cultural and lexical changes: It switched from using terms such as "subnormal" or "handicapped" to definitions such as "disabled" or "differently able", which enhance the person rather than the deficiency of the bearer.

The next principal directions are provided by act no. 104/1992 (framework act for the assistance, social integration and rights of disabled persons) and act no. 328/2000 (framework act for the implementation of the integrated system of interventions and social services). More recently, we have experienced a transposition of the ICF (International Classification of Functioning) and the articles listed in the UN Convention on the Rights for Persons with Disabilities.

The development of operational strategies, particularly designated to promote the culture of disability, was established in Italy in the current year. The Center on Disability (Osservatorio sulle disabilità) chaired by the minister of labor, involves observers stationed at the regional level and associations of disabled people, with the inclusion of union representatives.

In the discussion of statistical data we refer to the national situation, but since Italy consists of regions, we have chosen to focus on the operating modality put in place by the Veneto Region.

*Statistics on disability in Italy*⁶

The main source of data used to estimate the number of people with disabilities present in Italy is the ISTAT survey on health status and use of health services of 2004-2005, it is however partial and must be integrated to

⁶ www.handicapincifre.it

⁷ Regione Veneto, *Servizi per la disabilità, anno 2007*, scaricabile integralmente da: www.venetosociale.it

arrive at an overall estimate. The survey does not include children up to 5 years, as the instrument used in the research is not likely to provide useful guidelines for this population.

According to estimates, in Italy there are 2,609,000 people with disabilities, equivalent to 4.8% of the population over the age of 6 living in the family. The estimate is based on a very restrictive criterion of disability, and persons with disabilities are considered to be those who, during interview, reported a total lack of autonomy for at least one essential function of everyday life. Moreover, the estimate rises to 6,606,000 people, or 12% of the population that lives in the family over the age of 6, if we consider all the people who have experienced an appreciable difficulty in performing these essential functions. People who suffer from some form of mental disability, but are able to carry out these essential activities, are excluded.

Certification, investigations and protection⁷

Civil invalidity

The recognition of civil disability may be requested for:

- Children with chronic illnesses or permanent disabilities, both physical, psychological and intellectual, which involve one or more of the following conditions:
 - Persistent difficulties to perform tasks and functions
 - Deafness with hearing loss greater than 60dB on the better ear (calculated at frequencies 500-1000-2000 Hz)
 - Need for continuing assistance
- Adults with chronic illnesses or permanent disabilities, both physical, psychological and intellectual which involve one or more of the following conditions:
 - Reduction of work capacity greater than 33%
 - Need for continuing assistance

Benefits

- Disability of 100%, exemption on pharmaceutical ticket
- Disability of 67%, ticket exemption on specialist and laboratory services
- Disability of 46%, entry in enrollment list for the employment of disabled people
- Disability of 74-99%, monthly check or 100% civilian disability pension calculated on the income limits set annually by the national legislation.

- Elderly (over 65 years) with chronic illnesses or permanent disabilities, both physical, psychological and intellectual, which involve one or more of the following conditions:

- Persistent difficulties to perform tasks and functions
- Need for continuing assistance

In alternative of seeking CIVIL invalidation

- Recognition of blindness can be obtained from:
 - Totally blind
 - Subjects that have a residual binocular perimeter less than 3%
 - Subjects that have a residual binocular perimeter less than 10%
 - Subjects that have a rectified residual vision, not exceeding one twentieth for both eyes
- The recognition of deafness can be obtained from:
 - Those who are suffering from congenital deafness or acquired during the developmental age, which has prevented the learning of spoken language

Investigation of the condition of disability

The determination of the condition of disability may be requested by those who have a physical disability, mental or sensory impairment stabilized or progressive, causing learning difficulties, reports, or work integration that lead to a situation of disadvantage or social exclusion. The condition is recognized as a serious handicap to those who have reduced personal autonomy, making it

necessary to intervene permanently and continuously on the individual who is no longer capable of caring for him- or herself and in relationship with others.

The determination of the condition of disability is needed to access targeted employment: people with more than 45% disability are entitled to employment in companies with tasks that meet the requirements suited to their abilities.

Forms of protection

In Italy, there are forms of protection for the safeguard and security of people who have limits of autonomy and therefore difficulty in managing their assets and interests. With act no. 6 /2004 the figure of the support administrator (curator) was introduced which is a major social and cultural institutional innovation, issued for the protection of human rights and dignity of people deprived of all or part of their autonomy to act. The support administrator is responsible for offering support in activities of daily living. The support may include both financial matters such as: collection of salary, sale of a home, acceptance of an inheritance, etc..., or decisions relating to health or personal problems. Considering that interdiction and disqualification involve severe limitations in the ability to act, the support administrator allows the disabled person to keep a greater autonomy in making decisions, remaining, in its specificity, a protagonist in the social context.

Services⁸

<i>Title</i>	<i>Service Description</i>	<i>Numbers of Educators expected and functions</i>
Complex Operative Unit of Neuropsychiatry of Childhood and Adolescent	Pursues semi-ambulatory and semi-residential activities for children, preadolescents and adolescents with Neuropsych disorders and behavioral changes. Also ensures the neuro-motor rehabilitation development during the evolutive age	3 Educators Educational functions
District operating Unit and adults disability	Ensures the social and psychological response at the district level of the disabled adult population, (aged 18 to 65 years) through measures to promote autonomy and integration	1 Educator Educational functions

⁸ I servizi descritti sono attivi nella Regione Veneto, i dati sono stati desunti dal Dgr n. 84 del 2007 e dal sito: www.venetosociale.it alla voce "Pubblicazioni"

<i>Title</i>	<i>Service Description</i> (such as attendance at day centers, support for the family, acceptance in residential structures ...).	<i>Numbers of Educators expected and functions</i>
Home care procedures	Social welfare procedures planned on the basic needs of the person and paid by the municipality, according to its criteria for access. Professional figure expected: Social-Health operator	Educator figure not expected
Education and Social Handicap Integration Service (SISS)	Takes care of the child's basic needs (nourishment, personal hygiene, etc.) and it accompanies him in the acquisition of his autonomy and school activities. Assists all children who attend public schools and subsidized education schools, from kindergarten to the second cycle (high schools and vocational training institutes). Also helps children and adults attending summer recreation centers and climate stays created by the municipalities and private social organizations.	Educator figure not expected
Integration employment service (SIL)	Supporting and tracking of people entering employment, and in charge of disabled persons and persons in care by the Department of Mental Health and Addictions. Works in collaboration with the departments of employment, with the municipality social services, and with ULSS social services, as well as with the resources of the territory. Through the Guidance Center also offers support to children with disabilities and their families in the choice of schooling and training	Not definite legal standard. SIL, in the Veneto Region, represents 61% of staff employed. Functions: counseling, orientation, assessment of self autonomy and their working capacity, development of social integration projects, employment mediation, and supervision.
Day Center for people with disabilities	Daytime territorial service for people with different disability profiles of self-sufficiency, which provides assistance to an educational-rehabilitative-care. Receptive capacity: up to 30 guests organized into groups	From Standard (DGR n. 84, 2007) 1 educator per 10 guests Educational functions and/or coordination functions
Housing community for people with disabilities	A service that welcomes adults with no family or unable to remain at their household. Purpose: Reception and management of daily life, oriented to the protection of the person, the development of social skills and rehabilitation,	From Standard (DGR n. 84, 2007) 1 educator per 10 guests Educational functions and/or coordination functions

Title	Service Description	Numbers of Educators expected and functions
	or even the realization of experiences of independent living. Prompt to host (and/or programmed). Receptive capacity: 10 seats.	
Residential community	Residential services for disabled people with severe and very serious limitations, both physical and mental, in which multidimensional assessment results nevertheless make it clear that it is impossible to provide home care or offer other special facilities for the disabled, with lower verge of protection. The service is aimed at adolescents and adults with major high levels of dependence on health care and rehabilitation. Receptive capacity: maximum 20 guests and organized into different groups for illnesses compatible.	From Standard (DGR n. 84, 2007) 2 educators per 20 guests Educational functions and/or coordination functions
Residential Health Assistant (RSA) for persons with disabilities	Residential services for disabled people with physical and mental limitations of autonomy, in which multidimensional assessment results nevertheless make it clear that it is impossible to provide home care or offer other special facilities for the disabled. The R.S.A aims to the care and provision of health services and the functional recovery of persons predominantly not self sufficient. The receptive capacity is minimum 20 guests up to a maximum of 40 guests	From Standard (DGR n. 84, 2007) 1 educator per 20 guests Educational functions

The right to employment of persons with disabilities

Regulations⁹

In Italy the act no. 68/1999, "Standards of the right to employment of people with disabilities", is applied for the inclusion of:

- a) persons of working age suffering from physical, mental or sensory and intellectual disabilities, resulting in a reduced capacity to work of more than 45 %, determined by the relevant committees for approval of civil disability.
- b) persons with disabilities with a working disability exceeding 33 %, established by the National Institute for Insurance against labor accidents and occupational diseases (INAIL) pursuant to the current provisions;
- c) persons who are blind or deaf and dumb.

d) persons who are war invalids, civil disabled from war and disabled servicemen with disabilities ascribed from the first to eighth class.

1. The private and public employers are required to have their workers employed in the categories mentioned above in the following manner:

- a) seven percent of employees, if work-force exceed 50 employees;
- b) two workers, if work-force include 36 to 50 employees;
- c) one worker, if they employ 15 to 35 employees.

2. For private employers that employ 15 to 35 employees the act as in paragraph 1, applies only in cases of new recruitment.

⁹ www.handilex.org

Social Cooperative

Social cooperatives are a special category of labor organizations, characterized by pursuing the general interest of the community to promote human and social integration of citizens through:

- management of social, health and education services (cooperatives type A);
- accomplishment of different activities - agricultural, industrial, commercial services - aimed at providing employment for disadvantaged people (cooperatives of type B).

This is the definition given in Article 1 of Law 8/11/1991 n ° 381, which governs the social cooperatives and to which reference should be made to know the specific obligations and prohibitions. The same law governs the figure of the volunteer and the disadvantaged member, and it provides agreement between public and Type B social cooperatives for work integration. The cooperatives of type B may offer different services, the most common are: gardening, maintenance of public parks, restaurants, handicrafts (ceramics, book-binding ...) and so on.

Assessment

SIL data on employment integration of people with disabilities living in the Veneto Region:

The SIL (Labor Service Integration, established by Regional Law n.16/2001) is a social-health service based on the principle of social inclusion of people with disabilities and/or socially disadvantaged and plays an important connection between employment services and the local system.

The tasks of SIL are:

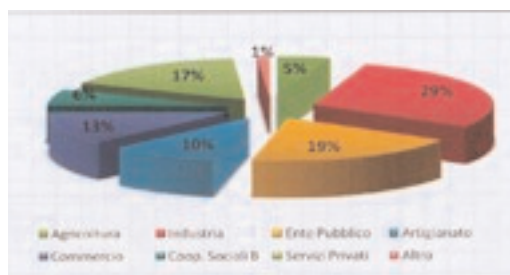
- knowledge and assessment of potential and individual needs of persons and businesses;
- planning and management of individual paths for a positive match in work integration between demand and labor offer;
- monitoring experience;
- promoting collaboration between institutional figures in the business world, in the system of vocational training, in social cooperatives and in associations of disabled people and their families.

There are 6,994 individuals dependent on the SIL in the

Veneto Region in 2007 who are divided into five categories:

- Persons with disabilities (including physical disability, intellectual and sensory);
- Persons with psychological distress (meaning people with psychological problems and neuropsychiatric);
- People with drug problems;
- People with alcohol problems;
- People with other disadvantages.

The network of public and private companies that have collaborated with SIL in 2007 for the implementation of employment integration projects aimed at people with disabilities is depicted in the following illustration:



The role of education

- aimed at people with disabilities

Requirements of the social educator

With reference to the mentioned regional regulatory law, requirements to perform are:

1. Diploma of Social Educator Animator (regional three year course)
2. University Diploma as Social Educator
3. Degree in Education or Science Education, specializing as a social educator, or other equivalent qualifications recognized by the state and the Veneto Region

The educational functions

One common procedure in the educational functions is accomplished by the "Working For Project" task, which develops the general targets previously stabilized by the UMVD (Unità Valutativa Ultradimensionale Distrettuale), Multidimensional Evaluating Unit District. UMVD is an institutional medical team that first makes a general evaluation the disabled person and then decides which suitable service to apply, diurnal or residential. Only at

this point the Social Services take charge of the disabled, and the social educator elaborates and applies the proper individual project.

In many services the educator is a key figure in the definition and documentation of the "custom project" (PP). The social educator follows roughly the following steps:

1. Reading the client's needs and the needs of the family and its social context
2. Assessment of responsiveness in terms of internal structure and possible integration and resource of network services
3. Prediction of results you wish to reach
4. Sharing with other professionals involved in the care and identification of the operator responsible for Custom Projects (PP)
5. Sharing information with the client and/or with his or her family in the definition of the PP
6. Formalization of the PP and description of specific activities, time of realization, frequency and prerogative of procedures or performances.
7. Definition of procedures and means of verification
8. Monitoring and documentation of results in itinerate
9. Evaluation of results according to a system of follow up, even after the procedure, in relation to PP

The educational tasks within the daily services or residential facilities also provide the organization with activities through modules or groups in relation to the type, needs and potential of the people with disabilities.

Functions of coordination

The coordination function, as defined in the regional regulations (DGR 84/2007 Annex A) refers to tasks of direction and technical support to the work of operators also in relation to their training, promotion and evaluation of the quality of services, monitoring and documentation of experience, experimentation of innovative services, all in junction with the educational, social and health services, always collaborating with the families and the local community in order to promote pathways of integration with the territory.

Activities for disabled people who use the daily or residential services

In the list below are some of the overall socio-educatio-

nal activities to be undertaken in various services, depending on structural availability and needs of the recipients observed in personalized projects. These are occupational activities mainly aimed at learning techniques that can be linked to job placement or paid work. The activities can be conducted by other professionals besides social educators, if they have jurisdiction, and also by other specialist figures (engineers, masters of art, experts, craftsmen).

Laboratory of Ceramic

Computer Lab

Laboratory, animated reading and creative writing weaving workshop

Laboratory for the production of baskets, wicker and rattan

Other thematic workshops, depending on availability and handcraft vocation of the territory (e.g. binding, marbled paper, masks ...)

Gardening and cultivation of vegetable gardens

Hippo therapy

Swimming

Animal-assisted Therapy (Pet Therapy)

Territory outings

According to the cognitive survey "The use of 'non-verbal language' in day-care for people with disabilities" conducted by the Veneto Region in collaboration with the University Ca 'Foscari of Venice, it is important to note the identification of four implementation areas of interventions that use non-verbal language:

Locomotion

Music Therapy

Graphic and pictorial activities

Theater

These activities include, in most cases, the services of an outside expert, but the role of education is still essential to the connection between the expert, the group and other professional figures.

To the educators also evaluate documents and file procedures. These procedures can also be put on line to be known and shared by other Italian services working with disabled people.

Experiments

During a conference held in Rome October 23 2009, the

AMISL project was presented – **Development of informal skills of operators and participatory evaluation for the improvement of services dedicated to older persons with disabilities.** The use of Sophrology is highlighted here.

The originality of the Sophrology method (founded in 1960 by Alfonso Caycedo) lies in directing the attention on the psychophysical harmonic state and on the positive phenomena of consciousness, (rather than to the negative or pathological one), in order to establish or restore harmony between body and mind. One aim is to

focus attention on the patient's pleasant feelings and well-being sensations, favoring a withdrawal from a painful contingent situation and leading to general relaxation. Interesting is the application of relaxation therapy at IPAB San Michele in Rome where, through an innovative workshop, relaxation therapy techniques are suited to the needs and the timing of the patients. The innovative aspect is to transmit the tools and methodologies of relaxation therapy to educators and social-health professionals as a support to their profession in the relationship with patients or clients.

Appendix 5. Intervention and the role of the social educator

By Barbara Sestito

Working with persons with disabilities – the role of the social educator

Friedrich Nietzsche, the philosopher, argues that what is done for love always occurs beyond good and evil.

Referring to working with people with disabilities as a primary, means to examine our behavior towards people with disabilities, regarding them not as victims and making sure not to fall into that form of compassion or even disinterest towards them.

We should examine our attitudes towards those who are different from us and shed light on how these attitudes are projected in all that has until now been achieved for the disabled. It's not enough to diagnose the capacity of disabled people, but it would be good to know how the disabled person feels about him- or herself as an individual, what he or she thinks of his or her family, and how he or she feels about people's reaction towards their person.

A false and harmful widespread belief is to consider disability a disease. The concept of disease is defined by reference to the body's state of the health. As we know, however, disability and disease have very different meanings. In the state of disease you feel the expectation of healing precisely, as the healing restores the body's state of integrity. The handicap can not be seen, therefore, as a disease because the handicap is not transitory but a permanent condition. Disability is rather an anomaly (from the greek word "omalos", indicating what is not smooth) and therefore a diversity and durable state of living with a full and complete intellectual, psychological and social process, even if based on other channels of reference caused by the presence of diversity.

“Handicap” is the result of interaction between individual disabilities and social expectations such as autonomy, communication, locomotion, socializing and standard behavior

A definition of disability as formulated above has no absolute value but is only relative, changing with the variation of the concept usually present in society at dif-

ferent times of its development. It opposes the diagnostic medical labels used to name the person declaring the bearer of a specific syndrome (autistic, psychotic etc.) and rejects any evaluation of quantitative (IQ) which beyond the labels offers concrete elements, so you can design, build and test didactic, educational interventions.

The philosophy which inspires this kind of definition is that of “adaptive behavior”. According to this philosophy, it is not important to know what the skills of the disabled person would have been if he or she was “normal” as it is more important to evaluate the person with disability with regard to behavior “test” which may be different from those of normal development, focusing on repertoires of adaptive behavior as they are defined by the environmental demands: analysis will focus on places and environments report on the skills most often used in these contexts.

The rehabilitative intervention for people with disabilities focuses on what the person is unable to manifest in relation to specific expectations, the deficiency of the disability and the skills, strengths and expertise of the disabled person.

The disability is also evaluated on what the subject appears to manifest too frequently which represents a value of non-adaptive behaviors that cause damage to the subject itself and hinder its development, cognitive and emotional - relational.

This second great class may be indicated by the term “behavior problem” or “mark behaviors” (self-injury, aggression, etc.) which are also called “goal behaviors” to increase the functional behaviors by the individual in order to adjust its living environment and relationship. Both “mark behaviors” and “goal behaviors” can be treated with rehabilitative interventions.

The behavioral method is based on observation of behavior, which is broken into many small, observable units, so that anyone can be measured in objective terms.

Strategic elements in forming an educational program according to the behavioral methods are: stimulus, response and consequence.

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- 1) Stimulus: means any object or event in the concrete world that would give the opportunity to respond;
 - 2) Response: means any activity or behavior which the subject performs in the presence of the stimulus;
 - 3) Consequence: this refers to what happens to the subject after the response.

Whenever you want to teach a new behavior or improve an existing one it is important:

- 1) To assess the exact response (objective) that you want from the subject; ;
- 2) Choose one or more stimulus that facilitate the issuance of the response;
- 3) Choose one or more reinforcing consequences that increase the probability of releasing the desired response.

The reinforcement is therefore something that is appreciated by the person. The reinforcement, if given at the right time, increases the probability that the response will reoccur in the future.

The rehabilitation establishes therefore, the objective of limiting the impact of disabling conditions through interventions that help to preserve the highest level of independence compatible with a given clinical condition.

It is configured as a multidimensional approach that involves several professionals, aimed at improving the quality of life for patients with disabilities.

Promoting a better quality of life for patients and caregivers, can be obtained through specific techniques addressed to the person and to the optimization of environmental characteristics, in order to facilitate the adaptive relationship and reduce the level of disability. It is important to involve caregivers in the rehabilitation project and consider them a resource that must be supported by appropriate training and, if necessary, psychological support.

Social educators within a rehabilitation context of persons with disabilities are professionals who: plan and implement projects with intentionality and continuity, observe and analyze the needs of the persons they work for and with, report the resources of the person, manage and verify the educational interventions, with the idea of multi-disciplinary integration; who are involved in care

development and recovery of social skills and capacity report (which should be done in a helpful and sympathetic manner).

The social educator focuses his or her actions on the complexity of the individual and not only on the individual's state of health, whether physical or mental. The disabled prior to this, is a person, a human individual, and as such should be seen.

At the moment, when no one remembers this complexity, the intervention of social educators declines and becomes fragmented and incomplete.

Education has the tools to evolve and adapt to any change, even though it may be difficult to accept adapting to changes often consolidated.

However, the social educator has the duty to find a strategy which offers, although sometimes in temporary and mostly individualized form, comfort or relief to the problem.

The word "educate" – from the Latin word "educare" – means feed or heal, but also extract, bring out, bring forth what is within, bring out potential.

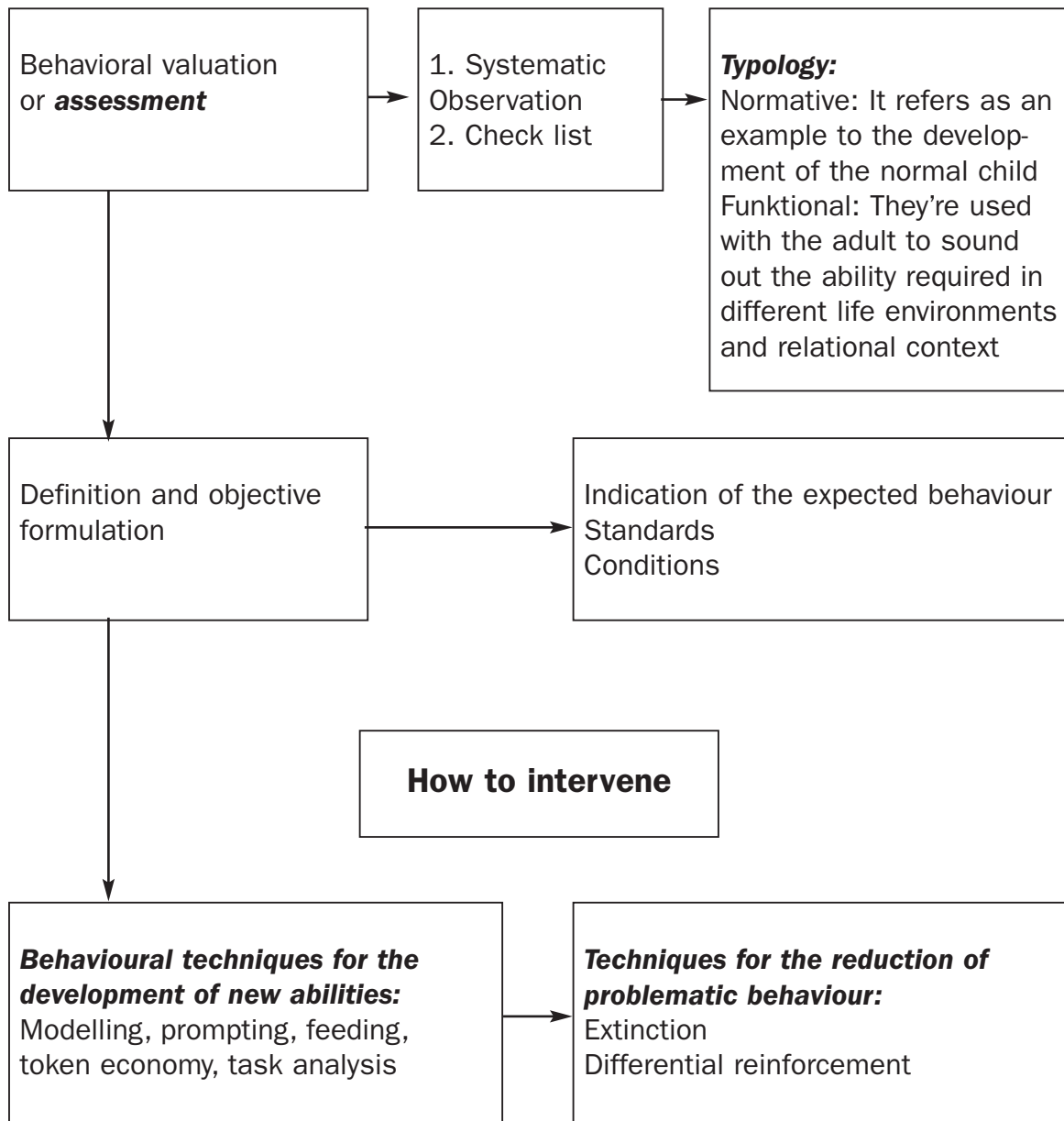
"Educate" means to take charge of caring for others, trying to involve all agents that may be helpful for this purpose, first of all the family.

Last, "educate" means to bring light to consciousness, to potential or hidden skills which can become the heritage of the history of life that characterizes every person.

The social educator is a figure now firmly structured within the social and health services, with a specificity in order to promote understanding on the entity of the person that has both limits and potential.

The social educator is oriented towards reducing social problems, to the maintenance or enhancement of psychological well-being and social rehabilitation in the broadest sense, in order to catalyze the vital dimension and help optimize a quality of life and a dignity, rewarding for the person, reducing the deficiency and enhancing the resources.

Rehabilitative intervention in those with handicaps



Appendix 6. Functions of the social educator in the field of mental health

By CEESC, Col·legi Educadores i Educadors Socials de Catalunya

1. Functions regarding users

- Making the interview of connections with the service and making an initial offer of activities.
- Favouring the user's connections with the services and with the group.
- Support and aid relation – the social educator is a referent for the user, the social educator is a figure of support with which the user will be able to detect abilities, difficulties and interests; the user will be given guidance in improvement processes and will be consulted and understood in moments of doubt and conflict.
- Promoting the autonomy of the person helped, making the users think about the therapeutic itinerary to follow (preparing/reaching a consensus with them on the objectives of the PIRR/PTI), respecting their own decisions and the personal moment in which they are.
- Offering group spaces to promote and stimulate participants' cognitive and expressive abilities.
- Giving users information or advice (and keep their company, if necessary) about leisure, social and cultural resources of their community.
- Mediating between users and their environment.
- Facilitating the reflection on the selfstigma which mental illness involves.
- Looking after user's rights and duties.

2. Functions regarding families

- Facilitating the relation and communication processes between users and their families.
- Getting families involved in users' therapeutic and rehabilitation processes.
- Offering resources and strategies to reduce the emotion expressed.
- Participating in the monitoring of psycho-educational groups aimed at users and their families.
- Collaborating in speeches to give information and welcome users to the service.

3. Functions regarding the work team

- Coordinating information and reaching a consensus, in the interests of users, on interventions with all the professionals and services involved.
- Participating actively in the planning, implementation and assessment of the different intervention projects and programmes.
- Ensuring that the socializing and integrating purpose is kept, considering the individual as a whole, working with the abilities and potentials, preventing the biased concept of purely clinical and medical rehabilitation.
- Preparing social and educational reports.
- Controlling work placement processes.
- Giving support and advice to the team of social educators.

4. Functions regarding the community

- Bringing the reality of mental health closer to the community, breaking stigmas and false believes related to these illnesses.
- Getting agents from outside mental health network involved, in order to facilitate the integration of affected people of the community.
- Knowing the services and the social, cultural, and leisure equipments around the service and the users who consider the social educator a referent.
- Collaborating in the preparation of a file registering information about services, equipments and associations in the area.
- Carrying out the monitoring of the users who do activities in the community.
- Promoting, preparing and monitoring the community intervention projects related to the fight against the stigma of mental illness, as well as encouraging autonomy.
- Doing research into and coordinating groups of volunteers.

