AUTISME-EUROPE **AUTISM-EUROPE**

AISBL

TRAINING MODULES

FOR POLICY DECISION MAKERS AND PROFESSIONALS OF SERVICES FOR PERSONS WITH AUTISM SPECTRUM DISORDERS (ASD) AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

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For Diversity Against Discrimination

TRAINING MODULES

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INTRODUCTION

EQUAL OPPORTUNITIES FOR PERSONS WITH COMPLEX DEPENDENCY NEEDS DISABILITIES

Yannis Vardakastanis, President European Disability Forum (EDF-FEPH)

Equal opportunities for persons with Complex Dependency Needs Disabilities are a difficult, but crucial topic. Difficult, because we face today great barriers in society for the full and equal participation of persons with complex dependency needs. Crucial, because we cannot and will not compromise when it comes to the most fundamental human rights and the very essence of the value and the dignity of the human being.

The full inclusion and participation of all disabled people in society is the ultimate goal for the disability movement. The European Disability Forum, the umbrella organisation of all disabled people at EU level, composed of 29 national platforms, and European federations representing different groups (like Autism Europe), is convinced that independent living is crucial if we are to allow for such inclusion and participation. Institutionalisation, on the other hand, can only lead to exclusion and is in itself a violation of basic fundamental human rights.

This is true for all people, including persons with complex dependency needs disabilities. 2007 is the year of equal opportunities. What do equal opportunities mean? “Equal opportunities” does not mean that all people can have the same goals and achieve the same results. It means that none should be deprived of a chance to develop their own skills and bring their specific talents and capacities into society.

Today people with complex dependency needs experience major barriers to the full enjoyment of their rights. Some of them have “inner” barriers represented by the very severity of their impairments. Some of them are condemned to dependency because the society does not provide for the positive actions needed to ensure the development of their unique potential. Moreover, because often they cannot represent themselves independently without support, they are often hidden away, ignored and exposed to discrimination and abuse. Thus, they are the most excluded among the excluded, and one of the most discriminated groups in our society.

Nevertheless, regardless of the nature and the severity of their impairments, disabled persons with complex dependency needs are entitled to enjoy the same human and fundamental rights, and equal opportunities for a life without discrimination in all its dimensions, as anyone else. Today, this is not reality, despite International and European human rights instruments which solemnly declare the equal rights and value of every human being. Many disabled people live in large residential institutions, where there is no or insufficient possibilities for personal development and self-realization. EDF demands that all disabled people should be

protected from all forms of coercion and oppressive forms of living. The need for a definitive change in society, from institutionalisation towards inclusion and participation of disabled people is therefore urgent.
What does independent living mean for persons with complex dependency needs disabilities? It means full respect of our human rights, essentially the rights to equal recognition before the law, including the right to have and exercise legal capacity, right to choice of place to live and being included in the community, right to physical and mental integrity, the right not to being subjected to cruel, inhuman and degrading treatment, and punishment, not to be deprived of liberty because of a disability, but also right to inclusive education, to communication, accessibility, social and cultural life, employment are key issues, affecting directly persons with complex dependency needs disabilities.

It also means having the dignity to make the choice that one is able to make. The scope of choice is vast, and for many persons with complex dependency needs there is a need for support in taking many decisions, by a reliable person who understands their personal circumstances and whom they trust.

Denying those rights to any person, is denying his or her equal value and dignity.
Therefore, everyone must feel its responsibility and work actively to promote independent living. We will not achieve this aim if we do not work together. But together we can make it possible and we have to make it possible.

There is not one single, but various, ways to achieve independent living. Being independent does not necessarily mean living on your own or being able to manage without support. On the contrary – and this is certainly true when it comes to people with complex dependency needs disabilities – a high level of support and assistance and even protection by persons that they trust will be indispensable tools for achieving independence for those individuals.

It is essential that people with complex dependency needs to have access to a variety and high level of support including to assert their own preferences and choices in order to live their every day lives in dignity and equality. This demands both a flexible and individualised approach, and individualized services, including personal assistance, which are adapted to everyone’s unique needs that must be developed on the basis of expert assessment and respect of fundamental rights.

The basic principle should be that each individual gets the support that he or she needs in order to live included in society. Some people need support 24 hours per day and this must be catered for. The lack of adapted care can have irreparable consequences on the development of the person and their ability to achieve self-determination, independence, social inclusion and a dignified life at an adult age, and exposes persons with complex dependency needs to institutionalisation and abuse.

Furthermore, disabled individuals are often subject to disrespectful and unaware attitudes, based on misperceptions of what disability really is. Therefore, there is an important work to be done in promoting better disability awareness of persons without disabilities as obstacles are often created by lack of knowledge and prejudice. Disabled people will not consider themselves as equal as long as they are not seen or treated as equal.

The adoption in December 2006 of a Convention on the Rights of Persons with Disabilities by the United Nations represents a major step in the fight for independent living of all disabled people. This is a comprehensive piece of legislation, which was also signed by the European Union, as the first international conventions signed by our European institutions, in March this year. Although this is a major achievement for the disability movement throughout the world, the major challenge persists: to translate the text into concrete measures in practice.

For the European Union, this will mean adapting existing legislation and adopting new legislation in its areas of competences. The EDF 1million4disability campaign collected 1.288.000 signatures of EU citizens in favor of the adoption of a horizontal EU directive on the rights and dignity of disabled people, covering all areas of life. This would be possible under the Article 13 of the EC Treaty.

The European Union must also ensure that no EU funding from the structural funds of any other financial instrument will be used for financing the construction or renovation of any large residential institutions. Instead, all efforts and financial support should be targeted at promoting and implementing independent living opportunities. National and regional organisation must also be proactive in ensuring that these principles are implemented in the operational programmes of the funds, including through their participation in the monitoring committees.

Another key challenge is the debate at European level on the quality of social services of general interest. We are calling the European Commission to present guidelines in this area, following a first recommendation from the High Level Group on Disability (composed of member States representatives, civil society, and chaired by the European Commission) to the EU social protection committee. Moreover legislation in the area of health services is also expected this autumn, together with a communication on abuse and violence against elderly people. It is also important that we work together with organisations of elderly people to bring community living at the forefront in the debates on social services.

MODULE 1

KEY CONCEPTS OF THE HUMAN RIGHTS-BASED APPROACH

Giampiero Griffo, National Council on Disability (CND), Italy

Training kit on Human Rights, MURINET project

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1. The cultural context

The human rights approach is a cultural revolution in the reading of the condition of people with disabilities. This change in perspective is a conceptual system that reconstructs the relationship between people’s characteristics and the ways in which society permits or limits their access to rights, goods and services and allows or impedes their full participation in the life of the society. This new view is based on some essential concepts that transform the actions and perceptions of governments and members of society regarding people with disabilities.

1.1 Brief history of the condition of people with disabilities over the centuries

Since ancient times people with disabilities have been considered negatively. Taking the history and culture of various countries and continents as a starting point, one can reconstruct the form of treatment they have undergone.

In recent centuries this negative view has been embodied in similar treatments in all countries, based on segregation, different treatment justified by health conditions, and intervention models that created special treatments, often far removed from ordinary social life: it is the medical model that attributes to the condition of subjective limitation, to illness, the disadvantaged condition of people with disabilities.

The social model, on the other hand, highlights the fact that disability is a social relationship and that people with disabilities undergo the limitations and prejudices created by society. The World Health Organization’s ICF, which is the scientific reference framework for this issue, emphasizes that disability depends on the interaction between environmental, social and personal factors. The more society embraces people’s characteristics and develops their abilities, the more it is able to remove barriers, obstacles and prejudices.

1.2 Disability and human rights

Disability is an evolving concept. The human rights-based approach highlights the fact that people with disabilities are invisible citizens because of the segregation and social exclusion produced by society. They are discriminated against and do not have equal opportunities.
They are subject to unjustified differential treatment compared with other citizens, which continually causes violations of their human rights.

2. The most important concepts

2.1 Disability

Disability is a social relationship between the characteristics of people and the extent to which society is able to take them into account. Disability is not a subjective condition of people, but depends on environmental, social and individual factors, as the WHO's ICF underlines.

Disability is a condition that every person goes through over the course of their life (as a child, in old age and in various other situations) and which belongs to the entire human race. Disability is an evolving concept that needs to be considered in connection with the cultural and material conditions of each country (see Preamble Point e). It is important to link this concept to the definition of persons with disabilities in the Convention (Art. 1).

2.2 Equal opportunity

Being excluded and segregated, persons with disabilities do not have the same opportunity to choose as other people. Equal opportunity, according to the Standard Rules, means that "the needs of each and every individual are equally important" and "that those needs must be made the basis for the planning of societies" and thus "all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation" in society.

2.3 Accessibility and universal design

To offer equal opportunities it is necessary to remove barriers and obstacles that impede full participation in society. Accessibility means that all people must have access to the "various systems of society and the environment, such as services, activities, information and documentation" (Standard Rules).

Since disability belongs to the entire human race, society must design and plan all its activities and policies with the aim of including all citizens. The "universal design" approach allows the characteristics of all people in a community and nation to be taken into account. Universal design "means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. 'Universal design' shall not exclude assistive devices for particular groups of persons with disabilities where this is needed" (Art. 2).

2.4 Non-discrimination

The medical model of disability has brought about differential approaches and treatment compared with other people, thus developing solutions and actions that impoverish people with disabilities and cause continual violations of human rights. Indeed, all unjustified differential treatment is a violation of human rights. "Persons with disabilities […] have the right to remain within their local communities" and to "receive the support they need within the ordinary structures of education, health, employment and social services" (Standard Rules).

In order to combat the former situation, anti-discrimination legislation has been created, which includes the protection of people with disabilities, prohibiting any discrimination based on disability through a legal basis that provides for the removal of discriminatory conditions using “reasonable accommodation” (Art. 5). Anti-discrimination legislation has been introduced by some countries at the national level (the United States of America, Australia, New Zealand, Canada, the United Kingdom) and by the European Communities at the regional level.

2.5 Multiple discrimination

Discrimination affects people on the basis of characteristics that are subject to differential treatment, prejudice and obstacles and barriers to full participation in society. When such features of gender, race, culture, religion, political opinions, age, and disability combine, multiple discriminations are produced which make the persons concerned still more vulnerable. A typical example is women with disabilities, whose access to rights, goods, services and participation in society can be severely limited.

2.6 Independent living

The obstacles and barriers, differential treatment and negative views concerning people with disabilities, particularly those who cannot represent themselves or require complex assistance, have in the past led to such people being institutionalized. In reality, these people have the same human rights as everyone else and must be supported in their acquisition of autonomy, self-determination, independence and interindependence. It was for this reason that the independent living movement arose, first in the United States of America at the end of the 1960s, and then throughout the world, through its own philosophy and appropriate solutions, such as centres for independent living and personal assistants.

2.7 Social impoverishment and empowerment

Disability is a cause and an effect of poverty. The differential treatment that people with disabilities undergo has produced a social impoverishment in access to rights, goods and services that combines and often multiplies with economic poverty in a negative cycle that leads to social exclusion. For this reason, people with disabilities represent almost half the world’s poor, given that more than 80% of these people live in developing countries (Preamble Point t). In order to break this vicious circle it is necessary to act both by changing society’s approach to people with disabilities and by working with these people for individual and social empowerment. The United Nations global initiative against poverty, the Millennium Development Goals, should focus on people with disabilities as a priority.

2.8 Social inclusion

In order to transform a society that excludes and discriminates, it is necessary to aim for the construction of inclusive societies, in which everyone can participate and contribute to the development of society. The path from exclusion to integration produces a presence in society of people with disabilities who adapt to rules that have already been established by the community that receives them. Inclusion, meanwhile, is a process that provides for the people included to have the same opportunities and decision-making powers on how to organize society as others. Inclusion is a right based on the full participation of people with disabilities in all aspects of life, on an equal footing with others, without discrimination, respecting dignity and valuing human diversity, through appropriate action: overcoming of obstacles and prejudices and support based on mainstreaming in order to live in local communities.

2.9 Participation

The construction of inclusive societies implies that the people included are protagonists in the process of inclusion, as experts on the way in which society must treat them. This means that people with disabilities must be present with the same opportunities as other members of society in decisions on all policies, action and plans that concern them. Therefore, the participation of people with disabilities and organizations that represent them is a necessary methodology/action, based on the slogan/right “Nothing about us without us”.

2.10 Inclusive development

Economic development theories consider the creation of a group of people who are excluded from the benefits of development to be a necessary consequence of this development. Development mechanisms are in fact often tied to conditions of disadvantage and unequal opportunities created by society itself. In the case of people with disabilities these conditions are found to be caused by mechanisms of discrimination and social exclusion that the United Nations Convention has made clear. On this basis the necessity arises for inclusive development that does not produce mechanisms of social and economic impoverishment but ensures respect for the human rights of all citizens.

2.11 Human diversity

The condition of disability is an experience that all human beings have lived, live and will live through. It is therefore important to consider disability as one of the features of human diversity. The history of negative cultural views and of the treatment that some characteristics of human beings have undergone over the centuries has given people with disabilities a social stigma, loading these characteristics (and therefore all the people who possess them) with social undesirability. It is therefore important to include disability as one of the many differences that distinguish human beings, placing disability among the ordinary characteristics of human beings and removing social stigma.

MODULE 2

RISKS OF SPECIFIC DISCRIMINATION TOWARDS PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Donata Vivanti, President Autism-Europe

RISKS OF SPECIFIC DISCRIMINATION TOWARDS PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Donata Vivanti, President Autism-Europe

Because of the complexity of their needs and their incapacity to protest in any way, persons with ASD or other complex dependency needs disabilities are particularly exposed to discrimination in any field and setting, and form an especially vulnerable group, also among persons with disability.

1) Education

- **Failure to ensure education**

In Greece, persons with ASD or other complex dependency needs disabilities are usually excluded from the world of education, even specialised education. In France, more than one third of children with ASD or other complex dependency needs disabilities have no educational provision and are cared for exclusively by their families. The effects of this shortage become even more acutely felt with the onset of adolescence and adulthood. In many other EU countries families are supposed to take in charge the full responsibility of finding adapted facilities for providing education for their children with ASD or other complex dependency needs disabilities. The education services, including the specialised schools, sometimes put pressure on parents to keep their children at home because “the school is not equipped to meet their needs”.

The collective complaint lodged by Autism Europe to the Committee for Social Rights of the Council of Europe against France, claiming for a discrimination of children and adults with Autism Spectrum Disorders (ASD) in the field of education highlighted this situation. Whilst France is not the most defaulting EU country, the Committee of Social Rights concluded that “ *the situation of children and adults with autism in France in the field of education constitutes a violation of Articles 15§1 and 17§1 whether alone or read in combination with Article E of the revised European Social Charter.* The Committee noted that *in the case of autistic children and adults, even after the enactment of the Disabled Persons Policy Act of 30 June 1975, France has failed to achieve sufficient progress in advancing the provision of education for persons with autism.* Moreover, the Committee considered that *“the proportion of children with autism being educated in either general or specialist schools is much lower than in the case of other children, whether or not disabled. It is also established that there is a chronic shortage of care and support facilities for autistic adults*. The Committee also recalled the impact that this shortage *“will have for groups with heightened vulnerabilities as well as for others persons affected including, especially, their families on whom falls the heaviest burden in the event of institutional shortcomings.”*

An 8 years old child with cerebral palsy and multiple disability has never received an education programme in his life on the ground of the severity of his impairments and the complexity of his needs. In his life, he has never known anything else but his bedroom at home and his relatives.

- **Failure to provide effective education**

Ensuring access to education services to children with ASD and other complex dependency needs disabilities does not mean ensuring effective education. For pupils with ASD and other complex dependency needs disabilities, education services, including special schools, often fail to provide:

- appropriate education plans, functional for self-determination, social inclusion and dignity, observable and measurable objectives affecting the pupil's participation in the community and family life,
- specific teaching strategies taking in account major learning difficulties, and adequate support.

(From the « Code of Good Practice on Prevention of Violence against Persons with Autism », Autisme-Europe, 1998, with the support of the Daphne programme)

… The picture communication method used by the centre in C. had been very beneficial, but the day-care centre categorically refused to use it. "He must snap out of his condition himself." "Our job isn't to educate!" Normally our child was left to his own devices and the educators never knew where he was when it was time to go home at 4 p.m. He came back home dirty, with no belt round his trousers, shoelaces undone and smelling of tobacco. The children lived there in a cloud of cigarette smoke, as the educators spent their time smoking, next to the radiators in winter and in the sun in summer. Sometimes he came home showing signs of having been attacked by another child, the sort of thing which the lack of supervision easily led to. Once when it was time to come home there was an accident which could have ended tragically. The outside gate was open: there was no educator keeping a look-out and our son escaped and ran across the main road in front of my eyes. It was a miracle that only a bicycle was passing by at the time. I start trembling whenever I think about it, even today. At the age of 12 our son was no longer continent, during the day or at night, he ate with his hands, he was violent, hostile, smeared his bedroom walls with his own excrement and smashed windows. Finally, in 1991, he was taken in by a specialised institute for the deaf and blind at P. We moved house, quit our jobs. A month later our child was calm and relaxed (no medication). A few months later still he was continent again and had learned to sit at table. The institution uses sign language and pictures to communicate. In fact it concentrates on education: independence and social skills. It also places great emphasis on contacts with parents: weekends for parents and collaboration in education programmes. Over the last 7 years G. has made progress. He is happy and our life has returned to something like normal: going on holidays, eating out in restaurants and so on. He is still severely disabled of course and will always need a protected life, but the main thing is that he is flourishing at his own level.

- **Failure to assess individual educational needs**

Because of a shortage of trained personnel, education services accepting pupils with ASD and other complex dependency needs disabilities can fail to provide ongoing assessment of the individual needs, strengths, potential and motivation. Ongoing specialised assessment and a partnership between parents and professionals is crucial in order to determine appropriate educational programmes to pupils with ASD and complex dependency needs disabilities.

- **Failure to provide life-long education**

Adults with ASD and other complex dependency needs disabilities are usually excluded from education because of their learning difficulties, whilst the very severity of their disabilities requires life-long education adapted to their specific needs, to develop the social and personal skills needed to access professional training, a job, albeit a protected one, and as independent as possible a life in the community in which they belong.

2) Vocational training and employment

In the field of Employment and vocational training, the area covered by the Directive 2000/78/CE is still not sufficient to respond to the needs of persons with ASD and other complex dependency needs disabilities. The issue for persons with severe intellectual and developmental disabilities is not their ability or otherwise to work, but the discrimination they suffer from through lack of adapted support.

- **Failure to provide proper vocational training facilities**

Adults with ASD and other complex dependency needs disabilities are usually excluded from vocational training facilities. Persons with severe intellectual and developmental disabilities that enjoy adapted training are subsequently able to work. Conversely, the absence of early, individualised and continuous training has irreparable consequences on their ability to gain employment at an adult age.

- **Failure to provide adequate support at the workplace**

Adequate support at the workplace (adaptation of the environment, supervision by professionals, tasks appropriate to their disability…) is an essential condition for persons with ASD and other complex dependency needs disabilities in order to benefit from the services that do exist for people with disabilities, such as sheltered workshops. The lack of training and of adapted support explains, to a large extent, why people with severe intellectual and developmental disabilities are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term. This is independent of their ability or otherwise to work, even though the discrimination that they suffer from should be fought against by the EU Directive 2000/78/CE.

Results of a survey launched by Autism-Europe on the employment of persons with autism or other complex dependency needs disabilities (2002).

In the vast majority of cases (61.5% of cases), persons with autism or other complex dependency needs disability do not want to or cannot work. Directly linked to this result, we notice that these people only rarely receive professional and/or continuous training (37%), which can probably explain, at least partially, the impossibility or non-willingness to work Although out of the area of this investigation, it can be pointed out that the lack of educational services in childhood, not allowing a preparation for social life, is an aggravating factor of the disability. These two factors combined, lack of training and of adapted support, explain to a large extent why people with autism or other complex dependency needs disability are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term.

3) Social protection

- **Failure to provide and fund proper facilities**

Denying proper facilities means, in fact, depriving persons with ASD or other complex dependency needs disabilities of the opportunity to develop their potential, self-determination and choice. The cornerstone of effective social services for persons with ASD or other complex dependency needs disabilities to achieve and sustain successful functioning as independently as possible, and to exercise choice and participation, is individualisation of programmes. To achieve dignity, self-determination and social inclusion, persons with ASD and other complex dependency needs disabilities need life-long active programmes and individual, intensive and permanent support, as well as appropriate activities designed to give their lives a purpose and develop their skills and interests.

Results of a survey by Autism-Europe on the social participation of persons with Autism or other complex dependency needs disabilities (2002)

According to this survey, the participation of persons with autism or other complex dependency needs disabilities in social life remains difficult, if not inexistent, in the majority of cases (57%). Unfortunately, barriers to this participation are still numerous, mainly due to a failure to adapt the environment (36%), lack of adequate services (24%) or negative attitudes from the general public (18,3%).

- **Shortage of qualified staff in social services.**

The quality of staff of social services for persons with ASD and other complex dependency needs disability is generally not ensured by the social systems, whilst it is crucial to ensure the appropriate and sometimes sophisticated approaches needed to enable them to make choices concerning all the aspects of their lives and to implement practices which respect their individual rights and integrity. Generic support by unskilled social workers does not ensure the implementation of proper, individually tailored programmes, which require a deep knowledge of alternative-augmentative communication strategies, and of individual assessment tools, continuous and consequent training of the staff and external supervision of the individual plans. Moreover, staff lacking qualifications will be vulnerable, lacking job security and subject to managerial whims in today's economic climate.

(From the « Code of Good Practice on Prevention of Violence against Persons with Autism », Autisme-Europe, 1998, with the support of the Daphne programme)

"Stanislaw Tomkiewicz and Pascal Vivet (1991) do not think that there is any prototype victim: no one category of children in institutions has a monopoly of institutional violence. Similarly, no category is free from such violence. What does vary is the type of violence: children with multiple handicaps encounter a lack of attention, negligence and neglect, those with mental impairments suffer excess conditioning. "Cases of ill treatment and sexual abuse are not just isolated events, unfortunately, and just registering them is enough to demonstrate our inability not only to prevent them but also to take action on them. There are legal provisions requiring professionals to report them, but other laws protecting employees' rights are sometimes used by the latter in an obstructive manner, setting in motion complex procedures which discourage employers. In most cases the cohesive defence reflex of the profession works to the detriment of victims. Fear of the damage caused to their reputation by such publicity and controversy usually leads to facts being concealed, thereby subjecting victims and their families to yet more injustice".

- **Failure to assess the quality of services**

Many EU countries do not ensure any control by officialdom over practices operated by both residential institutions and day-care settings. Quality assessment systems adopted by some countries fail to assess the degree of obligation and the degree of acceptance for each person with ASD or other complex dependency needs disability placed in an institution and to ensure them freedom from abuse or exploitation. The very services that are supposed to provide care to persons with ASD and other complex dependency needs disabilities, sometimes neglect their individual rights and needs or give rise to unacceptable practices or violence. Persons with ASD and other complex dependency needs disabilities are unfortunately not the only ones to suffer from adverse treatment in institutions, but they are at greater risk because for them it is difficult, or indeed impossible, to say what has happened to them and express their feelings about it. Because of their incapacity to protest in any way, persons with ASD and other complex dependency needs disabilities are particularly exposed to unacceptable practices or negligence in any setting.

Testimony by parents of an adolescent with autism
From the « Code of Good Practice on Prevention of Violence against Persons with Autism », Autisme-Europe, 1998, with the support of the Daphne programme.

One evening we were about to give him his bath as usual after he had come back from the day centre. When we undressed him, we saw that he had deep cuts all over his back and bruises on his neck, shoulders and arms. We immediately called our family doctor who examined C. and certified the condition he was in following the day spent at the centre. We decided to go with him to the centre the next day. The staff were not pleased to see us as we had not told them in advance that we were coming. We insisted on seeing the supervisor, *feeling that we had a right to an explanation. We were finally allowed to see her and we gave her the medical certificate. She expressed surprise and said that it hadn't happened there. We replied that it certainly hadn't happened at home, nor in the minibus which brought him home. The driver would have told us, especially as he was in practice the only person to whom we could talk about C's behaviour. We were informed by the centre's psychiatrist without any notice that the centre would no longer be accepting C. There was no warning, no adaptation period and no consideration given to any alternative place he could go to except the specialist hospital as an in-patient, which we rejected. We realised that we couldn't deal with this kind of abuse on our own, so we decided not to entrust C. to any other establishment and to keep him at home. Five years on, we are convinced that this was the right choice. But it has meant my wife having to give up her professional career and apply for early retirement from the civil service.*

- **Failure to provide and fund inclusive community based services**

Policy of Inclusion should never be used to deny any service to any individual or to provide symbolic or token services which may give the illusion of provision whilst in reality denying opportunity. Individual support at home is not the proper solution for persons with ASD or other complex dependency needs disabilities. Delegating the care of persons with ASD or other complex dependency needs disabilities to their families without sufficient, adequate and qualified support does not foster their inclusion. On the contrary, it actually extends the exclusion to all family members and condemns persons with ASD and other complex dependency needs disabilities to life-long dependency and institutionalisation in adulthood. Because of the complexity of their condition, the institutionalisation in large residential services is not an exception but still the rule after the death of their parents. Social systems are not willing to invest in the quality of life of persons with ASD or other complex dependency needs disabilities, nor to take in charge the daily rate needed to ensure lifelong individualized programmes and support. As a consequence, they maintain large residential institutions which allow a low staff/user ratio, but deny in fact persons with ASD and other complex dependency needs disabilities their fundamental right to live fulfilling, self-determined lives within their unique possibilities. It is therefore crucial that alternative residential facilities oriented towards users' rights and individual needs are provided and adequately funded by social systems,

Testimony by M.:J.: Préfaut, author of the book, : « Maman, pas l'hôpital », published by Editions Laffont, 1997, from the « Code of Good Practice on Prevention of Violence against Persons with Autism », Autisme-Europe, 1998, with the support of the Daphne programme

In 1994, I preferred to put an end to the suffering of my daughter (who has autism) rather than let her endure once again the horror of being confined in Montepellier psychiatric Hospital, or any other hospital, because in France we have nothing else to offer adults who are experiencing an acute anxiety crisis than the chemical straight jacket and full time confinement in a room with nothing more than a mattress on the floor. After my terrible act on 7th August 1994, I went to the police, I was judged in the Assizes. I spent six weeks in prison just after the tragedy and I was given a five year suspended sentence. I have been judged and sentenced but the hospital has not been judged for failure to assist someone in danger.

4) Health care and (re)habilitation

- **Failure to assess medical needs.**

No training on ASD and other complex dependency needs disabilities is provided in the curricula of physicians and nurses by most EU Universities. The lack of competences on how to diagnose current health problems in persons with ASD or other complex dependency needs by the health professionals can lead to severe consequences. The most common cause of anticipated death in persons with Autism Spectrum Disorders is peritonitis, as a consequence of undiagnosed chronic appendicitis.

A 20 year-old girl with severe autism and intellectual disability died last year in her bed. At the autopsy, peritonitis caused by an undiagnosed chronic appendicitis was found to be the cause of the decease. The girl had manifested for a long time self -mutilation, treated by means of behavioural approaches and neuroleptics, without providing any clinic examination aimed to understand if the self-mutilation could be caused by physical pain.

- **Failure to ensure proper medical checks and treatment**.

Access to hospitals, as well as to dentists, opticians or other physicians for current health problems is difficult for persons with ASD and other complex dependency needs disabilities because of a lack of awareness of their special needs in terms of individual support during hospitalisation or day care, strategies aimed to inform them of the practices needed for the medical intervention and reasonable adjustments of the environment. Persons with intellectual and developmental disabilities need to be treated for general health problems in health services equipped to deal with their intellectual impairments and challenging behaviours. Moreover, in some EU countries, persons with ASD and other complex dependency needs disabilities are denied access to the waiting lists for organ transplantation.

Results of a survey launched by Autism-Europe on health issues of persons with autism or other complex dependency needs disabilities (2002).

Regarding access to general health services by persons with autism or other complex dependency needs disabilities for medical problems other than their specific impairments, the survey showed that a significant portion of general health services lack competence in the special needs of their children (38.16%), and fail to provide appropriate reception (35%), continuity of care (46.9%), easy access to the service (39.1%), information to parents (43.4%) and prevention (46.3%).

A 40-year-old man with severe mental retardation, suffering from pulmonary cancer, was denied his remaining in a rehabilitation centre equipped to provide adapted assistance and treatment for cancer, on the ground of the severity of his disability and of the daily cost of the rehabilitation centre. He was sent back home to his old father, without any support but some hours of home assistance, notwithstanding their impossibility to provide him the needed treatments for cancer.

A 9-year-old child with severe autism and heart disease, has been denied access to the waiting list for heart transplantation on the ground of the severity of his disability

- **Failure to provide early identification, diagnosis, individual assessment and intervention related to disability**

The lack of skilled health professionals and proper services does not ensure early appropriate diagnosis, individual assessment and the implementation of individual habilitation plans, leading to further disability. Whilst it is recognised that early intervention is crucial for fostering the development of social communication skills in children with ASD, severe mental retardation or severe communication impairments, the health services skilled in these and other complex dependency needs disability fields are widely insufficient to ensure an early and adapted diagnosis to all the people in needs.

Results of a survey launched by Autism-Europe on health issues of persons with autism or other complex dependency needs disabilities (2002).

The survey showed that, whilst most families (73%) contacted the health service before their child was 2 years old, the vast majority (71%) only received a proper diagnosis after the child was 3 years or older. Directly linked to this result, we noted that the diagnosis was made mainly by a private specialist (31%), while parents seemed to be more capable of making the diagnosis themselves (18,4%) than either paediatricians (12%) or family doctors (2.4%). In the majority of cases (63%), the parents received only verbal information concerning the diagnosis and its consequences for their child's condition, whilst only 11,3% received a written report, and 15.7% received no information at all. A significant number of families (40.4%) never received a functional assessment of their child's real skills and potential. More than one third of the families believes that the staff of specialised health care services are not motivated (35.9%) nor take into account the family's needs (43.9%) or priorities (43.9%).

- **Failure to provide (re)habilitation services and programmes**

In many EU countries, disabled children and adults are regularly denied (re)habilitation programmes on the ground of their complex dependency needs and their impossibility to be cured. Some persons with severe disabilities, such as persons with severe mental retardation, autism spectrum disorders or brain injury are in fact condemned to life-long dependency because of a lack of adapted (re)habilitation services and programmes, whilst international experiences have shown that many can achieve independence, self-determination and dignity by means of early, continuous and specific cognitive / behavioural (re)habilitation. Quality of life, free choice and dignity are not considered to be sufficient reasons for ensuring the expensive support and services needed to implement intensive and permanent (re)habilitation programmes for persons with complex dependency needs.

Results of a survey launched by Autism-Europe on health issues of persons with autism or other complex dependency needs disabilities (2002).

The results of this survey show that more than one third (37.9%) of persons with autism or other complex dependency needs disabilities have never had access to a habilitation programme. In more than half of those who had access to a habilitation programme (53.6%), the health care service does not provide any continuity of care after childhood

- **Pharmacological abuse**[1]

Though there is no specific medication for ASD, medications can be used to control symptoms (for example: restlessness, stereotypy, irritability, auto and hetero-aggressiveness, depression, isolation...). There are also associated diseases that need specific medication (for example, epilepsy).

The lack of skilled health professionals and qualified health services can have dramatic consequences on the development of the individual potentials of persons with ASD or other complex dependency needs disabilities, on their dignity and quality of life. Unsuitable treatments can lead to serious problems in a person's wellbeing or physical health. The lack of proper (re)habilitation services and trained staff can lead to dealing with the challenging behaviours of persons with ASD or other complex dependency needs disabilities by means of improper or inappropriate use of medical drugs, often without the informed consent of parents or against their will.

Each medication should be submitted to a rigorous and continued assessment of its effects (desirable and side effects). Only after effective evaluation can one decide to maintain (in which quantity) or to stop the medication.

Results of a survey launched by Autism-Europe on health issues of persons with autism or other complex dependency needs disabilities (2002).

According to this survey, a large amount (61%) of persons with autism or another complex dependency needs disability receive medications. In this group, only 15% enjoy a regular follow-up of the effects of the medication, whilst in 16.9% the service/doctor that prescribed the medication does not provide any follow-up at all.

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[1] *« Code of Good Practice on Prevention of Violence against Persons with Autism », Autisme-Europe, 1998, with the support of the Daphne programme*

MODULE 3

10 PRINCIPLES OF PHARMAUTISM

Joaquin Fuentes (1998)

10 PRINCIPLES OF PHARMAUTISM

by Joaquin Fuentes (1998)

1. No, there is no drug to treat autism. Many drugs were tested, but none has solved the main problems related to what is called autism.

2. Yes, some drugs can efficiently treat psychiatric disorders or behavioural problems experienced by people with autism or other complex dependency needs disabilities.

3. No, drugs should not be used if we are unable to achieve, through other methods, the necessary progress. On the contrary, drugs are likely to complicate even more the situation.

4. Yes, drugs can supplement a multimodal treatment and make other interventions more efficient.

5. No, drugs cannot substitute for other social or educational treatments and cannot offset structural shortages, i.e. a lack of qualified staff.

6. Yes, one should bear in mind that drug prescription is an attempt without any certainty as to the result. In principle, a drug should not be given all life long.

7. No, psychotropic drugs should not be given without the certainty that behavioural problems are not of physical origin, more especially in the case of children or non verbal people (restlessness can be due to a toothache, a headache or otitis, etc.).

8. Yes, the instructions given by the medical staff must be adhered to : the dosage should no be increased or reduced without permission ; the treatments should no be shortened or prolonged without necessary control.

9. No, there are no psychotropic drugs without side effects. Nearly all drugs have either positive or negative effects. Generally speaking, one has to weigh the pros and cons.

10. Yes, people with autism or other complex dependency needs disabilities, to the best of their abilities, the families and the professionals concerned must be involved, warned about the limits, the potential risks and the beneficial effects of drugs. People with autism or other complex dependency needs disabilities and/or their legal guardians are entitled to give their informed consent and it is up to the prescriber to provide the necessary information so that a decision can be made with full knowledge of the facts.

MODULE 4

DISCRIMINATION OF PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES IN THE FIELD OF THE INTERNAL MARKET

POVERTY AND DISABILITY

Donata Vivanti, Vice-President European Disability Forum
(EDF-FEPH)

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Disability causes poverty.
There is a negative correlation between disability and level of education. Education is central to individual evolution and provides each person with the possibility to fully participate in society, to access the labour market and to develop one's potential. In some EU Member States, education is not ensured to all, and in some cases, disabled people are totally excluded from upper grade schools, universities and vocational training programmes.

This exclusion leads disabled people to be two to three times more unemployed than non-disabled people. Many disabled persons are 'discouraged workers' and don't even attempt to enter the labour force. They are therefore classified as inactive.
The more severe the degree of disability, the lower the participation in the labour force. Only 20% of people with severe disabilities are employed, compared to 68% for those without disabilities.

Poverty causes disabilities.
Poverty can furthermore lead to secondary disabilities for those individuals who are already disabled, as a result of poor living conditions, poor access to health care, poor health conditions endangering employment, lack of education opportunities etc.

Together, poverty and disability create a vicious circle. Breaking the vicious circle of poverty and disability demands consolidated social protection provisions supporting people with disabilities to reach their full potential as individuals, to lead full and independent lives, to contribute to and participate in society. Social protection policies relying on measures creating inactive benefit dependency will not break the vicious circle and should be discouraged.

People with disabilities have economic potential and the capacity to become productive citizens and positively contribute to the economic and employment growth. Given that persons with disabilities represent around 10% of the population, the short term costs of effective social protection for people with disabilities will be surpassed by the long-term savings to societies. Countries will enjoy large productivity gains and economic returns when disabled people are allowed to develop their skills, intellectual and physical potential and engage in economic activities.

MODULE 5

A GENERAL OVERVIEW ON HARM AND SUFFERING EXPERIENCED BY DISABLED PERSONS UNABLE TO REPRESENT THEMSELVES

Christopher Williams, Institute of Education, University of London (UK)

Code of Good Practice on Prevention of Violence against Persons with Autism
AutIsm-Europe 1998

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Christopher Williams, Institute of Education, University of London (UK)

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HARM AND SUFFERING – THE EUROPEAN DIMENSION

1. Crime.

A crime can be committed by an *act* (e.g. someone hits someone else) or, less often, by an *omission* - a failure of duty that leads to harm (e.g. a factory manger does not ensure that machinery is safe). Crimes can arise from a *deliberate* act or omission (e.g. a punch), or sometimes by *reckless* behaviour (e.g. driving a car without care). Technically a crime is against the state, not against the victim. Therefore the justice system will usually proceed without reference to the wishes of the victim. If found guilty, the offender is punished by the court on behalf of the state and only sometimes is compensation awarded to the victim.

Crimes experienced by persons with ASD or other complex dependency needs disabilities include:
Killing - homicide, murder, manslaughter, death arising from a failure of duty to care.
Abduction - being taken away, without consent, by force or threat, without lawful reason to do so.
Assault - technically any form of unwanted touch is an assault, and some acts that do not involve contact such as threatening phone calls might be classed as assault.
Poisoning - suffering or death caused by a harmful substance, including medical drugs if given without consent.
Sexual offences - being touched in a sexual way without consent.
Verbal abuse that is likely to cause fear of violence.
False imprisonment - being kept in a place by force or threat, unless there is lawful reason to do so or in the case of an emergency to prevent immediate harm to an individual or others.
Loss of property - an unlawful removal of property with intent to deprive the owner permanently - theft, burglary.
Deception - money or property is taken without the owner fully understanding and agreeing to the purpose - ‘confidence tricks’, fraud.
Damage - breaking or harming personal property.
Incitement - being told and prompted to do something wrong, such as breaking a shop window.

2. Civil Offences.

Some offences are civil not criminal (e.g. defamation); some are both civil and criminal (e.g. assault). Civil offences are technically against individuals who have suffered personal loss, not the state, so the state will not bring the case on behalf of the victim and usually the court does not punish the perpetrator. A civil case can usually be brought when an individual has suffered some form of *loss* because of the act or omission of another person or organisation, and the victim seeks a *compensation* payment as redress. The loss could be financial, to health (physical or mental), or of future potential (e.g. ability to get a job). Sometimes the loss is only symbolic and a token compensation award is made, which acknowledges a wrongful, but minor, act. The level of proof required to win a civil case is usually lower than in a criminal case, so the civil courts are often used when a case is hard to prove or if a criminal case has failed. Civil cases can relate to an act or omission, and are common concerning the latter, particularly when there is a failure of a duty to care.

Civil offences suffered by people with developmental disabilities include:
Failure of a duty to care, e.g. a professional care worker does not provide medication or food.
Avoidable mistakes which cause harm or suffering.
Administrative mistakes, e.g. failure to pay a state benefit to which an individual is entitled.
Defamation - includes unfounded accusations that a person has committed an offence, for example if a staff member said incorrectly, "John hit Marie". A UK newspaper was successfully sued for calling a 6 year-old child with behaviour problems arising from meningitis, 'The worst brat in Britain.'

1.3 Bad Practice.

Much of what is suffered by people with intellectual, developmental or other complex dependency needs disabilities is neither a criminal nor civil offence, but is still clearly unacceptable. Many care organisations, and most professions, will have formal codes of practice which set standards (e.g. the *British Psychological Society*, Code of Conduct[2]). If an act or omission breaches a code (national or international), or does not match up to the norms of professional behaviour that could reasonably be expected of a trained professional (e.g. what could be found a standard textbook), there are usually procedures which may result in disciplinary action such as loss of a job, small fines, or loss of membership of a professional body. Some forms of bad practice do not contravene professional codes, but are contrary to human rights statements or accepted norms of behaviour, for example clinical experimentation without the consent of the patient.

Bad practice suffered by disabled people unable to represent themselves includes:
Failure to respect human dignity, e.g. letting a person go out shopping dressed in pyjamas.
Failure to assess needs, e.g. education or medical.
Failure to ensure proper medical checks and treatment - dentist, optician, female hygiene.
Pharmacological abuse - the improper or inappropriate use of medical drugs.
Failures of state care which lead to abandonment of disabled children because parents cannot cope.
Experimentation - clinical, psychological or educational research without consent. In 1994 it was revealed that people with intellectual disabilities in US institutions had been used for research about the effects of radiation, which included injecting them with plutonium.
Failure to identify and diagnose autism and other impairments, which leads to inadequate care and sometimes the improper detention of people who behave in an "anti-social" manner that is misunderstood.

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[2] BPS (1985) **Code of Conduct for psychologists**, British Psychological Society: London.

1.4 Harassment.

People with learning disabilities commonly suffer inappropriate and unpleasant behaviour from peers and other non-professionals, which worries or distresses them. These actions cannot be dealt with under ‘bad practice’ because those concerned are not covered by the codes of practice. Harassment is usually not against the law, but is clearly upsetting particularly if regular and inescapable. (But if harassment includes a threat of violence it is probably unlawful.) In some countries extremist groups harass people with disabilities as they do people of minority race groups, sometimes on the basis of neo-facist belief. Harassment in relation to race is unlawful in many countries, but not in relation to disability. The guiding principle for a response to harassment is *reciprocity* - “behave to other people as you would wish them to behave to you”.

Harassment suffered by people with developmental disabilities includes:
Name calling - “stupid”, “imbecile” “cretin”, “debile”, “defect”
Teasing - unpleasant remarks about physical appearance or personal habits.
Racial comments - unpleasant remarks based on a person’s race or ethnic group.
Sexual comments - unpleasant or unwanted comments relating to a person’s sex.
Alienation - being forced away from the main group of people.
Workplace harassment, which often leads to people leaving or losing their jobs.

Racist and “disablist” harassment

Many European nations have legislation to prevent and redress racial harassment. None has legislation to respond to similar harassment on the basis of disability. For example, if a skinhead says as a black man walks past:

“Let’s go and hit that black monkey. We don’t want people from the jungle around here.”

the comment would be unlawful in many countries. But if almost identical words were used as a man with autism or other intellectual disability walked past,

“Let’s go and hit that stupid imbecile. We don’t want people from the asylum around here.”

no offence would be committed. This difference arises because most anti-racist legislation is justified on the basis of maintaining public order, not on the basis of upholding human rights. It is feared that, if people from minority race groups are harassed, this will lead to a violent response. The reason that anti-harassment laws do not extend to people with disabilities is that there is little likelihood of a violent response from disabled people as a whole. This is morally indefensible, and not in accord with European principles of equitable human rights.

1.5 Abuse of power

Knowingly or unknowingly, organisations and social institutions often cause harm or suffering to people with disabilities because of the imbalance of the power relationship. This is generally unrecognised because the victims are rarely able to respond through public protest. The suffering can stem from harassment, maladministration, or administrative systems that are designed to meet the needs of the majority of the population but do not account for the different circumstances of people with disabilities.

Abuse of power suffered by disabled people unable to represent themselves includes:

Being kept in closed institutions - hospitals, schools, “homes”, prisons - when forms of care in the community would be more appropriate. (This often arises because professionals wish to preserve their “empires” based around an institution.)

Inhuman and degrading practices in institutions, include making people who do not have a clinical condition wear night clothes all day, and punishments for breaking institutional rules such as being denied meals or TV use, being sent to bed, a ban on visits by relatives, etc.

Improper behaviour by police - people with learning disabilities are often detained improperly simply because of a complaint from a member of the public.

Harassment through public administration, e.g. people who have no TV (perhaps because they are blind), are told to sign declarations that they have no TV by licensing authorities such as the BBC; maladministration by welfare officials which leads to under-payment of benefits.

Abuse within the justice system, e.g. forms of questioning in court, or a failure to proceed with a case, that would not be tolerated if the witness did not have disabilities.

Manipulation - some people with developmental disabilities can easily be persuaded to do or say things that they do not understand, which may harm themselves or others. For example, a woman might be taught by a therapist to say that a step-parent has sexually assaulted her. In some circumstances a court might accept that manipulation constitutes incitement, but in general, manipulation is not covered by the law because the law is rarely framed to respond to the unique circumstances of mentally vulnerable people.

1.6 Other forms of harm

Beyond these categories two other significant forms of suffering must be acknowledged, although it is outside the scope of this book to discuss specific strategies for prevention and redress.

The **causes of disability** often stem from unlawful or improper acts or omissions. Assaults or poor medical care during pregnancy can cause impairments in the unborn child. Redress through the civil courts in relation to medical negligence can achieve large compensation payments in some European countries, but not in others. Acquired Brain Injury often arises from poor childcare, for example if children are dropped or fall on their heads. Environmental causes of intellectual disabilities are increasing (e.g. pollution such as lead, mercury, PCBs, radiation).[3] Redress is rare because environmental law does not protect human beings, and it is not clear in most European countries whether unborn children, who are usually most vulnerable to environmental impacts, have full legal status as victims.[4]

Political violence (war, civil conflict, terrorism) is a significant cause of disability, and of increased suffering by people with disabilities. The trauma and absence of health care suffered by pregnant women in the Balkan conflict zones is known to have increased the number of babies born with disabilities. Since the end of the Cold War, the inhuman conditions within many state orphanages in Eastern and Central Europe have been exposed. During the Balkan conflicts, people in institutions often suffered far more than others because the 'everyone for themselves' survival instinct during conflict leaves the weakest in a community uniquely vulnerable.

1.7 The unique aspect - the "chain reaction"

The links between the types of harm suffered are often unique to the circumstances of people with disabilities. Recognising the links and the cumulative "chain reaction" - how one form of harm causes another and then another - is therefore a crucial part of the understanding of the nature of the whole problem.

The starting point of a chain reaction is often the failure to diagnose autism and other developmental disabilities. This can lead to inadequate care and the possibility that an individual might behave in an anti-social way. As a result, that person may be convicted of a criminal offence, and imprisoned. In prisons the person is then likely to suffer serious bullying and intimidation, which will probably create or increase aggression. On release, the individual might re-offend and the circle starts again.

Injustice fuels aggression in all human beings. A British therapist working with victims with learning disabilities concludes, "The best form of therapy is justice." If a person with developmental disabilities suffers constant victimisation which is never redressed, this can lead to aggressive behaviour against others, and to sanctions including detention in prison or hospital that will lead to further victimisation. This situation can arise even if the initial victimisation is low-level. One young man who broke a shop window explained that he did it because children were always teasing him. He stated, "I couldn't get back by hitting the children, could I. So I broke the window instead."

When families experience the victimisation of a disabled relative, and justice is hard to achieve, this often causes families to break apart. The long struggle to persuade professionals, police, prosecutors, and courts that a serious wrong has been suffered causes arguments and disagreements, often between those who wish to fight on and those who do not. VOICE, a parent-led organisation for victims with learning disabilities in the UK, reported at one time that, in nearly all the families it supported, the outcome was separation or divorce.

At a more serious level, there are reports of parents who have killed their disabled children, because inadequate support from public services has created a situation of desperation in

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[3] Williams, C. (1997) **Terminus brain: the environmental threats to human intelligence**, Cassell: London.

[4] Williams, C. (ed.) (1998) **Environmental victims: new risks, new injustice**, Earthscan: London, p11-12.

which there seemed no other option. The inadequate support can include a failure to prevent the victimisation of a disabled child by others. In the UK, a mother and father killed themselves and their daughter by connecting a pipe from the exhaust of their car to the interior. This followed twenty years of complaining about the services they had received. The parents left a note saying, “We went on as long as we could, but doctors and social workers...couldn’t care less...and we finally have given in.” At the inquest, many instances of bad practice came to light. A psychiatrist had even been told by the mother that she would kill her daughter, but he took no action. The parents had also complained to the social services that their daughter had been assaulted. This included a bruise four inches in diameter. Care workers had said that it was self-inflicted, yet it was on the side of the woman’s upper arm and clearly resulted from a bite. The social worker overseeing the investigation of the case stated publicly, “I know this sort of thing is not acceptable for people with disabilities, but it happens all the time.”

One of the major tasks for professionals is to recognise and prevent the cumulative and compounding “knock-on” effects of harm and suffering.

1.1.8 Responsibility for wrongdoing

Punishment for wrongdoing is ethically improper if the person concerned does not understand that an act is wrong, and punishment is unlikely to have any effect if a person does not comprehend the link between the act and the punishment. In some member states, there are sophisticated systems for screening defendants and offenders who have mental impairments to ensure that those who should not be held responsible for their actions are diverted from the normal court processes and receive appropriate help.

In some cases a ‘trial of the facts’ is held to ensure that any resultant detention under mental health legislation is not excessive in the light of the offence committed. (There have been cases in which people have been forcibly held in psychiatric hospitals for decades, when the offence was minor and would not usually attract a prison sentence, for example stealing a bottle of milk.) Currently there is no consistency between member states. A person who steals a bar of chocolate might be handed directly to a social worker in one nation, could be sent to prison in another (as a result of not paying the fine), or detained for many years in a hospital under mental health legislation elsewhere.

MODULE 6

RISK FACTORS INHERENT IN THE STRUCTURES OF INSTITUTIONS AND STAFF WORKING IN THEM

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Code of Good Practice on Prevention of Violence against Persons with Autism,
AutIsm-Europe 1998

RISK FACTORS INHERENT IN THE STRUCTURES OF INSTITUTIONS AND STAFF WORKING IN THEM

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Code of Good Practice on Prevention of Violence against Persons with Autism, AutIsm-Europe 1998

Introduction

Going beyond the disability of autism itself, society is having to come to terms with horrific statistics concerning violence, including sexual violence, perpetrated in families and institutions (for example schools, parishes and youth movements). Gruesome stories in the press provoke horror mingled with disbelief. Contrary to popular belief, such deviant behaviour does not arise exclusively in situations of extreme poverty and degradation. And while there is legal provision for dealing with offenders, the threat of punishment is seemingly not enough to deter people from moving from thought to deed.

It is indeed paradoxical that settings which are supposed to provide care and education can also institutionalise violence or give rise to isolated incidents of violence.

Any discussion of risk factors leading to violence and ill treatment in institutions should reflect the determination of our so-called civilised societies to improve the lot of every individual, including the weakest. These include people with autism, whose handling in traditional institutional settings raises all kinds of questions. Many professionals admit their powerlessness and helplessness when confronted with such a bewildering disability. Staying apart, withdrawing, showing indifference to other people and objects, resisting change, all these traits are obstacles to living together in harmony. But ignorance of these difficulties, which are specific to autism, often leads adult protagonists, whether parents or professionals, to respond inappropriately, thereby compounding behavioural problems and also opening the way to various types of ill treatment which we shall attempt to define.

There are many accounts of unacceptable practices affecting people with autism in institutions, in both hospital and day-care settings. People with autism are unfortunately not the only ones to suffer such ill treatment in institutions, but they are at greater risk because they find it so difficult, or indeed impossible, to say what has happened to them and express their feelings about it.

We must therefore bear the condition of a person with autism in mind when looking at situations which can lead to violence in the structure of organisations.

1. TYPES OF ILL TREATMENT IN INSTITUTIONS

Ill treatment often involves physical violence, lack of care provision and negligence which lead to serious problems in a person's well-being or physical health. We shall also have to consider the risk of abuse and sexual aggression which certain situations can give rise to.
But ill treatment also includes many other practices which are more insidious and, for that very reason, just as worrying.

Despite our great concern and against our will, our daughter was put under very heavy medication by the doctor in charge of her day centre. She was given heavy doses of neuroleptics despite the fact that they paralysed her dangerously. When she was back from her day centre, my husband and myself had to walk in front of her to prevent her from hurting herself by falling flat on her face. She had bruises and cuts everywhere. One day she almost drown in the swimming pool. When I complained that the medication made her drowsy, the doctor responded : « It is because she wants to be in your arms that she keeps falling ». My daughter was often scolded by staff members in front of me and her friends because she would not stand straight and she was dribbling a lot.
Why don't someone do something to protect these innocent victims from their tormentors ?
For the last three years, my daughter has been living with us and without any medication. We have finally found a neuropsychiatrist who really understands her problems. We now have a happy family life again. (L.P.)

In 1994 Eliane Corbet defined violence in institutions as "anything which contradicts or violates the laws of development (development in psycho-affective, cognitive, physical and social terms), anything which places the interests of the institution above those of the child".

She lists the following practices:
- psychological violence (which damages future psychological balance),
- bad language (insults, swearwords, humiliations) which affect self-esteem and one's view of one's family,
- threats (revolving around the continuity of the relationship or acceptance in the setting) which are sometimes implemented,
- blackmailing the person into cooperating,
- excessive checks on a person, invading his or her privacy and thereby reflecting a desire to dominate him or her,
- taking the child or adolescent away from his or her family,
- arbitrary decisions, or an excess of prohibitions,
- violence "by omission", ignoring the child, who is left to his own devices.

To this list we would add the following abuses which occur all too frequently in provision for people with autism:
- harmful medical prescriptions, issued for the convenience of carers rather than for the benefit of the person with autism,
- failure to take account of physical health problems (including toothaches or stomach pains which lie behind a number of challenging behaviours),
- neglecting personal hygiene (in the expectation that the person with autism should take care of himself/herself),
- ignoring the person's interests and food preferences (imposing menus without any regard for personal tastes),
- lack of activities or repetitive activities which are not geared to the person's difficulties or abilities,
- too much time spent waiting (causing anxiety and therefore stress) to suit the interests of staff.

Stanislaw Tomkiewicz and Pascal Vivet (1991) do not think that there is any prototype victim: no one category of children in institutions has a monopoly of institutional violence. Similarly, no category is free from such violence. What does vary is the type of violence: children with multiple handicaps encounter a lack of attention, negligence and neglect, those with mental impairments suffer excess conditioning, while social cases are subject to excessive discipline, repression and sexual abuse.

One evening we were about to give him his bath as usual after he had come back from the day centre. When we undressed him, we saw that he had deep cuts all over his back and bruises on his neck, shoulders and arms. We immediately called our family doctor who examined C. and certified the condition he was in following the day spent at the centre. We decided to go with him to the centre the next day. The staff were not pleased to see us as we had not told them in advance that we were coming. We insisted on seeing the supervisor, feeling that we had a right to an explanation. We were finally allowed to see her and we gave her the medical certificate. She expressed surprise and said that it hadn't happened there. We replied that it certainly hadn't happened at home, nor in the minibus which brought him home. The driver would have told us, especially as he was in practice the only person to whom we could talk about C's behaviour.

We were informed by the centre's psychiatrist without any notice that the centre would no longer be accepting C. There was no warning, no adaptation period and no consideration given to any alternative place he could go to except the specialist hospital as an in-patient, which we rejected. We realised that we couldn't deal with this kind of abuse on our own, so we decided not to entrust C. to any other establishment and to keep him at home. Five years on, we are convinced that this was the right choice. But it has meant my wife having to give up her professional career and apply for early retirement from the civil service.

Cases of ill treatment and sexual abuse are not just isolated events, unfortunately, and just registering them is enough to demonstrate our inability not only to prevent them but also to take action on them. There are legal provisions requiring professionals to report them, but other laws protecting employees' rights are sometimes used by the latter in an obstructive manner, setting in motion complex procedures which discourage employers. In most cases the cohesive defence reflex of the profession works to the detriment of victims. Fear of the damage caused to their reputation by such publicity and controversy usually leads to facts being concealed, thereby subjecting victims and their families to yet more injustice.

However, as we have seen, ill treatment of “clients” in institutions does not occur only when there is a move to commit acts of violence. It is often commonplace in a more insidious way. An example is the way professionals in residential homes can take over an environment without considering the residents around them (two staff members exchanging loud remarks in a living room where people with disabilities are watching a television programme, or two others, on different floors, commenting to each other on a resident’s state of health, incidentally enabling others to overhear intimate details about his or her life and health).

As people with autism are unable to protest in any way, they are particularly exposed. For this and for other reasons we shall look into, they form an especially vulnerable group.

Special vulnerability of people with autism

Perhaps we should start by accepting the fact that the first act of violence a person with autism suffers is being born with autism. Surely the first injustice is to be imprisoned by this disability which scientists tell us is incurable.
For a person with autism, every tiny detail has its importance. The unforeseen absence of an educator, changes in a programme of activities, unpredictable use of time: all real situations which for a person with autism can take on huge significance. Difficulties inherent in starting and organising an activity, the problem of generalisation, the lack of verbal expression or inappropriate language use complicate the relationship between him and the people around him still further.

When symptoms of autism are incorrectly interpreted, the person's solitude and distress are compounded. He usually finds himself placed suddenly in an institutional environment with a whole set of rules most of which he cannot understand. It is not surprising that his reaction should be a marked increase in behavioural problems, making his acceptance by his companions and indeed by professionals that more difficult.

The second act of violence is encountered by the family whose life suddenly undergoes upheaval. With nobody to turn to when the first signs of the disorder appear, disagreement and then despair take hold among family members, and can in some cases lead to ill treatment (see example below). Until recently, some practitioners advocated removing the person with autism from natural family ties and affection in the interests of his health and a possible cure. The violence of this separation condemned the person with autism to social and family exclusion which was wholly unjustified. Parents were at the same time ostracised and deprived of proper advice which might have enabled them to accept and work with their child, and thus lived in a climate of violence.

More up-to-date thinking on autism should now enable us to avoid such situations. But even today, some methods of treatment exclude any collaboration with parents, who are regarded as "difficult" or "pathological". Medical information is kept secret, with neither the person with autism nor the parents being allowed access to it. Above all, the person with autism is denied the love and support which only his parents and close family can give him.

2. RISK FACTORS - SITUATIONS WHICH CAN LEAD TO VIOLENCE

a) <u>Lack of proper structures</u>

Children and adolescents with autism are usually excluded from the world of education, even specialised education. More than a third of French children with autism have no educational provision and are cared for exclusively by their families. The effects of this shortage of proper facilities become even more acutely felt with the onset of adolescence and adulthood.

The ultimate “solution” for some people is still lifelong confinement in a hospital, where physical restraint devices and chemotherapy bring about an intolerable regression. The hospital, which should be a place of caring and a springboard to achieving a cure, becomes a place of ossification and boredom. This appalling truth, which does not in any way call into question the professionalism of carers, must be exposed.

My child, D., is 20 years old and is in the psychiatric hospital in V, because there is no room for her in the specialised care centre. She is not ill treated as such, but suffers because of a lack of care and specialised attention. She is bladder-incontinent and yet, due to temporary staff shortages and problems with the water supply, there were times when she was having a bath just twice a week.

Staff shortages also mean that D. is often tied to her pushchair during the day and tied by her wrists and ankles to her bed at night. How can you expect a human being to feel happy in such conditions? Fortunately, I am still fit enough to have her at home once a week. I can then bathe her, take her for a walk and give her some of the cuddles she so desperately needs. I have to keep a very close eye on her that one day, but at least she is free in her movements. It is not easy for me at all, but what will happen to her when I am no longer able to provide for her? Parents, never abandon your children: however little you may be able to do for them, it helps them to live.

An article in *Le Monde* of 23 May 1998 provided details of the physical restraint techniques which were used in a specialised hospital on people with autism who had symptoms of self-injury. According to the psychiatrist in charge, these methods were “a cruel choice, but often the only way to protect people from themselves”.

A few years ago in France a mother killed her daughter rather than see her face such a future, as she and her family were no longer able to provide her with aid and assistance. This act of violence was also one of ultimate despair and was not punished by the courts, almost as though our society was acknowledging that it had failed to give this young girl and her family the support which might have avoided the tragedy.

Even when children or adolescents have benefited from appropriate education or therapy for a number of years, once they become adults, their physical and mental condition declines because of the lack of appropriate provision, while their parents stand by, helpless onlookers.

We would argue that this lack of provision is in itself a further act of violence against people with autism and their families. Another is the lack of any control by officialdom over selection procedures operated by private institutions. Harmful decisions are taken, with so-called “severe” cases in low-income families usually being left to one side because of the temptation to take on people with a higher degree of autonomy and to make selections with the idea of forming groups of people who have fewer challenging behaviours.

b) Lack of training for professionals

There was no dialogue with parents. The diagnosis of autism which had been confirmed by our family doctor was always denied whenever we mentioned it. After a few months, G. was forbidden to use the swimming pool. We were amazed, because he had always loved water. But "it would give him too much pleasure and could damage communication development" (sic).
The picture communication method used by the centre in C. had been very beneficial, but the day-care centre categorically refused to use it. "He must snap out of his condition himself." "Our job isn't to educate!" Normally our child was left to his own devices and the educators never knew where he was when it was time to go home at 4 p.m. He came back home dirty, with no belt round his trousers, shoelaces undone and smelling of tobacco. The children lived there in a cloud of cigarette smoke, as the educators spent their time smoking, next to the radiators in winter and in the sun in summer. Sometimes he came home showing signs of having been attacked by another child, the sort of thing which the lack of supervision easily led to. Once when it was time to come home there was an accident which could have ended tragically. The outside gate was open: there was no educator keeping a look-out and our son escaped and ran across the main road in front of my eyes. It was a miracle that only a bicycle was passing by at the time. I start trembling whenever I think about it, even today. At the age of 12 our son was no longer continent, during the day or at night, he ate with his hands, he was violent, hostile, smeared his bedroom walls with his own excrement and smashed windows. Finally, in 1991, he was taken in by a specialised institute for the deaf and blind at P. We moved house, quit our jobs. A month later our child was calm and relaxed (no medication). A few months later still he was continent again and had learned to sit at table. The institution uses sign language and pictures to communicate. In fact it concentrates on education: independence and social skills. It also places great emphasis on contacts with parents: weekends for parents and collaboration in education programmes. Over the last 7 years G. has made progress. He is happy and our life has returned to something like normal: going on holidays, eating out in restaurants and so on. He is still severely disabled of course and will always need a protected life, but the main thing is that he is flourishing at his own level.

What can one say of all those earlier years wasted, especially given the amount of learning which happens in childhood. What a terrible waste for these children and their families! And this wasn't so long ago. Never again! (M. B.)

In the field of autism in particular, the definition of violence in an institution as "anything which contradicts or violates the laws of development" (E. Corbet 1994) means that we must reassess our knowledge. Like any other human being, the person with autism wants to learn and do things, but can only do so in a setting which is geared to her level of development. In 1983 Alfred and Françoise Brauner took up the challenge in their clearly defined "educational steps", banking on trust and giving these "children on the outside" the chance to show their potential and those working with them the tools needed to help them do so.

The work of Eric Schopler and his team in North Carolina has proved that early diagnosis and education can give the child with autism and his or her family hope for better social inclusion. To pursue this aim, any educational initiatives we use must be well understood and based on a person's achievements and potential, excluding any idea of repression or punishment as utterly inappropriate. People working with those with autism are now able to understand the particular characteristics of this disorder, especially sensory problems which can be identified much more accurately. Special methodological tools enable professionals to home in on an individual's skills or difficulties, assess his level of understanding and deploy appropriate communication methods, using them to create interaction between the person with autism and his family or professionals. Accounts supplied by so-called “high functioning” people with autism can only encourage us to develop this type of active aid relationship involving people with autism and their families.

However, traditional training methods are not always a good introduction for future practitioners and, still worse, may leave them poorly equipped to deal with people who have pervasive development disorders. Many professionals still perceive autism in the same way as the general public does, as a whole range of bizarre or aggressive behaviour patterns, and the behaviour is often interpreted in a way which fails to take account of the disability's inherent difficulties.

Recent research on autism means that professionals working today should follow ongoing training and join the “cultural revolution” in order to understand better the problems of the people with autism who are in their care.

b) Psychological and social patterns

In a paper submitted in 1988 to the Créteil Faculty of Medicine (University of Paris Val de Marne) Dr Michel Preel expounded his “ideas on aggression by educators against children suffering from intellectual disabilities in a medical-educational institute”. He sets out to study the reasons behind acts which were morally wrong but not actual offences in the eyes of the law and which could be seen by their perpetrators as being unfortunate and abnormal. He also suggests a neurological approach, carries out a comparative analysis with animal ethology, and includes a sociological assessment. Some of his conclusions are relevant to our discussion. “Neurobiology tells us that aggressive behaviour cannot be perceived in isolation: it forms part of all kinds of behaviour. Animal ethology shows us that aggression is a normal phenomenon and is present in all group structures. It ensures the cohesiveness of a community and enables individuals to earn respect. If an educator is aggressive, it means he is trying to defend his territory against an intrusion or himself against perceived domination by the child he is caring for. Sociological research also shows that increased aggression or aggression control can both be attributed to the environment. Specialised research into relationships in a therapeutic context reveal the notion of defence mechanisms. It would appear that, in their relationships with children who are mentally disabled and who may therefore also lack the capacity to show affection and suffer from personality disorders, educators experience a feeling of unhappiness...” In this way, “aggression very often becomes the symptom of the loss of all hope concerning the children”. Preel's general conclusion is that there is no easy way out: the underlying causes of this kind of aggression are to be found in a whole range of factors. It is necessary to go back further and look at the phenomena which trigger acts of aggression.

This is what Stanislaw Tomkiewicz and Pascal Vivet (1991) have tried to do. They give specific examples of actual cases of ill treatment in institutions and describe some features of institutions as being likely to encourage violence. These include:

- unquestioning enforcement of an ideology: “this occurs when an ideology is considered as paramount and its interests as higher than those of users, regardless of whether it is behavioural, psychoanalytic, Marxist or Catholic”. “If more importance is attributed to the theory than to the children and adolescents themselves, then violence is likely to occur sooner or later.”
- shortage of qualified staff: “the quality of educators is of crucial importance. Staff lacking qualifications will be vulnerable, lacking job security and subject to managerial whims in today’s economic climate.”
- all-powerful director: “usually obsessed by a particular ideology. But other types of dictatorship, such as an institution in the grip of union power, can lead to ill treatment in the form of neglect of children,”
- the image of the institution: “upheld by both management and those working under it, the implicit objective is to glorify the institution’s method rather than to justify it and to stifle any debate and, especially, any accusation of violence.”

FRUSTRATION: the senior doctor and his team had tried in vain to persuade us that their practice of continually provoking the people with autism was in fact “a therapeutic method to test their resistance and reaction to being thwarted in what they want to do”. The approach was wholly illogical because as soon as a child reacted, he was immediately subdued by being given neuroleptics!

SUMMONS: C. and his parents were summoned by a “tribunal” consisting of the senior doctor and the supervisor. The boy was scolded and the parents ordered to put a stop to the situation.

EXPULSION: children could be expelled for periods of 24 hours up to 3 days, with no consideration given to the problem of looking after them if the mother was working.

This, they claimed, was all part of the therapy (M.A., France).

3. RISK PREVENTION

Professionals must always act in line with practices which respect the individual’s physical and moral integrity.

We know that to bring together individuals who, on account of their condition, have to live in some kind of community is not a natural way of life to which we ourselves would aspire. Nevertheless we must carefully assess the degree of obligation and the degree of acceptance for each person placed in an institution. Achievements and success will only come through cooperation and understanding.

No person with a disability should be deprived of the freedom to develop his or her own way of life in an independent way. To make homes and institutions more human, this aspiration must underlie all objectives which are pursued, even if only symbolically. Regardless of the disability and the level of understanding, every disabled person must be allowed to see what is happening around him, why he is no longer living with his parents, why he must face up to his responsibilities as an adult. Activities must be appropriate and designed to give his life a purpose and develop his skills and interests. He should be enabled by appropriate methods to make choices concerning work and leisure.

In the case of autism, the challenge has to be met by proper training, but also by observation and, especially, action and original thinking to alleviate the person's disorder.

Prevention also requires us to look at staff recruitment procedures in institutions and at the organisation and supervision of staff through intervention mechanisms which have been tried and tested and are clear and effective, so as to avoid confusion and misunderstandings.

To counter ill treatment, a growing phenomenon in society at large, the main resources deployed are now methods of prevention: coaching children, platforms for speaking out, support associations for victims, telephone hotlines and so on. Procedures in the specific case of autism should be no different.

CONCLUSION

Our conviction, all the firmer for being based on solid evidence, is that the accumulation of difficulties due to the complex nature of autism places those suffering from it in a particularly vulnerable position.

People with autism have a rigidity about them which can provoke in us that violence which we turn to as a last resort when we cannot understand, are discouraged, or exhausted. Furthermore it is not always easy to assess the degree of mental handicap in a person with autism. Behavioural problems are often wrongly interpreted as being inherent in a person's character. It is too easy to interpret them as provocations or refusals, and to get involved in a pattern of repression and punishment.

Researchers and scientists must focus their work and experiments in such a way as to highlight the underlying nature of deficits characterising autism, and in particular to shed light on their sensory problems, an area where little is still known.

Our hope is to see an end to the spiral of violence which is alien and inimical to family, professional and person with autism, alike. To bring this about we need to:

- understand that the only well-intentioned therapy is to understand better the world of the person with autism and the way he operates, which differs so greatly from our accepted standards and codes,
- train ourselves to adopt an active approach so that we can make specific choices about the levels of support to provide in order to achieve objectives which may be modest but whose very realism will be a guarantee of success,

- be actively aware of the difficulties encountered by the family and give priority to any course of action which enhances the position of the person with autism in the family unit,
- work in close cooperation with families in order to learn from the insight they provide into their children and to exchange with them freely information and results,
- remember that working alongside a person with autism may mean learning to live with failure but also means being able to celebrate a tiny step forward.

MODULE 7

INTERNATIONAL LEGAL FRAMEWORK AND SOCIAL POLICY IN THE FIELD OF DISABILITY

Donata Vivanti, President of Autism-Europe

INTERNATIONAL LEGAL FRAMEWORK AND SOCIAL POLICY IN THE FIELD OF DISABILITY

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THE RIGHTS-BASED APROACH TO DISABILITY[5]

In the new millennium, the disabled persons' community is fighting for a new conception in the approach to disability. This new conception demands a paradigmatic shift from the so-called "medical" model towards a "social" model of disability. The "medical" model is an approach to disability that puts the impairment in the foreground whilst the person fades into the background. On the contrary, the rights-based approach to disability promotes a shift in values away from this model towards a social model that sees persons with disabilities as active subjects with rights and not passive objects of assistance.

According to a rights-based approach, and in relation to the available international and European legal framework, access to fundamental rights, such as healthcare, (re)habilitation and life-long education, cannot be denied to any person on the grounds of disability or other conditions, including age. From this perspective, healthcare, social care and school systems cannot, in any event, restrict or violate any individual right recognised by international and national normative sources. Access for all to (re)habilitation programmes and to education systems should be recognised as a priority and ensured, regardless of the nature or severity of the disability. Moreover, eventual financial claims invoked by national or local Authorities cannot, in any event, justify a restriction to fundamental rights. Following existing ordinances issued by presiding judges on these matters, Public Authorities are obliged to allocate adequate support to children with severe disabilities because the concept of damage to the person not only includes the physical and mental integrity of the person but also damage caused by lesion of an inalienable and fundamental human right. The justification adopted by Public Authorities concerning the insufficiency o available financial resources is therefore irrelevant in the face of inviolable subjective rights.

According to the rights-based approach to disability, rules and regulations, policies and provisions are established in order to secure human and fundamental rights and to meet individual needs.

Article 14 of the European Convention on Human Rights[6] states that the principle of equality means treating equals equally and providing different adapted measures for people in a different situation. In particular,[7] "the right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly

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[5] *Preamble from Autism Europe Position on Care for Persons with ASD,*

[6] ***The European Convention on Human Rights**: was adopted in 1950 and contains a number of fundamental rights and freedoms of a political nature such as the right to life, prohibition of torture, right to liberty and security, right to a fair trial, the right to respect for private and family life, freedom of thought, conscience and religion, freedom of expression, and the prohibition of discrimination.*

[7] *Thlimmenos case [Thlimmenos c. Grèce [GC], n o 34369/97, CEDH 2000-IV, § 44)*

different." In other words, human difference in a democratic society should be viewed positively and should be responded to with discernment in order to ensure real and effective equality.

The principle of equality, by underlying the need to treat differently persons whose situation are different, states the conditions to ensure equal opportunities to all. All services to people with disabilities should be characterised by an individual perspective. This means that they should tackle the needs of each individual with the aim to improve the quality of life and equality of opportunities of the persons concerned. Recognising and meeting special needs are the key of inclusion for persons with disabilities.

Article 15 of the Revised Social Charter[8] states the right to independence, social integration and participation in the life of the community. To this end, States which have signed up to and ratified the Charter) have an obligation:
1. to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;
2. to promote their full social integration and participation in the life of the community in particular through measures, …

It should be noted that Article 15 applies to all persons with disabilities regardless of the nature and origin of their disability and irrespective of their age. It thus clearly covers both children and adults.

Disability policies are essentially the responsibility of member States. Nevertheless, although the policy instruments of the European Institutions are not binding on member States, European policies impact the situation of people with disabilities at national level because they are taken into account by the Member States as guide–lines in developing national disability policies.

Equality of opportunity is the objective of the European Union[9] strategy on disability, which aims to enable disabled people to enjoy their right to dignity, equal treatment, independent living and participation in society.

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[8] *The European Social Charter: was adopted in 1961 and guarantees a number of economic and social rights including employment related rights, the right to education, the right to social security and health related rights. The ESC was revised in 1996 to introduce new rights such as the right to protection against poverty and social exclusion, the right to housing and the right to protection in cases where employment is terminated. Additionally, the revised ESC amended certain rights and improved the protection for disabled people (see further below).*

[9] *In 1957 six Western European countries established an international organisation to promote economic cooperation. This organisation was originally called the European Economic Community (EEC). Over the years the EEC evolved and obtained greater powers. It also changed its name, becoming firstly the European Community (EC), and now the European Union (EU). Today the EU is not only concerned with economic matters, but also with social policy and human rights. In addition the EU has significantly expanded its membership, being made up of 25 Member States as of 1 May 2004. Further expansion eastwards is to be expected.*

The EU Disability Action Plan (DAP), established by the European Commission[10] to mainstream disability issues into relevant Community policies and develop concrete actions in crucial areas to enhance the integration of people with disabilities, provides a framework to develop the EU disability strategy. The DAP identifies operational objectives and actions, focusing on the active inclusion of people with disabilities and on mainstreaming disability issues in relevant Community policies. Incorporating disability issues into the lifelong learning concept and processes is one of the priority actions of the EU Disability Action Plan 2006-2007, as well as " promoting quality, affordable and accessible social services and support to disabled people through consolidated social protection and inclusion provisions ….”

The Council of Europe[11] has adopted a number of initiatives aimed at securing and strengthening the position of persons with disabilities in society as well as fighting discrimination against persons with disabilities. To this end, the Committee of Ministers[12] has adopted a number of resolutions and recommendations with the aim of establishing policies directed towards persons with disabilities. In 1992, for example, the Committee of Ministers adopted Recommendation no. R(92)6 on a coherent policy for people with disabilities.

The Council of Europe Disability Action Plan 2006-2015 establishes the policy agenda of the Council of Europe to promote the rights and full participation of people with disabilities in society (Recommendation Rec(2006)5) under the authority of the Directorate General of Social Cohesion. Council of Europe Action Plan is unique in Europe as negotiated and agreed by member States, with the active involvement of disabled people’s organizations
It is a plan that commits Member States to take action to ensure respect of human rights of disabled people across all areas of life.

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[10] *The Commission is the executive and the main administrative body of the EU. The Commission is headed by 25 Commissioners, each nominated by a Member State.*
The Commission has two main tasks:

- *to propose legislation and policy. The Commission is the only institution which can propose new legislation. It is then up to the Council and the Parliament to adopt, amend or reject that legislation.*
- *to monitor compliance with the law by Member States. The Commission has the task of ensuring that Member States comply with EU law. If the States do not do this, the Commission can take them to the European Court of Justice.*

[11] *The Council of Europe (CoE) is a regional political organisation established in 1949 by a number of West European countries with the aim of “safeguarding and realising the ideals and principles which are their common heritage and facilitating their economic and social progress.” Among these ideals and principles is the maintenance and further realisation of human rights and fundamental freedoms (Article 2 Statute of the Council of Europe). Since its beginning, the CoE has enlarged its membership so that currently 45 countries are now a part of the organisation. The CoE should not be confused with the European Union (or one of the European Union’s institutions, the European Council), while in some respects the activities of the European Union and the CoE overlap and converge (for example on the area of human rights). Nevertheless, the CoE’s core activities are centred around the protection of human rights, the promotion of democracy and the rule of law, and the strengthening of social cohesion and cultural diversity.*

[12] *The Committee of Ministers is the CoE’s decision-making body and is made up of the Ministers of Foreign Affairs of all the Member States. The Committee’s main tasks are the encouragement of political dialogue, the conclusion of new conventions/treaties and agreements, and the supervision of Member States' compliance with their treaty obligations. The Committee may make recommendations to Member States.*

Social protection policies should rely on these principles, which reflect a change of mentality and a shift of paradigm from a medical approach, emphasising impairments, towards a social approach to disability, emphasising the rights perspective of disability, and putting forward individual potential and needs. Under this perspective, social protection provisions should ensure that social inclusion and anti-poverty strategies recognise and meet the specific needs of people with disabilities. To this aim, co-ordination between and across administrative departments and public and private providers of social services are needed.

Active participation of relevant actors, and in particular involvement of representative organisations of people with disabilities at every stage of policy making, are key elements in planning, designing, implementing and monitoring social protection policies, provisions and services. Allocation of social services and support should be based on assessment of individual needs, with special focus on people with disabilities at risk of social exclusion.

The Communication from the European Commission on the situation of disabled people in the enlarged European Union COM (20005) 604 final 28.11.2005) recognises that Health Care Services are also crucial for the wellbeing of disabled people. The European Disability Action Plan 2006-2007 has established as a priority at the core of EU mainstreaming actions to promote access to quality care services**.** Consequently, Health and Disability strategies need to be coordinated, both at the EU and at Member States level. There is indeed a need for coordination among these types of services in order to deliver integrated and comprehensive solutions to people with disabilities.

According to a social approach to disability, persons with disabilities need positive measures to achieve independence, social inclusion and participation. For many persons with disabilities, these positive measures include rehabilitation or habilitation programmes.
Rehabilitation services ensuring individually tailored habilitation or rehabilitation programmes, which are aimed at fostering independence, inclusion and participation, should therefore be delivered by the health systems according to the individual needs of each person.

Indeed, the shift of paradigm from a medical model towards a social model of disability does not mean that the health system is exempted from ensuring the right to habilitation or rehabilitation to persons with disabilities. On the contrary, this means that rehabilitation programmes for persons with disabilities should not aim to erase diversity in order to achieve "normality", whatever it means. This means that habilitation and rehabilitation programmes should help persons with disabilities to achieve their fullest individual potential by alleviating difficulties with which they are confronted, stemming from society or from their condition.

Moreover, persons with disabilities and their representatives should be actively involved in drawing up individually tailored habilitation or rehabilitation plans, as well as in any decision affecting their lives. A coherent policy for the rehabilitation of people with disabilities should therefore be consequent to the aim of enabling persons with disabilities to achieve the highest degree of individual ability, independence and participation in society by preventing the deterioration of disability and alleviating its consequences.

The right of persons with disabilities to comprehensive, individually tailored rehabilitation services and programmes, including the availability of assistive devices and technologies, with the aim to support their inclusion and participation in society, is also recognised in the UN Convention for the promotion and protection of the rights of persons with disabilities (Art.26). Moreover, the EU Charter of Fundamental Rights - notably its article 26 -recognises as a fundamental right "the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community".

Since the entitlement to the enjoyment of rights admits no hierarchy, the nature or severity of impairments cannot justify the denial of the right to habilitation or rehabilitation. The Committee of Ministers Recommendation No. R (92) 6 on a coherent policy for people with disabilities recognises that rehabilitation of people with disabilities, by virtue of the economic and social integration it achieves, is a duty of the community, that it guarantees human dignity …. and that it should be included among the priority objectives of any society. Denying to persons with disabilities appropriate comprehensive habilitation or rehabilitation programmes can result in many people becoming unnecessarily dependent. On the contrary, ensuring the availability, accessibility and affordability of proper habilitation and rehabilitation services to persons with disabilities is a condition for them to enjoy equal opportunities to develop their fullest individual potential and to contribute to the social and economic development of their countries, as well as a means to securing democracy and social cohesion.

A small but growing number of people with disabilities are in need of a high level of support. This group represents a challenge for both social and rehabilitation policies. A shortage of appropriate social and habilitation / rehabilitation services and lack of coordination across relevant authorities, agencies and providers can affect the dependency of these people much more than the nature or severity of their impairments.

MODULE 8

THE UN CONVENTION FOR THE PROMOTION AND PROTECTION OF THE RIGHTS OF PERSONS WITH DISABILITIES

IMPLICATIONS FOR PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Donata Vivanti, President of Autism-Europe

THE UN CONVENTION FOR THE PROMOTION AND PROTECTION OF THE RIGHTS OF PERSONS WITH DISABILITIES

IMPLICATIONS FOR PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Donata Vivanti, **President of Autism-Europe**

… the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation.
(UN STANDARD RULES ON THE EQUALIZATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES – Art.25)

Despite the existing international and European legal instruments and undertakings, stating human rights for all, and proclaiming that everyone is entitled to all the rights and freedoms, without distinction of any kind, it has been recognized that "*persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world*"[13].

Therefore, a long process launched by the disability community began in order to foster the full enjoyment of human rights by all persons with disabilities by means of a legal instrument comprehensive of all their different needs, as well as fitting for the different cultures and political situations across the world. This process, started in 2001, led to the conception, drafting and adoption of the **UN Convention on the Promotion and Protection of the Rights of Persons with Disabilities** on August 25th 2006**.** This new Convention does not establish new rights for persons with disabilities. It is based on existing human rights Treaties (see Annexe 1) and their application to people with disabilities.

ASD and other Complex Dependency Needs Disabilities are not explicitly mentioned in the UN Convention articles, but in the Preamble, where it is recognized "*the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support".*

In actual fact, mentioning ASD and other complex dependency needs disabilities in the Convention articles could lead to the misunderstanding that they represent an exception to the rules among disabilities. Articles where they are not explicitly mentioned could be interpreted as if they were not entitled to enjoy the right set forth in. Moreover, legal instruments cannot allow exceptions of any kind. The special needs of persons with ASD and other complex dependency needs disabilities must be taken into account in the policies to be implemented in order to guarantee their full enjoyment of the rights stated in the UN Convention, without discrimination. Nonetheless, the strongly rights oriented perspective of disability introduced by this Convention represents a unique opportunity to radically change

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[13] *UN Draft Convention on the rights of persons with disabilities and draft optional protocol: Preamble*

mentalities and policies towards persons with ASD and other complex dependency needs disabilities, who are still the excluded among the excluded from the enjoyment of human rights.

It is universally recognised that persons with ASD and other complex dependency needs disabilities form an especially vulnerable group also among persons with disabilities because of the very complexity of their needs and their incapacity to protest in any way. Nevertheless, they should not be considered nor treated as an exception to the rules among persons with disabilities, nor a population who ARE NOT ABLE to achieve goals such as independence, self determination and dignity, and, as a consequence, are just objects for pity and charity. This misconception is enforced in many countries by surviving rural cultures that consider the new generations as a resource for ensuring the protection of older generations in later life. This has led to the "medical" concept of disability, putting the impairment in the foreground with the person fading into the background, and has generated monsters, such as the big institutions, where all persons with ASD and other complex dependency needs disabilities were, and often currently are, condemned to live from their infancy in dependency without rights, wishes or hopes.

Following this same misconception, ASD and other complex dependency needs disabilities were the family's affair.

In a society where ASD and other complex dependency needs disabilities were considered a burden, families which refused to recover their children in institutions were, and very often currently are, left alone to deal with their child's needs. Thus, parents of persons with ASD and other complex dependency needs disabilities were, and still are, discriminated and excluded from the labour market, leisure and social relationships. For them there is no rest and no holidays, falling ill is a luxury, the other children are neglected and all the family members, confronted with the challenges of their daily life and with the uncertain future of their children, very soon become the victims of exhaustion and despair. As such, they are themselves considered as objects of pity and charity, and the support provided, if any, is aimed at relieving them of their "burden" more than at ensuring their children rights and dignity and improving the quality of life of all the family members.

Policies inspired by this misconception are still talking about and planning for "places" for persons with ASD and other complex dependency needs disabilities. On the contrary, parents of persons with ASD and other complex dependency needs disabilities are not demanding places. What they are demanding for their children are rights and opportunities to achieve their unique potential and live as fulfilling and dignified a life as anyone else's. The burden they want to be relieved of is not their children's disability, but their unjustified exclusion from full participation in society.

The UN Convention, reaffirming "… *that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind*", will represent a crucial instrument for fostering a radical change in the daily lives of persons with ASD or other complex dependency needs disabilities and their families.

RIGHT TO HEALTH AND (RE)HABILITATION IN THE UN CONVENTION

5) RIGHT TO HEALTH

1.1) BACKGROUND

Nowadays, the needs of persons with ASD and other complex dependency needs disabilities in terms of health care are not sufficiently taken into account and human rights violations against them take place daily in this field around the world. The first reason of this unjustified discrimination lies in the "medical model" of disability that fosters in the health systems, services and staff the idea that persons with ASD and other complex dependency needs disabilities are not worthy to be cured, as for them a "pitying death" would represent a relief and freedom from a deprived life. Thus, the severity of the disability is pleaded as an alibi to deny expensive interventions.

Moreover, most health systems and services plead budget restrictions to deny the support needed to cope with the particular difficulties, including major communication impairments, cognitive impairments and challenging behaviours, of persons with ASD and other complex dependency needs disabilities in terms of:

- reasonable adjustments of the health care environment
- individual support during hospitalisation or day care,
- skilled health professionals in terms of proper and early diagnosis, appropriate treatment, and pain or disease manifestations in PWCDND,
- correct and suitable information on their health conditions and needs for them or their parents

1.2) THE RIGHT TO HEALTH IN THE UN CONVENTION: NEW OPPORTUNITIES FOR PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Article 25[1] of the UN Convention prohibits all forms of discrimination, reaffirming that *"persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability",* and that "*States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services...".*

Under this perspective, there is no budget justification for denying persons with ASD and other complex dependency needs disabilities any form of support needed to access to "*the same range, quality and standard of free or affordable health care and programmes as provided other persons"*, or for neglecting their individual needs in this field.

1.3) RECOMMENDATIONS TO IMPLEMENT THE RIGHT TO HEALTH OF PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES FOLLOWING THE UN CONVENTION

Concrete measures are urgently needed in order to implement the right to health for persons with ASD and other complex dependency needs disabilities, including:

- reasonable accommodations of health care facilities, such as:

    - accessibility of health care environments, avoiding waiting time, avoiding noisy and confusing settings…
    - ongoing personal support during all the phases of health care in public or private services, including hospitalisation or day care, by parents, personal assistants, or other skilled professionals provided by the health services
- available, suitable and reliable health services for
    - identification and early diagnosis
    - prevention, diagnosis and treatment of general health problems in persons with ASD and other complex dependency needs disabilities
- skilled health professionals, by means of:
    - compulsory training on the human rights, dignity, autonomy and needs of persons with disabilities, including pain or disease manifestations in persons with ASD and other complex dependency needs disabilities, in the curricula of all health professionals (physicians, paediatricians, dentists, therapists, nurses…)
    - available and reliable training programmes for specialised health professionals in the field of proper and early diagnosis and appropriate treatments of ASD and other complex dependency needs disabilities

2. RIGHT TO (RE)HABILITATION[14]

2.1) BACKGROUND

Nowadays, many persons with ASD and other complex dependency needs disabilities do not have access to (re)habilitation programmes and facilities, on the ground of the severity of their impairments, and of the high cost of those provisions compared to their impossibility to be cured. Quality of life, free choice and dignity are not considered to be sufficient reasons for ensuring the expensive support and services needed to implement adequate and permanent (re)habilitation programmes for persons with ASD and other complex dependency needs disabilities.

This failure generates much suffering and additional handicaps, preventing persons with ASD and other complex dependency needs disabilities from achieving the maximum of their unique potential, independence, dignity and capacity of informed choice and self-advocacy. Unsuitable treatments can lead to serious problems in their wellbeing or physical health. The lack of trained staff can lead to improper or inappropriate use of medical drugs and to pharmacological abuse, often without the informed consent of parents or persons with ASD and other complex dependency needs disabilities themselves, or against their will.

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[14] Following the UN Standard Rules for the Equalization of Opportunities for Persons with Disabilities[2], *"The term "rehabilitation" refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. … It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation".*

2.2) THE RIGHT TO (RE)HABILITATION IN THE UN CONVENTION: NEW OPPORTUNITIES FOR PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Article 26 on Habilitation and rehabilitation establishes the principle that "*Habilitation and rehabilitation services and programmes … are based on the multidisciplinary assessment of individual needs and strengths", "support participation and inclusion in the community and all aspects of society, and* are aimed to support person with disability in attaining and maintaining *" their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life".*

In this Article, the Un Convention reaffirms the priority of the person on his/her impairments in the rehabilitation or habilitation process, and goes beyond the old "medical" model of disability, according to which rehabilitation was intended to restore "normal" capacities.

2.3) RECOMMENDATIONS TO IMPLEMENT THE RIGHT TO HABILITATION AND REHABILITATION OF PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES FOLLOWING THE UN CONVENTION

Concrete measures are urgently needed in order to implement the right to (re)habilitation for persons with ASD and other complex dependency needs disabilities, including:

- available, suitable and reliable health services for identification and early diagnosis,
-
- available, suitable and reliable (re)habilitation services, providing adequate (re)habilitation programmes:
    - aiming to achieve the maximum of the individual potentials, dignity and autonomy of persons with ASD and other complex dependency needs disabilities
    - respecting the individual wishes and priorities
    - involving parents and/or other family members as active partners of the (re)habilitation process, in the respect of their willingness

- skilled professionals in the fields of (re)habilitation strategies and ethical issues related to ASD and other complex dependency needs disabilities, by means of:
    - compulsory training on human rights, dignity and autonomy of persons with disabilities in the curricula of all (re)habilitation professionals
    - available, reliable and suitable training programmes in the field of proper and early diagnosis of ASD and other complex dependency needs disabilities
    - available, reliable and suitable training programmes in the field of proper (re)habitation strategies for ASD and other complex dependency needs disabilities

3). ROLE OF REGIONAL AND NATIONAL INSTITUTIONS IN ENSURING THE IMPLEMENTATION OF THE RIGHTS TO HEALTH AND REHABILITATION AS ESTABLISHED BY THE UN CONVENTION

Regional Institutions, such as the **European Union**, will have the role of fostering the implementation of those rights established in the UN convention by means of a consequent specific **Directive on Disability**, where the needs of persons with ASD and other complex dependency needs disabilities should be explicitly mentioned. Nevertheless, the main responsibility for ensuring the concrete measures needed to provide "*care of the same quality"* and adequate health and rehabilitation services for persons with ASD and other complex dependency needs disabilities, by means of **adequate health policies**, rests on the ratifying **States Parties**.

MODULE 9

ENSURING RIGHTS TO PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES THROUGH THE PROVISION OF QUALITY SERVICES

Joaquin Fuentes
Autism Europe’s VII International Congress, Lisbon 2003

ENSURING RIGHTS TO PERSONS WITH ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES THROUGH THE PROVISION OF QUALITY SERVICES

Joaquin Fuentes, Autism Europe's VII International Congress, Lisbon 2003

The task of ensuring rights to persons with ASD and other complex dependency needs disabilities constitutes a community effort to provide services based on clinical, educational and social needs. Good practice requires to be supported by sound research and up-dated scientific knowledge, while respecting accepted ethical principles.

These universal principles include:

- No-malfeasance (avoid wrong doing);
- Justice (assure equality of all persons);
- Autonomy (decide with knowledge and without coercion) and
- Beneficence (maximize good, minimize harm to individual and society).

Many problems challenge, nevertheless, their application in the field of ASD and other complex dependency needs disabilities:

1. first, the great diversity of persons presenting ASD or another complex dependency needs disability aspect that underlines the need for mandatory personalization;
2. secondly, the fact that many persons with ASD and other complex dependency needs disability are included in what is commonly referred to as vulnerable population, the population at risk of being abused due to their limitations for giving informed consent and assent;
3. thirdly, the relative lack of evidence-based solid research to guide our practice.

With these antecedents it can be understood that in the area of complex dependency needs conditions that cannot be cured and/or are present in persons with disabilities, there are many opportunities for pseudo- science, abandonment or even, frank malfeasance and abuse.

There are different ways to tackle these pitfalls, including:

- the dissemination of available information;
- the use of collective (parents or persons with autism societies) and individual representations (legally authorized representatives);
- the imperative co-participation of the clients;
- the fostering of well designed treatment research projects;
- the publication of results in peer reviewed scientific journals;
- the agreement on practice parameters by specialised committees and societies;
- the application of pre-defined intervention protocols and procedures;
- the thrust for total quality and auditing processes;
- the consideration of guidelines in evaluating treatments for autism;
- the active defence of human rights;
- the search for individually defined quality of life outcomes, and
- the development of institutional bioethical subcommittees.

MODULE 10

HUMAN RIGHTS AND PROVISION OF SERVICES

Ramon Barinaga, Director Gautena Association
Autism-Europe’s VIII International Congress, Oslo, 2007

HUMAN RIGHTS AND PROVISION OF SERVICES

Ramon Barinaga, Director Gautena Association
Autism-Europe's VIII International Congress, Oslo, 2007

All of us, regardless of our condition, as citizens, are entitled to rights, and we also think that community based services are the best way to answer the needs and desires of people with ASD.

In developed countries, the Welfare State has been the answer to social rights, but I want to highlight that in many countries, also in Europe, the so-called fourth pillar of the Welfare State after Education, Health and Pensions, the "Social Services", is still the weakest. So, still in many places there is work to be done until Social Services develop in an appropriate manner.

The approach developed by the Spanish Confederation of Parents Societies in Learning Disability (www.feaps.org) establishes a three axes perspective to orient the management in the field of services for disabled persons unable to represent themselves:

- quality of life of the individual and his or her family, as the objective of our work, as Robert Schalock of the American Association on Intellectual and Developmental Disabilities www.aamr.org and others have defined;
- the European total quality model (EFQM) www.efqm.org as a reference to management,
- ethics as a mandatory input in our work.

Management, when it is good, everywhere, has to be with common sense. Common sense asks us to merge generic instruments – like for instance the total quality models- and add to them the specific knowledge and experience from every specific field. Through a good management approach the three perspectives –quality of life; total quality model; and ethics- can be reasonably brought together.

The EFQM model tells us that we have to focus on the **impact on the client,** in our case in the outcome on the disabled persons unable to represent themselves, of our personalised support plan, having at the same time in mind the impact on the family measured in terms of quality of life. But also suggesting that we take into consideration the society at large and give importance to the relationship with public administration to whom we have to return their trust in us through effectiveness and efficiency.

The Model also encourages us to apply good **leadership**. In our societies, it is a key question having a good balance between the three kinds of leadership we can find:

- the leadership of families, which is extremely important,
- the technical leadership – the specialised staff -
- the managerial leadership that helps to bring together all the perspectives.

The EFQM Model says that services must be run through **processes** that determine "who" is going to do "what", "when", "how", "where", and about the importance of using **indicators** in the key aspects of the management. A Map of Processes under EFQM includes:

- "operational processes" – from the "admittance" to the "individualised support plan"
- "strategic processes" – from "strategic management", to "knowledge management and staff management"-,
- "support processes" – as "continuous improvement", "Infrastructure management and financial management"-.

According to the principles of the Model, the **development and involvement of staff** must be implemented by supporting them in the day to day running, through things like:

- giving enough time to prepare materials,
- having meeting,
- receiving support from specialists and senior staff,
- consistent annual training plans based on a knowledge management strategy,
- measuring the level of satisfaction of staff
- studying the "burn out".

But also some other things can be done in this regard. For instance,

- developing a "staff exchange" programme, oriented primarily to direct care staff, but also to senior staff, with programmes in different countries,
- establishing "improvement teams", made up of staff particularly interested in the improvement in terms of quality of different aspects of the day to day running of the services,
- developing a communication policy
- giving staff the possibility of making suggestions and complaints.

The basic principles of the EFQM Model are "**learning, innovation and continuous improvement**".

As far as "**learning**" is concerned we think that we all learn by doing. That is why it is important to give value to the day-to-day work through the identification of internal good practices. And of course it is very useful, besides, to have an open mind, trying to learn from others and exchanging with them your own knowledge.

As regards "**innovation**", it concerns three levels:

- technical (developing protocols),
- managerial (doing "benchmarking" with relevant organisations)
- social (introducing ethical guidelines).

Continuous improvement is another of the objectives highlighted amongst the quality model principles. Continuous improvement should be understood to be an arrow, permanently taut and pointing towards improvement. This desire to improve must be implanted at all levels.

- at a professional, technical level (introduction of most up-to-date methodologies and instruments),
- in management (use of methodologies and systems such as ISO and EFQM),
- at a managerial level (training plans to update the commitment of those families with managerial responsibilities in the Association)

MODULE 11

ETHICS AND RESEARCH IN THE FIELD OF ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

AUTISM EUROPE – IACAPAP - ESCAP
Position Paper on Care for Persons with ASD

ETHICS AND RESEARCH IN THE FIELD OF ASD AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

AUTISM EUROPE – IACAPAP - ESCAP

Position Paper on Care for Persons with ASD

Research on autism and associated disorders will help to develop concepts, research methodologies, and treatment approaches that can be utilized in relation to other, early onset and emergent developmental, psychiatric, and serious emotional disorders.[15]

Scientific research is much needed in the fields of neurobiology, as well as in psychological functioning and cognitive processes which are specifically impaired in autism, in order to develop new reliable instruments for early detection, diagnosis and individual assessment, more adapted education strategies and more efficient and effective intervention. Because of the severity and complexity of the disability resulting from ASD and the intensity of care needed, controlled studies are also essential in order to identify, spread awareness and support the implementation of effective comprehensive care models. Moreover, studies should be performed on the human, social and financial costs of the impact of ASD on families, especially when they are alone in meeting their children’s needs.

Biomedical research should reach citizens with Autism Spectrum Disorders (ASD) since they are currently underrepresented or absent in the research efforts made in most countries. Newer and more effective ways of counteracting the negative consequences of these disorders on the quality of life of persons with ASD are needed. Discovering better ways of treating and perhaps preventing these disorders should be made a health priority. But the substantial needs of this group of citizens do not imply that all research proposals should be carried out. Research programs need to be carefully assessed. Most people with ASD fall into the category of vulnerable persons, those for whom fair informed consent is a challenge – as happens with minors, older citizens with disabilities or people with restricted freedom of choice. Ethical committees must assure, with special care in these cases, that the potential benefit is much greater than the risk involved and that a fair due process has taken place.

The Council of Europe has established that it is essential that research conducted with vulnerable subjects be guided by the likelihood of direct benefit for the individual person[16]. In exceptional cases significant improvement in the scientific understanding of an individual’s condition, disease, or disorder, justifies research that has the aim of conferring benefit to the person concerned or to other people in the same age category or having the same condition3. It is widely accepted that when a vulnerable person is an adult, he or she should participate in the consent procedure in the best possible way. The positive opinion of minors (defined as “assent”) should be taken into account, always considering their age and maturity. Visual aids, augmented communication systems, “easy reading texts” and systematic observation of

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[15] From the Venice Declaration, IACAPAP, 1998

[16] Council of Europe. Additional protocol to the convention on human rights and biomedicine concerning biomedical research. Article 15.2. ETS Nº 195. Strasbourg: Council of Europe; 2005.

their reactions by legally authorized representatives are of paramount importance in this population.

Autism Europe supports the application of the following seven ethical requirements for clinical research in ASD as defined by Chen and col.[17]:

1. social or scientific value,
2. scientific validity,
3. fair subject selection,
4. favourable risk-benefit ratio,
5. independent review,
6. informed consent, and
7. respect for potential and enrolled research participants.

These requirements do not apply only to clinical trials of new medications but also to complex neuroscience studies, ASD screening procedures in the general population, and genetic testing. In conclusion, research in this field is necessary and parent associations should encourage participation in scientifically solid projects, but only on the condition that they have been approved by appropriate bioethical committees.

To ensure adequate consideration of the characteristics and needs of persons with autism, the contribution of field experts and representatives from ASD associations should be sought by Ethical Committees reviewing research projects with these subjects. Moreover, joint lobbying by experts, professional societies and parent associations in national and European agencies should facilitate the allocation of appropriate resources for research in ASD.

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[17] Chen DT, Miller FG, Rosenstein DL. Ethical aspects of research in the etiology of autism (review). Ment Retard Dev. Disabil Res Rev 2003;9(1):48-53

MODULE 12

ETHICS OF RESEARCH ON INTELLECTUAL DISABILITIES AND AUTISM

THE POINT OF VIEW OF A PARENT

Paul Tréhin, Vice-President of Autism-Europe

ETHICS OF RESEARCH ON INTELLECTUAL DISABILITIES AND AUTISM
THE POINT OF VIEW OF A PARENT

Paul Tréhin, Vice-President of Autism-Europe

We will successively address the following points:

1. **DEFINING THE RESEARCH DOMAIN**
2. **MEDICAL RESEARCH**
3. **NON MEDICAL RESEARCH**
4. **IMPACT OF IT AND COMMUNICATION TECHNOLOGIES ON RESEARCH**
5. **TOWARDS A GREATER COOPERATION BETWEEN PARENTS AND PROFESSIONNALS AT THE RESEARCH LEVEL**

1. DEFINING THE RESEARCH DOMAIN

Beyond the general category of "*mental handicap*"[1], it is necessary that research specialists be in a position to compare results on the basis of coherent definitions, accepted by the international scientific community. However, from an ethical point of view, research specificity shouldn't imply a segregation of people but should provides the possibility to bring to each individual therapeutic and educational interventions which will best fit their needs and foster a higher level of autonomy for a maximal social integration of these people.

Resolving progressively nosographic entities ambiguities

We can but observe the ambiguity of some nosographic entities in the domain of intellectual disabilities. In the public at large, this is often source of confusion and sometimes fears. For professionals, it limits their capability to provide better services.

Refining the phenotype:
Clinical analysis of behavioral symptoms

Most pathologies at the origin of intellectual disabilities are only known as syndromes, through a clinical analysis of behavioural symptoms. To improve research, it is necessary to refine the phenotype of each condition causing a disability. In the case of autism, given the heterogeneous population, this is even more necessary.

Classifications : Research must continue for better diagnostic scales, integrating neuro-biological parameters.

Biology : Looking for biological markers may help differentiate subgroups with more homogeneous characteristics.

Neuro-physiology : Better neurological exploration techniques may also help determining more precise phenotype.

Neuro-psychology : Linking psychological symptoms to neurological information may lead to a finer understanding of subgroups among people with autism.

Genetics : genetic markers may provide the elements for an early grouping of sub categories in autism.

Through an iterative process, better phenotypes will lead to better subgroups identification and possibly easier to find common neuro-biological characteristics, in turn leading to the discovery of other finer characteristics.

Impact of refined nosography

Improvement of research

Refining definition is not just a scientific exercise, it has several implications on scientific research itself and also on the quality of services that will be provided to people with autism.

More serious epidemiological statistics Better defined populations may finally permit more reliable demographic estimates for the various syndromes.

Comparative studies across different teams It will be easier to compare results across international research teams throughout the world.

Increase of populations for statistical analysis In a single country, the number of cases that can be analysed is vastly insufficient for a proper statistical analysis. Refined nosographic entities, will allow aggregation of studies across several countries.

Improvement of services

Treatments and therapeutical intervention Several studies relate some therapies with metabolic or neurological conditions associated to autism. So far, interventions are based upon "***trial and error***", parents may be tempted to use treatments on their child without much scientific proof about the treatment positive effect.. Better classification of subgroups reacting to specific therapies or approaches may be defined, reducing the "***trial and error***" situation.

Education services adapted to cognitive profiles Up to a few years ago, children with fragile X were regrouped with autistic people. Later clinical analysis demonstrated slight differences in approaches to be used with those people than with people with classical autism. This would apply to many other syndromes too loosely defined so far.

Risk of dispersion of efforts While a finer definition of conditions is necessary for research purpose, it may create barriers to communication and political weakness in the parent advocacy movements.

Need for cross pathology exchanges We must however consider the risk of having defined so many sub categories that we will find no expert in any one of them. The problem is to accommodate the needs for refined categories in view of research while keeping in mind that several subcategories may very well need very similar treatments.

Need for political union Very narrow definitions of syndromes may have another adverse effect, they create subgroups of very small sizes with limited political powers. It would be useful to keep in the classifications some "umbrella" categories which could serve as link between parents when they need to act as pressure groups.

2. MEDICAL RESEARCH

Basic ethical principles generally used in medical research must also be applied to research on intellectual disability.

It should be linked to the well being of the research subjects Medical research must be aimed at improving the life quality of the person situation participating to the research, and as an absolute minimum, that of people who have a similar pathology. It must be made in view of immediate or future improvement of the quality of their lives. A few unscrupulous research professionals seem to have forgotten that fundamental principle, using people with a intellectual disability to test the efficiency of some therapy or even non therapeutic treatments which had no relation with the disability of these persons.

It should not be harmful: immediate, short term or long term pain, discomfort resulting from the research protocol.

Confidentiality Respect for individual privacy should apply as for any other person.

Professional qualification of researchers and staffs Most researchers are serious professionals, some self-promoted researchers can be quite harmful. A research quality label should protect people with an intellectual disability and their families against charlatans.

Additional precautions for people with intellectual disabilities on top of basic ethical principles :

Getting real consent using appropriate means of communication The scientific language is not very accessible to "*lay people*", it is even less so for people who have an intellectual disability. Obtaining the consent must be sought, clear explanations given to the maximum individual comprehension and expression capabilities. If necessary, alternative and augmentative communication techniques must be used. Professionals must watch carefully the person in order to stop the experiment if they suspect pain or discomfort.

In case of severe disabilities, parental consent If the person's disability is too severe, parents or legal representative consent must be sought. Explanations must be clear and complete but expressed with understandable words.

Avoid confusing or negative language Some words may scare or hurt the feelings of people with intellectual disabilities. Their difficulty in understanding language doesn’t stop them to understand a lot of what we say in front of them. In the case of autism, images and metaphors are out of reach even for many “high functioning” individuals.

Select sample populations to minimize negative impacts In the case of well defined pathologies and if the research isn't aimed at or linked to the severity of the disability, one should consider addressing in priority sub groups with least severe impairments, more able to understand the research situation and an express an effective consent.

Limit stress caused by research apparatus The environment where research is being conducted is often awe inspiring: equipment, cold rooms, bright lights, people dressed in white, smells of medications, etc. Try to receive participants in a friendly environment, and if some complex equipment is indispensable for the research goals, take the time to let the person adapt to the situation.

Information on research results

The research results are often not available or at least not accessible to the public who might most benefit from those results.

Information of people with intellectual disabilities Persons directly involved must be informed of the results of research to which they participated, through adapted means of communication, at their comprehension level.

Information of families and others in general Families concerned by those results need to know, for eventual preventive action and to avoid medical complications resulting from the pathology in the early development years. We have seen examples of research heavily involving families, for which none ever heard anything on the results. One can understand that these families will not accept wholeheartedly to participate to other research programs.

Information of field personnel It is necessary to inform the field personnel, facing daily practical questions. Once confronted to a concrete reality they may formulate some critiques of research results. Research professionals should feel these critiques as validity test of their results, or of the way they communicate those results..

Need for cross-fertilisation

Links between research, clinic and education A better link between research organisations and the potential fall-out, short term, mid term and long term, is of the utmost importance for the comprehension of the goals of these researches.

Links between research on different intellectual disabilities Exchanges between research in different fields of intellectual disabilities can be a source of tremendous values, some support for people with intellectual disabilities can come from solutions used for people with sensory or motor disabilities. These exchanges shouldn’t be limited to research professionals but concern also the field professionals.

Going beyond medical research

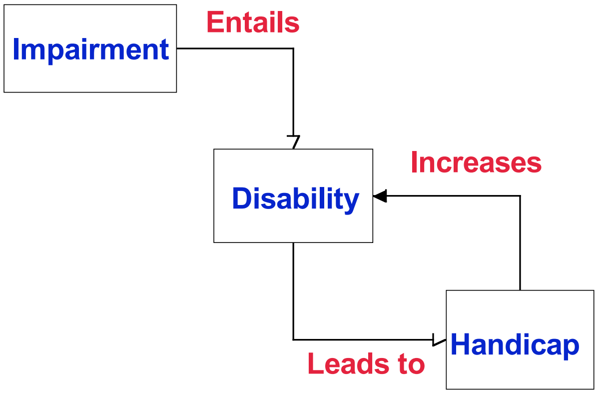

Figure 1 : Dynamics of the 1980 World Health Organisation Classification of Handicaps

The WHO classification[2] distinguishes "disease", causing "impairment", entailing "disability", itself cause of "handicap" at the social level (Figure 1). Research is primarily aimed at the medical understanding of the condition causing the disability or at the development of the therapies destined to prevent or treat the disease or the impairment. Some research is orientated towards the reduction of disabilities, and very few to the possibilities of reducing the handicap.

Preponderance of medical research

Most Medical Research in the field of intellectual disabilities is aimed at preventing or curing pathological conditions. This is the impairment level. It does sometimes address individual rehabilitation at the disability level, but almost never at the social level, that is the handicap.

Prevention / treatment of illness & impairment This is the traditional domain of medical intervention. Research is here aimed at finding a cure and if possible to prevent the illness that causes the impairment.

Medical research Occasionally addresses the reduction of disability We are here in the field of rehabilitation, that is, techniques which try to supplement impaired functions via therapies or prosthesis, but without having a cure as a goal. Note that in the domain of intellectual disabilities, the medical field is not very much involved in this aspect.

Medical research rarely addresses the possibilities to reduce handicap Even after having worked on impairments and tried to reduce the disability, it remains difficult for some people to be mainstreamed in the society. This is by and large out of the field of medical research. Very few research efforts have been made here.

3. NON MEDICAL RESEARCH

A large research field, is hence open (Lambert Chipman Rondal 1981, Zigler Hodapp 1995).[3,4]

Psychological / neuro-psychological research

For this type of research, one must better understand intellectual processes among people with an intellectual disability: memorisation,[5] language, motor coordination, etc. These processes may vary considerably from one pathology to another. From the study of these psychological specificities, research strategies can be derived.[6-8]

Positive approach of testing Items series must be constructed in a way that when a person reaches of his/her limits at a certain item, that person shouldn't fell this as a personal failure. During the test, a failed item may be concluded by a neutral "*Good, let's go on*", and by moving to the next series of items. The talent of the psychologist will count here as much as the initial design of the test.

Verification of task understanding The tasks must be easily understandable by the person. It is rather frequent that the failure to an item of the test result from not understanding the instructions rather than to the inability to execute the task itself. It is fundamental to be extremely precise about which capability one is trying to assess and that the test items indeed actually assess that capability.

Slower task execution Research professionals not used to work with people with a intellectual disability may be driven to conclude that a person can't pass a certain item level, given the slowness task execution during the test.

Build up trust There can be an extreme sensitivity to environment, and for autism to an unpredicted change. Try to avoid major changes in places and schedules. Think about setting up a training and adaptation period for the person being tested. Try to set the experiment in a comforting, warm and caring atmosphere. The risk of not observing these recommendations, besides the risk of behavior problem, is that the experimentations be biased by these conditions.

Quicker fatigue Take into account the greater fatigability of people with a intellectual disability. Organise pauses to allow the person to rest.

All these recommendations have two major goals: 1 make the person with an intellectual disability feel more comfortable and 2 as a result of the first goal, ensure a maximum validity to the experimental observations avoiding an artificial under-evaluation of capabilities.

Educational research

There are several research levels that could lead to better education

Using latest knowledge on learning processes It would be very important that more researches look at specific learning processes in other intellectual disabilities. Some excellent research programs on special education do exist: university of Aix en Provence[9] or at the « Institut de Pédagogie Curative » in Fribourg. [6]

New teaching methods Research on applying new neuro-psychological understandings on learning disabilities is quite necessary. These are partly integrated in new education strategies for people with autism. This is also the case for children with William's syndrome or fragile X syndrome.

New educational tools Fairly little research is made in this field, teachers have developed excellent methods but through long trial and error and field experience. For techniques such as computer-assisted education, there are very few pluri-disciplinary research integrating the current knowledge on autism.

Research on new technologies

In the domain of technological aides destined to people with an intellectual disability, researches endeavoured at the level of serious university teams[10] or in private laboratories are rare. In contrasts with the relative abundance[11] of research concerning support technologies for people with sensory or motor disabilities, researches endeavoured at the level of serious university teams or in private laboratories in the domain of technological aides destined to people with an intellectual disability, are rare:

Communication "*augmentatives*" technologies are generally used to compensate sensory or motor disabilities. It is interesting to note that efforts made for cerebral palsy primarily address motor aspects of the disability and not the intellectual aspect. There are however some researches in the specific domain of communication aides for people with autism[12] and for people with Down's syndrome.[13,14] Computer assisted communication tools supporting comprehension and expression through vocabulary or syntactic aides adapted to individual communication capabilities could be extremely useful to people with an intellectual disability.

Autonomy / Accessibility Research on reading aids for people who don't know how to read or haven't mastered enough reading mechanisms and research on Information accessibility systems based on icons or images (drawings or photos) should be vastly developed. Note that improvements in this domain might prove very useful for quite a lot of people without an intellectual disability.

Research on quality of life

It would be fundamental to consider new fields of research such as socio-economical research for example in matter of employment, on social integration, accessibility to leisure activities, it will be particularly important to conduct research there, in the framework of the major structural changes brought simultaneously by the new technologies and on going geopolitical transformation.

Work environment One shouldn’t assume that what is good for ordinary people is good also for people with an intellectual disability. In the case of autism, environmental factors can drastically improve or degrade the quality of the working experience. Sensory overload at work may create severe behavior problems, in turn leading to the exclusion of the person. Loose schedules will make life very unpredictable and hence difficult, etc. Survey and studies severely lack in this domain.

House Here too there is very little research done. Most research has been concentrated upon accessibility and house appliances remote control. Almost no research has been made to facilitate the use of various appliances and communication devices by people with an intellectual disability and even less by people with autism.

Leisure time There is a severe lack of games and other leisure time activities well adapted and individualised for people with intellectual disabilities. Research should be made, for example, to assess the level of cognitive skills necessary to use existing games in order to help select adapted ones.

A major information effort should be made to foster the launch of research programs destined to people with disabilities, be it in the direction of university laboratories or in the direction of industrials firms.

Research and studies on legal aspects

A completely new scientific and technological environment will also require new ethical considerations for the legal protection of people with intellectual disabilities and their families.

For example, the possibilities of identifying genetic disorders (or even just susceptibilities to develop disorders) long before birth, could drive some insurance companies or state services to reject any support for the parents of these children on the pretence that they knew, so it was their choice to have that child. The whole problem of gene patenting is still under discussion… All these observations entail the need to do research in matter of the rights of people with disabilities, and in particular those with intellectual disabilities who will not be in a position to defend their rights by the mere nature of their disability.

4. IMPACT OF INFORMATION AND COMMUNICATION TECHNOLOGIES (ICT) ON RESEARCH

Considerable effort must be made to inform persons who do research on the Internet about the limits of this media. But one mustn't "throw the baby out with the bath water".

Information quality
A lot of data is available on the web and is accessible by many levels of publics. There is a need to warranty the reliability of the source and to address the right people with the right words.

Speed of information distribution Access to data but more so the ease of research results publication, without any peer scientific review, often leads poorly informed people to consul documents with doubtful scientific quality.

Access by vulnerable populations Discussions on Internet are full of miracles solutions based upon special diets, pharmaceutical products, "auditory therapy" and many other… This is not to say that all these therapies are useless, just that they tend to be published all too soon, before any scientific testing has really been made.

Charlatanism, false information and rumours Scientifically unfounded theories can be proposed to parents, in particular to parents of young children, promising a "recovery" and taking them onto unsafe grounds. Any one can publish data on the Internet. Some may be charlatans, offering miracle cures. Some may be publishing incomplete, biased or plain false information. Well-presented data can lure parents in search of solutions. Rumours do not come from charlatanism, but often from good willing individuals who jump to conclusions a bit too fast some anecdotal information.

The only answer to this would be a greater participation of professionals in discussion lists in order to dispel those abuses.

Problem of organizing research

Deontology rules traditionally applied by research techniques don't protect enough the rights of the persons subjects of internet based researches. The mere nature of the media leads to a lowering of our individual protection barriers of which we are usually much more conscious in other circumstances[12]. Deontology rules applied by more traditional research techniques don't cover enough the persons concerned by these internet based researches (Jones 1994). The mere nature of the media leads to a lowering of our individual protection barriers of which we are usually much more conscious in other circumstances.

Ease of doing statistical analyses With the development of micro computers a great number of people have started to work on more or less scientific analysis of human subjects, creating uncontrolled data bases, constructing address files, using these files without paying much attention to elementary rules concerning privacy.

Statistical validity A great number of research projects conducted through Internet use biased samples: only addressing populations having access to Internet. Samples selected through Internet are rarely designed to be "*random samples*" and even less "*stratified random samples*". Many would be statisticians publish results directly extracted from the sample, with all the biases caused by the lack of stratification and randomness.

Confidentiality The confidentiality of responses is very hard to implement since one gets the messages trough e-mail with identified addresses. It would at least require the creation of a highly protected confidential file containing nominative information and providing only access to anonymous records to the analysts of the data.

Identification of participants At the opposite, one is never sure of the respondent identity, for example one can have problems in making sure that the population surveyed through internet is really responding under the right diagnostic category. The ease of developing surveys through Internet is only apparent.

Nice looking results The presentation of results with sophisticated graphic tools is far from warranting the scientific quality of those results.

Developing surveys through Internet is not as easy as it may seem at first.

5. COOPERATION BETWEEN PARENTS AND PROFESSIONNALS

A greater cooperation between parents and professionals at the research level should be Undertaken [13].

Parents need research

- **For the present improvement of their children lives**, parents need research that will bring improvements to the lives of children in the near future. For that, better links must be established between day to day requirements of families and research projects.
- **For the improvement of the lives of future generations** Parental associations are very conscious of the need for fundamental research even if the results are bound to be much more long term.

Research professionals need Parents

- **Parental consensus is required.** More than consensus, understanding and support is required for research to be really efficient. Parents will be more inclined to participate in research programs.
- **Parent's perception of intellectual disabilities and Autism** Parents tend to develop an acute understanding of autism, many do inform themselves about recent knowledge on autism and follow research programs at least in some fields. This leads them to see particular aspects of autism that would be useful research fields.

Question from a self advocate

Just in conclusion and as a base for further in depth thinking about the ethical aspects of research on autism and other intellectual disabilities, I would like to share this sentence written by an "***autistic person***", Jim Sinclair :[17]

" Whenever I see a presentation or exhibit about genetic research in autism, I ask politely :

Is the goal of this research to create a world that doesn't have any people like me in it ? "

MODULE 13

RESPECT FOR PERSONS WITH AUTISM AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

Paul Tréhin, Vice-President of Autism-Europe

RESPECT FOR PERSONS WITH AUTISM AND OTHER COMPLEX DEPENDENCY NEEDS DISABILITIES

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When an autistic person does not do what is expected of him/her, before concluding that that person does not want to do it, or is just showing bad will, one must always ask oneself

- First, if the person really **understood** what was demanded.

- Second, having verified that the person really understands, one must verify that the person **knows how to do** what is expected of him/her.

- Third, **never neglect any communication attempt** from the person with autism even if is just barely initiated or even inappropriate. On the contrary encourage any expression tentative through the using the best-adapted means, according to the communication abilities of the person.

After having checked that our expectation is well understood and that the person knows how to do it, then and only then can we conclude that the person doesn't want to do it. It is then necessary for us to try to understand why.

- There is in general a relatively simple explanation. It is important to understand this refusal because it will help us better understand the person and hence better respect that person.

- Once the reason for refusal is understood, depending upon the real importance of the expected activity, accept the refusal as a legitimate choice or else, try to convince the person of the importance of what we were expecting him or her to do.

This position is very important for us since very often an autistic person does not have the means to let us know of the difficulties he/she is facing with our demands. Very often the person does not know how to tell us "*I do not understand what you want*" nor "*I don't know how to do what you are asking me to do*", this is specifically the communication difficulty due to autism.

When we interpret too soon a lack of action as a refusal, we will insist directly, without realizing that it is useless to do so since the person will not understand if we don’t adapt our language or communication means to his/her level, or if we don’t try to verify that she/he does know how to do what we are asking to do.

Such an attitude leads almost every time to a tantrum or to a greater isolation of the person.

By accepting that there is a communication handicap, we will respect the right of this person to be different, accepting this right to be different, we give that person the possibility to progress and to use his/her potential strength to their best.

With these remarks in mind, the way we behave with people with autism should not differ from what we would do with other people: respect for their preferences within the limits of having them respect the ones of the people they live with.