



**EUROPEAN
disability
forum**

EXPLORING THE
RELATIONSHIP
BETWEEN
VIOLENCE AND
DISABILITY

THE RIGHTS
BASED
APPROACH

Who we are?

- **EDF is an umbrella organisation with full members in 27 EU countries, Norway, Iceland & 43 European organisations from all main disabilities and chronic illnesses**
- **Persons with disabilities & families organised in national and European federations as leaders**
- **Bringing the unified voice of disabled people in Europe**
- **Fighting for equal opportunities & human rights across the EU agenda**
- **Making sure that no decisions affecting disabled people are taken without them**

THE RIGHTS - BASED APPROACH TO DISABILITY

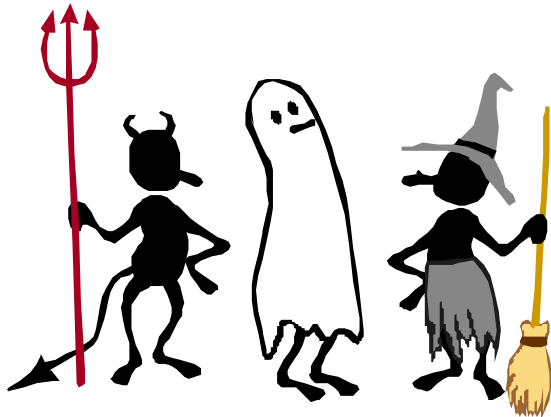
- **DISABLED CHILDREN ARE ENTITLED TO ENJOY THE SAME HUMAN AND FUNDAMENTAL RIGHTS, AND EQUAL OPPORTUNITIES**
- **DENYING HUMAN RIGHTS TO A CHILD MEANS DENYING THEIR HUMAN VALUE**

RESPECT OF HUMAN RIGHTS

- **Full recognition before the law**
- **Choice**
- **Support in taking decision**
- **Physical and mental integrity**
- **Freedom from coercion, punishment and inhuman or degrading treatments**



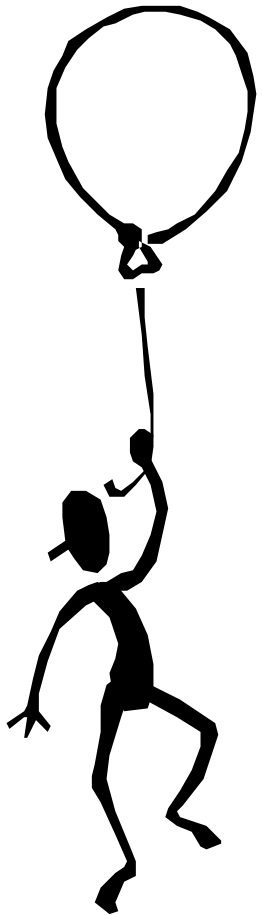
OUR ULTIMATE GOALS



Full inclusion and participation for all disabled children throughout

- **Legal instruments**
- **Policies**
- **Provisions and services**

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES



- **Disability as a Rights issue**
- **Must be translated in positive actions**

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Children with disabilities

- shall have equal rights,
- shall not be separated from their parents against their will, except in the child's best interests),
- in no case shall be separated from their parents on the basis of a disability of either the child or the parents (Article 23).

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Protecting the integrity of the person.

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others. **(Article 17)**

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

- **Laws and administrative measures must guarantee freedom from exploitation, violence and abuse. (Article 16)**
- **Education must foster their participation in society, their sense of dignity and self worth and the development of their personality, abilities and creativity (Article 24)**
- **Countries are to provide comprehensive habilitation and rehabilitation services to enable persons with disabilities to attain maximum independence and ability (Article 26)**

The challenge of complex dependency needs disabilities

- **(Children) with disabilities who**, due to the severity and complex nature of their impairment, **require a high level of support... require**

- **intensive and permanent quality services** geared to their specific needs

- **intensive planning and co-ordination** across relevant authorities, government agencies and service providers both at national and local levels

Their quality of life is very much dependent on the availability of appropriate and quality services that respond to their and their families' needs

(Coe Committee Of Ministers' Recommendation on Disability Action Plan 2006-2015)

CHILD ABUSE AND DISABILITY

Child abuse can cause disabilities

- **abuse-caused disabilities is estimated to represent 25% of all developmental disabilities (Baladerian, 1992)**
- **More than 50% of the children victims of severe neglect sustain permanent disabilities (including learning and cognitive disabilities)**

DISABILITY AND CHILD ABUSE

Disability increases vulnerability to abuse

- **Correlation between disability and children abuse**
- **Children with any type of disability are 3.44 times more likely to be a victim of abuse**
- **Children with developmental disabilities, are 4 to 10 more likely to be victims of abuse**

DISABILITY INCREASES VULNERABILITY TO ABUSE

Indirectly

- **Linked to society response to disability**
 - **Children with disabilities are not valued the same as other children**
 - **segregation, marginalisation, isolation (in segregating facilities or families)**
 - **Parents' fear to be forced to take their child out of facilities**
 - **No access to justice**
 - **No way provided to report abuse**

WHY DISABILITY INCREASES VULNERABILITY TO ABUSE

Directly

- **Because it is possible without being discovered**
 - **Children may not understand what abuses are**
 - **Communication problems make it difficult to verbalize abuse**
 - **No way to report abuse**

RISK FACTORS OF ABUSE

- **Behaviour disorders (physical abuse)**
- **Communication disorders (neglect)**

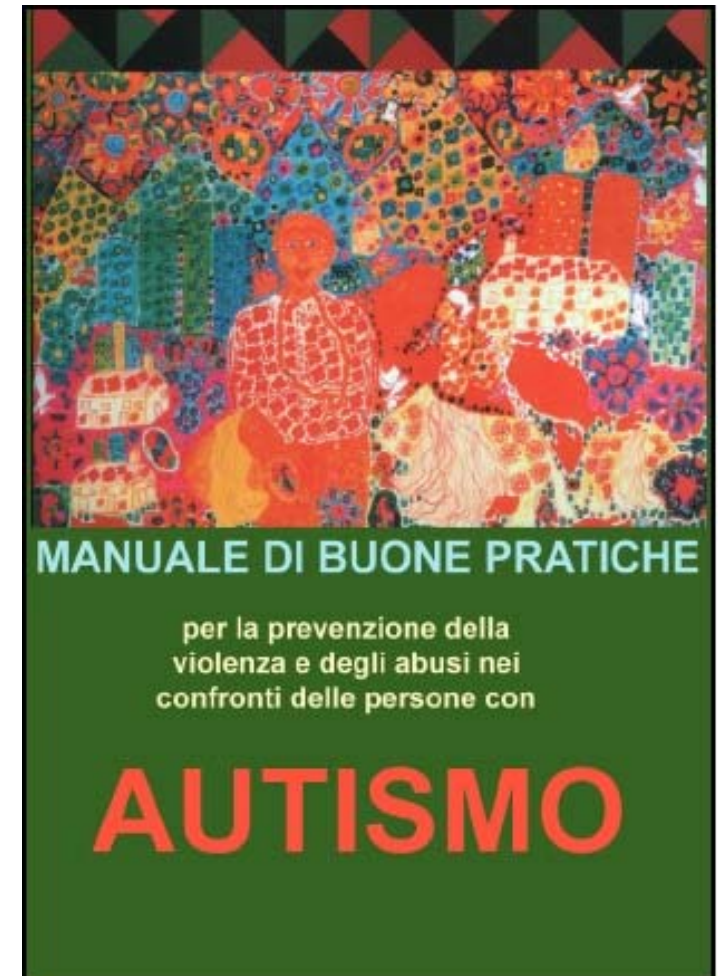
- **NEGLECT IS THE MOST PREVALENT FORM OF ABUSE (in children with or without disabilities)**

THE VULNERABILITY OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

Autism-Europe

**Code of Good Practices
for the Prevention of Violence towards
Persons with AUTISM**

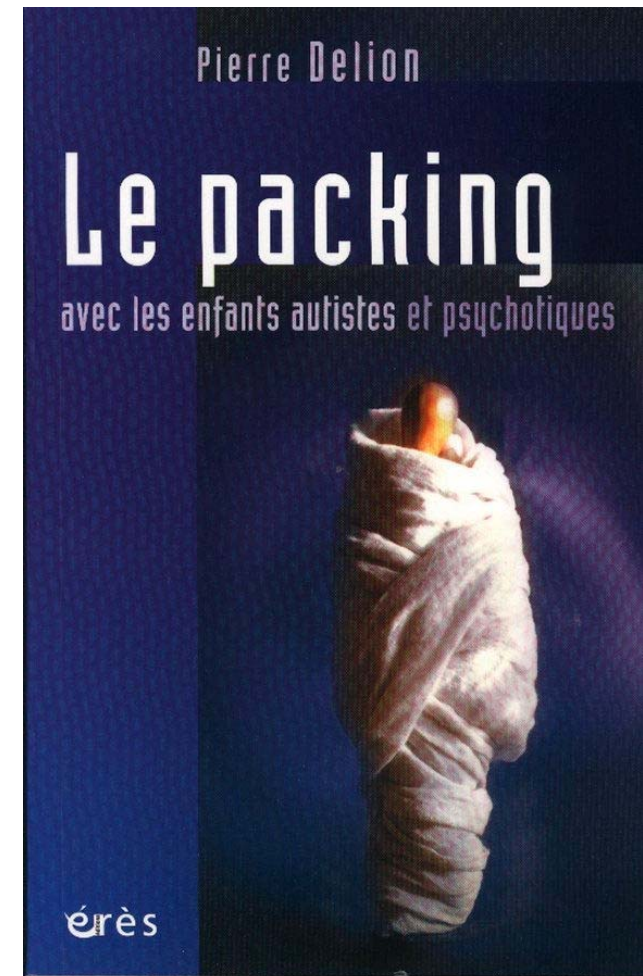
**With the support of DAPHNE initiative,
1998**



The “PACKING”

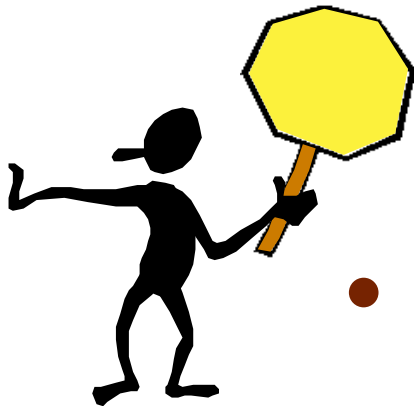
(Pierre Dellion, CHRU, Lille)

“consists in wrapping the patient several times a week using towels previously wet in cold water. The patient is then wrapped with blankets to help the body warm up. The envelopment lasts 45 minutes...The wrappings and the warming up which follows the initial chill seem to help the patient achieve a greater perception and integration of the body, allowing him to experience a greater sense of containment”.



DENYING SUPPORT

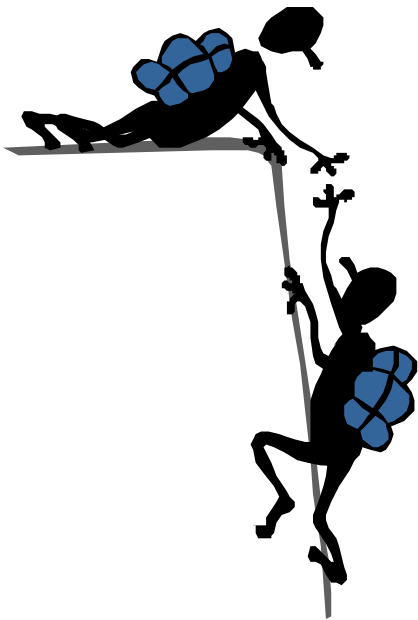
- **Lack of appropriate support**



Lack of self-determination

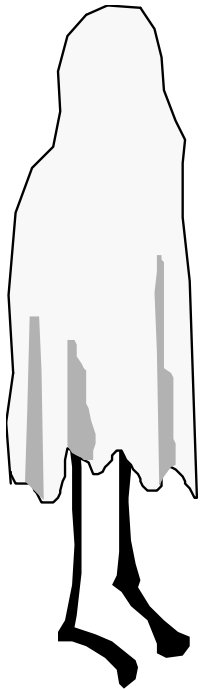
- **Dependency**
- **Exclusion**

ENSURING ADAPTED SUPPORT



- **Policy planning**
- **Mainstream provisions**
- **Flexible services**
- **Individually tailored support**
- **In a rights based perspective**

UNAPPROPRIATE SUPPORT AND SERVICES



- **Lack of opportunities**
- **Invisibility**
- **Discrimination**
- **Abuse**

PREVENTING NEGLECT

PROVIDING adequate provisions, experienced services (= positive discrimination)

• **Supporting children** with disabilities in reaching **individual potential** to lead full and **independent lives** (= providing equal opportunities)

• **Supporting their families in positive parenting**

– **Empowering** families (parent training)

– **Involving** families in every relevant issue concerning their children (participation)

RIGHTS-BASED SUPPORT

MEDICAL MODEL OF SUPPORT

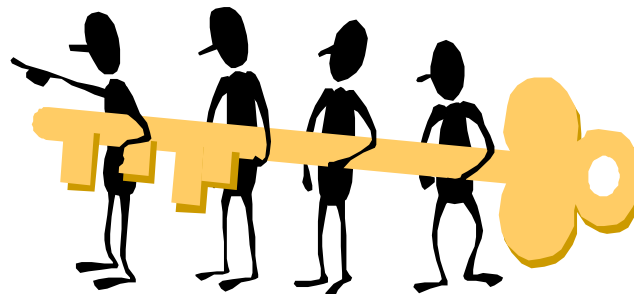
- ***Emphasis on Disability (negative perspective)***
- ***Tailored to impairments***
- ***Parents are not consulted***

SOCIAL MODEL OF SUPPORT

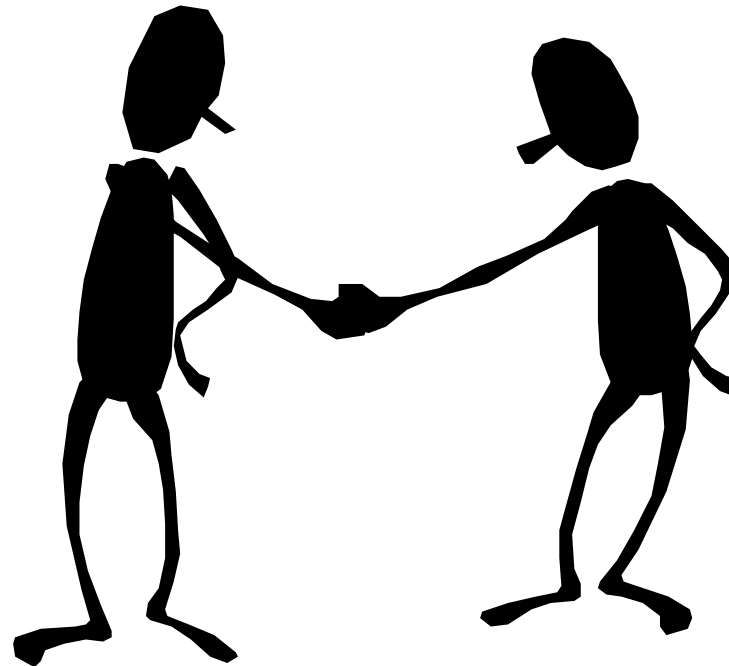
- **Emphasis on Potential (positive perspective)**
- **Tailored to individual needs**
- **Parents are fully involved**

Everybody has to feel its responsibility and work actively to promote the well-being and full development of children with disabilities.

We will not achieve this aim if we do not work together. Together, we can and we have to make it possible.



PREVENTING CONFLICTS BETWEEN FAMILIES AND PROFESSIONALS



**The alliance between parents and professionals
is crucial to the success of the care.**

UNDERSTANDING THE ROLE OF FAMILIES

- **The knowledge:** recognising family as a resource
- ***The role:*** *families have a primary educational role*
- ***The motivation:*** *nobody is as motivated as the family to improve the child's condition*
- ***The responsibility:***
 - *Defending the child's rights is an individual responsibility*
 - *Defending the child's rights is a duty (not an option)*

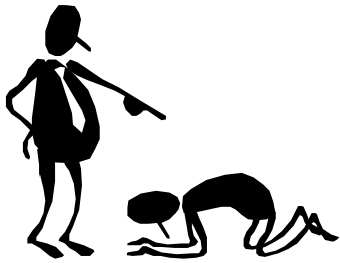
PREVENTING CONFLICTS

DISABILI, FAMIGLIE E OPERATORI: CHI E' IL PAZIENTE DIFFICILE?

*Strategies to build
collaborative relationships
in autism and
developmental disabilities*

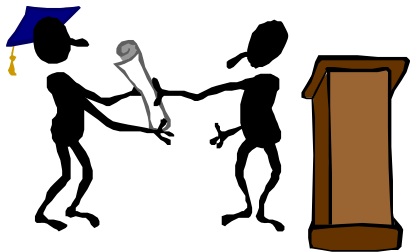
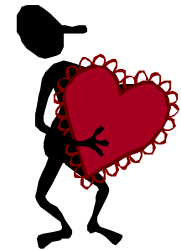


PREVENTING CONFLICTS RISK FACTORS



1. Prejudice: the family/the service is responsible for any failure

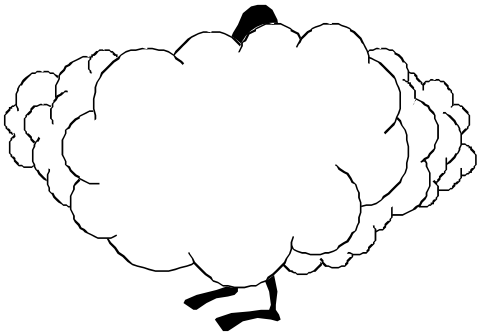
2. Attitude: taking the family's place



3. Unawareness: unrealistic expectancies

PROMOTING AWARENESS ON DISABILITY ISSUES

- *Fighting against:*
- **Prejudices**
- **Disrespectful and unaware attitudes**
- **Misperceptions**



PREJUDICE

*from: “Disabili, famiglie e operatori: chi e’ il paziente difficile?”
by Giacomo Vivanti*

Professional: *“it’s you the cause of your child’s problems. I can not tell it to you explicitly – as you are not ready to understand it ... In the meantime, I do not speak with you on what I am doing with your child (you would envy me, you would boycott my work, etc...).*

Parent: *“you are cruel and incompetent. I can not tell it to you explicitly - as I do not have anybody else to take care of my child – In the meantime, I try to keep a check on what you are doing (I furtively eye from the door, I ask insidious questions...) and to make you understand that you have to learn more (providing books, leaflets of congresses...).*

PREJUDICE

*from: “Disabili, famiglie e operatori: chi e’ il paziente difficile?”
by Giacomo Vivanti*

Professional: *“your behaviour clearly shows that you are diseased, and it strengthen my decision to exclude you from your child’s care”.*

Parent: *“your behaviour clearly shows that you do not have any competence nor motivation, as a consequence I will let my child under your care until I find something better.*

ATTITUDE

LOVE ? No, thanks

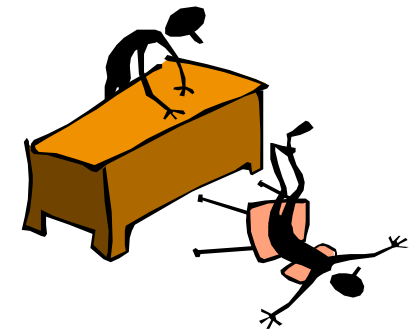
but:

- Empathy
- Positive approach
- Knowledge



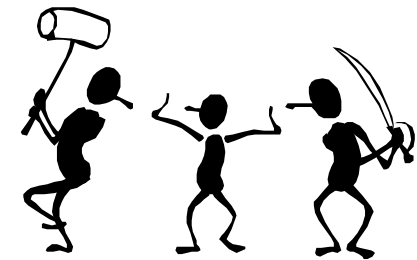
AVOIDING FURTHER BURDEN? No, thanks

- Family distress is higher when concrete skills are not provided
(Graziano e Diament, 1992)



IRREALISTIC EXPECTANCIES

- Frustration
- Conflicts
- Unreliable approaches



“My greatest chance, from both a human and a professional perspective, has been to have been in touch with the parent advocacy organisations fighting against discrimination of persons with disabilities far before starting to work with children with disabilities and their families”.

Giacomo Vivanti

Psychologist, Post-doctoral fellow, M.I.N.D. Institute, UC Davis, USA.