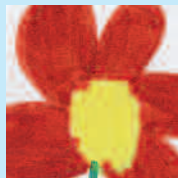




Making life a safe adventure

Strengthening families of children with disabilities
to prevent maltreatment





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Making life a safe adventure

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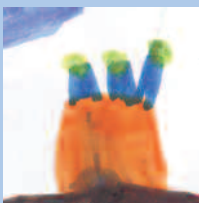
AN INITIATIVE OF EUROPEAN DISABILITY ORGANISATIONS

This booklet is the product of work within the framework of a European project funded under the Daphne Programme entitled *Children with disabilities and violence: primary prevention targeting families* (2005-2008).

An international consortium of disability related non-governmental non-profit organisations has been working on the issue of the prevention of violence against children in the domestic environment since 2002. An earlier project, *Childhood, disability and violence: empowering disability organisations to develop prevention strategies*, implemented between 2002-2004, aimed to promote awareness among associations and cooperatives of people with disabilities and their families about the issue. As such it was principally concerned with emancipation and with helping these organisations to develop their own view of the phenomenon. A booklet inviting other organisations to act in this regard is downloadable in different language editions from www.aiasbo.it/daphne.

For the current project the partnership was extended and other countries have been involved (see page 2 for a full list of their names). Work on the project has focussed on collecting the view points of stakeholders, on recording and describing instances of good practice in prevention and on the analysis of the impact of the project outcomes on the professional development of the workforce. As in the case of the first project, the views expressed in this booklet are the result of multidisciplinary team work, including the contribution of parents.





||| What is this booklet about? ||| Why has this booklet been written? ||| Who is this booklet addressed to? ||| What has informed the writing of the booklet?

Introduction



What is this booklet about?

This booklet is about the prevention of maltreatment of children with disabilities in the domestic environment. Research evidence shows that these children are more at risk of experiencing maltreatment than children without disabilities (See section 1 for an introduction). This is a complex issue, of global concern, that affects all socio-economic groups; it has a high emotional impact on families, professionals and the general public.

The UNICEF report *Violence against disabled children* (2005) states that: "Violence against children as a global concern will not end until disabled children are included in all outreach and prevention measures". In order to combat violence, the report recommends measures that involve both communities and families: awareness raising, the empowerment of families and children, appropriate support and services to cater for their needs.

Why has this booklet been written?

This booklet was written by an international consortium of organisations working for the benefit of people with disabilities. Most of them represent people with disabilities and/or families, while others provide community based services. They share a common approach to the prevention of the maltreatment of children with disabilities which is based on the empowerment of people (parents, children and professionals) and situations (the family context, the service delivery context, interaction and relationships between the actors). It is important that all professionals are aware of the risk of violence and of the forms it may take, and that they collaborate with the family in developing safe and protective environments in which all family members can feel secure and fully develop their potentials.

Such collaboration is not easy and this booklet aims to build a bridge between different views regarding the emotions, needs and expectations involved in raising a vulnerable child. It is hoped that it will help to improve communication between professionals and families.

In advancing the concept of prevention the booklet focuses on protective factors as corner stones for the construction of prevention strategies. The authors want to move away from the prejudice that disability automatically leads to depressing and risky situations, and will explore the individual, family and community resources that can be developed for preventative pur-



poses. This booklet highlights the importance of the family and of its strength and needs, and seeks to counter feelings of frustration, omnipotence or superiority among professionals by providing them with a concrete, and perhaps for some, new perspective on their work. This perspective is family strength oriented, as the authors believe that even when there is a risk of some form of maltreatment appropriate solutions are to be found with and within families.

Who is this booklet addressed to?

This booklet targets professionals who feel responsible for the well-being of children with disabilities and their families. Many of them intervene directly, providing care, advice or support in a social, health or educational setting; others might have a role of a more managerial or administrative nature, for example supervising teams, or planning and deciding levels of care and support. Others again might be involved in policy making, in the design and in the development of appropriate services that cater for the often complex needs of citizens. For all of them this booklet is expected to be useful as it highlights the importance of taking into account the expectations, ideas and opinions of people with disabilities and of their families in designing and delivering services that they will perceive as effective.

Although this is a field where many



professionals have doubts about the effectiveness of their intervention, it is important to be aware that all forms of intervention that aim at the empowerment of families potentially contribute to reduction of the risk of some form of maltreatment occurring. Families, people with disabilities and their representative organisations are also encouraged to read this booklet. We believe that they will find the information useful and that their support in encouraging its dissemination among professionals will further the development of knowledge based cooperation.

What has informed the writing of the booklet?

The writing of this booklet has been informed by an extensive review of the literature on the subject, by our own research among young adults with disabilities, parents and professionals across Europe (2. See section 3 for more information), by the analysis of preventive activities and services, and by the experience of the members of the consortium.

Readers are invited to contribute to the further shaping of the views of the authors on the issues at stake. A feedback form is therefore included in the last page of this booklet.



||| Understanding the issue ||| Forms of maltreatment related to disability



Maltreatment and disability



section 1

Understanding the issue

Child maltreatment is harm (or risk of harm) caused to a child by a parent, caregiver, or any other person responsible for the child's safety. The World Health Organisation distinguishes five subtypes of child maltreatment: physical abuse, sexual abuse, emotional abuse, neglect and negligent treatment and commercial or other exploitation.

1. For a comprehensive overview of this issue the authors recommend the reading of the booklet: "Childhood, Disability and Violence. Empowering disability organisations to develop prevention strategies". AIAS Bologna onlus (2004). Downloadable in various language editions from www.aiasbo.it/daphne.

Children with disabilities are at increased risk of some form of maltreatment (1): nevertheless, over the years research has moved away from treating disability per se as causally linked to maltreatment, towards an understanding of the factors that, associated with disability, lead to an increased risk of maltreatment.

Progress towards a complex view of the phenomenon has been favoured by the **systemic model** and the **ecologic model**.

The systemic model teaches that there is not a single type of family but that each family is unique, both in terms of structure and in terms of patterns of relationship, within and outside the family. Although the model defines principles and concepts for the understanding of family dynamics, each pattern of familiar relationship is strictly related to a particular phase and context of development.

A DEFINITION OF ABUSE

"Any act, or failure to act, which results in a significant breach of a vulnerable person's human rights, civil liberties, bodily integrity, dignity or general well-being, whether intended or inadvertent, including sexual relationships or financial transactions to which the person has not or can not validly consent, or which are deliberately exploitative. Abuse may be perpetrated by any person (including by other people with disabilities) but it is of special concern when it takes place within a relationship of trust characterised by powerful position.

In: *Safeguarding adults and children with disabilities against abuse*. Council of Europe (2003).

The ecological model broadens this perspective and proposes a multi-factorial view of maltreatment. As a tool it serves to enable us to understand how the condition of a family in a specific context is the outcome of the interaction of protective and risk factors at four levels (individual, relationship, community and societal).

Forms of maltreatment related to disability

The relationship between maltreatment and disability is complicated further by the types of maltreatment which are associated specifically with disability.

Nowadays, the notion that people with disabilities are disabled not only by their limitations but also by their environment is one that receives formal recognition(2). Environment in this context is to be understood in its widest sense as including both physical (architectural) and non physical (beliefs, prejudice, attitudes, etc.) factors. Indeed, with regard to the latter, mainstream popular, political and media culture shape the people's attitudes towards disability and influence the self-perception of a person with a disability and those of his or her family. Education, work, leisure, socialization, personal autonomy and the sexual expression of people with disabilities are affected by cultural and social prejudice which leads to discrimination, an important form of maltreatment, typically associated with disability (3). Negative stereotypes about people with disabilities usually depict them as totally dependent and in need of care, unproductive and intrinsically incompetent. Gender is not only a biological factor: society ascribes roles and attributes on the basis of sexual difference. Being a man or a woman with disability (or a father or a mother of a child with a disability) may, depending on the context, impact on the possibility of integration or on conditions of isolation. Within the community, people with disabilities are in a vulnerable position since they are exposed to multiple carers (4) who not only intervene regarding their health situation, but also have, or acquire, the power to decide about the development of their autonomy and relationships. Medical and hygienic approaches may lead to invasions of privacy. People with disabilities may be infantilised and denied their right to educational and social opportunities and to establish sexual relationships.

Ignorance and lack of training for staff working with people with disabilities can lead to partial understanding, or indeed erroneous interpretation, of the behaviour of people with disabilities and their complex needs. Professionals may not have the patience or the skills to recognise the potential of a person, or the impact of their steering role, with the result that they undermine their own efforts to support the realization of the person's potential or indeed his/her management of his/her own life. Behaviour defined as "disturbed" by medical and educational staff may represent the expression of forms of suffering or victimisation: lack of training may increase the risk that professionals fail to listen to such request for help. Moreover, when professionals are considered to be the people competent to make decisions, even professional practices which constitute forms of maltreatment, such as physical and psychological punishment as part of behavioural programmes, control and restraint, sedation and other pharmacological interventions may become socially accepted and legitimated.

2. "The International Classification of Functioning, Disability and Health" (ICF) adopted by the WHO is based on this concept. Ref. <http://www3.who.int/icf>

3. Ref. "The Convention on the Rights of Persons with Disabilities". United Nations (2006) and The Standard Rules on the Equalization of Opportunities for Persons with Disabilities. United Nations (1993).

4. When not otherwise specified, "carer" is to be understood as referring to both professional and voluntary caregivers, including parents and other relatives.



||| Defining prevention ||| Different levels for primary prevention



Prevention

section 2

Defining prevention

1. The booklet "Childhood, Disability and Violence. Empowering disability organisations to develop prevention strategies" contains a section about prevention, where definitions, levels and forms of prevention are analysed. Further cornerstones for the development of prevention strategies are listed. AIAS Bologna onlus (2004). Downloadable in various language editions from www.aiasbo.it/daphne.

2. Depending on how the entire population is defined, the various levels take on different meanings. All people with

Several theoretical models have been developed to categorise prevention in terms of timing, stages and target, distinguishing between primary, secondary and tertiary prevention (1). Primary prevention addresses issues that affect the entire population, while secondary prevention aims to protect specific groups that because of certain factors are more at risk of being victims than others (2). Tertiary prevention takes place after a problem has occurred, to remedy the effects or to avoid it happening again. This last level of prevention lies outside the scope of this publication.

Preventive strategies differ in nature or orientation depending on whether they are primarily reactive or proactive (Dubet and Vettenburg, 1999). A reactive strategy seeks to avert danger (3), whereas a proactive strategy tackles risks through positive actions, for example by enhancing the involvement of service users, developing key areas of practice, implementing quality assurance programmes, professional development of the workforce, information campaigns. Effective primary prevention, in situations of disability, is inevitably linked to awareness of the complexity of specific situations in terms of needs, resources and time related factors such as the developmental age of the child and the phase of life the family is passing through. An important source of complexity is the interaction between the actors involved. Each of these actors – families, professionals, institutions – represents a set of ideas, perceptions, attitudes and expectations that impacts on the way they construct and maintain relationships with each other. Analysing the complexity of the context is the key to the successful identification of the family needs.

disabilities are at a higher risk of becoming victims. Therefore in our specific case it can be argued that primary level prevention concerns the entire population of people with disabilities, while secondary level prevention regards groups with specific characteristics, for example children, or, even more specifically, girls with mental deficit living in institutes.

3. It can be harmful to over protect people with disabilities. The aim should be to ensure that they are protected to the same extent as other people.

Different levels for primary prevention

With regard to the care and protection of children with disabilities, primary prevention can be developed at different levels:

- individual (child)
- family (parents – child – siblings)
- community (incl. professionals)
- society

In what follows, **key concepts** are defined and elucidated for each level, together with their **impact on thinking about prevention**. Examples of **good practice** (⚙️) across Europe are included.

Individual level

KEY CONCEPTS

Individual rights

All children have the right to develop individual strategies of dealing efficaciously with the environment. This is a right that society guarantees to all people, disabled or not (Council of Europe, 2003). It includes handling negative experiences ⚙️ [1].



Dependency

An enduring condition of dependence on parents (and to a lesser extent on professional carers) increases the risk that power and responsibility regarding decisions is never (fully) transferred (Council of Europe, 2003).

IMPACT ON PREVENTION

If disability limits the possibility to verbally express needs and wishes, interlocutors should try to facilitate other means of expression. People with disabilities should be supported so that they can express their needs freely, without the fear of punishment or inappropriate reactions. Only through the development of potentialities can these rights be guaranteed and professional carers should be aware of this. In the case of behavioural disorders, professionals should work jointly with families to understand the behaviour of the person with disabilities in terms of a reaction to a context which may be uncertain or which may not match their developmental needs.

Although many routine decisions must be made proactively and sometimes on behalf of person with disability, individuals should be included and put at the centre of the decision process. Interventions should be based on the principles of full and informed consent and be tailored to the needs and preferences of the individual. The sense of self-realization and feelings of self-satisfaction can only develop when the fundamental right of a disabled person to take decisions about his/her own life is fully recognized .



I. Children and young people with intellectual disabilities are among the most vulnerable people in our society. Research in the UK shows that 8 out of 10 children and young people with an intellectual disability are bullied (Source: Mencap). Most of them do not feel safe in their communities because of bullying. Since this need was ascertained in 2007, **Mencap** has developed the Don't stick it, stop it!-campaign. The campaign is calling for children and young people, adults and the government to take action to stop bullying. Ref. www.dontstickit.org.uk. Positive actions can be undertaken to empower children to deal with negative experiences., The UK

charity **Kidscape** for example, works with children and young people under the age of 16, their parents/carers, and those who work with them. Their aim is to protect children from abuse and more specifically to prevent bullying and sexual abuse. **Kidscape** equips vulnerable children with practical non-threatening knowledge and skills in how to keep themselves safe and reduce the likelihood of future harm. With the help of parents, carers, teachers, police and other caring professionals, children are taught ways of dealing with bullies, approaches by strangers, and even adults they know who may try to harm them, and good sense defence . Ref. www.kidscape.org.uk

Self perception

The way children perceive themselves while growing up is determined by their interactions and exchanges with significant adults (Council of Europe, 2003).



The more or less explicit reactions of parents with respect to the child's attitudes and choices impact on the child's self-image and self representation. Through the choices and behaviour of adults, children with disabilities gradually become aware of their expectations and opinions concerning their potential and their limits. Many people with disabilities feel that their process of personal emancipation and their relational development is not understood by their parents and by other carers. It is difficult for young people with disabilities to manage overt or covert disagreement with their demand for autonomy in managing their own self care (in the areas of medical treatments, personal hygiene, education, work) and social life (in terms of friendships with or love for disabled and non-disabled peers), even if they believe or understand that this disagreement stems from their parents' anxieties on their behalf, particularly concerning emotional disappointment. Primary prevention at this level should therefore always seek a balance between the developmental potentialities of the child and the expectations of the family.

Family Level**KEY CONCEPTS****Complexity**

The systemic model defines the family as a natural conjunction of growth and care. It is based on patterns of interaction which constitute the structure of the family itself and regulate relationships with the other social systems such as the nuclear and original family, individuals, and the community. Inside the nuclear family there are three sub-systems: the couple, parents, and siblings. Each family negotiates the different roles and duties of its members in order to adapt to the challenges of life (Minuchin S., 1976).

IMPACT ON PREVENTION

Having a child with disability is not necessarily and primarily a story of "gloom and doom". If the appropriate support is available for the family, many parents manage to cope with the added demands and remain relatively resilient, reporting enjoyment of and satisfaction with their role (Vacca and Feinberg, 2000).

Disability represents an event (usually unexpected) that provokes reactions and requires adjustments both in the nuclear family and at other levels. Moreover, dealing on a daily basis with disability can stress parents who might ask for additional resources in order to cope 🌀 [II].



II. In Latvia the Association **Velku biedriba** promotes "motivation programs" for parents taking care of children with disabilities. As in other countries parents taking care of children with severe intellectual and/or physical disabilities in Latvia risk social exclusion. The goal of the program is to boost the self-confidence and self-esteem of parents of children with disabilities, in order reduce their social isolation and stress and improve the affective and emotional climate in family. Each

motivation program deals with a different theme and each theme is discussed in parent support groups. Examples of themes are: feelings and emotions, feelings of insecurity and helplessness, sadness as a natural part of life, crisis as a stimulating challenge in the family of children with disabilities. Parent support groups meet once or twice a month. About 150 parent are involved in 10 groups located all over Latvia. These groups are lead by professional psychologists.

> Complexity

The family is thus a dynamic system, developing through the cycle of life, facing expected and unexpected events, adjusting and adapting to internal and external changes as an ongoing process. The impact of internal and external events depends significantly on the phase in the cycle of life that family is passing through. The most challenging stages in the development of a family are: the establishment of the couple, the birth of children, the years up to school age, school age, adolescence and the attainment of full independence by grown up children (Sorrentino, 2006). Such changes are stressful because in order to cope with them the family has to be flexible, adapting its modes of functioning and calling upon new strategies. Pathologies and the dysfunctions can arise when the family is rigid and tries to maintain its original structure instead of adapting to new conditions.

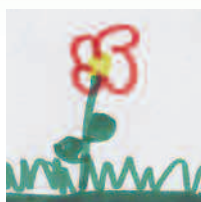
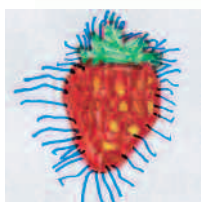
The professional challenge in the field of prevention is to discover the specific nature of the interaction between risk and protective factors, which is unique to each family, and to focus on protective factors, in order to reinforce family and individual strengths [III].

When a child with disabilities is born the family has to reorganize its structure; parents have to change their expectations and rearrange roles and duties. Parents need to review their expectations and dreams about the future often in situations of uncertainty about the child's development and the evolution of the situation. Helping families to find new patterns of relationships and to rearrange the internal organization by providing support can ease their adjustment to new environmental demands.



III. *The Portuguese program PIIP, based in the Coimbra district, is run by professionals from several services that cooperate in order to respond to the*

needs of children up to the age of 3 (occasionally up to 6) and of their families that are at biological or environmental risk. It aims to develop and implement a program that coordinates different but related services in the early intervention area using resources available in the local community; to cooperate with health, education and social security services in promoting a transdisciplinary and inter-agency model of action as the most suitable in the early intervention area; and to create transdisciplinary teams in order to provide a service based on a family-centred model that recognises parents as caregivers and essential in the decision-making of the entire intervention procedure. Systematic support is given to professionals and the quality of interventions is guaranteed through periodic training and staff meetings. PIIP was created by an inter-agency initiative and has been operative since 1989; it supports more than 300 children every year.





Communication of the diagnosis

The way in which the diagnosis is communicated can influence initial adjustment and acceptance, both at a cognitive and at an emotional level (Clements and Barnett, 2002).

The communication of the diagnosis generally causes shock, grief and anger. It is vital that parents manage to adapt gradually and in a flexible way to the disability of the child as this is the key both to the development of a positive attachment on the part of the parents in terms of responsiveness to the needs of the child and, conversely, to the development of feelings of trust and security on the part of the child with regard to the parents. In order to reinforce coping skills it is important that professionals establish contact with the family as soon as the disability is ascertained [IV]. Professionals should use a language that is accessible to describe the pathology, and should give parents the opportunity to ask questions and to express doubts. The presence of the child can help the professional to talk about him/her with the parents. Professionals should highlight the child's potentialities and the importance of positive relations between the parents and the child as a condition for realising these potentialities [V].



IV. *Vaimupuudega Laste Vanemate Ühing, a parents association in Estonia, promotes motivational programs for parents of children with mental disabilities.*

The organisation co-operates with doctors and maternity hospitals and provides support for the mothers of newborn babies with mental disabilities and Down syndrome.



V. *The project "Communication as initial care" was set up by the Bergamo Section of The Italian League against*

Muscular Dystrophy (Uildm) between 2004 and 2005. Parents who have received a diagnosis of neuromuscular disease and adults affected by some neuromuscular disease were interviewed in order to determine the long term impact of how the diagnosis was communicated on perceptions of the disability and the attitudes towards it. The results reveal that, even after many years, memories of how the

diagnosis was communicated are still fresh. All the parents interviewed were able to recall single words or expressions used by the doctors and even mimic their expressions; they remember where the communication took place and how much or how little empathy they felt with the communicator. Widening the focus from a relationship between doctors and parents, these results have also been interpreted from a sociological angle, focussing on the role of the social, cultural and relational context.

Denial

After the diagnosis has been communicated, and through out all the successive phases in the child's life, parents have to come to terms, both emotionally and cognitively, with their child's condition: how they do so depends on how they manage to integrate their understanding of the facts and realities associated with their child's condition and their own emotional reactions. The nature of this integration shapes the relationship between parents and child and how they face with the world outside the family (Barnett et al., 2003). Denial of the child's difficulties is a risk factor here: this attitude may lead parents to

Professionals who coordinate interventions for the child should frequently engage parents in dialogue and involve them in all phases of the decision making process: in this way is possible to highlight both the difficulties and the potentialities of the child and to get parents to recognise what environmental elements favour the development of their child. Parents feel stronger and less vulnerable when they are aware of what opportunities there are for their child's development and integration [VI].

Parents need to be informed and trained to spot positive signals so as to be in a position to encourage the development of their child's potential. Professionals have to work jointly with parents to increase their relational abilities with the child in terms of listening to their requests for physical and emotional closeness, even if they are not expressed verbally. Play has to be reinforced for its relational and communicative function: it is a right of every child and should not be relegated to second place because of the time that is needed for rehabilitation. Play – free of expect-



VI. The “Don Chisciotte” project is promoted by **Aut Aut ONLUS** Association for Children’s Families with Autism in Modena (Italy). The specific aim of the project is to help children aged from four to ten who have been diagnosed autistic to develop and enhance their basic social and personal autonomy outside the school context. Under the project, activity programmes are tailored specifically for each child according to their potentialities (assessed through observation) and the needs of their parents (assessed through individual

interviews). One example of these after school activities is cooking, which gives children the chance to gain a specific competence and to interact socially with their peers. Moreover, the project also seeks to train the participants to visually memorize their activities by providing them with a visual aide-mémoire in the form of an album of pictures to look at with their parents. As a record of gratifying experiences, this album has proved to be a useful tool for facilitating parental interaction and communication with their children.

> Denial

interpret the difficulties of their child as contrariness or laziness and this may reduce the possibility of interventions aimed at reinforcing the child’s potentialities. Such denial can often be combined with a failure to recognise the child’s true potential and this in turn may lead to hyperprotectiveness on the part of parents which can cause handicaps that are not directly result of the child’s disability. Hyperprotectiveness may be a strategy utilized by parents to defend themselves from public embarrassment for their child’s failures.

tations of learning and acquisition - allows the child and the parent to interact intimately and closely and to perceive each others body, emotions and sensations.



Sense of reality

There is a risk that disability may be seen by the parents as only a short-term problem with the result that everything is focused on the “struggle” against the disability (Scorgie and Sobsey, 2000). In such cases the family can loose contact with reality because it lives in the hope that one day disability of child will disappear. This attitude may even become an obstacle to the child’s development and to the establishment of functional relationships between the child and his/her parents.



Professionals should be aware that behind negation mechanisms there lies a need on the part of parents to defend themselves from something causing them suffering and a sense of helplessness. When parents feel overwhelmed by the disability of their child, their sense of inadequacy can cause grief but also anger. If parents feel or believe that they do not have the tools to deal with it, it becomes more and more difficult for parents to accept their child’s disability. Moreover, parents are aware that anger and aggressiveness are culturally and socially condemned and a sense of guilty may inhibit their search for adjustment strategies. Furnishing parents with rational and emotional support as soon as possible can boost their confidence in their ability to cope with disability, and such confidence will in turn help them to accept their child's disability.



Coping strategies

Research (25 Zanobini et al., 2005) demonstrates that there is a positive relationship between resilience and having good coping strategies and perceptions of:

- personal well-being - emotional balance
- the condition of the couple - division of roles, clear communication, shared responsibilities and decisions, reciprocal support
- the condition of the family - gratifying relationships with the other children and members of the family
- social situation - extra-familial relationships such as friends and colleagues.

Siblings

Siblings can play an important role in a family in which there is a child with disabilities. Parents often expect them to collaborate in the care of the child with disability, especially in the case of the first-born (Stalker and Connors, 2004).

Since almost all cultures define mothers as the primary caregivers, one form that preventive action can take is that of strengthening the mother emotionally and psychologically for the task of organising (together with her partner) the care of the child by helping her to maintain her own space outside the family in the shape of a job and or of friendships. The couple has to be perceived as the heart of the nuclear family and as a central core in the field of prevention. Strengthening the resources and potentialities of the nuclear family, both as wife and husband and as mother and father, enables it to cope more efficaciously and generates a sense of security. It is important to make a distinction between the conjugal couple and the parental couple. Many families with children with disabilities are one parent families because many couples cannot adapt to the birth of a child with disabilities: this risk is greater in the case of a dysfunctional relationship. In these conditions of conflict and struggle, professionals can help families to keep the level of the conjugal couple and the level of the parental couple separate, as they can function independently from each other.

A possible risk factor here is that a brother or sister may perceive family responsibilities as having a negative effect on their autonomy and on their extra-familial relationships with peers. Acceptance or rejection of disability on the part of siblings is often an expression of that of the parents.

By working with parents to reach a good level of understanding and acceptance of disability and to develop an optimistic attitude towards it, professionals can promote gratifying and affectionate relationships between siblings and the child with disability, thus reducing the risk of inappropriate behaviour towards the child or feelings of guilt. When parents transmit an attitude of respect and appreciation towards the child with disability to the other children, the latter develop altruistic modes of behaviour and internalize positive values, both of which are socially appreciated.



Community Level

KEY CONCEPTS

Professionals

At the level of community, different professional figures are involved in the care of the child and the family in different phases in the history of the family. The systemic and the ecological models view professionals as intimately related to families. They are not treated as though collocated in a higher position in a hierarchical system, disengaged from families and from the dynamics of intervention and outcomes. They interact with families and their interpretation their role is at least in part determined by their attitudes, ideas, emotions and beliefs.

IMPACT ON PREVENTION

Shared responsibility between parents and professionals in the care of children with disabilities requires reciprocity. Professionals need to be conscious of their specific role and their own attitudes towards the child with disabilities and his/her family if they hope to be objective in their evaluations and interventions. Professional neutrality can only be attained through awareness of all the factors, actors and interactions involved: otherwise there is a risk that judgements may be made on the basis of partial knowledge and that they may be erroneous. And only through such awareness – ranging from the personal level to the family and to societal prejudices and ideas – can professionals fully grasp the complexity and uniqueness of each situation, in terms of difficulties and potentialities and what choices are available in seeking to adopt the best strategy of care, from a protective point of view, for the child and his/her family. Cultural background, communicative capacity, personal style, and professional experience are just some of the factors which influence the relationship between the professional, the family and the child, and the professional's capacity to cooperate on a reciprocal basis. Efficacious intervention in the field of prevention also depends on timing, on the degree of collaboration and clear communication, and collaboration means teamwork in order to define priorities. When common objectives, languages and strategies are in place from the outset, parents are reassured by the presence of a framework within which they can work with professionals [VII].



VII. *On the 21st of June of 2006, a protocol to coordinate and favour activities targeting children with deafness and their families was signed in Bologna by the local health authorities, the university and the **Gualandi Foundation**, a private organization nationally recognised in the field of rehabilitation for deaf children and of staff training. The Foundation promoted this partnership in order to encourage synergistic cooperation in the field of diagnosis, therapy and rehabilitation for children deaf from birth, so as to avoid the fragmentation of care among different agencies as soon as possible. Another objective is a multi professional agreement on a schedule of interventions according to which specific interventions are carried out by a specific operator at a precise moment, to be drawn up as soon as possible after the diagnosis has been communicated. Other objectives include: linking all the types of interventions in a continuum to favour the development of child potentialities from the earliest years, providing help and support to the family, training for teachers and educators. Some of aspects of the agreement are still in the process of realization, such as the definition of a Screening Project and of a Master Project for educators and speech therapists.*



Education

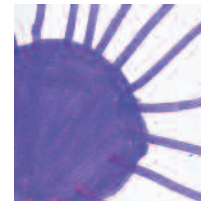
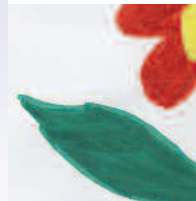
At community level, schools have a crucial role in the field of prevention. Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning. Parents have an inherent right to be consulted on the form of education best suited to the needs, circumstances and aspirations of their children. Mainstream i.e., non specialized schools with an inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all (Ref. The Salamanca Declaration, 1994).

When the child goes to school, he and his parents have to deal with the expectations raised in this context: often it is at this moment that child's difficulties become evident. Moreover, school is a place which offers the possibility of new social relationships with peers: it is at this point that degrees of acceptance or rejection begin to be perceived more clearly by both parents and by the child.



Both school and pre school establishments should offer a safe and inclusive environment, where intellectual and relational potentialities are identified and enhanced. Human differences are normal and learning must accordingly be adapted to the needs of the child rather than the child having to fit in to precise assumptions regarding the pace and nature of the learning process. Promoting a culture of equal opportunities means that children should be taught that all people are equal but different and that inside an inclusive context attentive to individual needs, each child can achieve educational progress and social inclusion. This attitude can be interiorised by children only if teachers, educators and the entire school staff act as models of acceptance and inclusion [VIII]. During all phases of development, activities aiming at the integration and participation of children with disabilities in educational and community activities are preventive in nature.

Social isolation might increase the risk of violence, which might lead to more social isolation. This downwards spiral needs to be turned in an upward spiral.



VIII. MDVI Euronet is a group of professionals dedicated to extending knowledge, understanding and best practice in the education of children and young people with Multiple Disabilities and a Visual Impairment (MDVI) regardless of educational placement. The MDVI Euronet group started its activity out of a desire to promote a holistic approach in the teaching of children with MDVI in order to empower children and to facilitate their full participation in family and social environments. The holistic approach treats the child with multiple disabilities not as the simple sum of multiple disabilities but as a person who should receive care of an integrated kind according to their different

competencies and difficulties. The MDVI Euronet group believes that the implementation of such a model would improve the technical competence of teachers and the quality of their interaction with other professionals involved in helping the children concerned and their families. The **Lega del Filo D'Oro**, an Italian associate, assesses the needs of children aged 6-13 years, paying particular to the views of those it considers most competent with respect to the child, namely the family and the operators concerned. Educators and teachers are trained to fill out a daily evaluation sheet which, in order to reduce the risk of frustration, takes into consideration even those achievements which might be perceived as minimal.

Society Level

KEY CONCEPTS

Stereotypes

At the level of society, protection starts from an awareness that disability does not necessarily lead to negative conditions of life and to maltreatment [IX]. The image that society as a whole has of disability impacts on individual perceptions of disability and has a negative influence on the realization of potential in terms of self-determination and on the development of the individual and the family. Moreover, a stereotype that sees all intervention as useless may trigger defence mechanisms in professionals and impact negatively on their efforts to sustain families (Thomas, 1999).



IMPACT ON PREVENTION

Policies tackling discrimination, mainstreaming disability issues and aiming at inclusion of people with disabilities, have a positive impact on prevention and need to be enhanced where possible.

Cultural factors play an important role in the perception of those actions and desires which are or are not considered “socially valuable and appreciated”. If based on a more positive view of disability and on the capacity of parents to cope with it, a lot of care and support actions would become more effective [X]. A multilevel analysis of cases and a systemic focus on potentialities and resources within each family, helps professionals to internalise a more positive and stereotype-free image of families with a child with disabilities. Thus empowered they are able to analyse situations more deeply without fear of discovering signals of difficulty or of a risk of maltreatment.



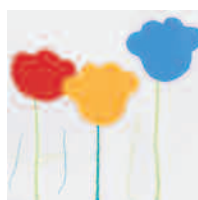
IX. *The Calamaio Project has been going since 1986 and was set up by the **Centre for Documentation of Handicap** (CDH), Bologna. The aim of the project is*

to promote a culture of integration with regard to disabled people in the context of school so as to undermine the negative image that is usually associated with them characterised by sadness, misfortune and need of care and support. Educators, animators and disabled operators organize activities in schools directed at students, parents and teachers in order to create possibilities of interaction in the belief that sharing joyful experiences with disabled people can reduce the risk of rejection and isolation. The designers of the project believe that through knowledge of, and real contact and closeness with, disabled people, it is possible to reduce the fear of the unknown that many have with regard to them and that awkwardness in relations with the disabled can be changed into positive relational experiences. The promotion of a culture of acceptance and integration would also change the perspectives and expectations of families.



X. *The **Sou capaz** campaign was created by the mother of a girl with Down Syndrome who, in opposition to still widespread ideas about these*

children, wanted to promote a new vision of them that sees them as individuals with ideas, desires and goals. The idea of the campaign arose after consulting other parents with similar concerns about the acceptance of Down Syndrome children by society, by their parents and by the extended family. Alongside the problem of acceptance there is the problem of beliefs and attitudes. This project seeks to stimulate positive thinking and the realization that anything is possible. Handicaps and difficulties should be discussed and demystified and accepted and managed when the need arises. The object of the project is not to create illusions - parents should be aware of the specific nature of this pathology - but they shouldn't surrender all their expectations of their children because they have an extra chromosome.





||| Introduction ||| Young adults with disabilities ||| Parents ||| Professionals



Actors



section 3

Introduction

The development of a safe and protective family environment in which all family members feel happy and can fully develop their potential lies at the heart of prevention. Such environments cannot be created with the wave a wand: they are the product of long term processes which involve factors internal and external to the family and which, for the most part, are “natural”, but which may on occasion require support in the shape of purpose-designed intervention. Various actors are involved in such processes and the needs and expectations of each and every one of them have to be taken into consideration.

This chapter will introduce these actors and represent their points of view by drawing on the results of a survey. Obviously, their points of view are the product their personal and professional experience. Any approach to multi level prevention should take these points of view into account.

The points of view examined here include perceptions concerning the past, present and future and are analysed with reference to the ecological model and its various levels. The points of view of the different actors involved are compared here only to show the complexity of the issues at stake and not in order to pass judgement. The aim is to take feelings and experiences seriously, not to simplify or trivialize them. If families and people with disabilities feel understood by the professionals who cater for their needs, their sense of security and self-respect will be reinforced. On the other hand, when people with disabilities and their families rely on professionals for help in facing moments of difficulty and crisis, the motivation of these professionals will be boosted by knowing how much trust and reliance is placed in them.

It should be noted that any statements made on the basis of survey results are only valid for the interviewed population: it is not the aim of the authors to make

absolute statements but to promote discussion about the development of primary prevention practices. Interpretive comments on the part of the authors are distinguished from the voices of the actors in the footnotes.

1. A similar difference between self perception and the perception of disability by parents and professionals is highlighted by Clare Connors and Kirsten Stalker in their survey into disabled children's understanding of disability. Connors and Stalker (2007).

Young adults with disabilities

The rather positive perceptions young adults with disabilities have about their life and relationships, challenging the risks highlighted by the literature and research on the subject, can be interpreted as a protective factor (1). Their self image denotes independence, optimism, sociability and psychological strength. Nevertheless, disability is perceived as having a quite a significant impact on a number of different aspects of life such as work, economic condition and social relationships. Gender does not seem to be perceived as playing a significant role in this regard. The young adults interviewed consider sexual relationships to be an important form of self realization, but they believe that their parents perceive the satisfaction of their sexual needs as not being particularly important for their future. Moreover, many of the young respondents declare that they have not yet found interlocutors to talk with comfortably about their sexual needs.

A SURVEY INVOLVING PROFESSIONALS, FAMILIES AND YOUNG ADULTS WITH DISABILITIES

Within the framework of the Daphne Project "Children with disabilities and Violence: Primary prevention targeting families", a survey was conducted concerning three distinct groups:

- Young adults with disabilities (183 respondents)
- Parents of children with disabilities (82 respondents)
- Professionals providing services to children with disabilities and their families (115 respondents)

The countries involved were: Italy, Portugal, Latvia, Estonia and Greece. A different questionnaire was designed and translated into the relevant languages for each group. The questionnaires were administered by interviewers/facilitators trained for the purpose between September 2006 and March 2007. Although the groups were different, the questionnaires concerned similar issues, with the result that opinions regarding key issues and reciprocal expectations could be compared. The key issues included the impact of disability on the lives of people, the assessment of critical moments in family history, expectations and evaluation regarding professional support and its usefulness in coping with tension and stress, and the impact of the environment/society/media on the lives of people.

The project team is aware that strictly speaking the results only have any validity for the surveyed population. The size of the surveyed population and its heterogeneity do not permit generalisations to be made. However, the aim of the survey was to collect suggestive feedback from the different groups concerning issues that lie at the heart of any prevention strategy that aims to tackle the development of stress in families. As such the purpose of the survey was limited to informing and underpinning the process of designing and writing information materials, including this booklet, and learning programmes for professionals working with families with children with disabilities.

Chapter 3 includes an account of the most significant opinions expressed by the surveyed populations. A full survey report can be downloaded from the web site www.aiasbo.it/daphne.

2. Different factors might have influenced this result: denial, compliance, social acceptance, lack of vocabulary to express difficulties.

Young adults consider their school years and adolescence as having been the most critical periods in their family history in terms of the occurrence of stressful situations that had to be coped with. It is during these years that the expectations of the family and society in terms of learning and relationships are felt most strongly and explicitly. Most of those interviewed remember their parents as having been strong and optimistic during these years, while anger, frustration, depression, tiredness and anxiety are very rarely reported. Moreover, the occurrence of aggressiveness is never mentioned (2).

During these critical years the resources in which they put most trust were their families, their parents, their friends and themselves. Professionals are not perceived as having been very helpful and the services they received are judged to have been insufficient with the exception of information and technological support. Moreover, psychological support was insufficient, according to the respondents, though they consider it to have been particularly important for dealing with stress and tension. Among the types of services they received, the following are regarded as having been useful: information, emotional and psychological support, rehabilitation, technical support and aids, respite care, parental training, leisure activities and peer support. Home visits are not considered helpful for the reduction of stress and tension.

Widening the focus from these critical periods to other phases of life, the respondents feel that they have been personally quite involved in rehabilitation projects and they judge the services they have been offered as having been beneficial in terms of helpfulness and continuity. The timing of intervention is prevalently perceived as corresponding to moments of greatest need. With regard to the future, professionals are perceived as a resource. Professionals are considered quite well trained in health related issues, in understanding needs and communication skills, but not sufficiently trained in preventing stress and maltreatment.

3. According to the young adults, knowledge of the impact of the pathology on the child development would have helped parents to manage the intense grief.

The respondents believe that the moment in which their parents received the diagnosis of disability was a very emotional one in their lives. Grief, frustration and shock are assumed to have been the emotions that were most strongly felt by their parents, while what was needed most at that moment, according to the young adults, was detailed information and prognoses about future development (3).

4. Positive family relationships definitely impact positively on the self image of young adults.

With regard to their childhood, the young adults interviewed perceive family relationships as having been positive. Their relationship with their parents is associated with esteem, freedom of expression, respect, encouragement, empathy, safety, happiness and dialogue (4). The same is true of their relationship with brothers and sisters (5). In comparison to their peers, young adults nevertheless feel that they have had fewer opportunities to express themselves. Sufficient, however, to allow for the creation of gratifying social relationships.

5. This outcome reinforces the hypothesis that parents play the role of relational mediator between the person with disability and siblings.

With regard to the future, young adults feel more confident than their parents. Beside themselves, their mother, professionals and friends are considered important resources for the future, while fathers are perceived as being of little help (6). Young adults consider friends a useful resource for the future, although they also believe that their parents do not agree with them about this. Extra-familial relationships prove to be important for creation of a sense of security and autonomy (7).

Regarding their views on society, young adults believe that state and health authorities have a responsibility to support families, and not only in an economic sense. In their view the state and political institutions currently diffuse a damaging image of disability as, if not a social cost, at least problematic. On the



6. It is possible that children get used to relying on their mothers and professional decisions and that the emotional role of fathers loses importance in consequence. There is a possibility of a vicious circle arising here in that because fathers do not feel useful they leave their role to others – creating the risk that young adults do not build solid personalities based on identification with both parental figures.

7. It is possible that parents are not completely aware of the experience and feeling of satisfaction that their children obtain through contact with peers.

other hand, health care workers, educational institutions and social workers are held to propagate an image of disability that is correct (8).

8. This perception may contribute to the trust young adults place in professionals who take decisions about their lives.

A note about this subsection

Although this section contains statements made on behalf of the entire sample, there are significant differences related to the country of origin of the respondents. A detailed analysis has not been possible within the framework of this booklet, but for detailed information, please refer to the research report available on the web site: www.aiasbo.it/daphne.

Parents

Even after many years, the parents who were interviewed refer to the communication of the diagnosis as having been a very critical moment. They identify detailed information as a priority need at that moment, but emotional and psychological support, prognoses about future development and the contact details of parents' associations are also considered important. In recalling that moment, grief is the emotion most often remembered.

When asked to survey their experience as parents up to the present time, parents perceive the disability of their child as having had quite a considerable impact on their social relationships, professional career, level of stress and individual well being. They do not believe that they have had enough time for themselves, for their friends, for leisure activities or for playing with their child. However, generally speaking, they perceive their personal well being as equal to that of other families (9). In assessing themselves as carers, interviewees describe themselves as sufficiently adequate, rather efficient, empathetic, competent and adaptable, while stress and anxiety are not felt to be representative or to have influenced their interaction with the child. In their view, relationships with the partner and the family have been little affected by the disability, although the time at the disposal for the couple is perceived as only just enough. Both for the present and for the future, rehabilitation, individual well being, autonomy in daily life, happiness, experiences of all kinds, friends and social relationships, personal care, satisfaction of sexual and emotional needs, school success and normality are all considered as rather important by both parents. With regard to the future, what both parents mainly feel is a sense of protectiveness, although sadness and anxiety are also often reported. They believe that future challenges will be sustained mainly by themselves, with the help of the partner and the family; friends, professionals and other family members are considered quite as important in this regard. With regard to both the present and the future, parents consider themselves, individually and as a couple, the most important of the resources available for dealing with the challenges of daily life and with critical moments.



9. There is an apparent contrast here between perceived general well being and the perceived impact of disability on life. This shows that although parents are very much aware of the impact of disability their attitudes towards it are positive and accepting. In other words, it shows their awareness of the complexity of their situation. Moreover, this confirms that although disability may demand greater adjustments of parents, it does not necessarily lead to a condition of suffering and inferiority.

10. Periods that can be considered as crucial for progressive acceptance of the condition of disability, inside and outside the family.

11. That the reaction of siblings is not reported by parents may be interpreted either as a wish not to involve their other children in the management of critical moments with the child with disability or as indicative of a tendency to undervalue the important and active role that siblings play inside families with a member with disability. Another hypothesis may be that although siblings are expected to collaborate in the care of the child with disability, especially the first-born, parents try to limit such involvement so that it does not adversely affect their autonomy and development. Anyway, since the attitude of siblings often reflects that of the parents, it is reasonable to assume that they behave like them.

Within this sample, roles are distributed within the family in accordance with the cultural stereotype that defines the mother as the primary caregiver.

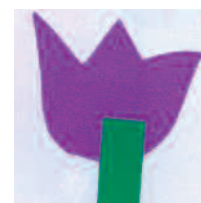
According to those interviewed, the periods which are most demanding in terms of coping strategies (10) are the first years of life and beginning school. Strength, self control and optimism, but also tiredness, are often felt by parents during critical moments. In their moments of difficulty in their relationship with their child, parents report that they sometimes get angry and depressed, look for external help, discuss with the child, and show anxiety and frustration; aggressiveness is never mentioned. The reactions of siblings during these moments are not reported in detail (11). Parents report that they put little trust in professionals during critical moments (12).

Generally speaking, parents find the following aspects of the services they have received to be unsatisfactory: their timing, their quantity and their continuity. However, some services are valued for their usefulness. Most of those interviewed believe that more technological support, rehabilitation, information, leisure activities, respite care services, multi-professionalism and home visits would have improved the development of their child. The climate in the family is another dimension that could have been improved through increased emotional and psychological support, training for parents and peer group empowerment. However, parents are more positive about personal relationships with professionals: for example they feel quite involved in rehabilitation projects for their child. They also have the impression that professionals consider them quite efficient, empathetic and competent in care, although a little bit stressed, anxious and rigid.

Generally speaking, parents think professionals have a positive image of them both as parents and as couple. Parents consider professionals sufficiently trained with regard to pathologies, understanding of the family and personal needs and communication skills, but they believe that they need to be better trained in the prevention of stress and maltreatment.

Widening the focus from the community to society, parents continually show a high awareness of the fact that the family of a child with disability needs support. They think that state and health authorities have a duty to share this burden with them. What emerges here is disillusionment with the attitude of the competent national authorities, since most parents believe that they diffuse an image of disability which depicts it as a cost and a problem. Health care and educational institutions, social services and the media seem to reproduce a two-faced image of disability: in some ways the image is positive, but it also represents disability as “a cost” and/or “a problem” (13). The church is considered to propagate an image that is largely positive.

12. This attitude may be due to the fact that parents believe they have not received enough help, especially information, psychological support and respite care services, forms of help that they consider to be very important for coping with tension and stress.



13. Confirming the complexity of cultural attitudes towards disability.

A note about this subsection

Compared to the view points of the young adults there are fewer national differences in survey results, although there are significant differences in thinking about the child's future, and the perceived happiness of the parents. This might have to do with many factors, among which the level of services available in a country, the acceptance of disability in society and inclusive policies. For more details, see the full research report, available on www.aiasbo.it/daphne.

A note about this subsection

As in the case of young disabled adults and parents in the corresponding sections above, within this framework we also represent the views of the professionals who were interviewed. Professionals represent the main target of this booklet. For this reason their viewpoints will, for the most part, be set against those of the young adults and the parents who were interviewed in order to highlight convergences and differences in ideas, expectations and attitudes. The sample is prevalently composed of social, educational and health professionals offering their services in variety of contexts. They typically have long term experience in working with children with multiple disabilities.

Professionals

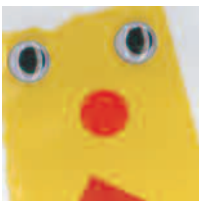
The professionals interviewed seem to be well aware of the importance of the moment of the communication of the diagnosis. Detailed information, psychological support and prognoses on future development are considered important at this moment, and grief is the emotion most often attributed to parents on receiving the diagnosis.

Compared to the young disabled adults, the professionals interviewed seem to attribute a higher impact to disability on the lives of the former than the young adults themselves, although both groups agree that the highest impact is on work, individual well being and the life of the couple. The self image that professionals attribute to young adults is less positive than that which this group attributes to itself in terms of independence, optimism, psychological strength, depression and professional gratification. Professionals depict young adults with disabilities as very sociable but also lonely. Moreover, professionals believe that parents underestimate the resources of their children, more so than the children do themselves. The result is that young adults are perceived as little satisfied about the quality of their own lives. Professionals attribute a higher impact to gender on the life of the child than young adults or parents do. While the other two groups do not perceive any significant impact of gender on life opportunities, professionals consider its impact to be insignificant only in education and rehabilitation. On other aspects of life some impact is perceived, especially with regard to the satisfaction of the sexual needs.

Sexuality is a typical area where misunderstandings emerge. Parents claim that they consider the satisfaction of the sexual needs of the child to be important both at present and for the future but this is not how things are perceived by young adults themselves. The professionals interviewed believe that this is the only aspect of their children's lives that parents consider of little importance. Young adults with disabilities report that that they have not yet found a comfortable interlocutor about the topic. On the other hand professionals declare that people with disability feel quite at ease in talking about their sexual needs with professionals, friends and partners, though they believe young adults feel little at ease in talking about this issue with mothers, fathers, teachers and other family members.

At the family level, professionals are well aware that disability impacts on stress levels and on individual well being, also because they know that parents have little time for other activities for themselves. Unlike parents, professionals believe disability has a significant impact on the life of the couple and has quite a bit of influence on social relationships and work.

The image that professionals have of parents, turns out to be more positive than the self image reported by parents. They are attributed qualities which cannot



14. According to professionals, adolescence is the phase in which families need most help. This belief may stem from the fact that the adolescence is generally recognised as a critical age for all youngsters. The presence of disabilities is assumed to complicate matters still further with regard to the satisfaction of needs concerning personal and social autonomy.

15. The occurrence of aggressiveness is not mentioned by either group of respondents. From a behavioural point of view, aggressiveness can lead to forms of physical or verbal maltreatment and it is therefore an emotion that professionals have to help parents to recognise and accept, in order to prevent explosions and extreme manifestations. Acceptance must start from the social context, since it filters and values feelings, modelling people and their understanding of personal emotions. In contexts in which aggressiveness is socially recognised as an expression of helplessness and suffering, prevention means that professionals have to attempt to use the tools at their disposal to help parents manage these emotions by building up confidence and a sense of security.

but have a positive impact on their relationship with the disabled child: efficiency, empathy, expertise in care, resilience, organizational ability, good quality interaction with the child, good levels of information. However, talking about parents, professionals also often report a sense of inadequacy, stress and anxiety. Rehabilitation, individual well-being, autonomy in daily life and happiness are, according to professionals, very important for parents.

Most professionals consider adolescence to be a critical phase, while parents consider the first years and school age more critical. Generally speaking, according to professionals, adolescence is the phase in which families need most professional help (14). Parents' reactions during critical moments are characterised by professionals as more negative than how they are described by the parents and young adults themselves: anger, frustration, depression, tiredness and anxiety are rated as quite frequent by the professionals, while strength, self control and optimism are not mentioned very frequently (15). Professionals believe that parents trust them at these times, although parents put their trust primarily in themselves and in the couple. In any case, the couple is valued by professionals as a resource at such times. Professionals believe that critical moments impact on the reaction of siblings and, unlike their parents, young adults seem to agree with this view (16).

The impression that professionals have of parents' perceptions of the future is more negative than that expressed by the parents themselves. To a certain extent parents admit to feelings of anxiety and sadness but they also say that their dominant emotion is one of protectiveness. Professionals, on the other hand, see parents as anxious, sad, impotent and uncertain. There is a large convergence of opinions about future resources: all groups believe that the parents will be the prime resource in facing future challenges. While professionals believe that they are perceived as very helpful by parents, parents do not agree with this opinion and claim to rely more on themselves. Young adults put their trust in the family, in professionals and in themselves. They also put more trust in friends than parents and professionals do.

With regard to services, professionals believe parents evaluate these positively in terms of usefulness, quality, efficiency and continuity, although they also believe that parents may feel little involved in the realization of rehabilitation projects for their children. Parents, on the other hand, agree with the perception of usefulness of the services received, but they do not consider them positively in terms of continuity and they do not complain about a lack of involvement. There is convergence concerning the importance of emotional and psychological support. Furthermore, there is convergence on the timing and the modality of the support: both professionals and parents believe it comes too late and often only when requested by parents. All samples consider professionals well trained in the field of pathology, personal and family needs and understanding and communication skills, while the all groups believe there is a need of more training with respect to stress and the prevention of maltreatment.

Regarding society, all the interviewees believe that the state, and more particularly the health authorities, has a responsibility to support families with members with disabilities. Like parents and young adults, professionals, too, believe that the state and politicians diffuse a negative image of disability representing it as a cost and a problem. Regarding the media there are positive and negative experiences (17). The social, educational and health contexts in which the professionals work, on the other hand, are judged as diffusing a positive image, although educational institutions often consider disability a problem. The church is seen as propagating a positive image of disability.

16. As mentioned earlier, it is possible that parents negate the impact of critical moments on the reactions of the siblings as a defence mechanism. They want to believe that the disability of the child does not affect emotional and relational life of other children in the family.

17. Media representation of disability is often based on stereotypes, with disabled characters depicted usually as heroes, or as tragic or sinister figures. When it comes to disabled people the media thus fail to develop characters with holistic, complex personalities capable of interpreting and shaping the own experience of disability. Such one-dimensional depictions of disability lack an understanding of the social and political dimensions of disability, which concern societal obstacles, rather than impairment.



||| Introduction ||| Personal ||| Individual ||| Family |||
Community ||| Society



Guiding principles for professionals

section 4

Introduction

This section lists principles that can guide professionals in successfully designing and delivering services to children with disabilities and their families. Success in this context means contributing effectively to the support of families coping with disability, and thus feeding strength.

The authors are aware that each and every situation encountered by a professional will be unique and determined by many factors. Furthermore there are differences in the role played by professionals and in their level of responsibility with regard to supporting families. The authors therefore refrain from providing *guidelines*, preferring to talk about *principles* that could guide and orient professionals in their professional practice.

The list starts with principles that impact on a personal, attitudinal level, followed by principles that relate to the individual, family, community and society levels.

Personal

- ☞ Many people and families cope successfully with disability. A vision that focuses purely on problems and difficulties could easily overlook potential resources and opportunities and may even result in initiatives that are intrusive in counterproductive ways if the family has already found its own natural balance.
- ☞ Nevertheless there are many families that experience difficulties in coping with disability. Problematic situations are always complex and they need to be analysed as such starting from a consideration of the various factors that have impacted on their genesis. Multi professional teamwork might be necessary in order to discover the relationship between these factors.

Experience based on a non directive help approach suggests that professionals whose approach is perceived as authentic, emphatic, congruent, positive and unconditionally positive with regard to others are likely to have more success in interpersonal relationships than professionals who do not manifest such an attitude (Rogers, 1980). Some people compare supportive relations to dancing as a couple: at moments you feel resistance and harmony and you act accordingly. Others compare it with travelling together. For sure the more families perceive the professional as part of their adventure, the more they will feel strengthened.

- ☞ “You are never too old to learn”, is especially true in this professional field. Developing knowledge, skills and other wider competencies, such as communication skills, leads to better results. Please refer to section 5 for more information.

Individual

- ☞ Services developed for the benefit of the child and based on the needs of the child are preventive in nature.
- ☞ Disability should be seen as a different condition of life, and each individual child should be perceived as a person with resources and the right to develop in their own unique way. Disability is a dynamic condition and support needs therefore to be dynamic and flexible. Needs and perceptions change over time. Intervention should always aim at increasing autonomy, even if this is a slow and long process.
- ☞ There is a subtle but important difference between being an expert in child development and knowing a child well. Parents and professionals should recognise each others expertise.
- ☞ Parental skills are important for every parent and the parents of children with disabilities are not an exception, but their training should receive particular attention.



Family

- ☞ The family should not be left alone but nor should it be overprotected. What counts is that communication channels between parents and professional care providers remain open, immediate and easy to activate.
- ☞ An important consideration in the evaluation of the quality of care is whether it is continuous and unconditional. Appropriate timing is also important. Support should not come too late.
- ☞ There is a direct relationship of dependency between how much support is accepted by parents and their appreciation of support on the one hand and their acceptance of disability on the other.
- ☞ Family expectations are difficult to meet when providing systems are based on asymmetric relationships, where the family asks and the professional has decisive power. Decisions about care should be the outcome of a shared process in which needs are matched with available resources. Information about resources should be accurate, understandable and transparent. If there is no consensus it might be the worth involving other professionals.



☞ Parents and professionals can learn a lot from each other, and needs expressed by families have to be taken seriously. Evaluations of intervention quality should be based on the views of both parents and professionals, and this can serve as a good starting point for further collective decision making. Feeding strength will prove to be difficult if patronising professionals substitute themselves for the family.

☞ Many people experiencing difficulties express themselves negatively. This is a natural reaction and good strategies for helping them will be based on not blaming them for this.

☞ Sometimes parents need to be supported in defining priorities. Professionals can have an important role here. It is important that these priorities are regularly updated.

☞ Interfamily communication is a key issue in feeding strength. Parents might need guidance and training in communicating with their children.

☞ Often siblings are not sufficiently considered in planning support, but they are part of the family and their well-being will contribute to the well-being of the entire nucleus.



Community

☞ The social context and the resources in the community need to be carefully evaluated and empowered where possible.

☞ Parents should be encouraged to share their experiences of coping with a child with disabilities: they can learn from each other and are strengthened when they recognise that their feelings are shared by others.

Society

☞ Prevention is not an optional activity or an out of place concept when it comes to supporting families. It is an approach that pre-empt others that aim to remedy or “repair” potentially stressful situations.

☞ Societies express themselves through the different services which are created to cater for the needs of children and families. It is important that professionals see themselves as “part of an answer” and not as “the answer”. This means that professionals should not to work alone but as part of a network with others, and that they should keep themselves informed about what resources are available. In this way they know where to get the most appropriate resources for specific needs. This might involve inter area collaboration between health, social and educational services, even on a local level..



Continuing professional development

section 5

Introduction

This section aims to raise awareness of how important it is that professionals in the field of family and child care continue to develop their competencies. Doing so will undoubtedly help them to improve the quality of the services they provide.

Continuing professional development (CPD) plays a fundamental role where professional intervention aiming at the empowerment of people and situations is concerned. It consists of reflective activity designed to improve an individual's attributes, knowledge, understanding and skills. It supports individual needs and improves professional practice (1).

*The education and training policies of EU Member States, in general terms, increasingly reflect a concern with **lifelong learning** and interpret it in a broad context that covers all types of learning, in all types of places, with all types of instruments and all types of pedagogical approaches. A lot of professional development takes place through formal education. But learning can also take place in an informal environment or while working with colleagues.*

*The aim of learning is to acquire **knowledge, skills and wider personal and professional competence**. These three elements are strictly related. Knowledge is basically factual and refers to what a person knows. Skills refer to what a person is able to do in a given situation. Other personal and professional competencies include autonomy and responsibility, communication, social and learning competence.*

Learning outcomes should ideally match what learners need to know, or do, with their new competencies. Learning should not only impact on the development of knowledge and skills, but also on personal and/or professional competencies.

1. Definition of CPD by the Training and development Agency for Schools in the UK
http://www.tda.gov.uk/teachers/continuingprofessionaldevelopment/cpd_guidance/what_is_cpd.aspx

A target for CPD

Professionals do not all have the same training needs. Factors that impact on training needs include: prior learning, work experience and professional role. Generally speaking a family with a child with disabilities will meet professionals from different areas of intervention:

- Health services (doctors, medical specialists, nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, etc.)
- Social services (such as social assistants, home care assistance, personal assistants, etc.)
- Educational services (such as teachers, special education teachers, educators, sport instructors, etc.)
- Other services (such as judges and lawyers, administrative staff belonging to public or private organisations, etc.)



Support for families with children with disabilities is organised differently in the various EU member states. Often there are even differences between regions within the same country. It is therefore difficult to identify a cross-European target audience for training in this field, based on educational, professional, disciplinary or sectorial background.

The authors therefore suggest that training needs should be defined according to the **role and responsibilities that professionals have in the process of effectively supporting families and the children**. In accordance with this approach, the following targets for training can be identified:

Professionals who provide practical support and care to families

These professionals typically work on a daily or almost daily basis with a limited number of families and in well defined contexts (normally homes). Their roles and responsibilities are confined to providing care, cleaning, simple nursery tasks, housekeeping, accompanying, etc. Their point of reference in the family are the parents or one of the parents with whom they plan their intervention. They typically work under supervision of a community care team manager to whom they report activities, results, problems.

Professionals who provide educational and rehabilitation services

These professionals typically work on a daily or almost daily basis with a limited number of children and families and in different contexts (homes, schools, day care centres, leisure centres). Their roles and responsibilities are well defined although their intervention is continually monitored and adjusted by themselves and by others. These activities typically concern specific medical support, rehabilitation and educational tasks, such as play activities, speech and language therapy, remedial teaching, sport instruction, etc. Their points of reference in the family are the children and the parents with whom they discuss their intervention. They typically work under the supervision of a team manager to whom they report and with whom they discuss activities, results, problems and observations and plan follow up intervention.

Professionals who manage support services

These professionals will typically work in an administrative office from where they analyse specific requests for services and interventions. They do not work on a daily basis with children or families (no direct intervention) although occasionally they might receive them or meet them in their daily environment to discuss situations, problems and possible solutions. They will typically have the decision making power to provide, manage (change) or interrupt support and care within certain administrative and budgetary limits. Typically they make decisions on the basis of accurate observations and data collection involving the members of the team providing care. Families will tend to consider them “responsible” for the quantity and quality of care.

Professionals who design services and move resources

These professionals will typically work in the departments of statutory bodies from where they analyse the generic need for services and interventions and implement policies by managing existing and new resources. They do not work on a daily basis with children or families but will meet team leaders and occasionally operators to discuss the improvement of services or the development of new ones. They will typically have a role in designing services although the final decision concerning their implementation will be taken at a higher (political) level.



Issues for learning

CPD should aim at reaching learning outcomes in the distinct areas that constitute competency: knowledge, skills, wider professional competencies.



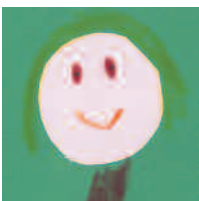
What follows is an overview of issues that could be addressed in training professionals.

Knowledge

- Explicative models and theory of maltreatment
- Protective and risk factors
- Indicators of maltreatment
- Models of family focussed intervention
- Models of relationships in “care-situations”
- Models of child development
- Types of disabilities and the impact on the child development
- Resources that might provide support
- Relevant legislation

Skills

- Ability to initiate and manage positive relationships with various members of the family
- Ability to work in a (multidisciplinary) team
- Ability to prioritise interventions
- Ability to identify and deal with negative emotions and defensive strategies
- Ability to identify competencies and potentialities of the child and to enhance these
- Ability to assess situations from different points of view
- Multifactor analysis in assessing situations



Wider professional competencies

- Good communication skills
- Good reporting skills
- Objectivity in assessing situations
- Recognition of their own limits in intervention
- Capacity to learn and learn from client
- Self evaluation

After having identified the target audience and its training needs, trainers or training providers could use the list to identify appropriate content issues to address in a learning programme. The same list could be used as a tool for the assessment of training needs, either by the learners, or by the organisations providing training.

Strategies aiming at prevention will typically be based on an interdisciplinary analysis of a determined context. In other words, good decisions in developing prevention policies will be based on a multidisciplinary analysis of the situation. For example, elements from psychology, sociology, pedagogy and public administration will all impact on any decision making regarding prevention measures. It is therefore recommended that learning programmes include issues from different disciplines.





Conclusions

The maltreatment of children with disabilities in the domestic environment is a global concern. Preventive action has to put the family, consisting of the person with a disability and his parents and siblings at the centre. In order to be effective, preventive action needs to take into account the complexity of the family nucleus, in terms of how its members interact and how they interact with others outside the nucleus (relatives, friends, community members) and the evolving needs of the family. In

consequence, formal care systems supporting families have to be multi-disciplinary in their approach and should have a primary role in the development of preventive actions. Good understanding and collaboration between families and professionals is a key factor for success in developing safe and protective environments where all family members can feel happy and fully develop their potentials. Professionals should continue to develop their competencies in this field.



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Easy-to-Read Summary

This publication is about the prevention of maltreatment of children with disabilities. It makes clear that if a family of a child with disabilities is supported well, life can be a great and safe adventure for all the members of that family. This thought is expressed in this logo and many European organisations agree.



A definition

Child maltreatment = harm caused to a child by a parent, carer, or any other person responsible for the child's safety.

The problem

Children with disabilities are at a bigger risk of some form of maltreatment than children without disabilities. The authors wanted to understand why this is and what can be done to protect children with disabilities.

Many forms of maltreatment are well known. Others are:

Unequal treatment and discrimination

Lack of the right to express ideas, opinions and desires

Lack of privacy

Lack of opportunities and the chance to have relationships

Possible solutions

To protect people with disabilities we need to:

Empower individuals.

Support families.

Make the community aware of this problem.

It is important that the families where these children live are made stronger, so that all members can do well.

It is important that families and professional carers respect and understand each other and work well together.

Opinions

We have also looked at how people with disabilities, their families, and professional carers see themselves and their situation. We have compared opinions, needs and expectations of these different groups in order to find explanations for possible problems in the understanding between them.

Young adults with disabilities:

- are positive about their lives, their relationships, their families and their future; think that disability limits their opportunities;
- think that the school years and adolescence were the most difficult periods in their family history;
- do not see professionals as very helpful to the family.

Families (parents):

- consider the communication of the diagnosis of disability a difficult moment;
- need detailed information, emotional and psychological support, and information about what to expect in the future;
- see themselves as good carers;
- are not very satisfied with the services they receive;
- think that the state and the health authorities should be more supportive.

Professionals:

- have a more negative view on the outcomes of disability than the young adults themselves;
- believe young adults are not very satisfied with the quality of their lives;
- consider young adults with disabilities very sociable but also lonely;
- believe that parents often do not see the abilities of their children;
- believe disability makes relations between parents more difficult, although many parents do not agree.

Training

Professionals working with people with disabilities should be well trained and continue to develop their skills.

Not all professionals have the same training needs. Previous learning, work experience and professional roles influence the training needs.

The authors believe that training needs depend on the role and responsibilities that professionals have in supporting families and children.

Feedback

Dear reader,

It would be very much appreciated if you could copy this page, write your comments and suggestions and return it to: AIAS Bologna onlus, Via Ferrara 32, 40139 Bologna, Italy or to Fax: + 39 051 466105. Alternatively you could send it to any of the partners responsible for this booklet (for their addresses, see page 2). Thanks in advance.

The authors

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