Roadmap for the Prevention

of Maltreatment of Persons with
Intellectual and/or Multiple Disabilities

Evaluation and Diagnosis

TITLE: Roadmap for the Prevention of Maltreatment of Persons with Intellectual and/or Multiple Disabilities

PROJECT COORDINATOR: Federação Nacional de Cooperativas de Solidariedade Social (FENACERCI – Portuguese National Federation of Social Solidarity Cooperatives)

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SUMMARY

This roadmap for the prevention of maltreatment of persons with intellectual and/or multiple disabilities is a tool for organisations working with the disabled.
Its aim is to identify, record and flag situations of maltreatment and set out a protocol for the prevention of and action against neglect, abuse, maltreatment and discrimination.
The concept of maltreatment is based on the Ecological Systems Theory.
The instrument used for evaluation and diagnosis focuses on three dimensions: the risk to disabled persons and their families, protection of disabled persons and their families and crime. Each qualitative dimension includes indicators that have been assessed by a multidisciplinary team. The result of the evaluation shows the degree of risk or protection for each dimension: none, low, moderate or high. Any crime must be reported to the authorities immediately.
Risk assessment serves as a basis for drafting an individual intervention plan aimed at preventing risk factors and fostering protection.
The roadmap recommends setting up committees for the protection of adults with disabilities and including concrete measures against maltreatment in the *2011-2013 National Disability Strategy*.

I. INTRODUCTION

This roadmap contains guidelines for organisations and their professionals working in the rehabilitation of people with disabilities, when it comes to the prevention of maltreatment of persons with intellectual and/or multiple disabilities.

The structure and initial format of this tool are based on two transnational research and development projects funded by the DAPHNE Programme: "Childhood, Disability & Violence"[1], "Making Life a Safe Adventure[2]" and on the needs identified by FENACERCI and the Portuguese working group with regard to the difficulties experienced by organisations and professionals in assessing, diagnosing, preventing and dealing with the maltreatment of persons with intellectual and/or multiple disabilities.

The Roadmap for the Prevention of Maltreatment of Persons with Intellectual and/or multiple Disabilities is the fruit of the scientific knowledge acquired and empirical work conducted, by FENACERCI on the issue of maltreatment. It constitutes a very useful instrument in that it is extremely important to adopt specific procedures for the prevention of maltreatment.

FENACERCI, with the support of Instituto Nacional para a Reabilitação, I.P. (Portuguese Rehabilitation Institute), has created an assessment and diagnosis tool to identify, record and flag maltreatment and set out a protocol for prevention of and action against neglect, abuse, maltreatment and discrimination in families or by the significant others of people with disabilities.

Since this roadmap was intended to reflect the needs of organisations working with persons with intellectual and/or multiple disabilities and their families, a multidisciplinary team was set up to work on drafting it. It received contributions from FENACERCI member organisations with vast knowledge in the area of maltreatment such as CERCICA and CERCIOEIRAS, from experts with publications and research in the area of maltreatment and disability, from academic sources such as the Faculdade de Motricidade Humana (University) and from specialists working in the field, such as those from Instituto de Medicina Legal (the Institute of Forensic Medicine) and Social Security Sevices.

The birth of this project revolved around creating a pioneering tool at Portuguese and European level in the areas of intellectual and/or multiple disabilities and maltreatment; raising the awareness of organisations and their professionals of the need to prevent maltreatment of persons with intellectual and/or multiple disabilities; minimising the phenomenon and strengthening the partnership between caregiving organisations, people with disabilities, their families and the community. It is also designed to use research and development to promote fundamental rights and guarantee equal opportunities for people with disabilities.

In view of all the above, as promoter of this roadmap and with the support of the *Subprograma Incluir Mais 2010* of Instituto Nacional para a Reabilitação (financial programme by Portuguese Rehabilitation Institute), FENACERCI recognises the advantages of concerted work and awareness of the issue and has developed a strategy for raising awareness of and combating domestic violence and the victimisation of people with disabilities. Thus, FENACERCI believes that this is a document that must remain constantly updated, with the support of the all suggestions for improvement from the organizations and professionals who adopt the document, committing themselves to provide such instrument updated on their *site*.

[1]The transnational partnership consisted of the following organisations: FENACERCI, Aias Bologna Onlus, Disability Now and Disminuidos Físicos de Aragón.
[2]The transnational partnership consisted of the following organisations: FENACERCI, Aias Bologna Onlus, Disability Now, Evpit and Sustento.

II. TAKING ACTION

Taking Action: Preventing Maltreatment of Persons with Intellectual and/or Multiple Disabilities

As an assessment and diagnosis tool, this roadmap proposes some guidelines to help each organisation draft a protocol for prevention and action in situations of neglect, abuse, maltreatment and discrimination by a disabled person's family or significant others. When doing so, each organisation must follow its own procedures based on the legal tools at their disposal for the maltreatment of persons with intellectual and/or multiple disabilities.

In view of the empirical and scientific work done by FENACERCI in this field, it is important to highlight the needs of rehabilitation professionals in their daily work when it comes to specific procedures for preventing maltreatment of the disabled. The vast majority of organisations have no formal mechanisms for preventing maltreatment though they do follow guidelines from their supervisory bodies[3]. In short, organisations have two types of needs. On the one hand, there is no comprehensive information or training in procedures for dealing with maltreatment within the family or at caregiving organisations and, on the other, there are no more technical instruments for assessing and diagnosing maltreatment situations.

Everyone is responsible for taking action in situations of maltreatment, including individuals, organisations, public bodies and social cooperatives that work with persons with intellectual and/or multiple disabilities to enforce the *Law on the Protection of Children and Young People at Risk* (Articles 5, 6 and 7 of Law 147/99 of 1 September), the *Criminal Code* (Article 152A — Maltreatment and violation of safety rules) and the *Convention on the Rights of Persons with Disabilities* (*in attachments*).

The *Convention on the Rights of Persons with Disabilities*[4] is a legal instrument promoting equal opportunities, better quality of life for people with disabilities and their participation as members of society and preventing obstacles, deprivations and violation of their rights all over the world. It focuses on extremely important areas in the recognition and promotion of the rights of the disabled, especially:

- Equality and non-discrimination;
- Accessibility;
- The right to life;
- Equal recognition before the law;
- Access to justice;
- Personal freedom and safety;
- Free circulation and nationality;
- The right to live independently and be included in the community;
- Personal mobility;
- Freedom of expression, opinion and access to information;
- Respect for privacy;
- Respect for the home and family;
- Education;
- Health;
- Work and employment;
- Participation in public, political and cultural life, recreation, leisure and sports.

More specifically, Article 16, Freedom from exploitation, violence and abuse, and Article 17, Protecting the integrity of the person, deal with violence and maltreatment.

Following Portugal's ratification of the Convention on the Rights of Persons with Disabilities and its Optional Protocol and the Council of Europe Disability Action Plan 2006-2015[5], Member States are urged to meet the needs of people with disabilities.

[3] Ministry of Labour and Social Solidarity (Social Security Institute, committees for the protection of children and young people) and Ministry of Health (Health Department).
[4] Adopted in New York on 30 March 2007, approved by Parliamentary Resolution 56/2009 of 30 June and ratified by Presidential Decree 71/2009 of 30 July.
[5] Approved at the Second European Conference of Ministers.

One of the results of this was the P*ortuguese Disability Strategy*[6] (2011-2013), which sprang from the *Action Plan for the Integration of Persons with Disabilities*[7] (2006-2009) and sets out a series of multi-annual plans for the promotion of rights and the guarantee of a dignified life for people with disabilities. It is aimed at proactive participation in the pursuit of these goals on the part of government bodies and civil society, with five strategic fields of activity:

- Disability and multiple discrimination;
- Justice and rights;
- Independence and quality of life;
- Accessibility and design for all;
- Administrative modernisation and information systems.

People with disabilities are considered to be at risk if their care-givers (family and organisations) endanger their safety, health, training, education or development or if this danger is the result of actions or omissions by the person in question or third parties, without them doing anything to change the situation. Intervention in a risk situation takes place at secondary (a committee for the protection of children and young people[8]) and tertiary level (court[9]). It is important to remove the people in question from the risk situation and to minimise it in order to create the right conditions for their proper development.

Knowledge and recognition of the rights of people with disabilities is a factor in their protection and the prevention of neglect, abuse and maltreatment. Monitoring of risk situations must be based on knowledge of what is happening to the disabled person in the family and community and it is necessary to identify and associate positive and negative influences and draft a personal intervention plan to protect the person's rights.

2.1. Risk and Protection Factors

Intervention in a case of potential maltreatment should be aimed at eliminating the risk factors and fostering protection factors. In other words, primary prevention strategies and integrated measures should be introduced at central and local level (social security and education and health services), with a view to action to deal with social, educational, cultural, economic and family conditions that jeopardise the rights of people with disabilities.

There is no direct correlation between disability and maltreatment. The risk factors for persons with intellectual and/or multiple disabilities are the same as those for people without disabilities. However, people with disabilities have difficulty guaranteeing their full, effective participation in society on an equal footing, which in itself makes them more vulnerable and can increase risk factors and trigger maltreatment.

There are specific forms of violence that directly affect persons with intellectual and/or multiple disabilities and arise from social and cultural convictions standing in the way of equal opportunities, such as their right to self-determination and power of decision.

Persons with intellectual and/or multiple disabilities are at an obvious disadvantage in relation to other types of disability as a direct result of their actual disability. An example of this is the inaccurate image that people with disabilities have of themselves and their status, rights and duties. In most cases, ideas such as getting married, having children and finding a job are perceived in a very particular way. Equally important is their perception of friendship, which is much the same, as everyone is a friend provided that they know them in their everyday lives. This makes them more vulnerable in certain situations and increases the chances of abuse.

Indeed, the difficulties that often exist in terms of communication and the possible (co) existence of self-harm may hinder the identification of abuse or maltreatment that they may be suffering. It is therefore extremely important not only for people with disabilities but also for the rest of the population to spot changes in behaviour, such as resistance to hygiene, diaper changing and physical contact, avoidance of persons of a particular gender or a specific person, deterioration in acquired skills or inappropriate sexual behaviour for their age.

In most cases, people with disabilities show exaggerated obedience to adults, difficulties in relating with others, aggressive behaviour and a great desire to please. On the other hand, they need permanent basic care when it comes to food, clothing, hygiene and safety, which are provided by their families or caregiving organisations and may constitute moments of stress increasing the risk of maltreatment.

Cases of maltreatment are failure to respect the rights of people with disabilities in terms of safety, hygiene, health, training, education and development.

Furthermore, among persons with intellectual and/or multiple disabilities, some of the indicators are also symptoms of certain conditions or disabilities, such as behavioural disorders, hyperactivity and attention deficit, which make it harder to detect possible maltreatment. In the event of injuries, wounds or other physical signs, it is necessary to be sure whether they alone constitute evidence of maltreatment. However, they may be signs of maltreatment when there are also other factors.

The following concepts must be borne in mind for an understanding of maltreatment of persons with intellectual and/or multiple disabilities:

- Maltreatment: is each and every situation that fails to respect all the rights of persons with intellectual and/or multiple disabilities, "*jeopardising their physical, emotional and social integrity and clearly and decisively affecting their entire development process*" (Reis, 2009: 59).

- Discrimination on the basis of disability: is "*any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation*", pursuant to Article 2 of the United Nations *Convention on the Rights of Persons with Disabilities*.

- Risk factors: are any influences that increase the likelihood of the occurrence or continuation of maltreatment. They consist of physical, psychological and social variables that foster changes in the setting in which they occur which prevent the proper development and socialisation of persons with intellectual and/or multiple disabilities.

- Protection factors: are any influences that reduce the likelihood of the occurrence or continuation of maltreatment. They consist of physical, psychological and social variables that favour individual and social development and can moderate risk factors and control or prevent their impact.

An understanding of the social phenomenon maltreatment should be based on the **Ecological Theory**.

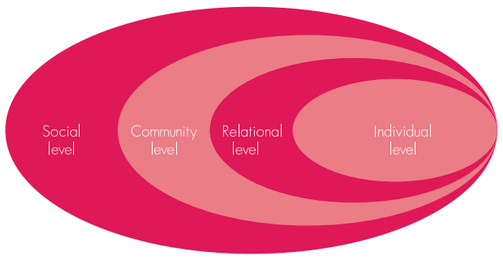


Figure 1 — Inspired by Urie Brofenbrenner Ecological Theory.

According to this approach, risk and protection factors are not static and interact dynamically with each other. They may trigger or inhibit potential maltreatment at four levels:

- Social level: It is essential to analyse social representations on the role of persons with intellectual and/or multiple disabilities in the family and society and the social framework and cultural values of the community in which they live.

[6] "Estratégia Nacional para a Deficiência" (ENDEF), Council of Ministers Resolution 97/2010 of 14 December.
[7] "Plano de Acção para a Integração das Pessoas com Deficiências ou Incapacidade" (PAIPDI).
[8] The forwarding to the Commission for the Protection of Children and Youth should be done if the person in question is a minor. If she/he is of legal age, the situation must be denounced to the police, to be routed to the competent court. Except, when the disabled person is subjected to provision measures of disability (Article 139 of the Civil Code).
[9] The court is only a tertiary entity in the case of people under the age of 18.

■ Community level: It is important to take stock of available community resources for people with disabilities and their families and facilitate access to them.

■ Relational level: Persons with intellectual and/or multiple disabilities are vulnerable members of the family and it is therefore necessary to analyse the family setting and dynamics and relations between its members. Experiences in these contexts may constitute sources of tension that foster possible maltreatment. The following situations represent risk factors:

- Insecure bonding, communication problems and/or deficient exercise of responsibilities;
- Particularly vulnerable elements: dependency, social exclusion, job insecurity, different dependencies and chronic disease, among others;
- Insufficient social, economic and psychological support;
- Structural and dysfunctional weaknesses in the family or work dynamic: unstable relationships, domestic violence and crises such as death, separation or divorce;
- Different forms of violence (domestic violence or bullying, for example).

■ Individual level: There are some aspects associated with each person with intellectual and/or multiple disabilities that may raise the risks. Some examples are particular vulnerabilities with regard to the satisfaction of their needs, personality and temperament traits that come into conflict with their carers (family and organisations).

An increase in protection factors fosters a disabled person's ability to overcome difficult situations. It is therefore important to provide care in line with the needs inherent in their stage of development.

2.2. Types of Maltreatment

Although there are many concepts for the classification of maltreatment associated with the different possible clinical forms, the phenomenon can be divided into different types, such as: neglect, physical, psychological or sexual abuse, munchausen by proxy syndrome, exploitation of labour, mendication and corruption. Let us examine each type in more detail:

■ Neglect: is the inability to satisfy the physical, organic, psychological, affective, social and cultural needs of persons with intellectual and/or multiple disabilities. As a rule, this type of maltreatment is ongoing and may manifest itself actively, i.e. when there is an intention to cause harm, or passively, when it is the result of ignorance, lack of understanding or inability on the part of carers (family and organisations).

Nonetheless, it is crucial to take account of the setting in which the evidence is observed, as the signs may not be a direct result of a shortcoming in the relationship between carers and the person with a disability. They may be caused by a precarious family, social and/or economic situation in which he or she lives.

Neglect is hard to diagnose and may take a number of forms: intrauterine, physical, emotional, school, mendication and abandonment (Reis, 2009: 81).

■ Physical abuse: consists of any intentional, non-accidental isolated or repeated action on the part of parents, caregivers or others with responsibility for persons with intellectual and/or multiple disabilities in order to cause physical harm (hurt, injure or destroy).

■ Psychological abuse: is the inability to provide persons with intellectual and/or multiple disabilities with the environment of tranquillity and emotional and affective wellbeing that is essential for their balanced growth, development and behaviour. This type of maltreatment includes different situations: absence or precariousness of appropriate care, inappropriate or even aggressive verbal interactions, inadequate socialisation, affective rejection, abandonment and even permanent contempt. This type of maltreatment causes "*greater difficulties in defining and diagnosing it and is the hardest to detect as it leaves no physical marks (...), though the scars are deep and dark in spite of not being visible*" (Reis, 2009: 72).

■ Sexual abuse: is based on a relationship of power or authority and entails acts aimed at the abuser's sexual satisfaction, in which people with disabilities are unable to understand that they are victims. If they do understand what is happening, they are not able to name the sexual abuse or are not capable of giving their free, informed consent. "*Sexual abuse includes a range of activities, such as indecent exposure, photography, pornographic films, contact with sexual organs, actual sexual intercourse and abnormal sexual acts*" (Reis, 2009: 75).

In these circumstances, persons with intellectual and/or multiple disabilities may mistake the relationship of power or authority for a "normal" expression of affection or they may be pressured to keep it a secret by the abuser, who is usually a person they trust involved in their everyday lives. The implicit social taboo (shame or fear) makes it difficult for them to ask for help.

■ Munchausen by proxy syndrome: is when a caregiver asserts that the person with intellectual and/or multiple disabilities has exhibited signs and symptoms in order to convince a clinical team that s/he is ill. It results in frequent hospitalisation, exhaustive diagnostic tests and invasive procedures. It is a rare form of maltreatment that poses severe diagnostic difficulties to health professionals. Some manifestation of this syndrome are, for example, giving a drug or medication to produce symptoms, adding blood or bacterial contaminants to urine samples, half-suffocating the person repeatedly and then taking him or her to hospital complaining of apnoea attacks.

The main indicators of this type of maltreatment are repeated hospitalisation and medical tests with no precise results, persistent symptoms that are hard to explain and disappear when the disabled person is away from the family or caregivers.

■ Exploitation of labour: is the use of disabled people's work to obtain economic benefits, where they are obliged to perform domestic or other tasks that exceed their limits ought to be done by adults, family members or caregivers and clearly interfere with their health, education and protection.

■ Mendicity: consists of regularly or sporadically using a person with intellectual and/or multiple disabilities to beg or when she/he begs of his or her own free will. An indicator of this form of maltreatment is if the disabled person, alone or with other people, begs or offers the use of his or her image (e.g. a photograph) to third parties for monetary benefit.

Mendicity is an act of neglect, as it may take several forms, such as physical, psycho-affective and educative or entail temporary or permanent abandonment. Abandonment is closely associated with mendicity because, for example, people with disabilities who beg in the streets are mainly victims of temporary abandonment, insufficient nutrition and a lack of medical supervision, hygiene or sleep and are left to beg alone.

■ Corruption: is conduct on the part of adults, family members or caregivers who are close to or have power over persons with intellectual and/or multiple disabilities that fosters anti-social or deviant behaviour, particularly in the areas of aggression, theft, sexuality and drug use and dealing. Examples of indicators of corruption are encouragement to steal and assault, creating drug dependency and use of the person to traffic in drugs.

III. GENERAL GUIDELINES

General Guidelines

During an assessment of maltreatment of a person with intellectual and/or multiple disabilities, a number of risk and protection factors must be taken into consideration so that the practitioners involved can evaluate the degree of risk and protection to which the person is subject in his or her family setting, peer group, residential or caregiving organisation and in the community as a whole.

Some guidelines have therefore been drawn up to help the practitioners and teams using this tool, so that they can implement a programme for the prevention and control of neglect, abuse, maltreatment or discrimination against persons with intellectual and/or multiple disabilities.

This assessment and diagnostic tool contains 15 dimensions. The dimensions subdivided into specific indicators are intended to reflect the ecological systems approach and consider individuals and their relationships in constant interaction. The tool covers the different risk and protection factors involved in possible cases of maltreatment. The first 13 dimensions are designed to characterise the individual situation, the family and social involvement of the person with intellectual and/or multiple disabilities. The last two are designed to help flag and describe possible maltreatment more specifically (physical and sexual abuse). The tool can be systematised as follows:

Individual level	**Risk dimensions** Biological and Developmental Affective, Emotional and Behavioural Health
	Protection dimension Disabled person
Family level	**Risk dimensions** Safety Nutrition Hygiene and Personal Care Family Characteristics 1 Family Characteristics 2 Financial and Housing Situation
	Protection dimension Family
Social level	**Risk dimensions** Social involvement Education
Crime	Physical abuse Sexual abuse

Figure 2 — Dimensions for assessing risk and protection factors inspired by the Ecological Theory and specific characterisation of maltreatment.

3.1. Instructions

Each dimension comprises an evaluation scale for the degree of risk and protection of the person with intellectual and/or multiple disabilities. Each indicator is ranked according to one of these scales.

EVALUATION SCALE	
0	Never / None
1	Once / Very rarely
3	Sometimes / Frequently
5	Often / Ongoing situation
X	Unknown/ Insufficient information
Z	Not applicable

EVALUATION SCALE	
0	Not present
5	Present
X	Unknown/ Insufficient information
Z	Not applicable

The totals obtained from each dimension are then added up and the final scale consulted. It has four degrees of risk or protection: none, low, moderate and high. The total and the degree of risk or protection are entered on the final chart, which shows the diagnosis of possible maltreatment.

There is a field for Remarks in each assessment dimension for teams to insert any additional relevant information.

3.2. Success factors in the assessment and diagnosis process

The success of this diagnosis and reflection depends on the following aspects:

■ Scope of application

- This is a tool for use in risk situations and when there are signs of maltreatment of a person with intellectual and/or multiple disabilities. Its scope of application is wide-ranging however and it extends to all people with disabilities. Any use of the term disabled "person or people with disabilities" in this documents refers to children, young people and adults. The same applies to the term "care-givers", where the approach must be made at two levels: family/significant others and service organizations.

■ Multidisciplinary team

- Each organisation wishing to use this tool should appoint a person to take charge of the process and set up a personalised, carefully selected team for the assessment and diagnosis of each case. The team members should represent the organisation's different functions and be working directly with the disabled, such as monitors, direct action assistants, psychologists, social workers, psychiatrists, psychomotricity specialists and therapists. The person in charge must belong to all the teams to ensure uniformity and each team must include a professional with specific competences in the field of violence and maltreatment.
- When flagging and monitoring risk and protection indicators, the multidisciplinary team needs to consider not only the person's behavioural characteristics, which are often associated with the specificities of his or her condition, but also take account of known family characteristics. For example:

1) A disabled person may smell bad because she/he has hormonal imbalances caused by daily medication.
2) Disabled people with serious joint limitations may be unable to wash their whole body every day.
3) People with autism and behaviour typical of the condition may not want to wear clothes appropriate to their age or the temperature.
4) A team assessing a structured family that is in monetary difficulties due to a problem of unemployment or who have low incomes, must inquire whether it is a situation of poverty or a case of neglect.

III.
GENERAL GUIDELINES

■ Training and awareness in organisations

- It is important for organisations to provide special training in the field of maltreatment to their team members. Discussing and reflecting on the concepts and limits of maltreatment of people with disabilities is a way for multidisciplinary teams to provide training and raise awareness of situations and prevent them in family and institutional settings. Furthermore, the use of the roadmap requires teams to employ a common language and be able to analyse cases. The complexity of the assessment of these situations requires in-depth discussion based on appropriate theoretical training.

■ Planning

- Before filling out the form, the multidisciplinary team must have all the facts necessary for completing the assessment and diagnosis of people with disabilities. They must have information on their economic, educational, cultural, social and family context. Additional information must be requested whenever appropriate (e.g. about a child or young person's performance at school, a medical report from the health centre or an opinion from social services). The necessary information must be obtained from bona fide sources, whenever possible using local social networks and an institutional rather than individual approach (e.g. caution should be exercised when asking neighbours for information, if this is considered relevant, as it may be incorrect or biased).
- Assessment and diagnosis should be scheduled in a timely fashion. Teams should assemble in a reserved space, enabling them to talk about all the issues without interruption from third parties, following the ethical and deontological principles that are professionally required.
- To carry out the process of assessment / diagnosis, should be reserved at least one hour of work.

■ Completing the form

- The multidisciplinary team must follow the instructions and answer all the indicators objectively. It is essential for the professionals involved to be aware that the process must be meticulous. No information should be concealed or judgements made as this may place the disabled person at risk.

■ Attitude to assessment

- The results of the assessment must be communicated within the organisation and to the people involved in the process (the disabled person, whenever she/he has the cognitive capacity to understand the situation, the family and professionals). The family's involvement in the assessment and diagnosis is extremely important and should be encouraged whenever possible, as its role as an agent of change is essential. In those cases where the family is suspected to be the perpetrator of abuse, the team / organization must act to preserve the safeguarding of the disabled person and may be counterproductive to inform immediately his family. Therefore, it must get in articulation with the protection services / court.
- Throughout the assessment and diagnosis, the team must be aware that their sphere of action allows them to evaluate the credibility of the facts rather than their veracity.
- The assessment and diagnosis and the personal intervention plan are confidential and protected by the organisation's ethical principles and its practitioners' code of conduct.

■ Personal Intervention Plan

- A personal intervention plan should be drawn up on the basis of the results of the assessment and diagnosis. It must involve all the stakeholders and ensure the integrity and safety of the disabled person. This plan must be **monitored every three months** by the team or a suitable practitioner appointed by it.
- The intervention must take place as soon as possible. The plan must have a specific time frame, which should be as short as possible, **preferably** no more than **one year**, so that the situation does not go on too long or deteriorate and the instrument is not used again for the same diagnosis, which may result in neglect.
- The disabled person's real interests must prevail throughout the assessment and diagnosis and the drafting and implementation of the personal intervention plan.
- After the time limit defined in the plan has ex-

pired, the organisation is no longer able to take action and must refer the situation to a higher level. Examples of competent bodies to be contacted are the **Instituto Nacional para a Reabilitação** (National Rehabilitation Institute)[10], **Social Security Services**, the **Ministry of Internal Administration**[11], **Mediation and Information Services for Persons with Disabilities or Disability** (SINPD)[12]; **Disability Ombudsman´s**; **Associação Portuguesa de Apoio à Vítima** (APAV - Portuguese Victim Support Association)[13], **Comissão Nacional de Protecção das Crianças e Jovens em Risco** (National Committees for the Protection of Children and Young People at Risk)[14], the local **courts**, **law enforcement agencies** (PSP or GNR), the **judiciary police** and the **national emergency number 112**, among others. In this field, **FENACERCI** acts as a mediator in cases of maltreatment reported to it and shares all information with the competent bodies.

Below, we set out a tool based on principles aimed at quality of the services provided to people with disabilities and expressing concerns in the area of neglect, abuse, maltreatment and discrimination. It is designed to offer organisations serving this population "*(...) rules, provisions and organisational dynamics to foster quality of life for clients in a framework of total respect for their rights*" (in Manual de Processos-chave, *Centro de Actividades Ocupacionais*, 2007: 72).

[10] Discrimination due to Disability or Aggravated Health Risk complaint form, available online.
[11] Public Administration complaint portal: https://queixaselectronicas.mai.gov.pt/.
[12] Public Administration complaint portal: http://www.inr.pt/content/1/18/simpd.
[13] National network of Victim Support Offices, in various Portuguese towns.
[14] Contact the local committee for the protection of children and young people.

IV. ASSESSMENT

AND DIAGNOSIS OF NEGLECT, ABUSE AND MALTREATMENT OF PERSONS WITH INTELLECTUAL AND/OR MULTIPLE DISABILITIES

4.1. Information

PERSONAL PARTICULARS					
Name					
Age				Sex	
ID / citizen's card no.				Contact phone number	
Address					
Postcode					
Service used					
CLOSE FAMILY MEMBERS					
Name	Relationship	Age	School attainment	Occupational situation	Marital status
Contact phone number					
Name of legal representative	Relationship	Age	School attainment	Occupational situation	Marital status
Contact phone number					
EXTENDED FAMILY MEMBERS					
Name	Relationship	Age	School attainment	Occupational situation	Marital status
Contact phone number					
BRIEF DESCRIPTION OF FAMILY					
CLINICAL SITUATION					
Type and degree of disability					
Associated conditions					
Medical supervision?	Yes ☐			No ☐	
On medication?	Yes ☐ Indicate medication:			No ☐	
CLIENT'S FUNCTIONAL PROFILE					
REMARKS					

IV.
ASSESSMENT

4.2. Assessing the risk to a disabled person

The assessment and diagnosis begins with an analysis of two individual dimensions designed to evaluate the biological-development and affecti-ve-emotional and behavioural status of the person with intellectual and/or multiple disabilities.

A. BIOLOGICAL AND DEVELOPMENTAL DIMENSION

This dimension covers relevant aspects that are risk factors of a biological and developmental nature. Information is gathered in this dimension to characterise the disabled person's situation and flag features of his or her development that may constitute an added risk or possible triggers of maltreatment.
The idea is to assess the stages of development of persons with intellectual or multiple disabilities in order to identify the most significant moments in their lives and those that may be associated with risk or protection factors that will help understand the situation and draft a personal intervention plan. This dimension is intended to flag developmental factors associated with potential risks of maltreatment rather than actual indicators of maltreatment.
The indicators in this dimension provide a better understanding of health and development issues associated with the disability and make it possible to identify, with the family, difficulties in the person's life path.

RISK DIMENSION A. BIOLOGICAL AND DEVELOPMENTAL		Not present	Present	Unknown / Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	Prenatal factors: chronic disease and/or disability, family history, cytomegalovirus and toxoplasmosis, among others.				
2.	Perinatal factors: <P10 for gestational age, peso < 1,500g, gestation < 32 weeks, Apgar <3 at first month and <7 at second, among others.				
3.	Postnatal factors: infections, acquired hydrocephaly, drug toxicity, damage caused by hospitalisation and administration of drugs, among others.				
4.	Alterations or impairment in psychomotor development				
5.	Disorders in cognitive development				
6.	Height and weight development not age-appropriate				
7.	Visual difficulties or impairment (e.g. blindness, poor sight)				
8.	Hearing difficulties or impairment				
9.	Language disorders				
10.	Motor disability or impairment				
	TOTAL				

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	34	50	
Moderate	18	33	
Low	1	17	
None		0	

REMARKS

B. AFFECTIVE-EMOTIONAL AND BEHAVIOURAL DIMENSION

This dimension includes two aspects: 1) changes in behaviour due to disability (e.g. mental health) and 2) changes in behaviour due to affective and emotional functioning. Behavioural aspects must always be interpreted on the basis of the disability itself, as some of these indicators may be characteristic of the condition and should therefore not be interpreted in the same way. This factor should be considered when completing this part of the form and the classification of behaviour should not be the same in the two situations. A concrete example for interpretation of this dimension is eating disorders, which may be a warning sign for the emotional dimension if there is a change in the person's eating habits or a loss of appetite. However, they are not a warning sign in people with eating difficulties, such as refusing to eat foods of a particular colour or texture, which is characteristic of people with autism.

The flagging of behavioural aspects, especially in an interpretation of emotional and affective functioning, must be regarded particularly from the point of view of changes in behaviour. This requires in-depth knowledge of the disabled person's behaviour towards his or her peers, family members and other caregivers. The indicators listed below must be specified and analysed for each person's individual characteristics, as they may be pointers for maltreatment or specific traits of the disability.

RISK DIMENSION B. AFFECTIVE-EMOTIONAL AND BEHAVIOURAL		Never/ None	Once/ Very rarely	Sometimes/ Frequently	Often / Ongoing situation	Unknown/ Insufficient information	Not applicable
		0	1	3	5	x	z
INDICATORS							
1.	Self-aggression						
2.	Aggression towards others						
3.	Passivity to behaviours requiring a reaction						
4.	Difficulties in relationship with family						
5.	Difficulties in relationship with care-givers						
6.	Difficulties in relationship with peers						
7.	Demonstration of fear of the family						
8.	Demonstration of fear of caregivers						
9.	Difficulty in playing						
10.	Difficulty in performing social and work activities						
11.	Apathy and lack of interest in activities						
12.	Isolation						
13.	Sleep disorders (e.g. night terrors, agitation, drowsiness, insomnia or anamnesis)						
14.	Sphincter control problems (e.g. enuresis, encopresis)						
15.	Eating disorders (e.g. changes in appetite; anorexia; bulimia)						
16.	Concrete or undetermined fears or phobias						
17.	Changes in emotional expression (e.g. uncontrolled crying or laughing)						
18.	Changes in behaviour (e.g. thumb--sucking, baby talk or nervous tics)						
19.	Constant attention seeking (e.g. shouting, hitting or pulling)						
20.	Strange behaviour (e.g. touching waste or eating faeces)						
	TOTAL						

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	68	100	
Moderate	35	67	
Low	1	34	
None		0	

REMARKS

4.3. Assessing the risk in the family

The assessment in this part of the roadmap focuses on the family and an evaluation of the risk and protection factors associated with it. It includes dimensions such as Health, Safety, Nutrition, Hygiene and Personal Care. The characterisation of family behaviour in these dimensions identifies typical patterns of action with the disabled person and assesses his or her autonomy and independence.

The indicators in dimensions C (Health), D (Safety), E (Nutrition) and F (Hygiene and Personal Care) constitute a constellation of signs that should be interpreted as a whole. Not all of them will have the same absolute weight in assessing maltreatment and they should be analysed in the behavioural dimension in light of the disabled person's individual characteristics. Nonetheless, these are very important involvement indicators, as they show the family level and help assess the family members' actions and attitude to the disabled person. Another important aspect to consider in the evaluation of this set of dimensions is the cultural issues, in order to avoid confusing rules and customs with risky situations. In the knowledge that much maltreatment occurs within the close family, these indicators are extremely important in assessing maltreatment. However, they require ethically correct collection methods and a collaborative approach with the family so that they do not feel threatened by the questions.

C. HEALTH DIMENSION

Regarding the health dimension indicators, it is important to acknowledge that some families' compliance with certain aspects (e.g. vaccination plans and keeping doctor's appointments, among others) may need to be monitored, for monetary reasons or ignorance of the need for them. Although the existence of these situations may constitute maltreatment, their assessment must take account of the type of family and its needs. Practitioners must begin immediate monitoring and intervention to minimise the risk.

RISK DIMENSION C. HEALTH		Not present	Present	Unknown / Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	Non-compliance with the national vaccination plan				
2.	Failure to attend routine and specialised doctor's appointments				
3.	Persistent infections				
4.	Repeated hospitalisation				
5.	Absence of necessary care in easily handled situations (e.g. giving an antipyretic or treating a wound)				
6.	Non-compliance with treatment guide (e.g. not giving medication, errors in prescribed treatment, self-medication)				
7.	Failure to seek timely assistance (e.g. going to hospital)				
8.	Lack of preventive health care (e.g. dental checkups, ophthalmology consultations)				
TOTAL					

GRADUATION			
Degree of risk	Minimum	Máximo	Retrieved Degree
High	38	40	
Moderate	15	27	
Low	1	14	
None		0	

REMARKS

D. SAFETY DIMENSION

In the safety dimension, the aim is to identify potential risks associated with parental supervision and safety that become even more significant for persons with intellectual and/or multiple disabilities because they may not have the individual resources for handling certain situations. It is therefore necessary to assess the risks of non-supervision or excessive supervision, which may result in parental neglect, which is more harmful when associated with a disability.

RISK DIMENSION D. SAFETY		Not present	Present	Unknown/ Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	Accidents due to lack of supervision				
2.	Temporary abandonment (e.g. the person is left at home alone for some time)				
3.	Exposure to family violence or conflicts				
TOTAL					

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	11	15	
Moderate	6	10	
Low	1	5	
None		0	

REMARKS

E. NUTRITION DIMENSION

The indicators in the nutrition dimension constitute another area for collecting information on risk factors and are mainly intended to assess family routines regarding appropriate mealtimes. It is also necessary to consider whether any nutrition problems identified fit in with the characteristics of a disorder (such as those found in autism) or whether they go beyond them. It is also necessary to assess whether some aspects of poor eating habits have to do with specific eating disorders (which must also be monitored, but not regarded exclusively as a sign of neglect) or in extreme cases with poverty and serious financial problems.

RISK DIMENSION E. NUTRITION		Not present	Present	Unknown / Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	No regular mealtimes				
2.	Malnutrition, dehydration, food poisoning				
3.	Poor eating habits: recurring irregular, incomplete meals (insufficient or excessive)				
	TOTAL				

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	11	15	
Moderate	6	10	
Low	1	5	
None		0	

REMARKS

F. HYGIENE AND PERSONAL CARE DIMENSION

The hygiene and personal care dimension consists of indicators for assessing the way in which the disabled person is cared for. As mentioned above, hygiene and personal care indicators should therefore be considered on the basis of the nature of the disability in order to distinguish between possible neglect and the subject's own characteristics. Clothing in particular must be related to the characteristics of each disability. Cultural aspects are also important in this dimension so that rules and customs are not mistaken for risk situations. The money factor must also be considered as the cause of some potential risk situations. These aspects are especially relevant to the personal intervention plan.

RISK DIMENSION F. HYGIENE AND PERSONAL CARE		Not present	Present	Unknown / Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	Lack of bodily hygiene (e.g. bathing, dirty hair, dirty or uncut nails)				
2.	Lack of dental hygiene or multiple caries				
3.	Dermatitis				
4.	Genital or anal erythema				
5.	Pediculosis (a skin problem caused by lice)				
6.	Scabies				
7.	Clothing and footwear inappropriate to season or size				
8.	Worn or torn clothing and footwear				
9.	Dirty clothing or footwear				
	TOTAL				

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	31	45	
Moderate	16	30	
Low	1	15	
None		0	

REMARKS

G. EDUCATION DIMENSION

The education dimension refers to parenthood and parental attitudes. It is designed to assess how the parents deal with their child's behaviour and ascertain whether their child-rearing styles and behaviour in certain situations facilitate or hinder the relationship. It also includes more general parental behaviour in caring for the disabled person, in terms of providing appropriate educative situations. The first set of indicators (parents' behaviour) points to how the parents deal with their children in difficult situations (tantrums, attention seeking and more complex behaviour related to their condition, type and degree of disability). As with any child or young person, it is important to assess to what extent parenting styles affect their development. In the case of persons with disabilities, this factor is even more important, as inappropriate parenting styles entail an added risk. Parenting style is known to have considerable influence on the development of certain behaviour in children, and extreme parenting styles (very permissive or strict) are known to be less effective than more democratic ones. The same applies to situations of disability and it is therefore important to ascertain whether a more authoritarian style is related to difficulty in allowing the disabled person some autonomy and independence (overprotection) or whether a more permissive style may be masking disinvestment. Other indicators are signs of possible disinvestment or even neglect (e.g. lack of interest in the disabled person's activity at the organisation). However, they should also be analysed from the point of view of frequent events rather than sporadic occurrences, which may have an explanation. One example of these situations is failure to respect the schedules of the caregiving organisation. This may represent an attitude of neglect and non-investment or may be associated with family organisation problems (overload of one of the members, for example). The latter situation is still important in the overall assessment of the risk of maltreatment, as it weakens the constellation of risk factors and exacerbates the situation. In isolation, it should not be regarded as a risk, however.

IV.
ASSESSMENT

RISK DIMENSION G. EDUCATION		Not present	Present	Unknown / Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	No strategies for dealing with challenging behaviour (e.g. sleep, tantrums and attention seeking)				
2.	Overly strict or permissive attitude				
3.	Non-attendance of meetings requested by monitoring practitioners				
4.	Failure to respect the schedules of the caregiving organisation				
5.	Absence of disabled person from organisation without prior notice or justification				
6.	Lack of interest in the disabled person's activity at the organisation				
7.	Severe, disciplinarian child-rearing practices				
8.	Deliberate, excessive physical restrictions (e.g. food and water; locking the person in a cupboard or small space; tying the person)				
9.	Unrealistic expectations from the disabled person (e.g. education, occupation or work)				
TOTAL					

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	31	45	
Moderate	16	30	
Low	1	15	
None		0	

REMARKS

H. FAMILY CHARACTERISTICS 1 DIMENSION

The next two dimensions constitute the relational dimension (at family level) of the theory used as a basis for this Roadmap. They are extremely important, as the family is everyone's first agent of socialisation and, for persons with disabilities, the family is a source of involvement that is likely to last over time and will sometimes be exclusive and therefore decisive in their development. The indicators in these two dimensions give an overview of the way the family functions in terms of support networks, everyday management (job, time, availability) and each family member's attitudes and beliefs with regard to disabilities. They are also intended to characterise events in the family's life that may constitute risk factors, such as divorce, an unwanted and unplanned pregnancy, separation, mental illness, drug addiction and others. These are two very important dimensions, as these indicators may not only constitute risk or protection factors but may also trigger maltreatment if associated with risk factors in other dimensions. If these indicators arise during the assessment of a young person or adult with a disability, they become factors that really can lead to maltreatment because of the disruption they cause in the family's life. If they occur in early life, they can compromise bonding and interfere with the person's entire affective and emotional development.

IV.
ASSESSMENT

RISK DIMENSION H. FAMILY CHARACTERISTICS 1		Never/ None	Once/ Very rarely	Sometimes/ Frequently	Often/ Ongoing situation	Unknown/ Insufficient information	Not applicable
		0	1	3	5	X	Z
INDICATORS							
1.	Lack of support from the nuclear family						
2.	Lack of support from extended family or neighbours						
3.	Conflctual relationships in the family						
4.	Lack of initiative in problem solving and decision making						
5.	Shortage of time to spend with the disabled person (e.g. for work reasons)						
6.	Manifestations of tiredness or emotional exhaustion in living with the disabled person						
7.	Negative ideas and attitudes to the disabled person (e.g. disparagement and disdain)						
8.	Implausible explanations of certain events by family members						
9.	Parent's inability to provide proper care for the disabled person (e.g. due to physical, mental, emotional or behavioural limitations)						
10.	Munchausen by proxy syndrome						
11.	Use of the disabled person for begging, exploitation of labour or other illegal acts (e.g. theft)						
12.	Commercial use of the disabled person's image						
	TOTAL						

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	41	60	
Moderate	21	40	
Low	1	20	
None		0	

REMARKS

I. FAMILY CHARACTERISTICS 2 DIMENSION

RISK DIMENSION I. FAMILY CHARACTERISTICS 2		Not present	Present	Unknown/ Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	Young or old parents (< 20 or > 40)				
2.	Inhibition of parental responsibilities				
3.	Unwanted pregnancy				
4.	Ethnic minorities with cultural and language barriers				
5.	Parents who were victims of abuse				
6.	Single-parent family				
7.	Large family (with 3 or more children)				
8.	Abuse of licit or illicit substances (e.g. drugs or alcohol)				
9.	Deviant behaviour (e.g. prostitution or delinquency)				
10.	Divorce, separation or death of a significant family member				
11.	History of mental illness				
12.	History of maltreatment (e.g. physical and verbal abuse)				
13.	Rejection of parental role				
	TOTAL				

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	44	65	
Moderate	23	43	
Low	1	22	
None		0	

REMARKS

J. FINANCIAL AND HOUSING SITUATION DIMENSION

Also in the social and economic field, the financial and housing dimension helps to characterise the socioeconomic aspects of the family and disabled person and create links with indicators flagged in other dimensions. We have mentioned that, in certain situations, it is essential to consider socioeconomic issues when assessing a risk indicator and allocate them a degree of frequency or intensity. The information collected in this dimension can be used to moderate other indicators flagged. This dimension is a very important aspect of the whole assessment process, as a precarious financial situation makes life more difficult and is usually associated with other indicators of different types. Precarious financial situations may be at the root of many other risk indicators and lead to changes in practices and attitudes, especially in situations of disability associated with incorrect beliefs and low expectations. A poor financial situation also affects families' everyday lives and often results in crises and an increased likelihood of maltreatment.

Throughout the process, economic factors must be regarded as conducive to risk situations. These aspects are extremely important when drafting a personal intervention plan.

RISK DIMENSION J. FINANCIAL AND HOUSING SITUATION		Not present	Present	Unknown/ Insufficient information	Not applicable
		0	5	X	Z
INDICATORS					
1.	Does not have own home (e.g. lives with family members or third parties)				
2.	Insalubrious housing (e.g. no electricity, water, gas, heating, basic sanitation)				
3.	Home in poor state of repair				
4.	Lack of home hygiene				
5.	Home too small for size of family household				
6.	Insufficient or inappropriate furniture for size of family household				
7.	Unemployment				
8.	*Per capita* income not enough to cover expenses				
9.	Inappropriate money management				
10.	Over-indebtedness				
	TOTAL				

GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	34	50	
Moderate	18	33	
Low	1	17	
None		0	

REMARKS

K. SOCIAL INVOLVEMENT DIMENSION

This dimension completes the assessment circle from a systemic point of view. Assuming that the different levels are dynamically and interactively related, an assessment of this dimension, more distanced from the person, makes it possible to understand the hypothetical phenomenon of maltreatment in different dimensions and look for the reasons behind it. Assessment of social involvement also helps to search for resources for intervention.

RISK DIMENSION K SOCIAL INVOLVEMENT	Not present	Present	Unknown/ Insufficient information	Not applicable
	0	5	X	Z
INDICATORS				
1. Social isolation (e.g. no family network, friends or neighbours)				
2. No economic or social support (e.g. subsidies, food)				
3. Difficulties in accessing community resources (e.g. not available nearby, poor location)				
4. Dependency on services (e.g. home help, social insertion income)				
5. No social support network (e.g. no vacancies in caregiving service organisation)				
TOTAL				

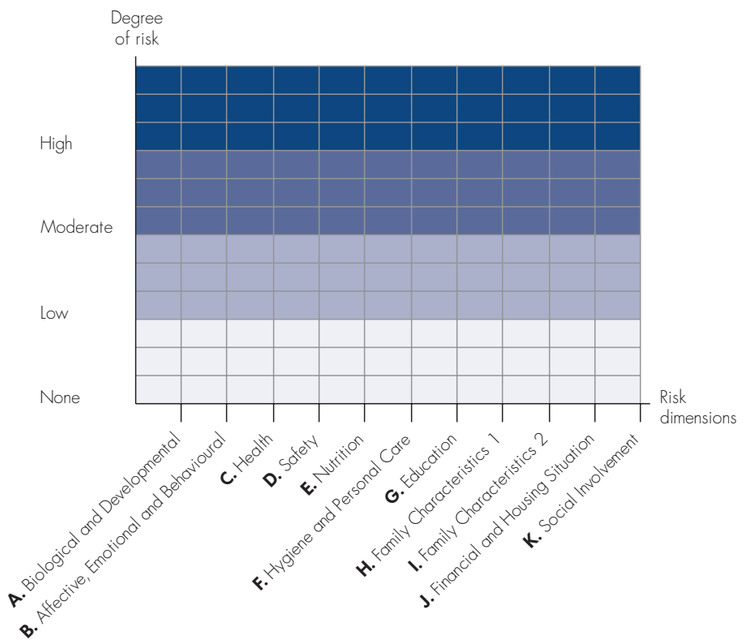
GRADUATION			
Degree of risk	Minimum	Maximum	Retrieved Degree
High	18	25	
Moderate	9	17	
Low	1	8	
None		0	

REMARKS

4.4. Risk dimension grid

4.4.1. RESULTS ANALYSIS

After obtaining the results, it is necessary to read and analyse them. This is how the team conducting an assessment and diagnosis of the risk to persons with intellectual and/or multiple disabilities will ascertain their position in relation to the risk dimensions. The degree of risk detected in each dimension is entered in the squares in a grid like the one below. The results can then be used to interpret the dimensions' positioning on the basis of the degree of risk in each one. Courses of action are suggested for each degree of risk in order to provide guidance and facilitate the teams' work.



When interpreting the results, the teams must bear in mind that although the different dimensions all have equal weightings in the overall risk profile, they are never really the same. Each one's weight will be the direct result of each situation and the general configuration of the disabled person's profile. The overall profile must therefore be interpreted with great care.
Although there may be dimensions with a high risk, the profile must be regarded as a whole and never as a dimension analysed separately (except for criminal acts). In other words, when a dimension has a high degree of risk, the team must fit it into the overall diagnosis in order to ascertain whether they are looking at a high risk situation or whether there are warning indicators arising separately that per se do not constitute maltreatment.

The team must analyse and reflect on each case, as set out in the guidelines throughout the roadmap. It is then responsible for drafting a personal intervention plan and/or reporting the situation to outside institutions.

Degree of Risk	Courses of Action
None	- Non-existence of risk should be regarded as a protection factor. The participative involvement of the partners (organisation, disabled person and family) should continue in order to ensure the person's protection.
Low	- It is necessary to assess the situation and plan intervention strategies with and for the family. - Draft a Personal Intervention Plan.
Moderate	- Promote and ensure the participative involvement of the partners (organisation, disabled person and family) to guarantee the person's total protection. - Draft a Personal Intervention Plan.
High	- Report the situation to the police, child protection authorities, victim support association, courts, among others. The organisation must play a cooperative role and facilitate the entire process.

IV.
ASSESSMENT

4.5. Assessing the degree of protection in disabled person within family

The assessment of protection factors abides by the same model as risk factors. In other words, the analysis of each individual situation must also focus on aspects that can mitigate the risk detected in the previous phase. In this tool, these indicators are specific to the individual and his or her family and social involvement. Protective factors must be assessed on two levels: characterisation of the situation itself, in which these indicators must be regarded as potential strong points in cases analysed and possible promoters of a lower risk, and the drafting of a personal intervention plan, in which the protection factors are decisive to the plan.

Assessment of the degree of protection includes individual aspects of the disabled person's ability to ask for help. This is a highly significant factor, in that persons with intellectual and/or multiple disabilities have serious difficulty in communicating, either because they have no common forms of communication or because they have cognitive difficulties in understanding the situations in which they are involved and of which they are potential victims.

It is essential to assess these aspects in order to understand the entire case so that there is not just a risk perspective. In particular, they are factors contributing to the personal intervention plan.

L. DISABLED PERSON DIMENSION

PROTECTION DIMENSION L. DISABLED PERSON	Never/ None	Once/ Very rarely	Sometimes/ Frequently	Often/ Ongoing situation	Unknown/ Insufficient information	Not applicable
	0	1	3	5	x	z
INDICATORS						
1. The disabled person is able to ask for help if necessary						
2. There are other people who provide the disabled person with safety, protection and wellbeing						
3. The caregivers ensure all the care required for the disabled person's development (e.g. health, hygiene, nutrition, clothing, education and safety)						
TOTAL						

GRADUATION			
Degree of protection	Minimum	Maximum	Retrieved Degree
High	11	15	
Moderate	6	10	
Low	1	5	
None		0	

REMARKS

M. FAMILY DIMENSION

As in the previous dimension, an assessment of the family's protection factors shows the characteristics of it and its members, who may constitute protective or risk factors, as possibly assessed in the previous dimension. The aspects in this dimension go somewhat beyond the family, as they also include social networks in the community. Other indicators show the family's ability to deal with more complex situations that can cause frustration. They also help to assess relationships between the members of the same family in order to find the ones who are strongest in certain situations. As in the previous dimension, this assessment will help to characterise each case appropriately and comprehensively and, in particular, to organise the personal intervention plan in more detail.

PROTECTION DIMENSION M. FAMILY		Never/ None	Once/ Very rarely	Sometimes/ Frequently	Often/ Ongoing situation	Unknown/ Insufficient information	Not applicable
		0	1	3	5	X	Z
INDICATORS							
1.	Support and mutual help between members of the nuclear family						
2.	Support from the extended family						
3.	Network of friends or neighbours						
4.	Cooperation by caregivers with monitoring practitioners						
5.	High self-esteem and tolerance of frustration						
6.	Motivation to begin a process of change and personal growth						
7.	Balance between firmness and flexibility in relation to the disabled person						
8.	Access to community resources (e.g. health, education)						
9.	Job stability						
10.	Home appropriate to household's needs						
11.	Good management of family income						
12.	Demonstration of responsibility in parental tasks						
	TOTAL						

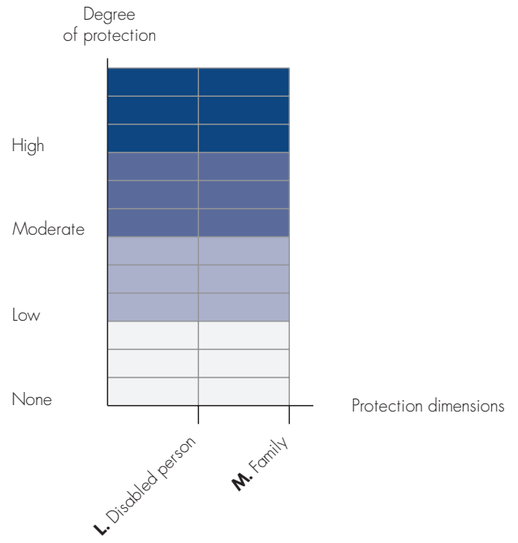
GRADUATION			
Degree of protection	Minimum	Maximum	Retrieved Degree
High	41	60	
Moderate	21	40	
Low	1	20	
None		0	

REMARKS

4.6. Protection dimension grid

4.6.1. RESULTS ANALYSIS

After obtaining the results, it is necessary to interpret and analyse them. This is how the team conducting an assessment and diagnosis of the degree of protection of persons with intellectual and/or multiple disabilities will ascertain their position in relation to the protection indicators. The degree of protection detected in each dimension is entered in the squares in a grid like the one below. The results can then be used to interpret the dimensions' positioning on the basis of the degree of protection in each one. Courses of action are suggested for each degree of protection in order to provide guidance and facilitate the teams' work.



Degree of Protection	Courses of Action
None	- Non-existent protection should be regarded as a risk factor.
Low	- It is necessary to assess the situation and plan intervention strategies with and for the family. - Draft a Personal Intervention Plan.
Moderate	- Urgent concerted, articulated intervention is necessary with the partners, involving the family, peer group and organisation to protect the disabled person. - Draft a Personal Intervention Plan.
High	- The disabled person and his or her family have good protection factors in their diagnosis. - Draft a Personal Intervention Plan for monitoring the situation with a timeline set by the team or close the file.

4.7. Flagging physical and sexual abuse situations

All the dimensions of analysis in this assessment and diagnosis tool contain indicators that may point to a crime, depending on their intensity, regularity and combination. A diagnosis showing a possible situation of physical or sexual abuse means that a crime may have been committed and the teams must report the case immediately to the public prosecutor's office, the police or the Institute of Forensic Medicine.

We now describe signs that may point to possible physical or sexual abuse. The physical signs described should be analysed in conjunction with other symptoms associated with these two types of maltreatment. All the dimensions in this tool must be used to analyse the symptoms, because, as mentioned above, it is not static and its assessment and diagnosis dimensions apply to the whole process.

N. PHYSICAL ABUSE DIMENSION

The following signs and symptoms must be analysed in a case of physical abuse:

RISK DIMENSION N. PHYSICAL ABUSE	
SIGNS	
1.	Unexplained bruises or injuries
2.	Injuries in different locations and different stages of healing
3.	Injuries with a pattern mark (e.g. belt, rope, bite or cigarette burn)
4.	New and old fractures
5.	Injuries in unusual places for accidental trauma (e.g. on the face, around the eyes, ears, mouth and neck or on the genitals and buttocks)
6.	Multiple recent or healed burns (e.g. cigarette burns on the palms, feet or genitals) in which it is easy to identify the object that caused them (e.g. clothes iron)
7.	Traumatic alopecia (partial or total hair loss)
8.	Bone injuries (e.g. long-bone fractures, spiral fractures and stiff or swollen joints)
9.	Concussion
10.	Internal injuries (e.g. intestinal trauma caused by a blow or kick, ruptured blood vessels or cerebral haemorrhage)
REMARKS	

IV.
ASSESSMENT

The most recurrent indicators of this type of maltreatment are inappropriate stories and justifications and refusal to explain the injury on the part of family or caregivers. The existence of contradictory explanations of the same situation from different interlocutors should be taken into account when analysing what the disabled person's family and caregivers have to say. Other relevant factors are delays in seeking medical attention, frequent absences from the organisation while waiting for injuries to heal, a history of old injuries and signs of violence that may not leave visible marks on the person's body (e.g. hitting with a wet towel).

O. SEXUAL ABUSE DIMENSION

The following signs and symptoms should be analysed in a case of sexual abuse:

RISK DIMENSION O. SEXUAL ABUSE	
SIGNS	
1.	Persistent or recurrent vaginal discharge
2.	Tearing of the hymen
3.	Vaginal or anal bleeding
4.	External injuries to the genitalia (e.g. redness, inflammation, fissures, lacerations, oedema, erythema)
5.	Contusions or petechiae in the oral mucosa or laceration of the labial fraenum
6.	Repeated urinary infections
7.	Semen on the disabled person's body or clothes
8.	Blood or unusual substances (lubricants) on the disabled person's body or clothes
9.	Pain in the genital or anal region
10.	Sexually transmitted diseases (e.g. gonorrhoea, syphilis, AIDS, etc.)
11.	Pregnancy
REMARKS	

IV.
ASSESSMENT

For people with intellectual and/or multiple disabilities, the most evident symptoms in a case of sexual abuse are pain in the vaginal or anal region, vulvar itching, constipation, encopresis and enuresis. Their conduct is more sexualised. They have an inappropriate interest in and knowledge of sexual matters and often engage in compulsive masturbation and sometimes sexually specific drawings or games. They may also suffer from functional disorders such as anorexia, bulimia, night terrors and recurrent, unexplained abdominal pain.

In the event of suspected sexual abuse reported by a third party and not the disabled person directly, "*to a health practitioner, social worker, a law enforcement agent or anyone else whose duty it is to handle this type of case, s/he must immediately collect information to ascertain the dimension and consistency of the suspicion. This preliminary approach will enlighten them on the type of abuse, when it occurred (or at least the last time, if repeated), its context (within or outside the family), the alleged abuser and the possibility of destruction of evidence*" (Magalhães, 2010: 139-140).

In the event of suspicion of recent abuse, the teams must follow procedures to preserve any biological trace evidence, which is essential for forensic examination.

PROCEDURES FOR PRESERVING BIOLOGICAL TRACE EVIDENCE [15]
Eat or drink
Wash their hands or brush their teeth
Bathe or wash their genitalia
Change their clothes or, if they have, preserve the clothes worn up to the time of the occurrence (including panty liners, sanitary towels or tampons) if possible dry and in paper bags
Wash their hands or clean or cut their nails
Comb their hair
Urinate or defecate and, if they have to, the product should be preserved in an appropriate receptacle (container for bacteriologicalurine tests, for example)
Touch, clean or tidy the place where the abuse occurred
Empty waste bins or flush the toilet
In the event of suspected sexual abuse, the team must refer victims to a forensic medicine service within 72 hours for a physical examination, collection of biological samples and psychological evaluation of the victim

[15] In Magalhães, 2010: 140.

V. PLAN

Personal Intervention Plan

After a qualitative and quantitative analysis of the risk and protection factors, it is essential to establish a method for intervention, prevention and management of cases of neglect, abuse and maltreatment so that they can be detected as early as possible. These cases should later be assessed, monitored and referred to services with more competencies in the matter, working and cooperating as a network to design a personal intervention plan.

This plan is established by all concerned at four levels: the disabled person, family members, caregiving organisations and the community. It is personalised for each client and sets out the goals of the intervention, activities, resources and methods and records results achieved. The plan requires at least **three-monthly monitoring** by the person in charge of implementing the personal intervention plan after the diagnosis. The monitoring should also use the dimensions that diagnosed low to high risk indicators and, in the case of those where the protection factors were low or non-existent, the assessment and diagnosis tool in order to look for changes for the better or worse that require a new plan to be drafted. If the plan is shelved, this should be recorded (in an occurrence file, for example) and the reasons and causes and possible case-appropriate solutions should be taken into consideration.

The personal intervention plan must last a maximum of **one year** (preferably), in order to protect the disabled person's real interests. The implementation of the plan requires the involvement of the family as an agent of change, the cooperation and joint accountability of caregiving organisations and all practitioners working directly with the disabled person and articulation with and the support of the social network in the local community.

V.
PLAN

PERSONAL INTERVENTION PLAN

Date drafted:

Date revised:

Duration:

Person in charge:

Dimension of analysis[15]:

PERSON WITH INTELLECTUAL AND/OR MULTIPLE DISABILITIES	FAMILY	CAREGIVING ORGANISATION	COMMUNITY (PARTNERSHIP)
Current situation			
Goal			
Resources (human, logistical, material, community)			
Intervention strategies			
Appraisal method			
Expected result			

[16] Repeat for all dimensions that need to be included in the personal intervention plan.

Date monitored:

	MONITORING 1	MONITORING 2	MONITORING 3
Person with intellectual and/or multiple disabilities			
Family			
Caregiving organisation			
Community (partnership)			

	MONITORING 1	MONITORING 2	MONITORING 3
Person with intellectual and/or multiple disabilities			
Family			
Caregiving organisation			
Community (partnership)			

Date assessed:

ASSESSMENT			
Person with intellectual and/or multiple disabilities			
Family			
Caregiving organisation			
Community (partnership)			

Signatures of persons involved:

Client:

Organisation:

Family member or legal representative:

Community (partnership):

■ The remit of Instituto Nacional para a Reabilitação, I.P. (National Rehabilitation Institute) is to foster equal opportunities, combat discrimination and nurture disabled persons with a view to promoting their fundamental rights. We therefore recommend that, when taking action, in conjunction with other governmental organisations, it considers the need to protect vulnerable adults (persons with disabilities, the elderly, drug addicts, etc) and exert pressure to ensure that this need is reflected in practice as a political priority. We also advocate that the necessary measures should be taken for committees for the protection of vulnerable adults to be set up in each municipality to ensure the protection and implementation of these people's rights.

■ As Portugal has ratified the *Convention on the Rights of Persons with Disabilities* and the *Optional Protocol*, it is essential to includes concrete measures and specific actions to protect disabled persons in cases of neglect, physical, psychological and sexual abuse, exploitation of labour, mendication and corruption under the *National Disability Strategy* (2011-2013).

■ FENACERCI, as the organisation representing social solidarity cooperatives with the fundamental remit of promoting the rights and quality of life of persons with intellectual and/or multiple disabilities and their families, will always act as a mediator in cases of maltreatment reported to it and share all information with the competent authorities.

Pointers for Future Research

■ A new dimension of analysis could be included in the assessment and diagnosis process in the *Roadmap for the Prevention of Maltreatment of Persons with Intellectual and/or multiple Disabilities* for cases of neglect, abuse, maltreatment and discrimination in an institutional setting. It should be based on the social response quality management manuals published by the Social Security Institute, which list dimensions and indicators for appraising maltreatment at institutions.

■ The *Roadmap for the Prevention of Maltreatment of Persons with Intellectual and/or multiple Disabilities* could be issued in digital format to make it easier for organisations to use this tool. The digitisation of the roadmap would facilitate the entire assessment and diagnosis process, make it possible to check the disabled person's situation against the grids of risk and protection dimensions and make personal intervention plans more instrumental and easier to insert in the organisation's formal, codified documents.

■ As an umbrella organisation, FENACERCI undertakes to:
- Continue its work in the area of maltreatment of persons with intellectual and/or multiple disabilities and seek more and better practices at national and international level;
- Post the assessment and diagnosis tool on its website (www.fenacerci.pt) in a format enabling all stakeholder individuals and organisations to make their contributions in order to ensure that it is a work in progress;
- Monitor the evolution of this social phenomenon in its network of members, foster research and development in this field and set up effective partnership networks involving close articulation with Instituto Nacional para a Reabilitação, I.P. (National Rehabilitation Institute).

VIII.
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IX.
ATTACHMENTS

Law 147/90 of 1 September (amended by Law 31/2003 of 22 August)
LAW ON THE PROTECTION OF CHILDREN AND YOUNG PEOPLE AT RISK

Article 5
Definitions

The following definitions shall be considered for the purpose of this law:

a) Child or young person - a person under 18 years old or a person under 21 years old who requests the continuation of an intervention commenced before s/he reached the age of 18;

b) De facto guardianship - the relationship between a child or young person and the person who takes on permanent child-rearing responsibilities;

c) Emergency situation - a situation of present or imminent risk to the life or physical integrity of a child or young person;

d) Entities – public, cooperative, social or private natural or legal persons that work with children and young people and are therefore entitled to intervene in promoting the rights and protection of a child or young person at risk;

e) Measure to promote rights and protection – action taken by the courts or child and young people's protection committees pursuant to this law to protect a child or young person at risk;

f) Promotion and protection agreement – written commitment between a court or child or young people's protection committee and the parents, legal representative or guardian and also a child or young person over 12 years of age setting out a plan for protection and the promotion of rights.

Article 6
General provision

The promotion of the rights and protection of children and young people at risk shall be the responsibility of the courts, childhood and youth authorities and child and young people's protection committees.

Article 7
Intervention by childhood and youth authorities

Intervention by childhood and youth authorities shall take place in agreement with the parents, legal representatives or legal guardians of the child or young person, as the case may be, pursuant to the principles and terms of this law.

CRIMINAL CODE
(approved by Decree-Law 48/95 of 15 March, with the latest amendments made by Law 40/2010 of 03 September)

Article 152
Domestic violence

1 — Whosoever, repeatedly or not, inflicts physical or mental maltreatment, including corporal punishment, deprivation of freedom or sexual abuse:
a) On a spouse or former spouse;
b) On a person of the same or opposite sex with whom the offender has or has had a spousal relationship, albeit with no cohabitation;
c) On a parent of a common descendent in the first degree; or
d) On a particularly defenceless person due to age, disability, illness, pregnancy or economic dependence living with him or her;
shall be punished with a prison sentence of one to five years, if s/he is not subject to a more severe penalty by force of another legal provision.
2 — In the case set out in the previous paragraph, if the offender commits the crime against a minor, in the presence of a minor, in the common dwelling or in the victim's dwelling, the penalty shall be a prison sentence of two to five years.
3 — If the acts set out in paragraph 1 result in:
a) Serious bodily harm, the offender shall be punished with a prison sentence of two to eight years;
b) Death, the offender shall be punished with a prison sentence of three to ten years.
4 - In the cases set out in the previous paragraphs, the accused may, in addition, be forbidden from any contact with the victim and forbidden from using or carrying weapons for a period of six months to five years and be obliged to attend domestic violence prevention programmes.
5 — The additional prohibition from contact with the victim may include being banned from his or her dwelling or workplace and compliance may be supervised by a remote monitoring device.
6 — Anyone convicted for a crime set out in this article may be prevented from exercising parental rights, guardianship or wardship for a period of one to ten years, depending on the severity of the offence and its connection with the offender's position.

Article 152.A
Maltreatment

1 — Whosoever has in their care or custody, is responsible for the rearing or education or employs a minor or a person who is particularly defenceless, due to age, disability, illness or pregnancy, and:
a) Repeatedly or not, inflicts physical or mental maltreatment, including corporal punishment, deprivation of freedom, sexual abuse or cruelty;
b) Employs him or her in dangerous, inhumane or prohibited activities; or
c) Overburdens him or her with excessive work;
shall be punished with a prison sentence of one to five years, if s/he is not subject to a more severe penalty by force of another legal provision.
2 — If the acts set out in the previous paragraph result in:
a) Serious bodily harm, the offender shall be punished with a prison sentence of two to eight years;
b) Death, the offender shall be punished with a prison sentence of three to ten years.

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Article 16
Freedom from exploitation, violence and abuse

1 — States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender -based aspects. 2 — States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender - and age -sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age -, gender - and disability -sensitive.
3 — In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4 — States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self -respect, dignity and autonomy of the person and takes into account gender - and age -specific needs.
5 — States Parties shall put in place effective legislation and policies, including women - and child -focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 17
Protecting the integrity of the person

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