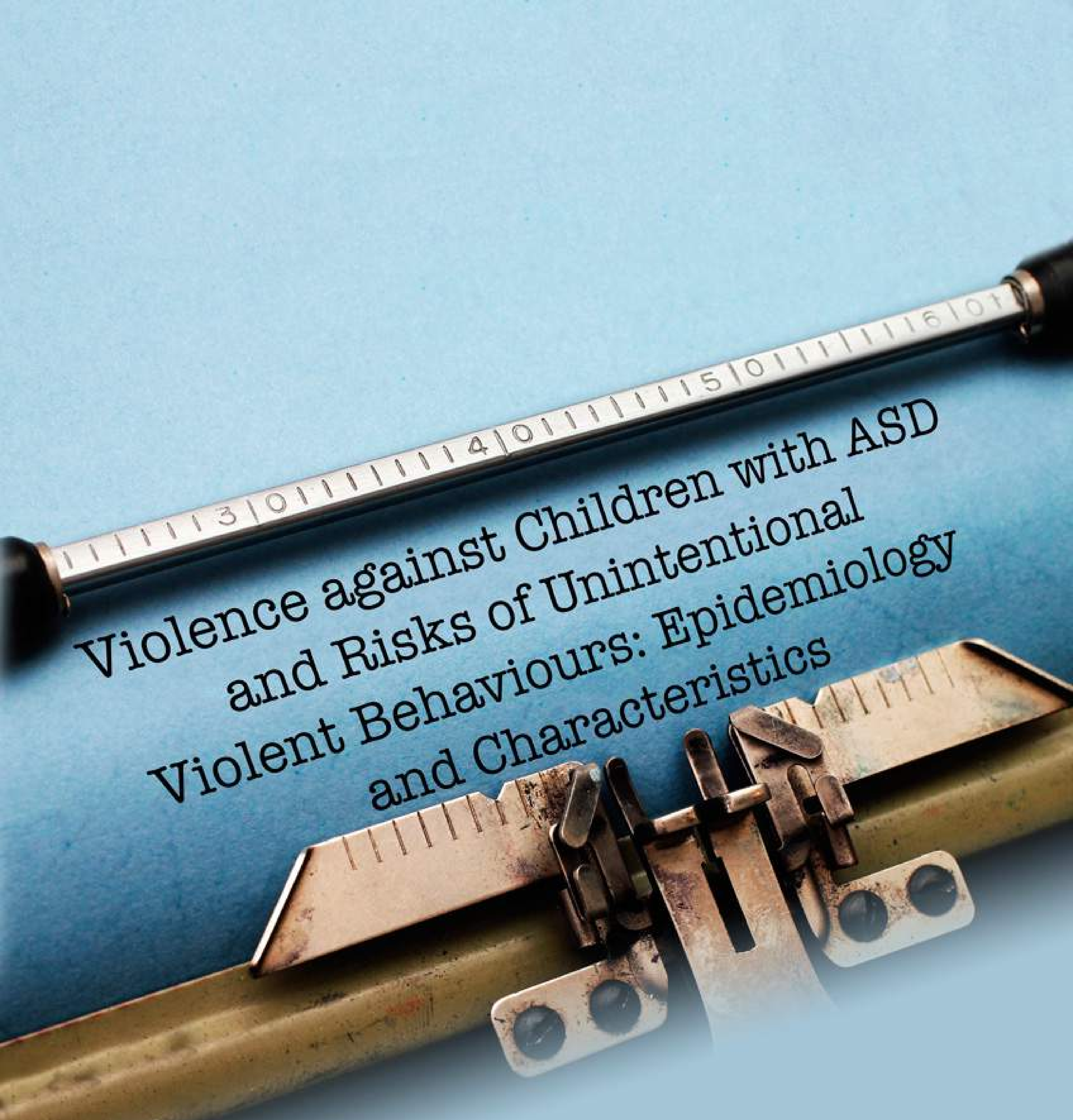

Violence against Children with ASD and Risks of Unintentional Violent Behaviours: Epidemiology and Characteristics

With the financial support from
the “DAPHNE III” Programme of the
European Commission

SPEAK UP

System for Protection and Empowerment
of Autistic Child as victim of abuse
or Unintentional Perpetrator

This publication has been produced with the financial support of the European-specific programme “DAPHNE III” (2007-2013) to prevent and combat violence against children, young people and women and to protect victims and groups at risk. The contents of this publication are the sole responsibility of Fondazione Il Cireneo, Focolare Maria Regina Association, National Autistic Society, Autismo Burgos, Autism Europe, Progetti Sociali, and can in no way be taken to reflect the views of the European Commission.

With the financial support from the “Daphne III” Programme of the European Union

SPEAK UP Project

System for Protection and Empowerment of Autistic Child as victim of abuse or Unintentional Perpetrator (Just/2012/DAP/AG/3192)

Research

Part 1.

Survey on the Epidemiology and Characteristics of population of investigated children victims or unintentionally perpetrators

Report and final considerations

PART 1

Index

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Introduction and methodology

The Speak Up project

The abuse and maltreatment of children with Autistic Spectrum Disorder (ASD) is 4 to 10 times more frequent in children with ASD than in the general population. Their social isolation and poor communication skills make them particularly vulnerable to abuse.

Moreover, there might be circumstances in which children with ASD can be unintentional perpetrators of violent behaviours towards themselves and others.
Both these issues are still underestimated and not adequately addressed.

The current protection system of children with ASD, as victims or as unintentional perpetrators, is inadequate in many EU Member States. This is due to a lack of adequate prevention tools and understanding amongst professionals providing assistance to children with ASD.

The SPEAK UP project intends to address this phenomenon at the European level, and proposes to develop operational tools of prevention and protection of children as victims or as unintentional perpetrators of violence.

The SPEAK UP project's overall objective is to further deepen, at European level, the study and development of intervention procedures in the field of abuse and maltreatment of children and young people with ASD.

As well as focusing on the fact that children and young people with ASD are often unintentional perpetrators of violence, the study aims to develop some operational tools for the prevention and protection of children as victims or as unintentional perpetrators of violence.

The Actions of the project are:

1. **RESEARCH**
   A research study at European level on the incidence of the phenomenon of abuse of children and young people with ASD. The research study is conducted through the collection and comparison of existing data and interviews to families with children with ASD, by highlighting their experiences in all the Member States involved in the project.

2. **PILOT PROGRAMME FOR THE PREVENTION OF THE RISK OF MALTREATMENT OF CHILDREN WITH ASD**
   The development and coordination of a programme for the prevention of the risk of maltreatment of children with ASD, addressed to the most vulnerable families and children from the participating countries. The programme has an integrated structure and includes actions of training, personalized counselling and caregiving approaches aimed at strengthening parental resilience.

3. **INFORMATION**
   Information and resources for the prevention and protection of children with ASD from abuse. Information materials and a dedicated multilingual website will be developed.

4. TWO EXPERIMENTAL INTERVENTION PROTOCOLS
The development of two experimental intervention protocols containing specific guidelines for action in the event of suspected violence. The first protocol is intended for the detection, reporting and protection of children with ASD as victims of abuse. The second protocol is intended for the prevention of violent behavior in children with ASD as unintentional perpetrators of violence.

The Survey

This report is the first part of the action research carried out within the Speak Up project. It presents the research results in the field of epidemiology, as well as the characteristics of children and young people with ASD as victims of abuse or as unintentional perpetrators.

This survey was carried out transnationally. Each of the partners involved in the project provided sample cases involving children with ASD as victims of abuse, as well as sample cases involving children and young people with ASD as unintentional perpetrators of violence. The research aims at researching the correlations between violence and the characteristics of autism, and the correlations between forms of maltreatment and their corresponding causes.

The European research group has developed two different questionnaires: questionnaire 1, for the survey on abused children or children suspected of being victims of abuse; questionnaire 2 for the survey on children and young people as perpetrators of violence. The questionnaires have been filled in by those operators recruited to the project in the participating countries. In order to adapt the research study to the ethical rules of the United Kingdom, the survey carried out on the English cases was, in some aspects, conducted using different modalities.

The survey aimed at correlating the following: abuse suffered or abuse perpetrated, the clinical characteristics of individuals with ASD and the existing risk and protection factors. In particular, this last research item was preparatory to draft a document presenting the "good practice" to be adopted in order to increase the protection against violence for children with ASD and to end the violence unintentionally perpetrated by them (Second Part).

As it is known, one of the distinguishing diagnostic characteristics of autism spectrum disorders relates to social relationships. This provides an indication on the kind of social issues that people with ASD find themselves confronted with during their development.

Abuse can be found among them, intended as physical maltreatment, psychological or sexual abuse. These issues affect not only people with ASD, but also individuals with different types of disabilities or with developmental problems, as well as neurotypical individuals.

Epidemiological data show that people with ASD have higher probability (from 4 to 10 times more than neurotypical people) of experiencing abuse.

People with ASD, especially those who need little support, may have a quite ordinary social life, interact with a number of different social environments, and therefore may appear to be neurotypical from many aspects. Nevertheless, their communication abilities and the way in which they perceive and interpret social relationships make them more vulnerable to abuse, but also, in specific cases, more prone to act unintentionally and inadequately. As a result, they may turn into unintentional perpetrators.

Abuse is quite often perpetrated within the family context, or even within the caregiving environment, where caregivers who experience high stress levels or who are not adequately trained can be led to resort to aggressive and manipulative types of behaviour.

The SPEAK UP project (System for the Protection and Empowerment of Autistic Children as victims of abuse or as Unintentional Perpetrators) aims at investigating such phenomena and the causes behind them, and identifying the necessary actions to limit their frequency.

The research study developed within this project is based on the administration of a questionnaire to parents of children and young people with ASD and to their operators, belonging to diverse European cultural contexts. The aim was that of collecting and comparing data and experiences collected from the EU member states involved in the project.

A total of 77 people (parents and operators) coming from the United Kingdom, Italy, Poland and Spain were interviewed. Data were collected in the form of questionnaire responses.

There are several problems connected to the data collected. The data provided by The National Autistic Society can only be partially compared to the data foreseen by the different sections of the survey, for the reasons given above. Moreover, partial answers were sometimes provided to some questions of the questionnaires.

Despite these limitations, meaningful data can be extracted from the information gathered. For example, physical maltreatment appears to prevail on other forms of abuse (psychological maltreatment, bullying, neglect, etc.).

As far as the abusers and the places where the abuse has taken place, a clear difference emerges between people with low-functioning autism (Autism) and people with high-functioning autism (Asperger).
The most common abuse environment for people with high-functioning autism appears to be the school, where they are victims of abuse perpetrated by classmates and other peers. Abuse for people with low-functioning autism seems to be more directly connected with their caregivers as abuse perpetrators (mother, father, therapist), but there are also cases where the abuse was perpetrated by peers, with or without ASD.

Data may be flawed by the fact that people with low-functioning autism are less likely to come in contact with the school environment, or may spend less time at school, especially when compared to countries other than Italy.

The prevailing risk and protection factors are particularly interesting. Reasons for physical maltreatment appear to be mainly associated with a lack of knowledge and understanding on the part of parents about problems experienced by people with autism, and with the burnout of operators, which is ascribable to a lack of competences about the management of people with ASD.

Triggers of physical abuse perpetrated by the caregiver may be initiated by types of behaviour that are perceived as being problematic (e.g. the physical aggressiveness against others and self-injurious physical aggressiveness displayed by the person with ASD). This reaction may, in turn, result from what can be defined as a form a psychological abuse towards the person with autism.

Due to the fact that they belong to a social minority group, people with autism live and co-exist within a culture of neurotypical individuals, which is based on different life experiences and feelings compared to theirs. Such cultural foreignness exacerbates the reactions of people with severe autism and makes life difficult for all the people with autism.

The lack of knowledge about autism and its characteristics leads caregivers to perpetrate minor and repetitive forms of abuse. This is the case of punishment for educational purposes, e.g. when individuals on the autism spectrum appear to be voluntarily avoiding to cooperate with others, or pretend not to be understanding something (i.e., when the child is asked to remain standing behind the classroom door because s/he didn’t greet when entering the classroom).

Every small act of abuse opens the door to other forms of abuse, while also having an impact on the way society perceives people on the autism spectrum. For example, a punishing reaction from a teacher leads fellow students to think that bullying people with autism is not something that serious, and that it can even be justified.

Pharmacological abuse and excessive treatment shall be considered as “submerged” issues that contribute to fuel the perception of people with autism as being less human than other human beings, and to objectify them, thus paving the way for additional abuse.

The survey shows that the highest risks for abuse and neglect lie in the following: children on the autism spectrum are denigrated and treated inadequately and violently; their parents do not possess adequate knowledge and skills in the field of ASD; the parent-child relationship seems inadequate; one or both parents have a mental illness; children on the autism spectrum need to receive special assistance, which may predispose operators to experience burnout.

Among the factors that protect a child from the risk of abuse or neglect, can be found the following: the child is well integrated into social life, and parents benefit from the social leadership of their child to enhance their life quality; parents receive appropriate training about the growth and development of their child; the parent-child interaction is reinforced within the healthcare centre; the home visiting services are well structured and scheduled; parents participate in parental support groups; parents receive support to help alleviate the tension; parents receive appropriate training to prevents them from using corporal punishment for the child.

Risk factors for child sexual abuse are associated with the following: the parent-child relation is inadequate; the child does not receive proper support in order to reduce/eliminate the social isolation s/he experience; the child does not receive adequate support to improve their skills.

Risk factors for child physical abuse are associated with the following: the child is subject to denigration, inappropriate or violent treatment by others; adults think of children on the autism spectrum as misfits in the society, and see the disability as something dishonourable to them;

parents lack the adequate knowledge and competences to manage the child; parents are not aware that their child runs the risk of being subject to abuse; children on the autism spectrum need to receive special assistance, which may predispose operators to experience burnout.

Protective factors that help keep children safe from physical abuse are associated with the following: parents are adequately informed about the growth and the development of their child; the healthcare centre contributes to reinforce the parent-child relationship; parents participate in parental support groups; the child receives adequate support to implement self-protection measures.

Risk factors for bullying among children with ASD include: caregivers not being adequately trained to recognise the signs of maltreatment; the organization that provides support to the child with ASD fails to integrate a process of “humanization” in the context of ASD; the child experience isolation from the outer world; the institution lacks specific procedures to correlate and monitor events of bullying.

Protective factors that help keep children safe from bullying are associated with the following: the local community bears responsibility for the well-being of disabled children; parents receive appropriate training about the growth and development of their child; the parent-child interaction is reinforced within the healthcare centre; the child receives adequate support to implement self-protection measures; the child receives instructions in relation to the understanding of the body and sex education; the child receives support on how to reduce/move out from social isolation.

As previously discussed, psychological abuse plays an important role because it may be a gateway to other forms of abuse.

Risk factors for psychological abuse among children with ASD are associated with the following: children are not aware that they deserve other forms of appreciation; caregivers are not adequately trained to recognise the signs of maltreatment; families think of children on the autism spectrum as misfits in the society, and see the disability as something dishonourable to them; parents lack the adequate knowledge and competences; parents are not aware that their child runs the risk of being subject to abuse.

Ultimately, the main protection factors from abuse seem to be associated with the training and preparation of caregivers in a general sense.

It therefore follows that parents, operators, caregiving professionals and so on need to possess thorough knowledge of autism, of the behavioural manifestation of autism and awareness of the adequate modalities to cope with it, in order to keep children on the autism spectrum safe from abuse.

As regards those subjects on the autism spectrum who have higher levels of education or are better integrated into society, the best way to keep them safe from abuse is to raise awareness among their classmates or peers according to the same modalities followed in the case of bullying, even when bullying itself is not directly mentioned.

Glossary of terms

Sexual abuse: unwanted sexual activity, with or without physical contact, to which the minor cannot freely give consent due to reasons connected to their age or to the force used by the abuser; sexual exploitation of a child or young person; child prostitution; child pornography.

Physical abuse: the presence of physical injury as a result of physical aggression, maltreatment, corporal punishment or severe outrage to physical integrity or to life.

Psychological abuse: emotional relationship characterised by continuous and repeated psychological pressure, emotional blackmailing, indifference, rejection, acts of denigration and devaluation that might impair or inhibit the development of cognitive-emotional skills such as intelligence, attention, perception and memory.

Pathology of treatment: the administration of improper treatment to the physical and/or mental needs of the child, with particular reference to age and development stage (inadequate treatment; excessive treatment). This also includes the Munchausen Syndrome by proxy or *Chemical abuse* (pharmacological abuse).

Physical and/or psychological neglect: the severe and/or persistent omission of care to the child or failures in some important areas related to the child upbringing, leading to severe implications for the health and the development of the child, or to developmental delays in the absence of organic causes.

Witnessed violence: the situation in which minors directly or indirectly witness violence, or experience the effects of abuse perpetrated against go-to persons or against individuals who are affectively meaningful for them.

1. Survey results

The project partners are Institutions and/or Service Providers operating in the United Kingdom, Italy, Poland and Spain. Data were collected with the collaboration of operators working for the Service Providers mentioned above, while the United Kingdom mainly collected data using interviews.

The samples interviewed are divided as follows:

- United Kingdom: 7 individuals with Autistic Spectrum Disorder (ASD);
- Italy: 20 individuals with ASD;
- Poland: 23 individuals with ASD;
- Spain: 20 individuals with ASD.

Chart 1 shows the general data of the sample.

Table 1 – General data on survey	Population	English population
Total Persons with ASD	63	7
Autism	37	2
Asperger	24	2
Other diagnosis	2	3
Sex male	51	
Sex female	12	
Age <5	3	
5<age<12	23	
12<age18	27	
age>18	10	

Charts 2 and 3 show the data with reference to the sample which was surveyed. Chart 2 shows the population of subjects who are victims of abuse. Chart 3 shows the population of subjects who are unintentional perpetrators of violence.

Table2 - Victims and diagnosis			
	Autism	Asperger	Other diagnosis
Male			
<5	1	1	0
5<age<12	8	5	0
12<age18	3	5	1
>18	1	1	1
Female			
<5	0	0	0
5<age<12	4	1	0
12<age18	1	1	0
<18	1	0	0

Table 3 – Perpetrators and diagnosis		
	Autism	Asperger
Male		
<5	1	0
5<age<12	4	0
12<age18	8	5
>18	3	3
Female		
<5	0	0
5<age<12	1	0
12<age18	1	2
>18	0	0

This Report is divided in two sections:

1. a general part referring to common data for the two surveyed groups (victims and perpetrators);
2. the first part referring to children with ASD as victims of abuse;
3. the second part referring to children with ASD as unintentional perpetrators.

2. General data from the two Surveys

The following Charts (4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14) show the characteristics of the entire population with ASD, including both victims of abuse and perpetrators of abuse. In particular:

- Chart 4 shows the diagnosis received;
- Chart 5 shows the types of school attended;
- Chart 6 shows the child's family;
- Chart 7 shows the age of diagnosis;
- Chart 8 shows the age of diagnosis of autism;
- Chart 9 shows the age of diagnosis of Asperger Syndrome;
- Chart 10 shows the intelligence quotient;
- Chart 11 shows the intelligence quotient of the subjects with a diagnosis of autism;
- Chart 12 shows the intelligence quotient of the subjects with a diagnosis of Asperger Syndrome;
- Chart 13 shows the age of first violence;
- Chart 14 shows the duration of abuse (in years).

Table 4 - Diagnosis ASD		
	absolute value	*percentage*
Autism	39	55,71%
Asperger	26	37,14%
Other diagnosis	5	7,14

Table 5 - Attending school		
	absolute value	*percentage*
Kindergarten	8	12,70%
Primary school	20	31,75%
Secondary school	17	26,98%
High school	3	4,76%
Professional school	4	6,35%
Other school	4	6,35%
Not attending	7	11,11%

Table 6 - Child's Family		
	absolute value	*percentage*
Origin Family	55	87,30%
Adoptive Family	2	3,17%
Public Structure	2	3,17
Mother alone	1	3,17%
Father alone	1	1,59%
Private Structure	1	1,59

Table 7 - Diagnosis' age		
	absolute value	*percentage*
Age <5	35	55,72%
5<age<12	30	43,47%
Age >12	4	5,79%

Table 8 - Autism diagnosis age

	absolute value	*percentage*
Age <5	29	80,55%
5<age<12	7	19,44%
Age >12	0	0,00%

Table 9 - Asperger diagnosis age

	absolute value	*percentage*
Age <5	4	16,66%
5<age<12	18	75,00%
Age >12	2	8,33%

Table 10 - Intelligence quotient

	absolute value	*percentage*
above average	9	14,29%
average	18	28,57%
below average	36	57,14%

Table 11 - Autism quotient intelligence

	absolute value	*percentage*
above average	0	0,00%
average	4	10,81%
below average	30	81,08%

Table 12 - Asperger quotient intelligence

	absolute value	*percentage*
above average	8	33,33%
average	16	66,66%
below average	1	4,16%

Table 13 - Age of first violence

	absolute value	*percentage*
Age < 5	17	32,07%
5<age<12	28	52,83%
Age >12	8	15,09%

Table 14 - Abuse duration

	absolute value	*percentage*
Age < 5	28	56,00%
5<age<11	22	44,00%
Age >11		

3. Survey on the Epidemiology and Characteristics of Violence against Children with ASD and on Risks an Protection Factors

3.1. Demographic information

The sample relating to children with ASD as victims of abuse is constituted by 35 individuals, 27 (77%) **males** and 8 (23%) **females**. 54% (n. 19) of victims are individuals with a **diagnosis** of autism, 40% (n. 14) of victims are individuals with Asperger Syndrome; 6% (n. 2) of victims have received another diagnosis.

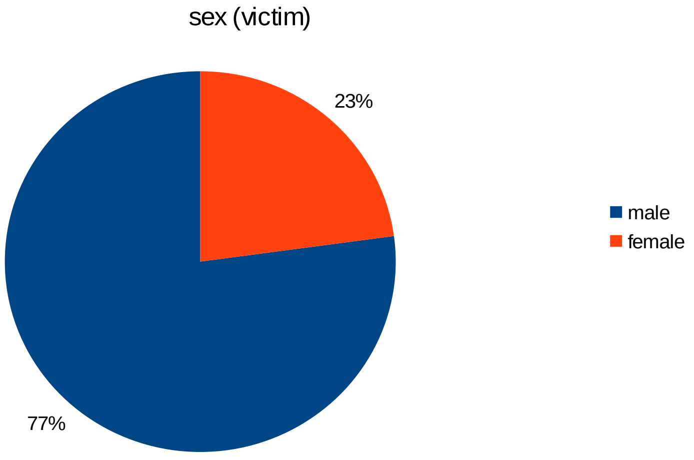

Figure 1

Most of the victims - 80 % - live with their family of origin. 20% of them live in single-parent families, adoptive families and public and private care facilities.

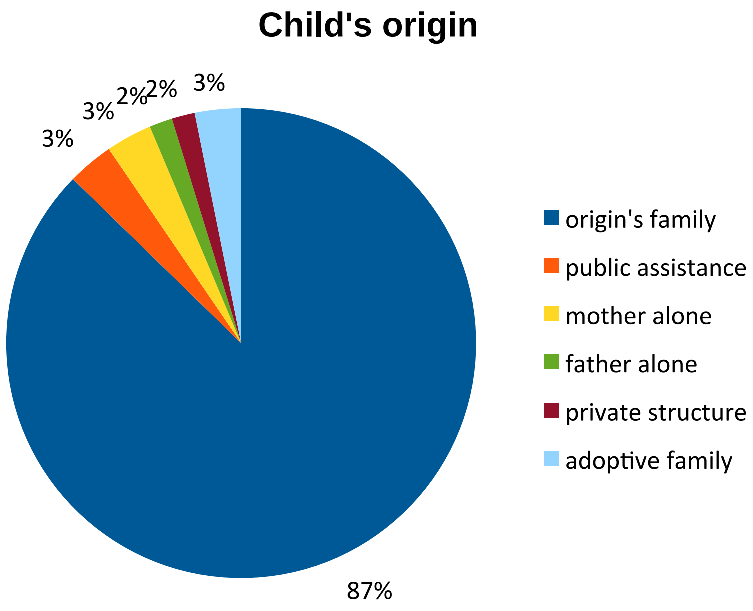

Figure 2

As far as the **socio-economic status of the family** is concerned (figure 3), 60% of families are on middle income, 37% of them are on a low income and 3% of them have an income below the poverty line.

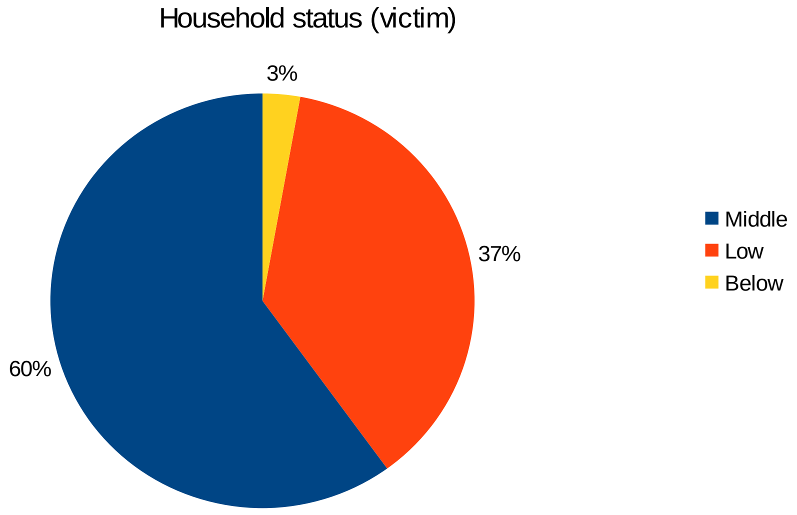

Figure 3

13% of children victims of abuse attend kindergarten, 32% of them attend primary school, 27% of them are enrolled in secondary school, while 11% of them attend upper secondary school or professional training schools. 11% of children are not in education.

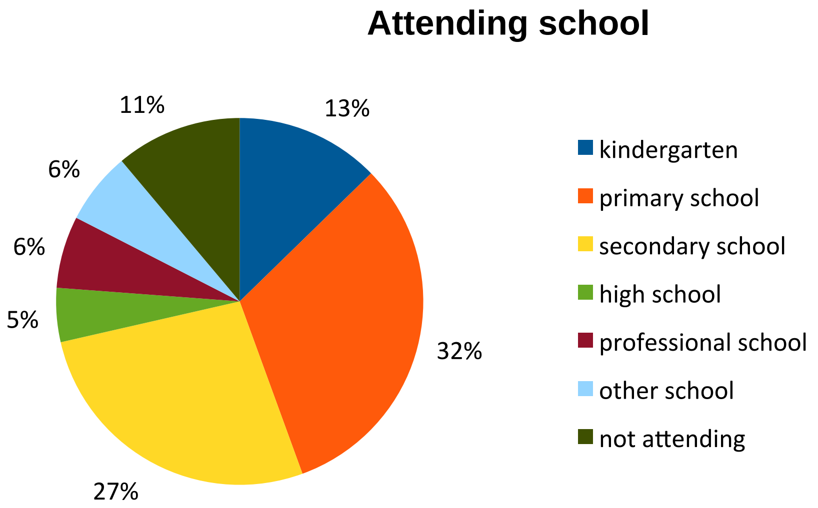

Figure 4

The **household levels of education** are as follows: (46%) secondary education, (29%) University education, (17%) upper-secondary education. No data are available for the remaining 9%.

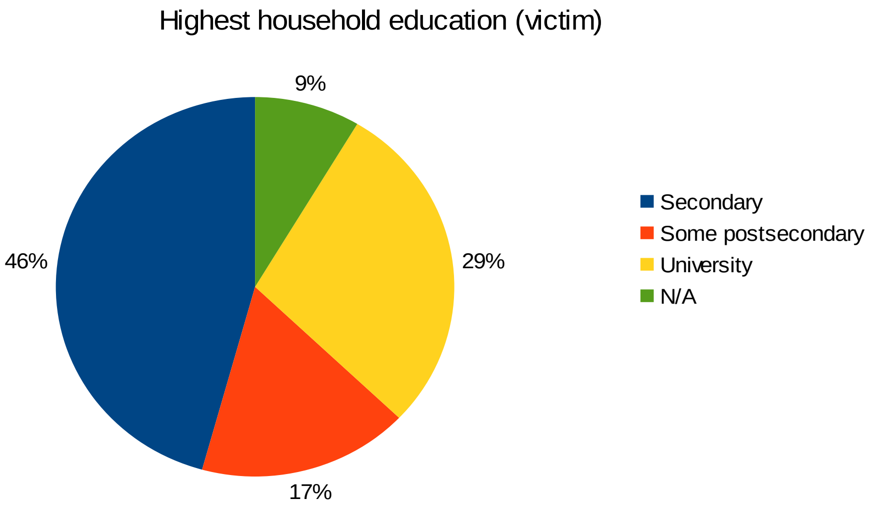

Figure 5

As far as the **area of residence of victims** is concerned, 86% of victims live in town and city areas, while 14% of victims live in rural areas.

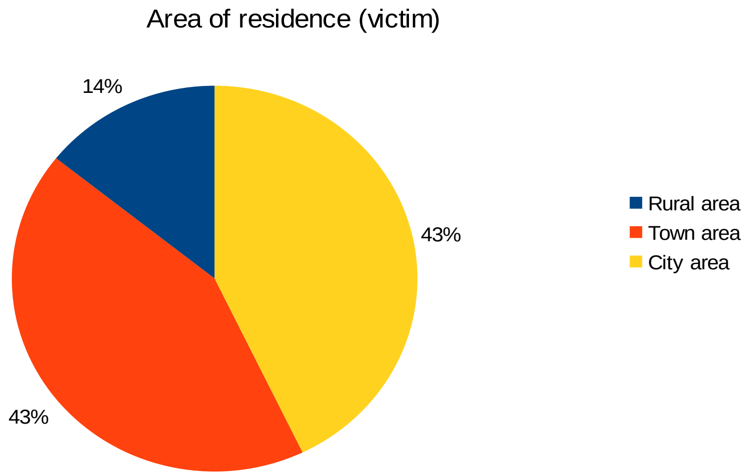

Figure 6

3.2. ASD Pathology information

In 48,57% of cases, the **autism diagnosis** was received under the age of 5 and between 5 and 12 years of age. Only 1 subject was diagnosed with autism after 12 years of age. The diagnosis of Asperger Syndrome shows a peak between 5 and 12 years of age. The diagnosis of autism shows a peak in the first 5 years of age.

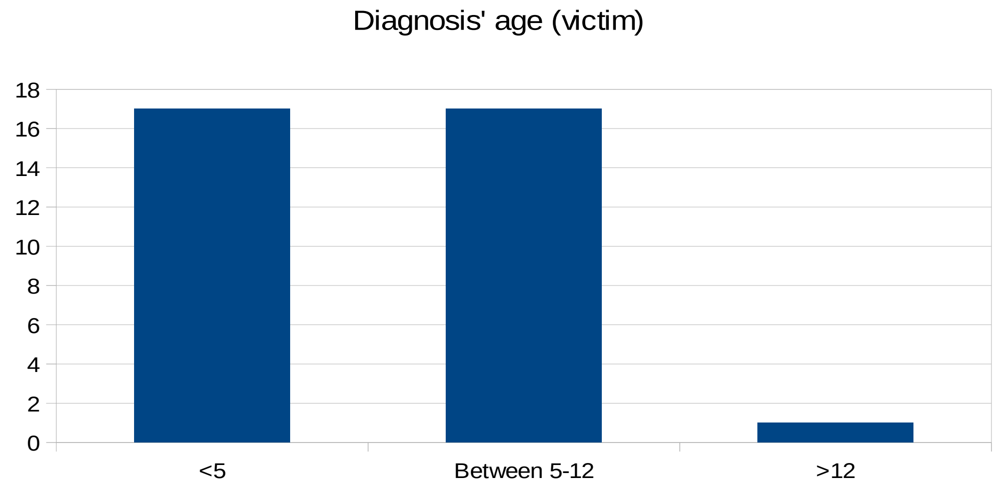

Figure 7

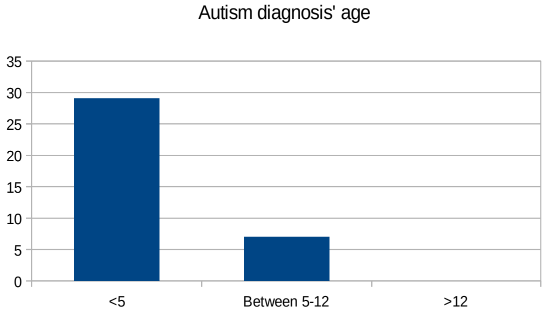

Figure 8

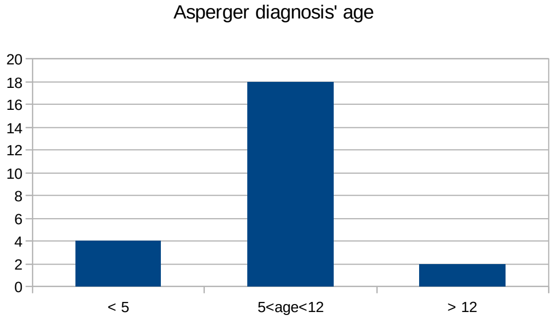

Figure 9

The **intelligence quotient of victims** is divided as follows: 51% of victims fall below average, 31% of victims have an average intelligence quotient, while 17% of victims show an above average intelligence quotient.

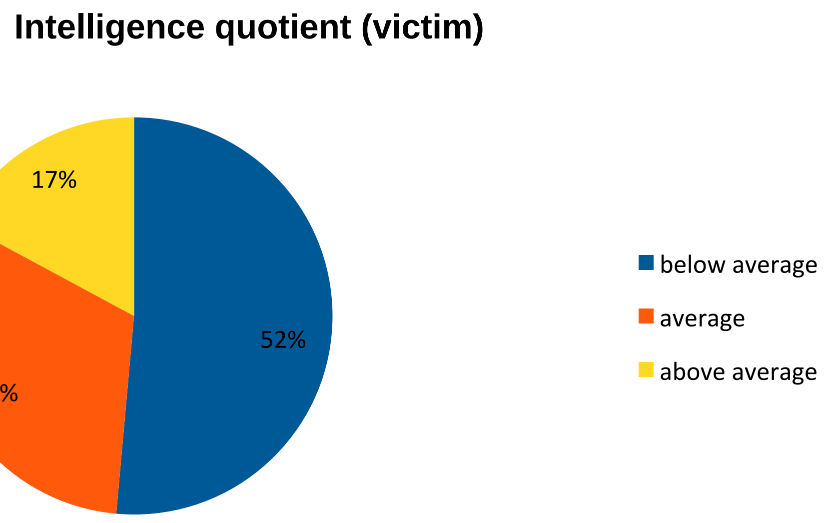

Figure 10

In detail, the survey item relating to **cognitive activity** highlights the following prevailing aspects:

- concrete thinking reaches 74%;
- putting in sequence reaches 68,5%;
- eye of details reaches 51,4%;
- excessive focus on details reaches 51,4%;
- the ability to make sense of the world and to assign a meaning to experiences is partially present, reaching 65,7%.

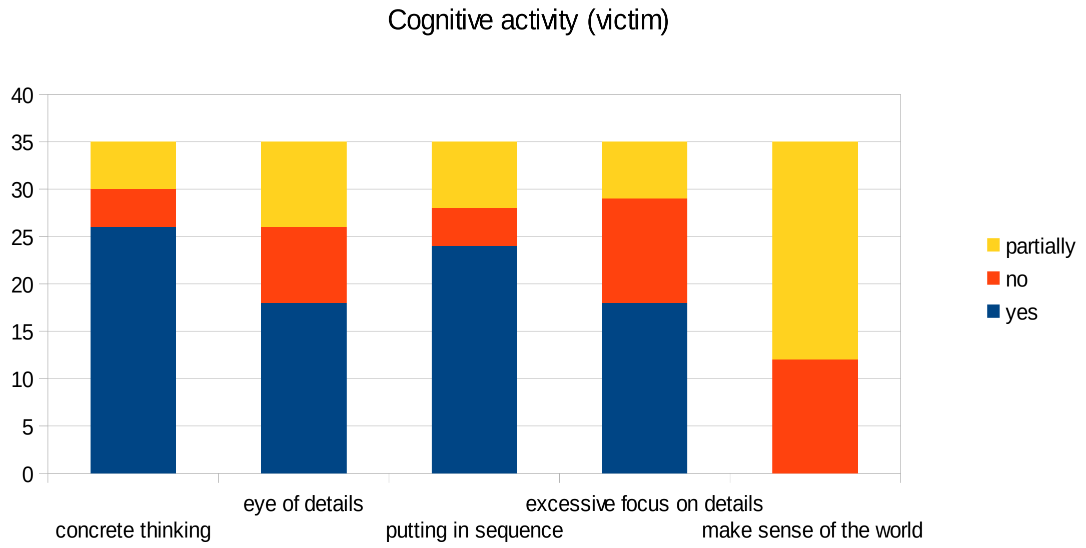

Figure 11

The data referring to **the communication ability** of victims are as follows:

- expressive language is present at a percentage of 45,7%, while it is absent/insufficient at a percentage of 54,3%;

- receptive language is present at a percentage of 48,57%**,** while it is absent/insufficient at a percentage of 51,43%;
- social interaction is absent/insufficient at a percentage of 97%;
- eye contact is absent/insufficient at a percentage of 80%, while it is slightly present at a percentage of 20%;
- expression of emotions is present at a percentage of 17,14% while it is absent/insufficient ability at a percentage of 85,57%;
- understanding of others is present at a percentage of 17,14%, while it is insufficient at a percentage of 45,71%.

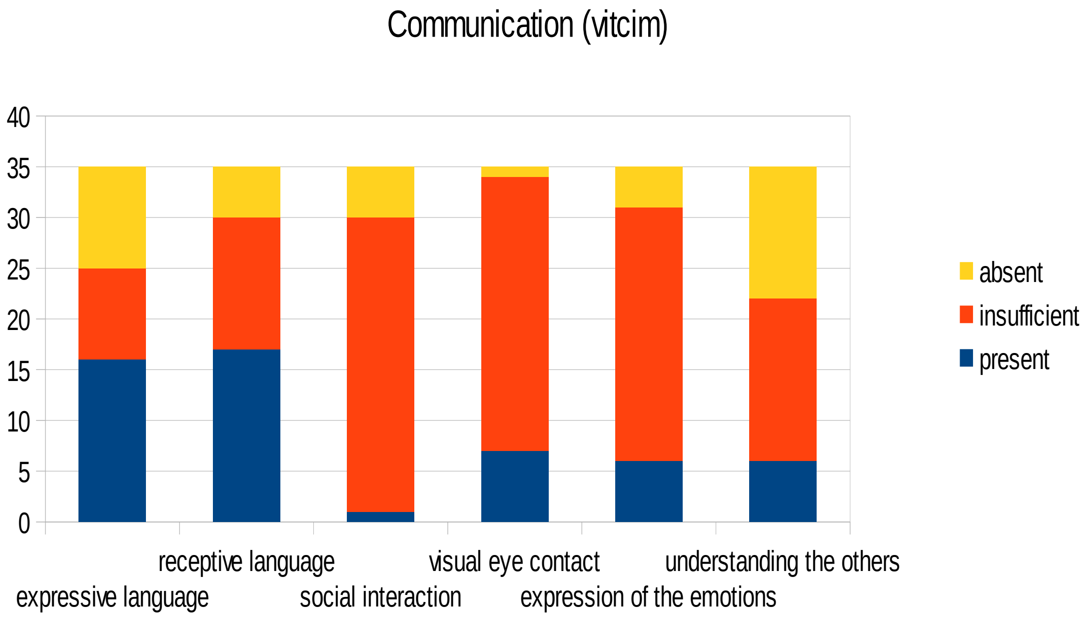

Figure 12

As far as **sensory capability** is concerned, the collected data show the following:

- 45,71% of cases show sensory hypersensibility, while 54,3% of cases show slight or no sensory hypersensibility;
- Hypo-sensibility can be observed in 48,57% of cases; while 51,4% of cases show slight or no hypo-sensibility.

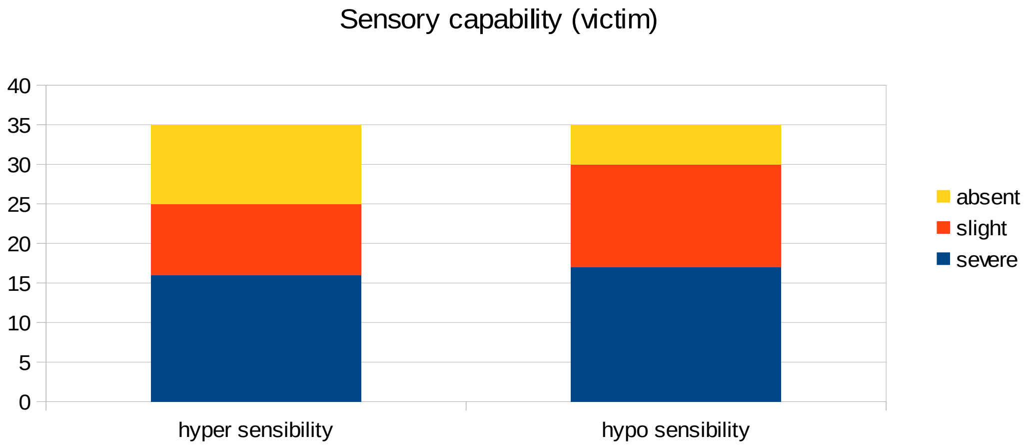

Figure 13

The data on **behavioural** aspects can be divided as follows:

- adherence to routine, observed in 65% of cases (n. 23);
- gross motor skills, observed in 28,57% of cases only, while being absent in 57% of cases;
- fine motor skills, observed in 22,85% of cases only; while being absent/insufficient in 77,14% of cases;
- problematic behaviour (self-aggression), observed in 31,4% of cases, while being absent/insufficient in 68,57% of cases.

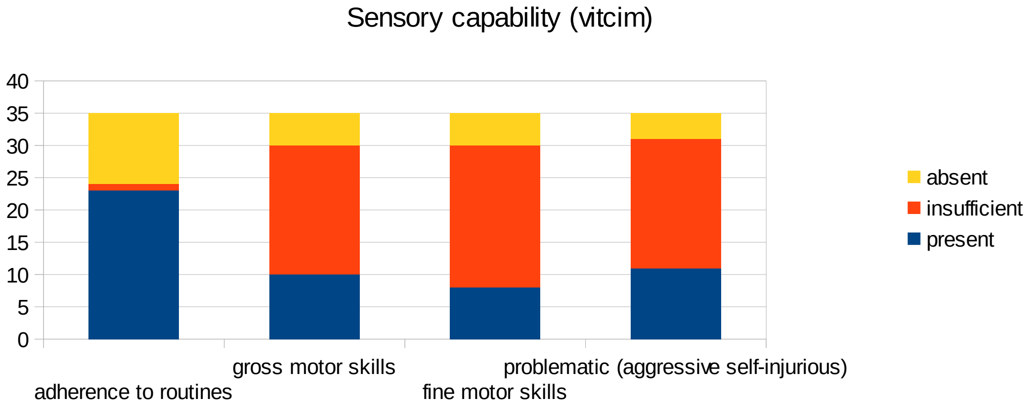

Figure 14

Physical and neurological problems show the following percentages:

- somatic pain is observed in a total of 22,8% of cases, while it is either insufficient, absent or occasional in 77,14% of cases;
- sensory disorders are observed in 28,57% of cases, while they are either insufficient, absent or occasional in 71,42% of cases;
- migraine is absent/insufficient/occasional in all cases;
- seizures are observed in 8,57% of cases;
- side effects from medications are observed in 8,57% of cases.

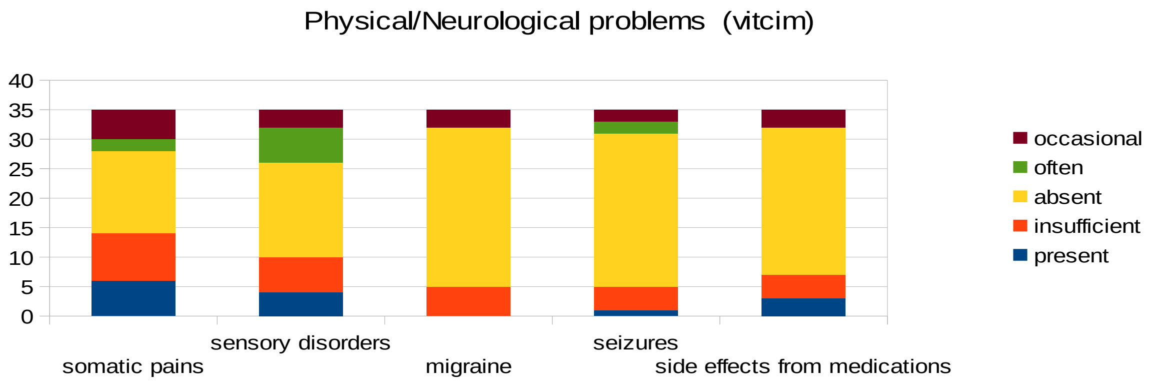

Figure 15

Data relating to the presence of **psychiatric problems** show that:

- depression can be observed in 11,42% of cases;
- attention deficit with hyperactivity can be observed in 57,14% of cases;
- anxiety disorders can be observed in 62,85% of cases;
- aggressive impulses can be observed in 62,85% of cases.

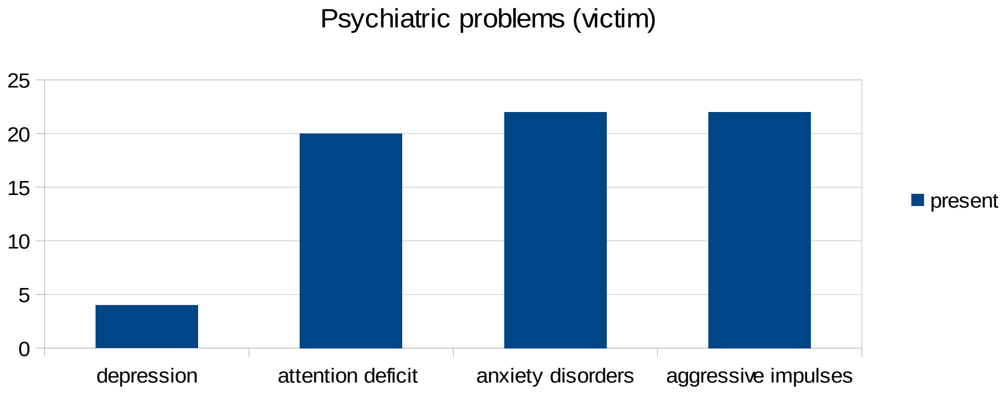

Figure 16

3.3 Maltreatment suffered/suspected (types and characteristics)

The **types of maltreatment** (figure 17) suffered by children with ASD in the surveyed sample are the following:

- **physical maltreatment in 33% of cases;**
- **psychological maltreatment in 26% of cases;**
- **psychological and affective neglect in 19% of cases;**
- **bullying in 9% of cases;**
- **drug abuse in 7% of cases;**
- **bad therapy treatment in 5% of cases.**

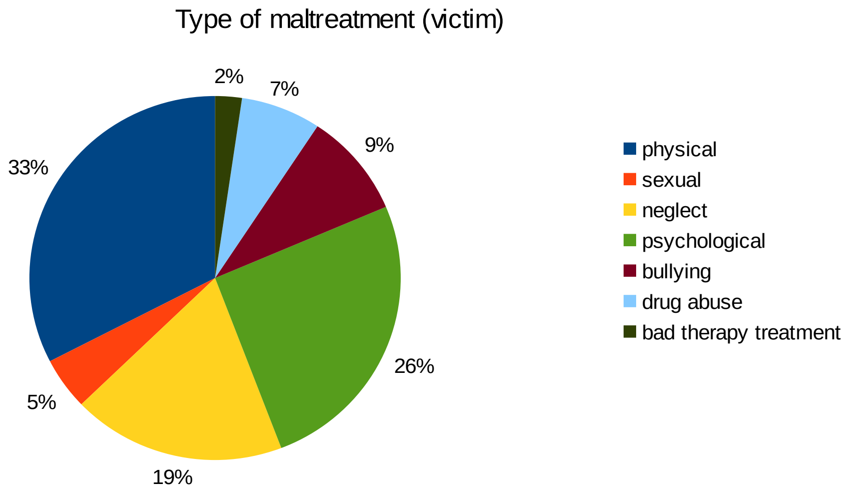

Figure 17

The **age of maltreatment** ranges from 1 to 14 years of age, with a peak between 4 and 10 years of age for a total of 21 individuals, equalling to 60%. The highest peak can be found at the age of 7, with 8 individuals in total, equalling to 22,85% (fig. n. 18).

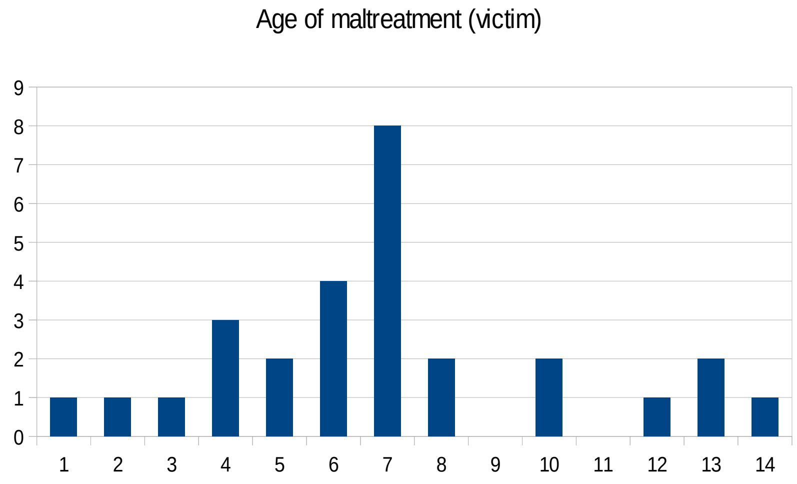

Figure 18

The **duration of maltreatment** is distributed along a period that ranges between 1 to 9 years in duration. Higher percentages reach either 2 or 7 years in duration for a total of 31 cases, equal to 88,57%.

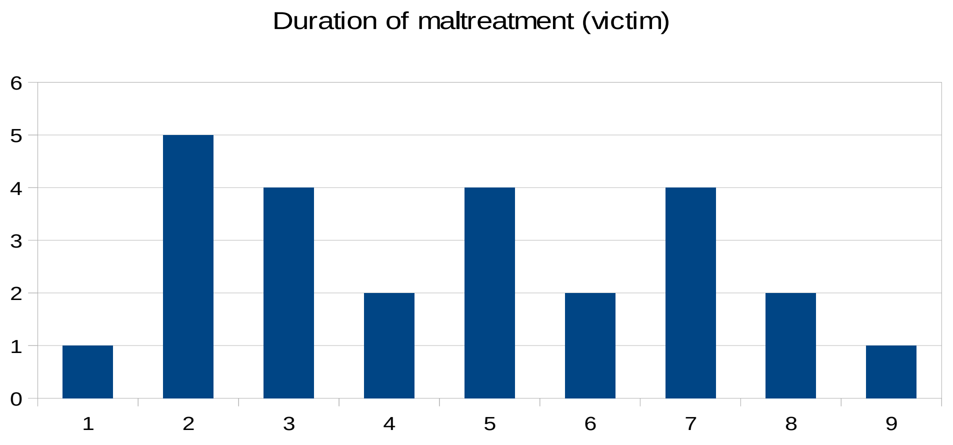

Figure 19

Abusers of children with ASD belong to all the categories of individuals children with ASD come into contact with. A higher incidence of institutional maltreatment occurring outside the family can be observed. **33%** (12) of abusers **are teachers**, 26% (9) are fathers, 19,7% (7) are classmates, 10 % are relatives, 7% are therapists and operators, and 5% are mothers.

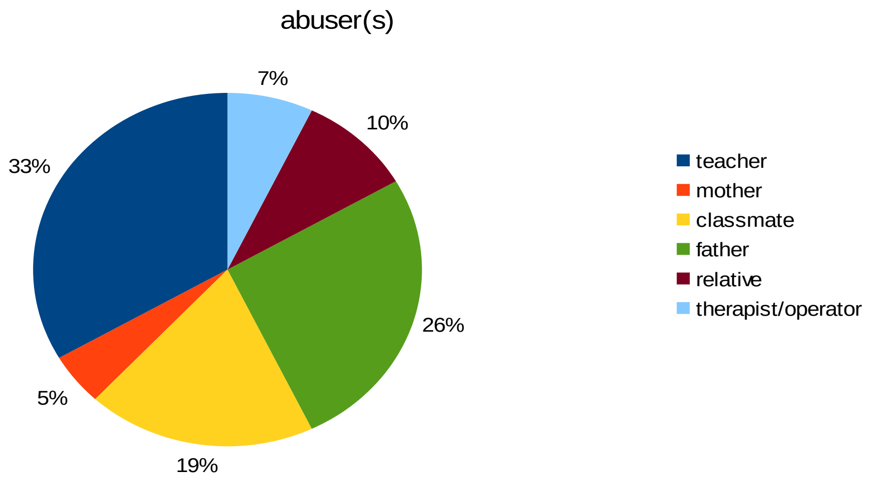

Figure 20

The **places of maltreatment** are connected to the environments associated with the abusers. School can be found right on top (44%), followed by home settings (41%), care and health centres (12%) and residential care settings (3%).

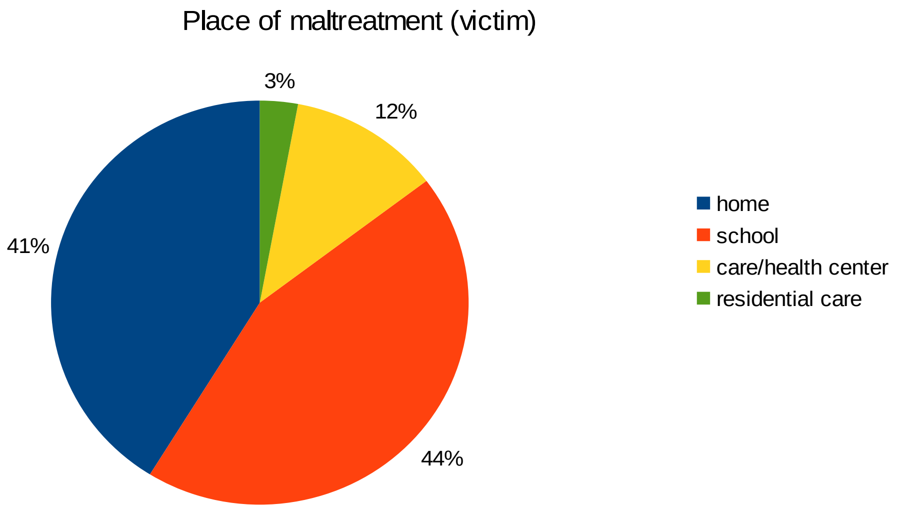

Figure 21

Short term consequences of maltreatment may vary, ranging from **behavioural disorders (79%)** to self-harming (9%) and violence against others (6%).

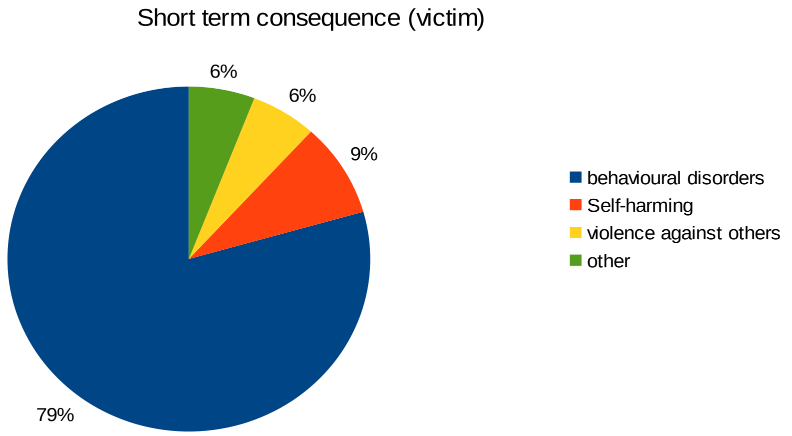

Figure 22

3.4. Risk factors

The analysis of section 4 of the Survey is related to **risk factors**. Risk factors were surveyed in order shed light on the most frequent factors that anticipate maltreatment.

The most **significant risk factors linked to the social context** are:

- denigration in 51% of cases;
- lack of sex education in 54% of cases;
- consciousness of not being appreciated by others in 48% of cases;
- and, above all, the **lack of training in recognising forms of maltreatment in 71,42% of cases.**

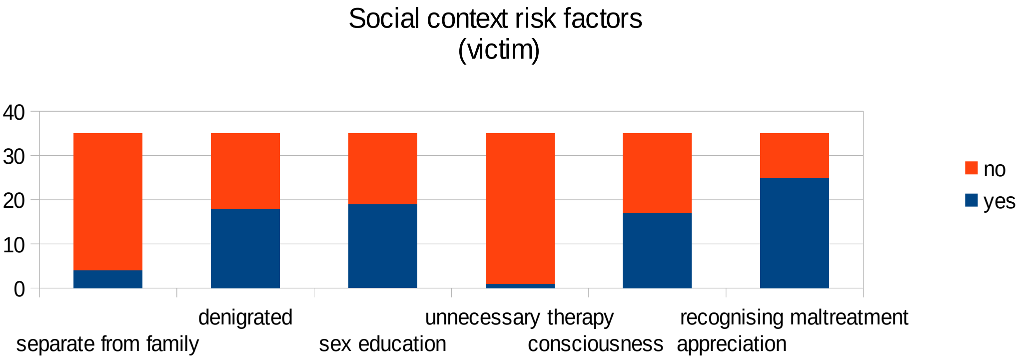

Figure 23

The **risk factors related to the family context** are all relevant. Among them, the following two are particularly important:

- lack of awareness about the risk of potentially being abused in 60% of cases;
- family discredit in 45,71% of cases.

The following elements appear not to play a significant role: burden of care, adequate parent-child bonding, lack of knowledge of the pathology.

In addition, as far as the **risk factors related to the family context** are concerned, only the job stability of the family has a significant impact (40%), while all the other factors taken into account (mental diseases of parents, parents' addiction to drug or alcohol, adequate parent-child bonding) seem not to be particularly significant.

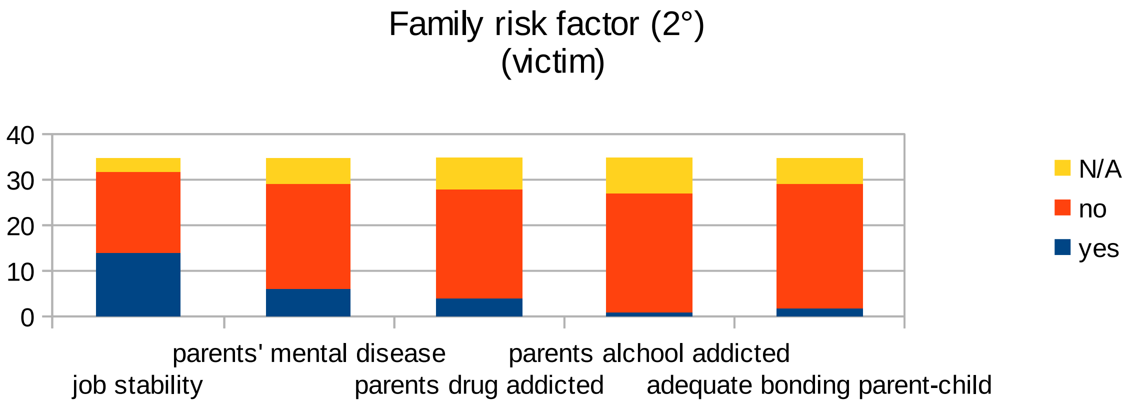

Figure 24

The **risk factors related to the child** show that the burnout of caregivers and the ability of the child to defend herself/himself appear not to constitute risk factors. In most cases they seem to be absent.

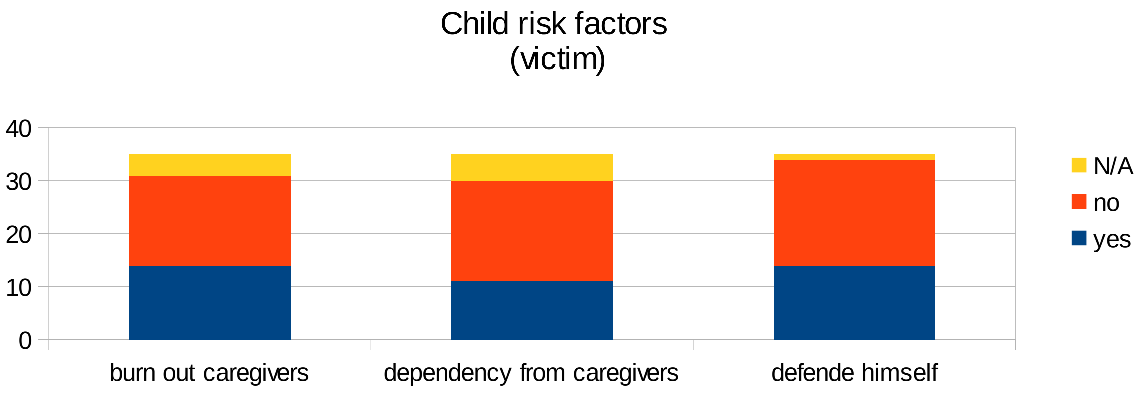

Figure 25

Among the **risk factors connected to the institutional context,** two elements are strikingly important:

- the humanization of centres in 94% of cases;
- the adoption of specific procedures for detection of maltreatment in 85,7% of cases.

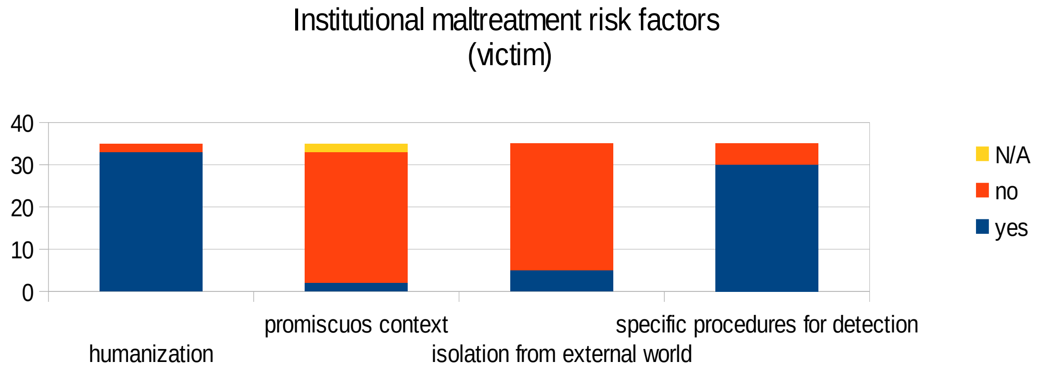

Figure 26

3.5. Preventive and protecting factors

Section 5 relates to the identification of **protection factors, namely those factors that may contribute to prevent and offset the risk of maltreatment**. This section takes different aspects into account. At the **social and community levels**, the adoption of measures that can implement the responsibilities of local communities appears highly relevant (51,4%). Other factors such as the inclusion of individuals into social life and the parents valorising the child have little significant impact.

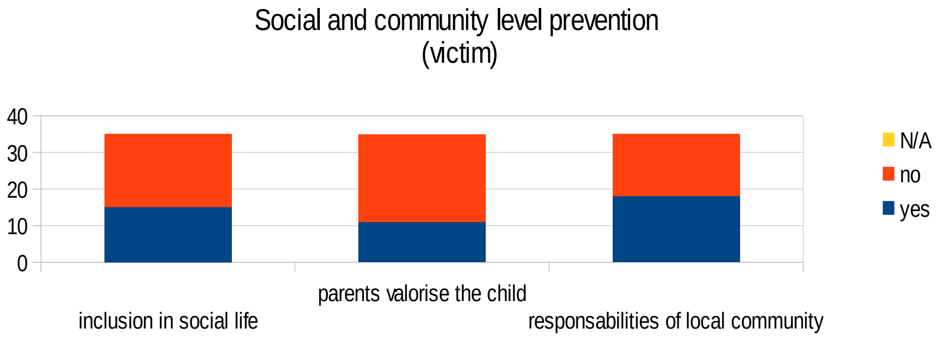

Figure 26

The **level of prevention in reference to the family** highlights that, among the cases analysed, a positive role is played by:

- parental training on children development and disability aspects (91,4%);
- strengthening of the interaction between care centres and families (88,5%);
- parental training on prevention and elimination of corporal punishments (85,7%);
- provision of support to parents to ease tensions (80%).

Prevention factors **outside the family and at the institutional level** include:

- operators being monitored (94%);
- appropriateness of procedures adopted by the staff (91%);
- adequate relation staff/children within the care centre (91%);
- adequate knowledge of the children's needs (88,57%);
- attention so that operators and caregivers are orientated towards building an open and constant relationship (82,85%);
- creation of an "open" institutional context (77,14%);
- involvement of caregivers into "training groups" aimed at raising their awareness about abuse (71,42%) - (25 individuals).

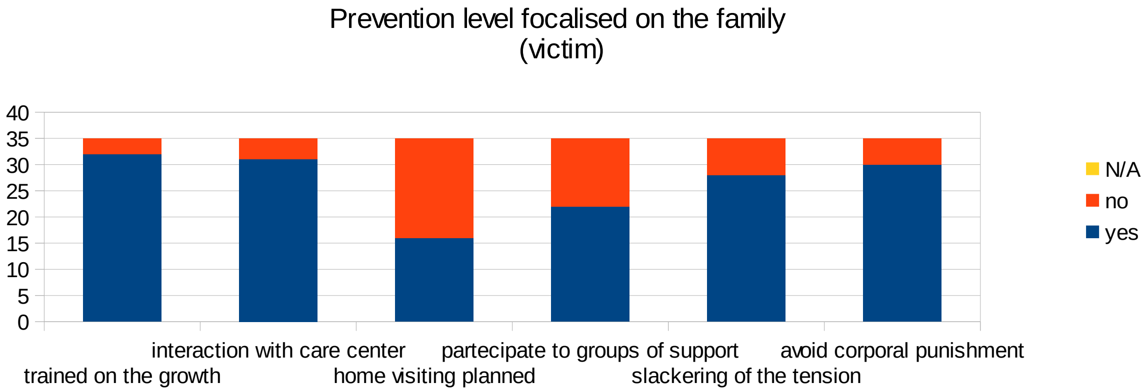

Figure 27

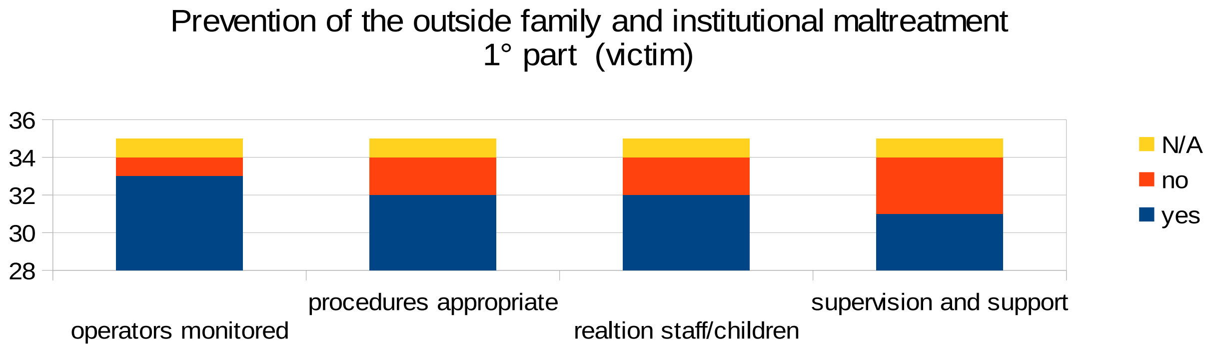

Figure 28

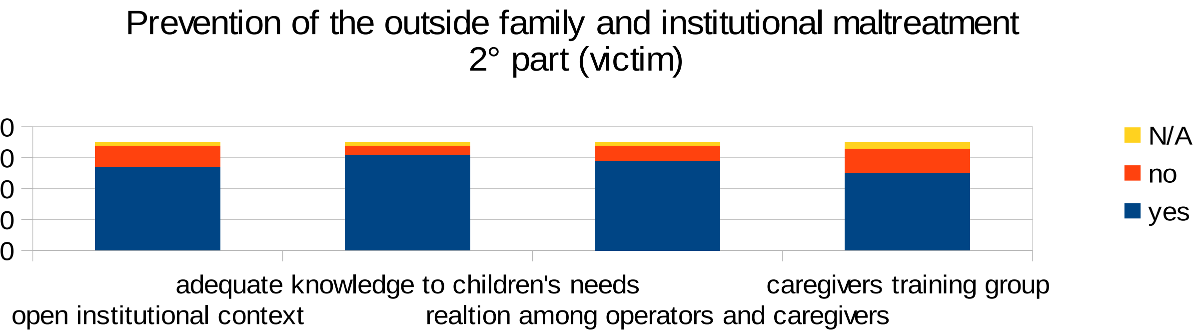

Figure 29

4. Survey on the Epidemiology and Characteristics of Violence Unintentionally Perpetrated by Children with ASD and on Risk and Protection Factors

4.1. Demographic information

The sample population of Questionnaire 2 (minors as perpetrators of maltreatment) is constituted by 28 individuals whose demographic characteristics are described in the following charts and tables.

Table 15 - Sex

	value	*percentage*
Male	24	86,00%
Female	4	14,00%

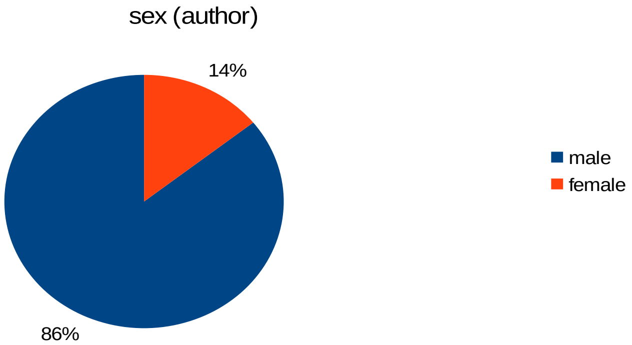

Figure 30

Table 16 - Child Family

	value	percentage
Origin family	26	93,00%
Adoptive Family	1	4,00%
Public Structure	1	4,00%

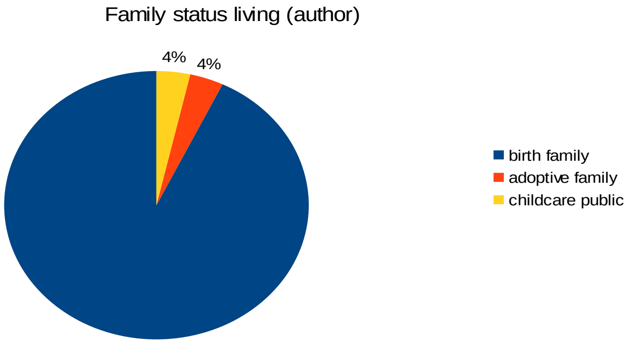

Figure 31

Table 17 - Economic Status

	value	percentage
Middle	19	68,00%
Low	8	29,00%
Below	1	4,00%

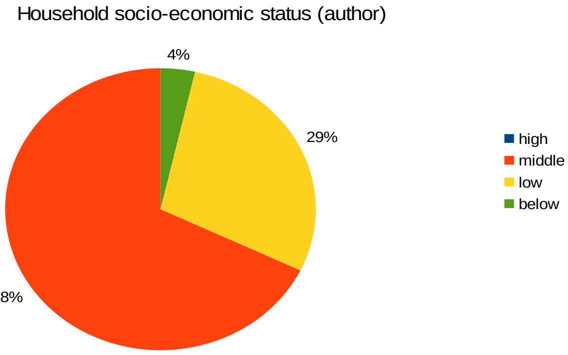

Figure 32

Table 18 Level of education		
	value	percentage
Some post secondary	10	36,00%
University degree	10	36,00%
Master /PHD	8	29,00%

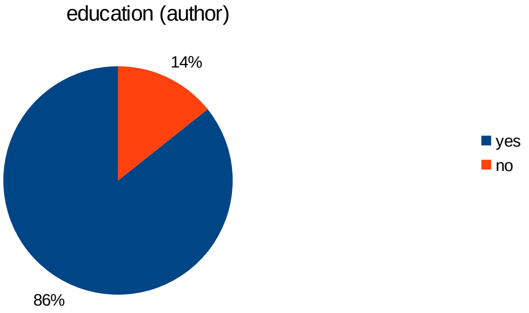

Figure 33

Almost all individuals (86%) from the sample population have received **school education**.

Table 19 Family status living		
	value	percentage
City	9	32,00%
Town	14	50,00%
Rural	5	18,00%

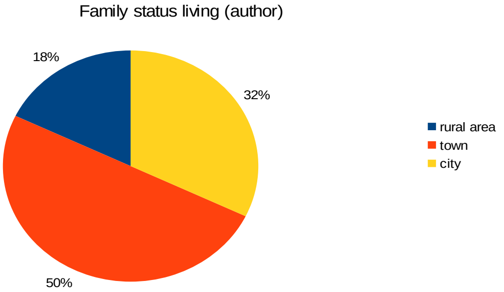

Figure 34

Table 20 Diagnosis ASD		
	value	percentage
Age < 5	15	53,57%
5<age<12	12	42,85%
>12	1	4,00%

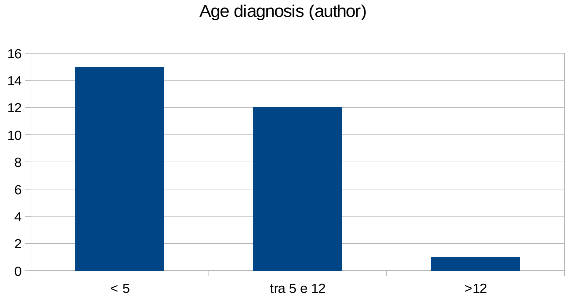

Figure 35

Even among unintentional perpetrators of violence, individuals who have received a **diagnosis of autism** show high incidence rates (64%) of population, followed by those with a **diagnosis of Asperger Syndrome** (36%).

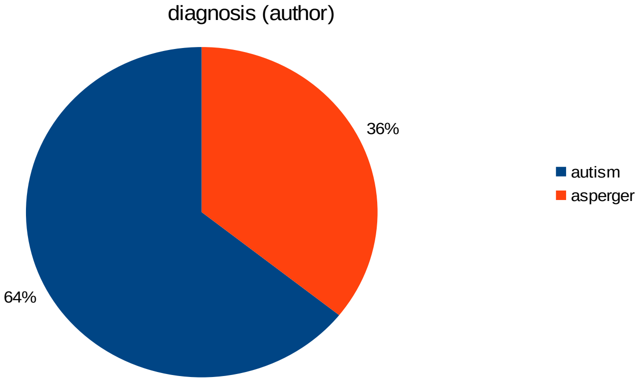

Figure 36

Table 21 Intelligence Quotient		
	value	percentage
Below average	19	68,00%
Average	7	25,00%
Abowe average	2	7,00%

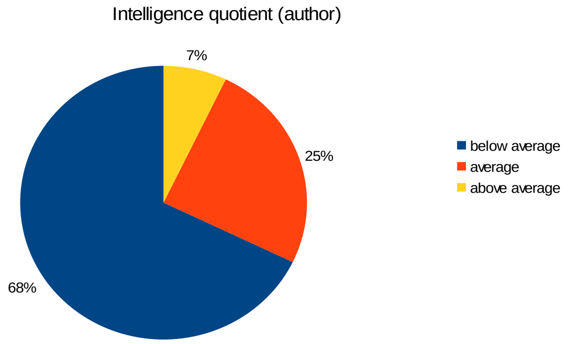

Figure 37

4.2. ASD Pathology information

The analysis of Section 2, which relates to **symptomatological characteristics**, shows that:

- concrete thinking can be observed in 67,85% of cases;
- difficulties in planning can also be observed in 67,85% of cases;
- excessive focus on details can be observed in 57,14% of cases;
- eye for details, instead, can be observed in 50% of cases;
- ability to understand the sense of the outside world can only be observed in 14,28% of cases.

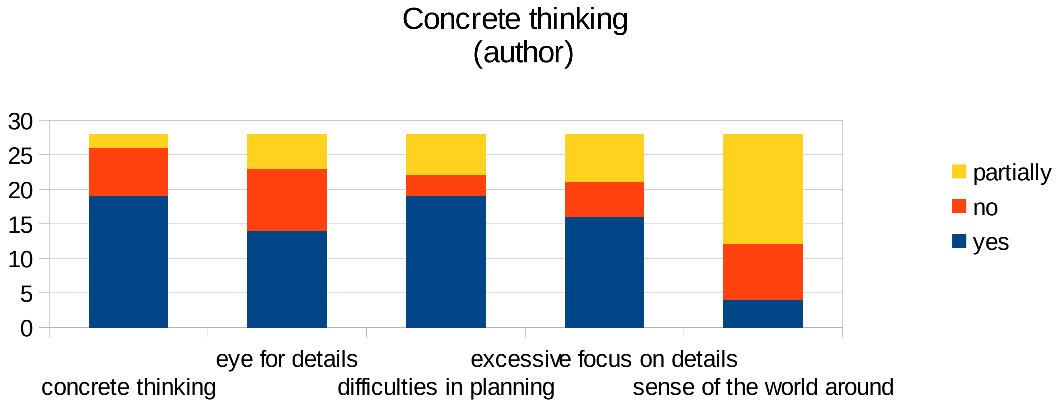

Figure 38

Communication skills are divided as follows:

- expressive language is present in 32,14% of cases;
- receptive language is present in 32,14% of cases;
- social interaction is only present in 17,85% of cases;
- visual eye contact is present in 32,14% of cases;
- expression of emotions is present in 21,42% of cases.

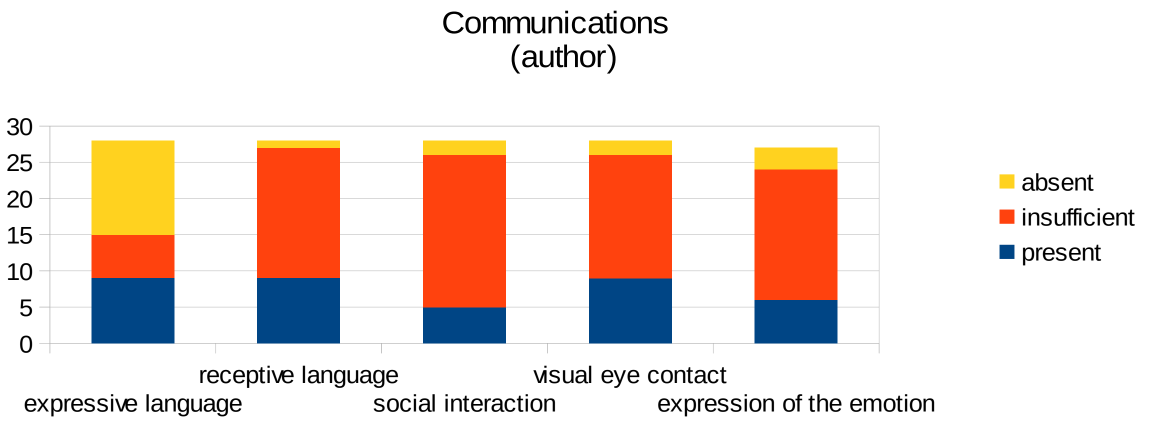

Figure 39

The same parameters indicated above are either absent/insufficient, at an incidence rate ranging between 70 and 80%.

As far as **sensory capability** is concerned, severe hypersensibility can be found in 60,7% of cases while severe hyposensibility can be found in 32,14% of cases.

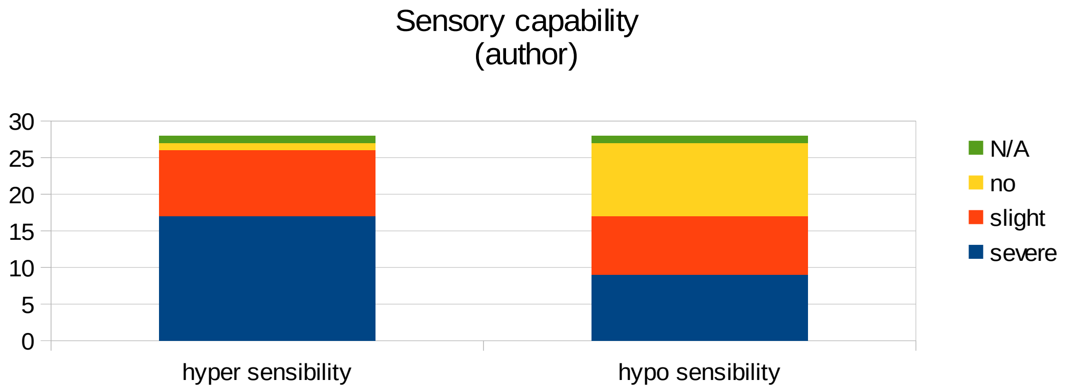

Figure 40

As far as **behaviour** is concerned, the analysis of the data collected shows the following characteristics:

- adherence to routine/stereotypes is present in 85,7% of cases;
- gross motor skills are present in 60,71% of cases;
- fine motor skills are absent/insufficient in 71,42% of cases;
- problematic/self-injurious behaviour is present in 46,42% of cases.

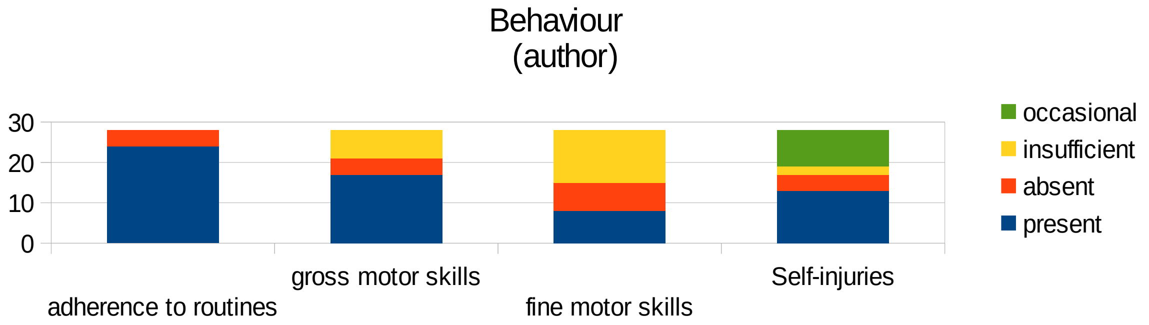

Figure 41

Psychiatric problems are distributed as follows:

- depression in 14,28% of cases;
- attention deficit and hyperactivity in 53,57% of cases;
- anxiety disorders in 46,42% of cases;
- aggressive impulses are significantly observed in 92,85% of cases.

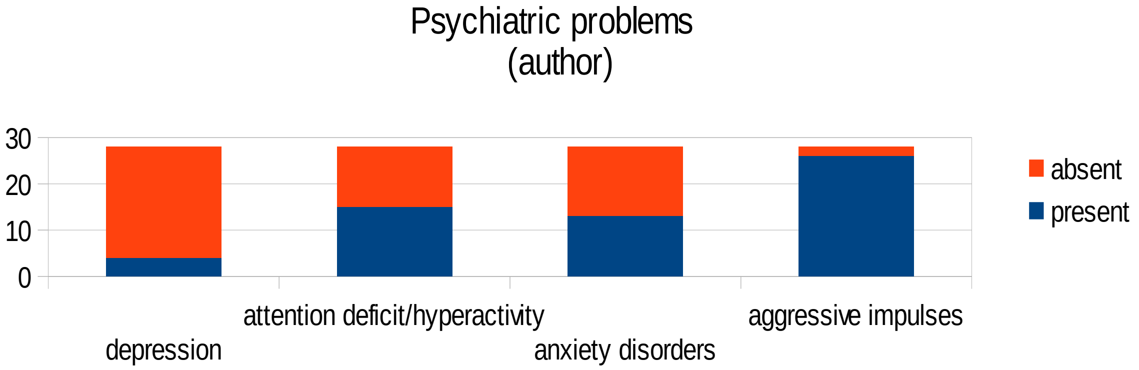

Figure 42

4.3. Perpetrated maltreatment and abuses (types and characteristics)

The third Section of Questionnaire 2 focuses on the types of **maltreatment perpetrated by young people with ASD** and their characteristics. The data show that:

- **maltreatment is almost always characterised by physical violence (87,09% of cases)**;
- **psychological maltreatment is present in 10% of cases**;
- **stalking behaviour is present in 3% of cases**.

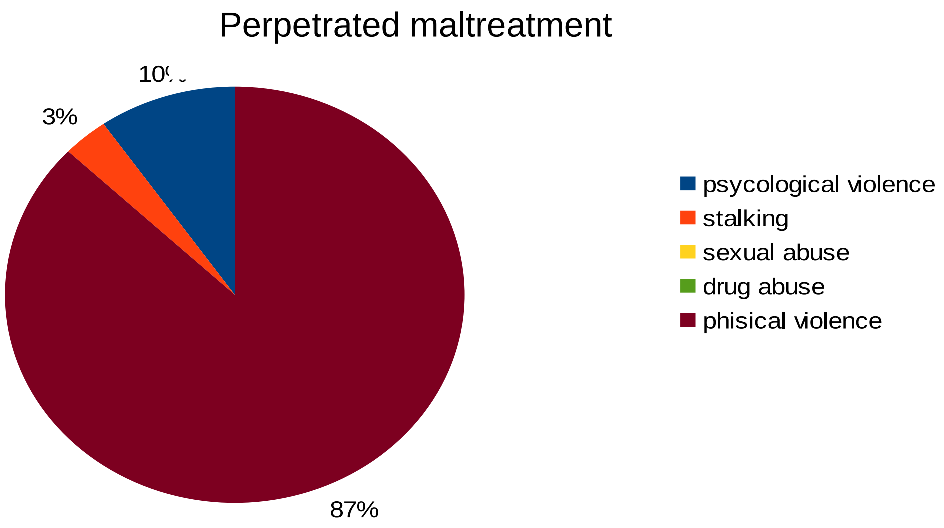

Figure 43

The age at which the **maltreatment was perpetrated** by the minor with ASD may vary. Covering different ages from 2 to 15, it shows a peak at the age of 10 (21,42%). Taking into account the foreseeable danger of the violence perpetrated, 46,42% of children and young people perpetrated maltreatment between the ages of 10 and 15.

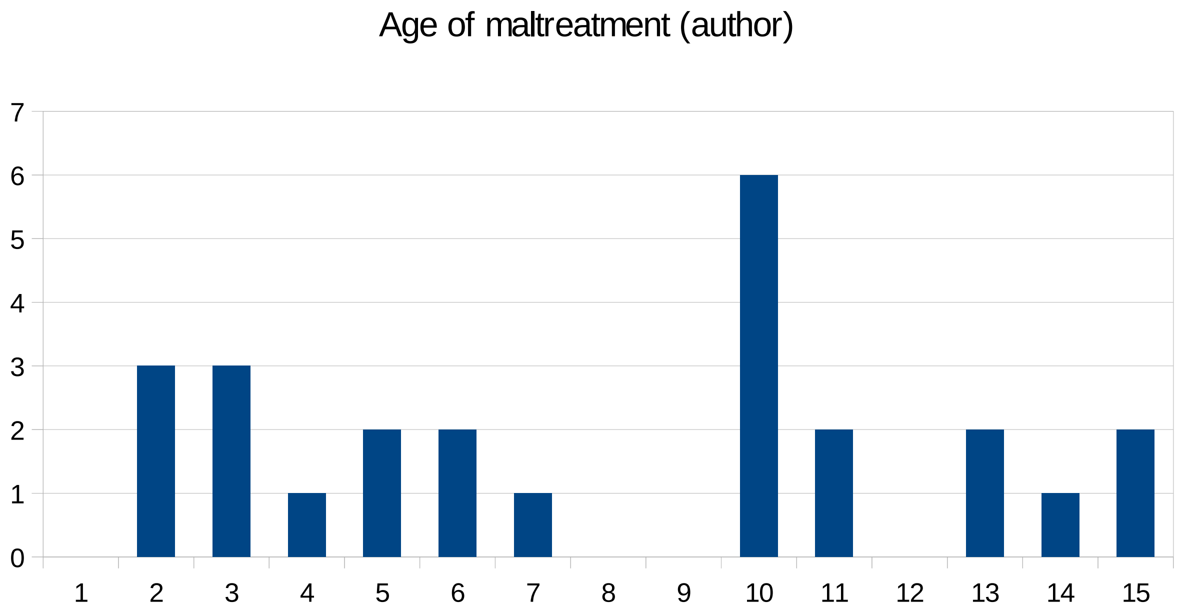

Figure 44

The **duration of** perpetrated **maltreatment** also covers a time span of 10 years, with a peak between 3 and 8 years of duration in 67,85 of cases%.

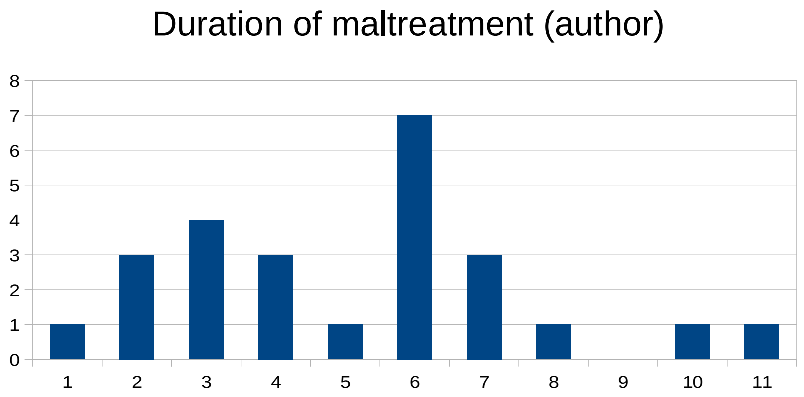

Figure 45

The victims of violence are diverse, and can be found among the members of the environments and the settings in which the minors with ASD live in. Among them, can be found:

- mothers in 25% of cases;
- fathers and therapists in 18% of cases;
- other peers in 13 % of cases;
- classmates in 12% of cases;
- teachers in 11 % cases.

Other victims of violence, showing very low percentages (9% in total), include: brothers and sisters, family friends and friends in general, boyfriends and girlfriends.

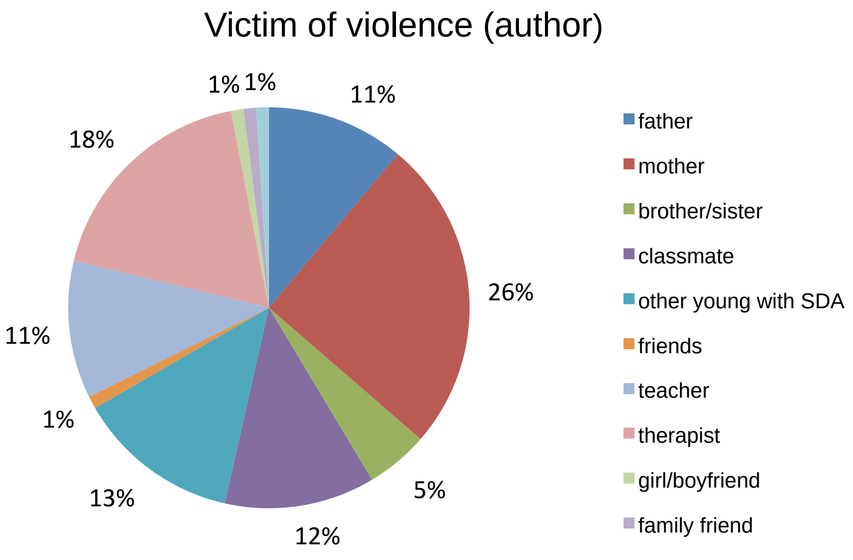

Figure 46

As far as the **awareness of the perpetrator about the violence perpetrated** is concerned, the available data show that:

- the perpetrator is aware in 11% of cases;
- the perpetrator has no awareness in 21% of cases;
- the perpetrator has partial awareness in 25% of cases;
- the perpetrator declares that they will do it again in 14% of cases.

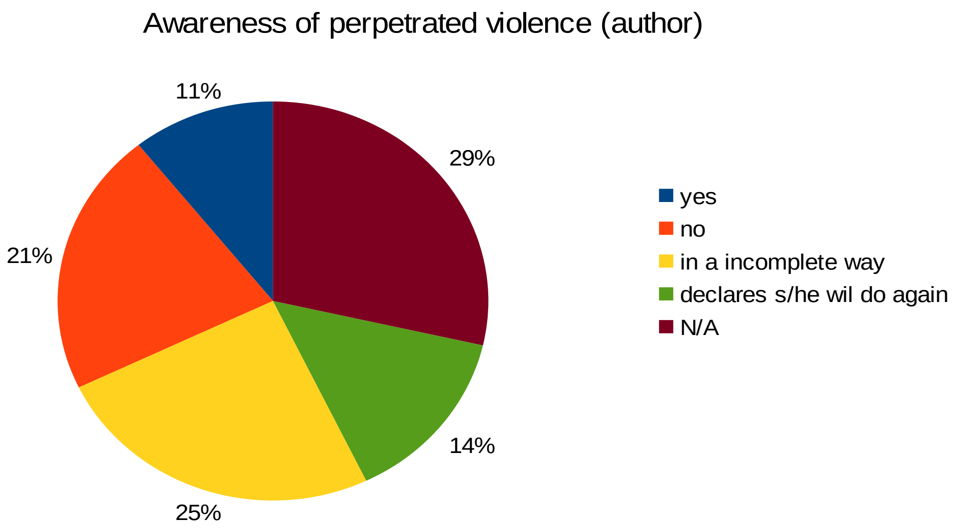

Figure 47

When asked if the subject had conducted **genetic examinations** (paragraph 3.5), the answer was negative in 96% of cases (27), and affirmative only in reference to one subject (4%).

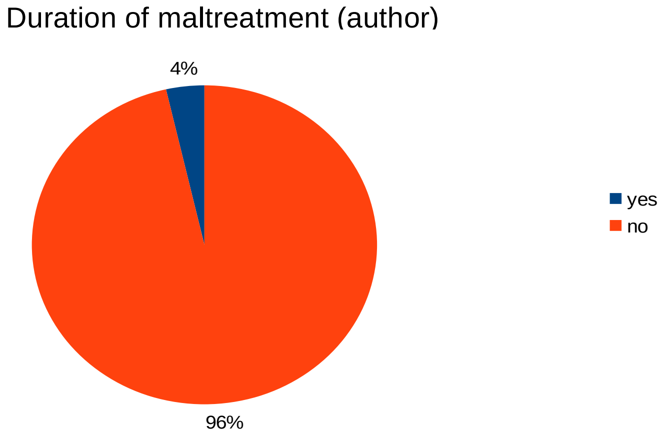

Figure 48

As far as the **profile of the young people** is concerned, it emerges that:

- none of them resulted as being addicted to drug or alcohol, or to have problems with the law;
- 42,85% of them have pharmacological addiction.

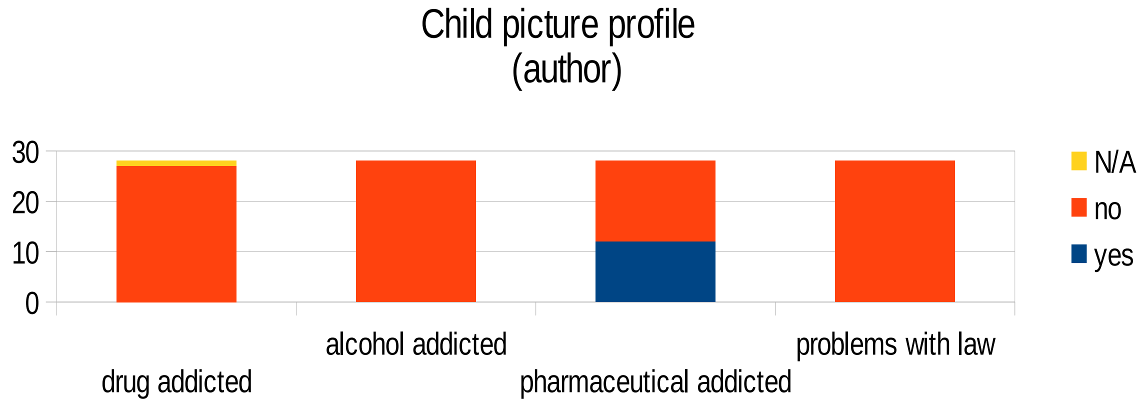

Figure 49

4.4. Risk factors

Section 4 (Risk Factors) shows that the highest risk factors, especially in relation to the **social context**, include the following:

- the persons involved in the support and care services are not sufficiently trained to detect and prevent aggressive behaviours from occurring (64,28%);
- the young person is not aware that they deserve respect from others (32,14)%;
- the young person did not receive adequate sex education (25%);
- denigration within the social context can be observed in 25% of cases;
- the separation from the family proves to be positive only in 10,7% of cases.

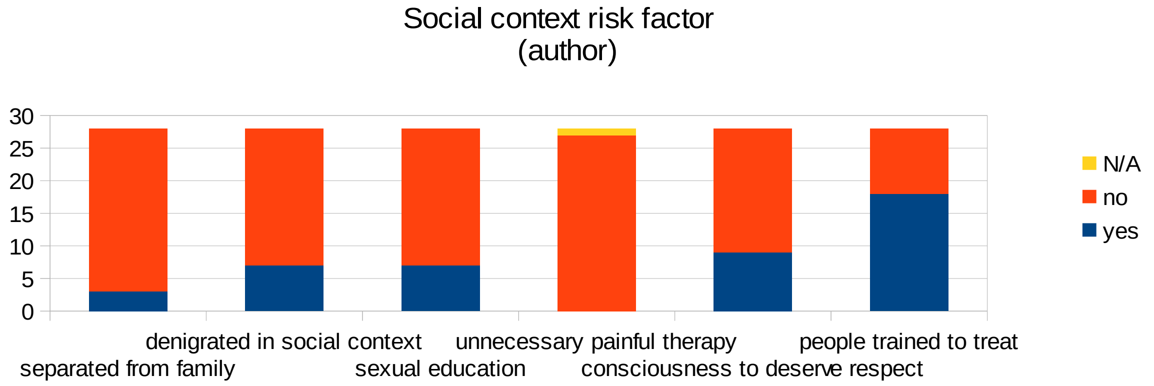

Figure 50

The analysis of **family risk factors** shows that risk factors can be ranked as follows:

- in the first place can be found the need from parents to have adequate knowledge and skills in order to respond to the specific problems of the child (75%);
- in those situations where parents are required to make particularly demanding efforts, they respond inadequately or they resort to corporal punishment (53,57%);
- parents are not alerted that their child runs a bigger risk to perpetrate abuse, and they do

not have sufficient knowledge that allows them to recognise that their child might be an abuser, nor to protect their child from perpetrating abuse (46,42%);
- the family think of their child as being a misfit, and see the disability as something dishonourable to them (39,28 %).

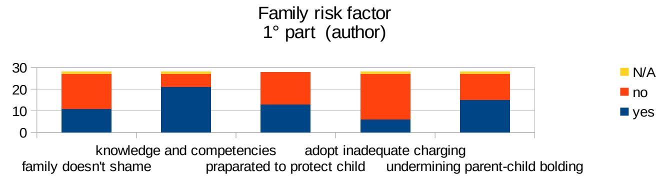

Figure 51

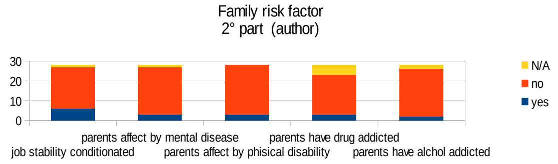

Figure 52

The analysis of **risk factors concerning the young person** shows the following:

- the caregivers' burnout is a risk factor in 75 % of cases;
- the young person is often provided assistance by the same caregiver, who eventually ends up giving in to the requests made by the young person (64,28 %);
- the young person’s age affects the chances of perpetrating abuse (39,28 %);
- the control of aggressive impulses can be observed 28,57% of cases;
- nearly or no influence would apparently derive from the intake of drugs or medicines.

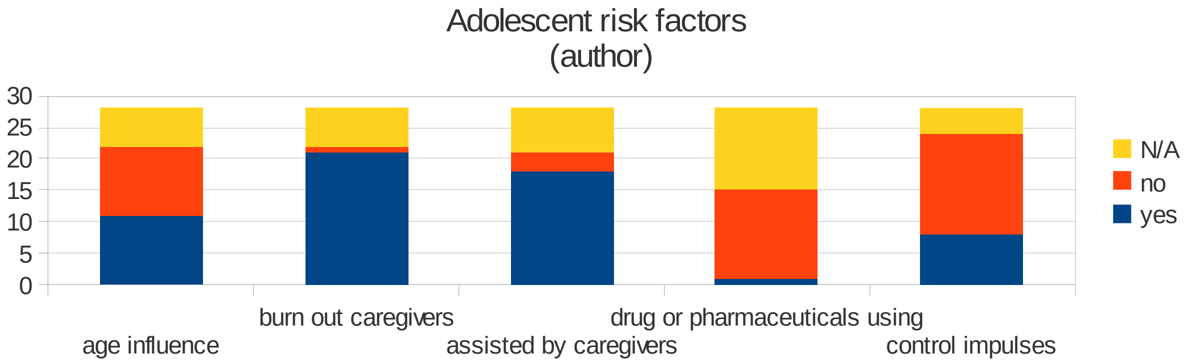

Figure 53

Risk factors related to institutional maltreatment all recorded positive answers about the need for institutions providing support to the young person to develop humanizing contexts. Institutions should be able to provide adequate assistance in order to meet the young people’s physical and psychological needs. Also, institutions should follow specific procedures to interpret signs of possible maltreatment and to prevent maltreatment from happening.

The young person who lives in a condition of isolation from the outer world runs a risk of being the victim of maltreatment in 25% of cases. Promiscuous caring is considered as being a risk factor in 3,57% of cases.

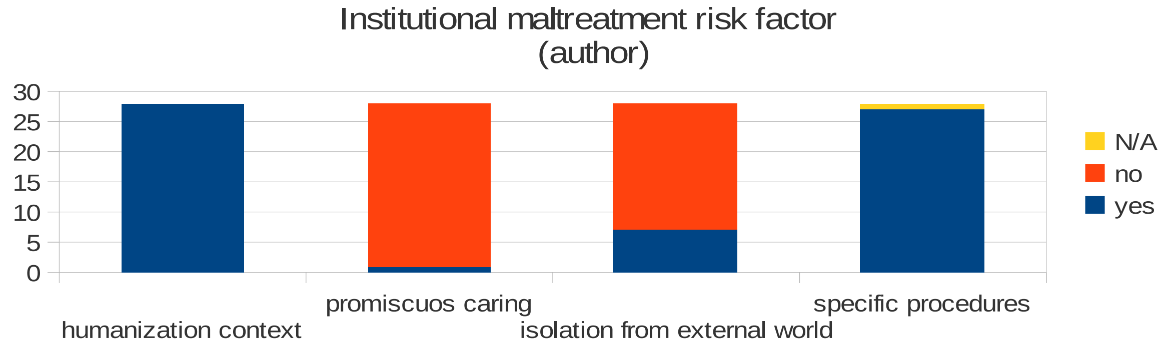

Figure 54

4.5.Preventive and protecting factors

Social and community factors of prevention include the following: a good level of inclusion (85,7%), the involvement of local communities in sharing responsibilities connected to the well-being of young people (17,85%); the involvement of young people's parents in community activities (14,28%).

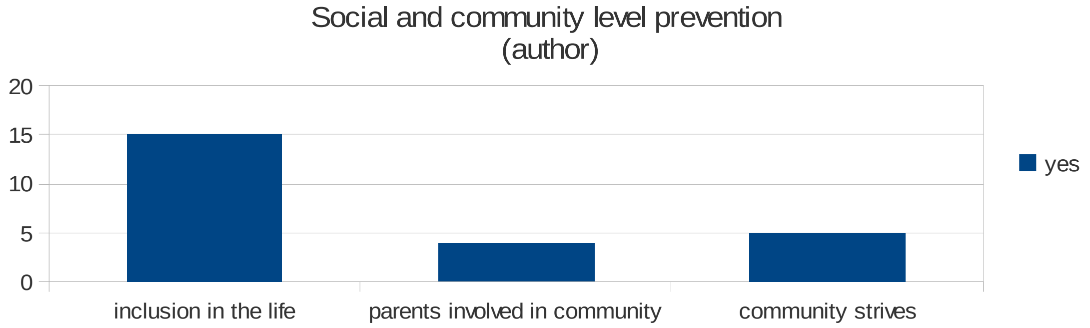

Figure 55

As for **the level of prevention focalised on the family,** the data analysed show the following:

- parent–child interaction remains the most important factor in 92,85% of cases;
- parental training on the growth, development and disability of the child is considered important in 85,71% of cases;
- parental training to avoid corporal punishment is considered important in 60,71% of cases;
- provision of support to parents in order for them to "ease" tensions is considered important in 50% of cases.

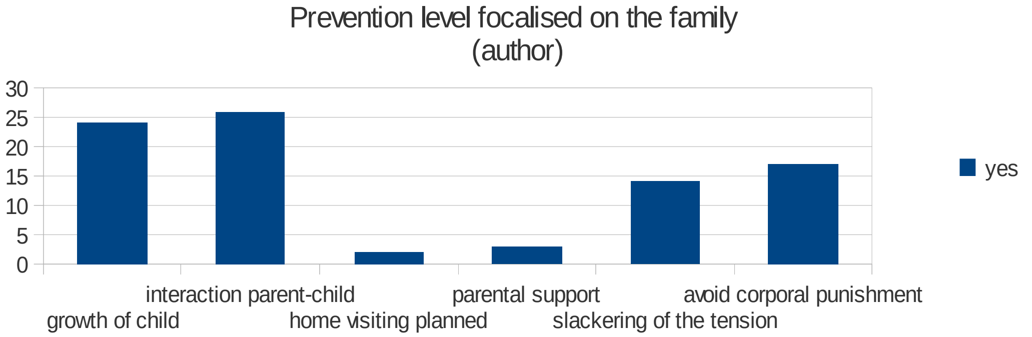

Figure 56

In order to identify the **factors of protection for adolescents**, it is observed that all the suggested actions are positively valued by the people interviewed, and they can be ranked as follows:

- prevention of aggressiveness and interventions to end isolation in 100% of cases;
- the adoption of adequate support measures to increase the communication skills of the adolescent, and the adoption of adequate prevention programmes in 92,85%;
- parental involvement in their child's education in 85,71% of cases;
- sex education ranks last (32,14%).

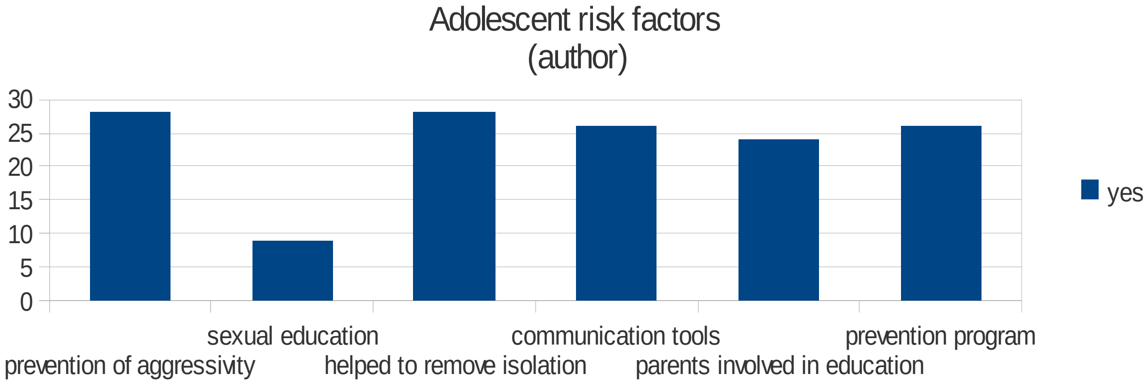

Figure 57

Factors of protection outside the family and outside institutional maltreatment prove to be equally effective, showing a high number of positive answers in 100% of the different items taken into account. These include: the need to adequately train both support and caregiving staff; the development of adequate relationships between staff members and the adolescents seeking assistance to the care and support centres; the provision of supervision and support to operators; an open institutional context; the knowledge of special needs of young people receiving assistance; an adequate relationship between operators and caregivers; the involvement of caregivers in training groups aimed at providing training on how to recognise aggressive behaviour.

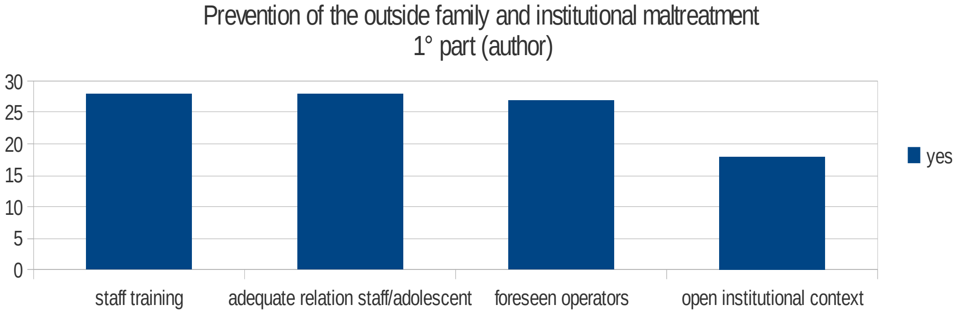

Figure 58

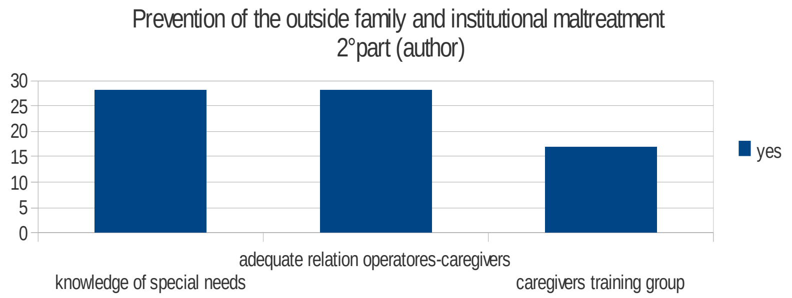
Prevention of the outside family and institutional maltreatment 2°part (author)
30
25
20
15
10
5
0
yes
knowledge of special needs
adequate relation operatores-caregivers
caregivers training group

Figure 59

6. Final Considerations

Due to the limited number of samples available and the specific features of the situations analysed, the data collected through these two surveys do not allow to make considerations that are valid for all the population with disorders of the autism spectrum, with specific reference to age, sex, demographic characteristics, times for diagnosis and aspects of symptomatology of the clinical expression.

By comparing the data from the literature it can be confirmed that male individuals with ASD are higher in numbers compared to females with ASD, and that the diagnosis of autism is given earlier in life when compared to the Asperger diagnosis. It is also confirmed that individuals with Asperger Syndrome show a higher intelligence quotient than individuals with autism.

These are the general data of the two populations of individuals with ASD that can be compared to the data coming from the available literature (MMWR, suppl. 2013 - Autism Europe, 2013).

As regards the results of the two surveys, it can be confirmed that individuals with ASD, especially those with intellectual disabilities, are at high risk of abuse, like all other disabled people (Sullivan & Knutson, 2000 – D.S. Mandell et al. 2005).

The aspects of symptomatology of this population are not significantly different from the ones that can be found in the available literature. The neurologic and psychiatric symptoms observed are not significant. The only exception relates to the side effects caused by medicines, which in some research studies are considered as being a factor that leads caregivers and other subjects to use abusive behaviour.

The maltreatment suffered is, in most cases (78%), constituted by **physical and psychological violence and neglect**. **The ages at which maltreatment was perpetrated cover the entire development stage of children, with a peak between 4 and 10 years of age.** The duration of abuse itself deserves special attention as for aspects of chronicity, as there are subjects who were **abused for 9 years** (L. Jones et al. 2012 – P.M. Sullivan – J.F. Knutson, 2000).

Abusers belong to all the categories of individuals who come into contact with minors with ASD: teachers, parents as well as classmates, therapists and operators. Home and school are the settings where abuse mainly occurs (85 %) (P.M. Sullivan – J.F. Knutson, 2000).

Behavioural disorders are the short-term consequences arising from abuse (79%), and they end up exacerbating the basic characteristics of symptomatology of young people with ASD.

Risk and protection factors are often symmetrical. Among the protection factors, on the one hand, **parental training about the aspects of growth and disability of the child** and a higher level of integration between the family and the therapy centre play a very significant role. Among the risk factors, on the other, **inadequate behaviours on the part of the family, also due to the family's lack of training (denigration, inability to recognise the abuse, lack of sexual education, etc.) constitute very relevant factors in relation to the sample surveyed.**

Additional statistically relevant protection factors include the following: an effective organization of therapy and support centres; the training and control of operators; the adoption and verification of protocols and procedures to recognise and report the abuse; an open and collaborative relationship between operators and families (Autism Europe, 1998 e 2013).

Risk factors such as the burnout of operators, the burden of cares and the lack of knowledge on the pathology have little or no importance in this survey. Only the stability of work of families appears to be important in relation to risk factors. This data draws the attention to *welfare state* policies related to the support given to families left with a heavy burden of care (disabled people, the elders, etc.) (D. Miller, 2002 -Autism Europe, 1998).

The population of individuals who received a diagnosis for ASD and who are unintentional victims of violence is mostly composed by males (86%). The data referring to demography, socio-economic status of families, features of symptomatology and age of diagnosis do not differ from the data previously discussed.

In this survey, individuals with a diagnosis autism who are found to be unintentional perpetrators of violence are higher in numbers (64%) than individuals with Asperger Syndrome (36%).

In addition, the analysis of associated psychiatric disorders reveals that individuals belonging to this population show greater aggressive impulses (92,85%) than the population of victims (62,85%). All the other features of psychiatric symptomatology are different.

The types of maltreatment perpetrated by these subjects are, for the most part, in the form of physical violence (87,09%). The age at which maltreatment begins shows a peak at around 10 years of age (21,42%). As already mentioned in the analytical section of this report, it shall be underlined that the age range of **young people perpetrating violence ranges from 10 to 15 years in 46,42% of cases**. This is a very significant element when it comes to the implementation of preventive measures (G. Bronsard, 2010, R. Mills, 2009 – B.G. Haskins and A. Silva, 2006).

In this case as well, the victims of maltreatment are parents, therapists (43%), as well as classmates, other peers with ASD and teachers (36%). (AA.VV. Nord J. Psychiatry, 2008)

Only 3 individuals (11%) show awareness about the violence they have perpetrated, while all the others have either no or partial awareness about it, or declare they will perpetrate violence again.

It is important to underline that according to the survey no young person has made use of drugs or alcohol, while 42,85% of the sample population has taken medicines.

Lacking or inadequate training of operators in recognising and preventing aggressive behaviour from occurring, **denigration** against the young people, **inadequate parental responses** to the child's needs and the **use of corporal punishment** are all predominant risk factors among social and family-related factors.

The burnout of caregivers and their condescending attitude towards young people with ASD are among the most common risk factors for the young people (75% and 64,28% respectively).

Significant gaps are identified within the institutions, and interventions are needed in order to end isolation of people on the autism spectrum and to promote their involvement in contexts of humanization as well as in contexts that are able to enhance their communication and interpersonal skills.

This survey also highlights that the **protection factors** at different levels require **significant levels of integration** into social life (85,7%), the **parental involvement in community activities** (14,28%); **parental training** in order to make parents able to communicate with their child, the elimination of corporal punishment of children, and parents should be provided with support in order to ease the tensions that they experience on a daily basis.

All the factors relating to the young people considered in this survey prove to be necessary and positive. Indeed, they aim at fostering the involvement of young people into social life, as well as improving their physical and psychological well-being. It should be noted that the data collected from the question relating to the importance-need of sex education do not display statistically significant relevance.

The survey supports the conclusion that **increasing the knowledge about autism and improving the social integration of people on the autism spectrum and their self-awareness can constitute a protection factor from the risk of being a victim of abuse**.

Knowledge on autism and effective training of operators and families in this field can prevent them from experiencing **burnout** and stress. In turn, these factors can generate different forms of violence, that can sometimes turn into psychological, physical, sexual and care-related abuse.

Abuse can be avoided by increasing the knowledge on autism, by sharing experiences and by preventing social isolation of people on the autism spectrum and their families from happening.

The social isolation of families prevents them from fully enjoying the social context. At the same time, social isolation implies that people with ASD and their families are not recognised as bearers of rights, and this prevents them from enjoying social respect. When the person on the autism spectrum is recognised as being a “person”, not despite their diversity but by virtue of the fact that they are bearers of values, then they will be finally be endowed with legal personality.

Avoiding stigma and increasing the involvement of people on the autism spectrum (defined by the DSM-5 as follows: “without accompanying intellectual impairment and without accompanying language impairment”) and their families in the decision-making process can help reducing the suffering deriving from abuse and improving the quality of their lives.

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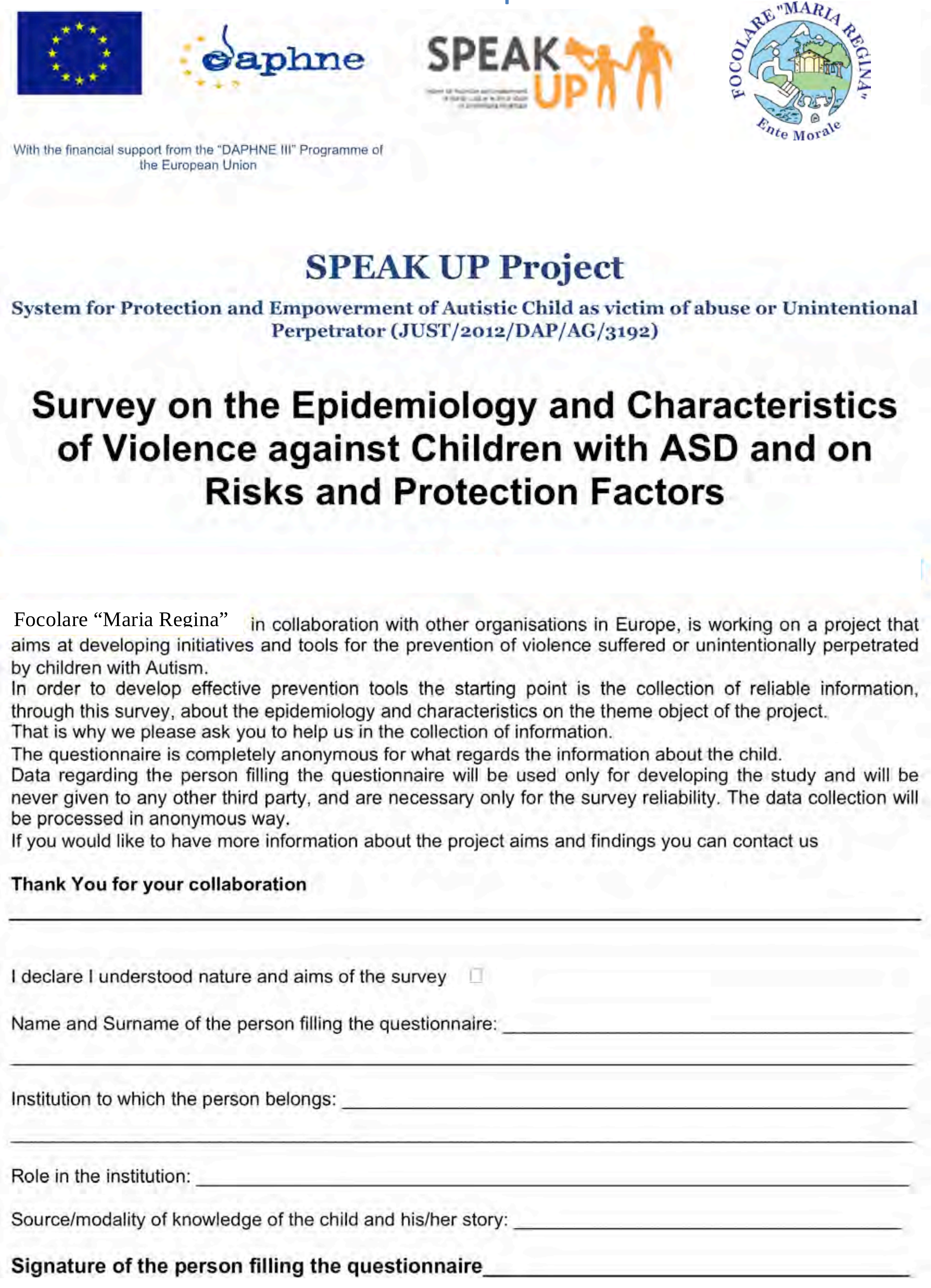
APPENDIX - The questionnaire



With the financial support from the "DAPHNE III" Programme of the European Union

SPEAK UP Project

System for Protection and Empowerment of Autistic Child as victim of abuse or Unintentional Perpetrator (JUST/2012/DAP/AG/3192)

Survey on the Epidemiology and Characteristics of Violence against Children with ASD and on Risks and Protection Factors

Focolare "Maria Regina" in collaboration with other organisations in Europe, is working on a project that aims at developing initiatives and tools for the prevention of violence suffered or unintentionally perpetrated by children with Autism.
In order to develop effective prevention tools the starting point is the collection of reliable information, through this survey, about the epidemiology and characteristics on the theme object of the project.
That is why we please ask you to help us in the collection of information.
The questionnaire is completely anonymous for what regards the information about the child.
Data regarding the person filling the questionnaire will be used only for developing the study and will be never given to any other third party, and are necessary only for the survey reliability. The data collection will be processed in anonymous way.
If you would like to have more information about the project aims and findings you can contact us

Thank You for your collaboration

I declare I understood nature and aims of the survey ☐

Name and Surname of the person filling the questionnaire: ______________________________
____

Institution to which the person belongs: ______________________________________
____

Role in the institution: ____

Source/modality of knowledge of the child and his/her story: __________________________

Signature of the person filling the questionnaire______________________________

SECTION 1. – Demographic information

1.1 Age _____ **1.2 Sex**: ☐ Male ☐ Female **1.3 Country of residence**: ________________________

1.4 Ethnicity: ☐ West Europe ☐ East Europe ☐ Africa ☐ Asia ☐ North America ☐ South America

1.5 Family status living of the child:
☐ Birth Family ☐ Adoptive Family ☐ Father in a new family ☐ Mother in a new family
☐ Lone P. (Father) ☐ Lone P. (Mother) ☐ Other relative: __________________
☐ Childcare Priv Instit. ☐ Childcare Pub Instit. ☐ Other: __________________________

1.6 Household's socio-economic status:
☐ High ☐ Middle ☐ Low ☐ Below poverty threshold

1.7 Highest level of education in the household:
☐ Secondary or less ☐ Some postsecondary ☐ University Degree ☐ Master/PhD

1.8 Is the father employed ☐ Yes ☐ No

1.9 Is the mother employed ☐ Yes ☐ No

1.10 Siblings: ☐ Brothers n.____ ☐ Sisters n.____ ☐ Rank in siblings ____

1.11 Education: Does (did) the child attend any education service? ☐ YES ☐ NO
IF YES:
☐ Infancy Sch. ☐ Primary Sch. ☐ Secondary Sch. ☐ Training Courses ☐ Other

1.12 Labour: Does (did) the child do any work (voluntary/paid) activity? ☐ YES ☐ NO

1.13 Area of residence
☐ Rural Area ☐ Town (<15k inhab.) ☐ Town (>15k <100k inhab.) ☐ City (> 100k inhab.) ☐ Suburbs

SECTION 2. – ASD Pathology information

2.1 Age of the child when the pathology was diagnosed: ______

2.2 Diagnosis: ☐ Autism ☐ Asperger ☐ Rett ☐ Other (Specify): ____________________________

2.3 Cognitive activity

2.3.1 Intelligence quotient: ☐ Below average ☐ Average ☐ Above average

2.3.2 Concrete thinking: ☐ Yes ☐ No ☐ Partially

2.3.3 Eye for details: ☐ Yes ☐ No ☐ Partially

2.3.4 Difficulties in planning and putting in sequence: ☐ Yes ☐ No ☐ Partially

2.3.5 Excessive focus on details: ☐ Yes ☐ No ☐ Partially

2.3.6 Make sense of the world around: ☐ Yes ☐ No ☐ Partially

2.4 Communication

2.4.1 Expressive Language ☐ Present ☐ Insufficient ☐ Absent

2.4.2 Receptive Language ☐ Present ☐ Insufficient ☐ Absent

2.4.3 Social Interaction ☐ Present ☐ Insufficient ☐ Absent

2.4.4 Visual Eye Contact ☐ Present ☐ Insufficient ☐ Absent

2.4.5 Expression of the emotions ☐ Present ☐ Insufficient ☐ Absent

2.4.6 Understanding the others (two way conversation) ☐ Present ☐ Insufficient ☐ Absent

2.5 Sensory capability

2.5.1 Hyper-sensibility ☐ Yes ☐ No

2.5.2 Hypo-sensibility ☐ Yes ☐ No

2.6 Behaviour

2.6.1 Adherence to routines/stereotypes ☐ Present ☐ Absent

2.6.2 Gross motor skills ☐ Present ☐ Absent ☐ Insufficient

2.6.3 Fine motor skills ☐ Present ☐ Absent ☐ Insufficient

2.6.4 Problematic (aggressive-self-injurious) ☐ Present ☐ Absent ☐ Occasional

2.7 Physical/Neurological Problems

2.7.1 Somatic Pains (dental/gastrointestinal/other) ☐ Present ☐ Absent

2.7.2 Sensory disorders (vision/hearing/other) ☐ Present ☐ Absent

2.7.3 Migraine ☐ Present ☐ Absent

2.7.4 Seizures ☐ Present ☐ Absent

2.7.5 Side effects from medications ☐ Present ☐ Absent

2.8 Psychiatric Problems

2.8.1 Depression ☐ Present ☐ Absent

2.8.2 Attention deficit/Hyperactivity ☐ Present ☐ Absent

2.8.3 Anxiety disorders ☐ Present ☐ Absent

2.8.4 Aggressive impulses ☐ Present ☐ Absent

SECTION 3. – Maltreatment suffered / suspected (types and characteristics)

3.1 Type of suffered/suspected maltreatment

☐ Physical Maltreatment ☐ Sexual abuse ☐ Neglect ☐ Psychological abuse
☐ Bullying ☐ Stalking ☐ Drug abuse ☐ Bad therapeutic treatment

☐ Other: ____________________

3.2 Times and duration

3.2.1 Age of the child when the maltreatment started (yy/mm) [____] [____]

3.2.2 Duration of the maltreatment (yy/mm) [____] [____]

3.3 Abuser(s)

☐ Father ☐ Mother ☐ Teacher ☐ School assistant
☐ Relative ☐ Classmate ☐ Unrelated ☐ Therapist/operator
☐ Acquaintance/Family friend ☐ Other: ____________________

3.4 Place where the maltreatment was perpetrated:

☐ Home
☐ Open Space (street, park, etc.)
☐ Other: ________________________
☐ School
☐ Residential care center
☐ Care/Health center
☐ Play/sport activity center

3.5 Identified short term consequences:

☐ Running away from home
☐ Self-harming
☐ Other: ________________________
☐ Suicide attempt
☐ Somatic disorders
☐ Behavioural disorders
☐ Violence against others

3.6 Consequences on the symptomatology (referred to SECTION 2)

(please, specify, if it is possible, how the maltreatment has influenced the ASD symptomatology)

____
____
____
____
____
____
____
____

3.7 Does the maltreated/abused child manifest consciousness of the suffered violence?

☐ Yes ☐ No ☐ In an incomplete/inadequate way

SECTION 4. – Risks factors (Which factors, in the different contexts, had a significant impact)

4.1 Social context risk factors

The child was separated from his/her family ☐ Yes ☐ No

The child was denigrated in the social context or was treated in an inadequate and/or violent way ☐ Yes ☐ No

Sexual education was considered ☐ Yes ☐ No

Unnecessary painful therapies were made in the thought that disabled child do not feel pain ☐ Yes ☐ No

The child has the consciousness to deserve other appreciation ☐ Yes ☐ No

People engaged in the assistance and caring were trained enough in recognising maltreatments ☐ Yes ☐ No

4.2 Family risk factors

The family does not consider the child a “diverse”, and does not see the disability as a shame and does not suffer the lack of a “normal” child ☐ Yes ☐ No

Parents have adequate knowledge and competencies to give an answer to particular requirements of the child ☐ Yes ☐ No

Parents are aware that their child has a greater risk to suffer abuses and were prepared to recognise and protect the child from at risk situations ☐ Yes ☐ No

In the conditions in which the child requires a particular and abiding effort, parents adopt adequate charging and never adopted any corporal punishments ☐ Yes ☐ No

The bonding parent-child are adequate ☐ Yes ☐ No

The economic effort required for assistance and caring of the child conditioned negatively the job stability of the parents ☐ Yes ☐ No

One or both the parents is(are) affected by a mental disease ☐ Yes ☐ No

One or both the parents is(are) affected by a disability ☐ Yes ☐ No

IF YES: (specify) ____

One or both the parents is(are) drug addicted ☐ Yes ☐ No

☐ One or both the parents is(are) alcohol addicted ☐ Yes ☐ No

---

4.3 Child risk factors

The particular and abiding caring needs has created a burn out on their caregivers ☐ Yes ☐ No

The emotive dependency of the child from his/her caregiver inhibit him/her to react against an abuse, also because s/he fears to lose the existing contact ☐ Yes ☐ No

The child can defend himself or report the suffered abuse ☐ Yes ☐ No

---

4.4 Institutional maltreatment risk factors

In the institutions which assists the child, there is a context of “humanization” and “listening” to his/her psychological and physical needs ☐ Yes ☐ No

The child lives in a promiscuous caring context with potentially violent and dangerous people ☐ Yes ☐ No

The child lives in isolation form the external world ☐ Yes ☐ No

In the institution there are specific procedures to report/monitoring the detections ☐ Yes ☐ No

SECTION 5. – Preventive, protecting factors (On the base of the observation of the disabled minor, which one of the following preventive/protective factors could and can be adopted?)

5.1 Social and community level prevention

The child receives a good inclusion in the different expressions of social life ☐ Yes ☐ No

Parents and relatives take advantage from social leadership competences to “valorise” their child ☐ Yes ☐ No

The local community has responsibilities for the wellbeing of disabled child ☐ Yes ☐ No

---

5.2 Prevention level focalised on the family

The parents are trained on the growth and development of the child and his/her disability ☐ Yes ☐ No

In the care centre the interaction parent-child is reinforced ☐ Yes ☐ No

“Home visiting” interventions are planned and developed ☐ Yes ☐ No

The parents participate to groups of parental support ☐ Yes ☐ No

The parents receive interventions able to represent a kind of “slackening” of the tension of the burden ☐ Yes ☐ No

The parents are trained to prevent and avoid “corporal punishment” ☐ Yes ☐ No

---

5.3 Prevention level focalised on the child

The child is helped to protect him/her-self ☐ Yes ☐ No

The child receives education on his/her body and on sexuality ☐ Yes ☐ No

The child is helped to reduce/eliminate social isolation ☐ Yes ☐ No

The child is supported with tools and competences to increase the capacity to communicate ☐ Yes ☐ No

The parents and the whole family are involved in the education of their child ☐ Yes ☐ No

The adopted prevention programmes are appropriate for the level of capability, culture and gender of the disabled child ☐ Yes ☐ No

---

5.4 Prevention of the outside family and institutional maltreatment

The operators that work with the child are monitored ☐ Yes ☐ No

The procedures for the training of the staff are appropriate ☐ Yes ☐ No

In the care centre an adequate relation staff/children is assured ☐ Yes ☐ No

Supervision and support interventions for the operators are foreseen ☐ Yes ☐ No

It is guaranteed an “open” institutional context that embraces family members and allows not planned evaluation meetings by external evaluators ☐ Yes ☐ No

Adequate knowledge about the special needs of disabled children is assured to caregivers ☐ Yes ☐ No

Relations among the operators of the institutions and the caregivers are familiar and based on an open and constant relation ☐ Yes ☐ No

The caregivers are involved in training group about the awareness of the abuse ☐ Yes ☐ No

SECTION 6. – Open Comment

The person filling the questionnaire report in the following lines any related further aspect of the case study:

SECTION 7. – **TO BE FILLED IF THE CHILD MAKES ANY KIND OF WORK ACTIVITY**

7.1 Work typology

☐ Protected employment ☐ Crafting laboratory ☐ Apprenticeship ☐ Other: ____________________

☐ Type of work activity: ____

7.2 Maltreatment/violence suffered within the work context by

☐ Employer ☐ Other workers ☐ Other: ______________________________

7.3 Type of suffered/suspected maltreatment

☐ Physical maltreatment ☐ Sexual abuse ☐ Neglect ☐ Psychological abuse
☐ Bullying ☐ Stalking ☐ Drug abuse ☐ Other: ____________________

SECTION 8. – **TO BE FILLED IF THE CHILD IS A PERPETRATOR OF VIOLENCE**

8.1 Presented self/other harmful behaviour(s)

☐ Suicide attempt ☐ Violence against peers ☐ Violence within the family

☐ Violence at school ☐ Homicide attempt ☐ Other: ______________________

8.1.1 The type of violence was the same of the suffered one (if any) ☐ Yes ☐ No ☐ Not relevant

8.2 Type of perpetrated maltreatment

☐ Physical Maltreatment ☐ Sexual abuse ☐ Neglect ☐ Psychological abuse
☐ Bullying ☐ Stalking ☐ Drug abuse ☐ Other: ____________________

8.3 Victims

☐ Family members ☐ Classmates ☐ Acquaintance/Family friend ☐ Therapists
☐ Teachers/sch. operators ☐ Another disabled p. ☐ Boyfriend/girlfriend

☐ Other: ____________________

8.4 The child manifests the awareness of the perpetrated violence

☐ Yes ☐ No ☐ In an incomplete way ☐ Declares s/he will do it again

☐ Other: ____

With the financial support from the "Daphne III" Programme of the European Union

SPEAK UP Project
System for Protection and Empowerment of Autistic Child as victim of abuse or Unintentional Perpetrator (Just/2012/DAP/AG/3192)

Research

Part 2.

Survey for the exchange of ideas and valid actions for protecting and young people with ASD in assisting and caring organization

Report and final considerations

PART 2

Index

Research conducted by Tatiana D’Ambrogio, Child Neuropsychiatrist and Health Director of Fondazione Il Cireneo Onlus per l’Autismo
Contributors: Germana Sorge, Chief of Fondazione Il Cireneo Onlus per l’Autismo; Serena Luciani, Psychologist and Psychotherapist; Lucia D’Agostino, Psychiatric Rehabilitation Technician
Editing and supervision: Graziano Foia

1. The Survey

The following report is the second part of the first research action held by Speak Up.

Its aim is to share the results of the research conducted in the involved countries, concerning the **Good Practices** existing in organizations for the support and care of children and young people with ASD.

The first stage of the project aimed at collecting and analysing the practices already existing in the Countries involved in the project. By means of an accurate bibliographic research, it was possible to point out those critical elements connected to the global care of people with ASD that, for the complexity of their needs, make a very vulnerable group, even among disabled people. An inadequate sanitary and/or educational intervention negatively impact people with autism as well as the whole reference system, families in particular. Along with other elements, they are relevant risk factors for the abuse and maltreatment of people with autistic spectrum diseases. The "Draft Code of Good Practice on prevention of violence against persons with autism", issued in 1998 by Autism Europe, underlines that there are **three** main classes of risk factors for maltreatment and abuse: **the lack of adequate facilities**; **the lack of professional training; the lack of proper support to families.**

On the basis of the data emerged, a questionnaire was prepared and then submitted to different organisations operating in the Countries involved.

The aim of this part of the research was not, obviously, to evaluate the quality of the services provided within the organisations, nor to assess the efficiency of their staff, but to collect the greatest possible amount of data concerning the standard procedures developed by institutions, with the purpose of preventing the onset of maltreatment and/or abuse and violent actions unintentionally perpetrated by people with ASD.

The questionnaire design allowed for open answers (semi-structured), allowing for comments and/or suggestions and for the promotion of a greater development of strategies and/or services oriented towards the prevention of maltreatment/abuse of people with ASD.

2. The questionnaire:

Survey for the exchange of ideas and valid actions for protecting children and young people with ASD in assisting and caring organization.

The questionnaire comprises three sections:

> **Section 1:** organisation of the service oriented towards the detection and prevention of violent behaviours.
>
> This section aims at identifying how the organisation is organized in terms of staff, availability of programmes to manage the interaction with families and with the school, and the corresponding procedures to be activated in case of suspected abuse/maltreatment.
>
> The open questions are designed to obtain answers about possible critical elements and suggestions for improvement.

Section 2: staff training.

This section of the questionnaire investigates the strategies that the organisation puts in place for the reduction of possible risk conditions in the perpetration of abuse/maltreatment. As for this, the following factors were taken into consideration: the training of staff in managing behavioural problems; the training of operators in detecting the possible reasons for these behaviours and among them, in particular, the presence of tools to understand possible physiological causes, with particular attention to physical pain. Included in this section are also questions concerning pharmaceutical treatments and the availability of procedures for the detection and management of pharmacological abuse.

Section 3: stress of workers and evaluation of burnout.

This section includes the analysis of the measures put in place for the reduction and the detection of possible signs and symptoms of burnout, and the corresponding procedures for its management.

Section 4: cases.

In this final section organizations are asked to describe the difficulties encountered in the management of a case of abuse they possibly had to deal with.

3. Survey Results

The results reported here come from the elaboration of the questionnaires filled in by institutions and/or service providers operating in the partner countries of the project, but also from other countries that participated in the research, upon being informed following the work of dissemination carried out by Autism Europe.

In particular, data were collected from:

Country of the organisations that filled in the questionnaires	
Spain	4
Poland	5
Italy	4
Luxembourg	1

Hereafter are reported the questions contained in the questionnaire named “Survey for the exchange of ideas and valid actions for protecting children and young people with ASD in assisting and caring organization” – (questionnaire in appendix) and a synthesis of the answers provided. The results are presented while maintaining the 4 sections the questionnaire is divided into.

3.1 Section 1: Service organization for the detection and prevention of violent behaviours

1.1 The question relates to the presence or otherwise of a dedicated person for the safeguarding of children with ASD. Most of the organisations (12/14) state the presence of such person, but they also contemplate the possibility to strengthen the service. Among the suggestions, it emerges, in particular, the need to be able to make reference to an agreed protocol, in order to facilitate the communication among the organisations and to identify the best strategies to deal with those situations of suspected/known abuse. It is also deemed important to invest in training, as a basic tool to increase awareness among families, operators and the general society about the different types of abuse and/or maltreatment suffered by victims with ASD. According to several organisations, such dedicated figure (or more than one), while operating within the organization, should be able to access the resources to create a safety net around the child and his/her family.

1.2 The question investigates whether a multidisciplinary team operates within the organisations. All the organisations indicate the presence of a multidisciplinary team that ensures a suitably wide range of interventions, and that also deals in different ways with those aspects relating to the protection against and prevention from abuse. The critical issues revolve around the difficulty to establish connections locally and with other agencies in order to ensure the protection and care of the minor.

1.3, 1.4., 1.5. and 1.7. pursue the aim of assessing the level of acceptance and involvement of the family on the path towards the care of the child/adolescent with ASD. The goal is that of improving the resilience of the family and to reduce the risk factors of possible abuse/maltreatment. This is the consequence of a lack of understanding on part of families for their own child, and a lack of training for managing problematic behaviours or the family's isolation. The analysis of the answers provided sheds light on the following:

1.3. The question asks if caregivers have contacts that allow them to reach the representatives of the organisations. All organizations (14/14) state that families are able to make contact with the representatives of the organisations, either through telephone contacts or by attending meetings where they can directly liaise with the operators. It is also deemed appropriate to facilitate communication by means of new technologies, and to develop, even within care pathways outside the organization, specialized services on Autistic Spectrum Disorders, in order to ensure continuity of support even outside the centres.

1.4. The question asks if a protected private space is available inside the organisations, where service users can meet their families and operators. All the answers provided (14/14) state that privacy is ensured by the law on data protection. There are, anyways, situations where, due to limited financial resources, it is not possible to create proper spaces inside the centre to make sure that meetings take place in a serene environment and in a comfortable space. The need to identify areas where families can meet in order to make the interaction easier among both service users and operators is raised in these situations. All the more so when the aim is that of supporting those families at higher risk of perpetrating abuse/maltreatment.

1.5. The question asks if any internal procedures are followed by the centres as for the care of the patient and their family. Most of the organisations (13/14) answered positively. In some cases the roles are well defined, there are procedures aimed at responding effectively to the different needs of service users and their families and, through frequent follow ups, the effectiveness of the actions put in place is assessed. A multidisciplinary team is usually in charge of specifically responding to the needs of service users and families. In case of more specific needs arise, organizations seek the assistance of external institutions (health, education, justice) by making contact with them. The aspects to be implemented mainly concern the possibility to allow for a greater exchange of information among operators, families, and external operators in order to be able to respond more specifically to specific, individual needs. It would be useful to pursue the cooperation with external operators who, although not dealing with the therapeutic pathway, would play a crucial role in the global care of service users (i.e. legal support). The importance of training for operators and the possibility to refer to a shared list of good practices to ensure continuous improvement in the management of cases is reaffirmed.

1.7 The question asks if the organisations promote activities for the families so to provide a better understanding of Autistic Spectrum Disorders, also by offering psychological support. The answers underline that organisations, although able to respond in a quite satisfactory way to the need of providing a space for families, encounter some difficulties when it comes to meeting different needs with the same efficacy. Given the complexity and different symptomatology through which the pathology is manifested during the development, it is often difficult to provide the service in a way that gives proper attention to different needs. In order to improve this service, the suggestion made is to foster greater cooperation among the different organisations involved, with the aim of sharing experiences and practices. Many organizations believe it is useful to resort to professional experts of abuse and maltreatment, so to receive a proper training to adequately deal with this topic with families.

1.6 The question investigates whether there is a professional expert within the organization who deals with the school-family relationship. Although all the organisations involved claim to have such professional (14/14), the answers provided must be assessed in the light of the different school regulations in place within the several countries involved. In some cases, reference is made to the existence of special needs schools or internal school services available within the organisation itself. In those countries where children with ASD have the possibility to attend public schools, together with children with typical development, it seems that the greatest difficulties derive from the fact that schools do not always seem to be prepared to face the needs of children and young people with ASD. This issue is mainly ascribable to the fact that, due to the scarcity of funds, it is not possible to ensure an ongoing exchange of information among organisations, schools and families. A proper exchange of information would allow for a global care of the individual with ASD, by creating a net for mutual support, in particular for the correct management of problematic behaviours. In light of this, most of the organisations involved in the questionnaire believe it is important to implement this service in order to allow for a greater cooperation among centres, schools and families. Another issue appears to be that special education teachers do not always hold a permanent assignment and teaching substitutions are frequent, even within the same school year. Such a situation further undermines the possibility to build a consistent and stable educational pathway for children with ASD, and further reduces the possibility of creating a network.

1.8 This question refers to the availability or otherwise of procedures that support families in dealing with possible behavioural crises occurring at home.
Most of the organisations state that they offer to families a space for listening, analysing and supervise the behavioural issues their patients display at home. At the same time, though, it emerges that sometimes it is not possible to meet the families' demand and needs for home visit services, as demand is greater than availability. All organisations believe it is important to access more funding in order to implement home visit services and/or streamline bureaucracy to activate such services, so to make more consistent the rehabilitative intervention and to provide adequate support to face the behavioural problems occurring in the domestic context.

1.9 and 1.10 refer instead to the procedures concerning the approach to be adopted when dealing with negligence, neglect or physical/mental abuse at home. In particular:

1.9. This question asks whether procedures are available to cope with situations of negligence or neglect happening within the family. Only 8 organization out of 14 indicate that such procedures are available, but most of the them also report some problems connected to such procedures. In case of suspected negligence or neglect, it can sometimes become difficult to prove a real situation of negligence or a case of family mismanagement in relation to a person with ASD. For example, some people with ASD show marked hypersensitivity or rigidity to specific stimuli. Getting an haircut, having their nails clipped or wearing new clothes can prove extremely difficult for them, and also for their families. These are not cases of negligence. The family, instead, is unable to manage such situations.

1.10. This questions asks if specific procedures are available to report cases of abuse to competent authorities, whenever there are clear signs of physical or mental abuse. Again, only 8 organizations out of 14 claim to be following a specific procedure in such circumstances. In addition, most of them declare that the lack of such procedures could lead to a drop in abuse reports.
This phenomenon can be partially ascribable to the difficulty in identifying, especially in non-verbal individuals with autism, clear signs of maltreatment. In some cases, these signs can actually be the result of self-injurious behaviour exhibited by individuals with ASD. Therefore, there is a risk of getting to the wrong conclusions. In addition to that, even in the case of reasonable suspicion of child abuse, people could still be reluctant to report the abuse because the different law enforcement services (the police and the judiciary) seem to lack the necessary knowledge and methodology to adequately investigate the matter and to take appropriate measures (how to perform an expert appraisal and what investigation methods should be conducted?). The suggestions given are those of setting up a specific service for disabled people who are victims of abuse, or to seek the counsel of an expert who is able to play an intermediary role among the social and legal services and the organisation reporting the abuse. The need to adopt clearer and

shared procedures in cases of abuse/maltreatment, ones that are developed with the support of local social, legal and medical authorities, is therefore reaffirmed.

In conclusion of the analysis of the data of this section, it appears evident that even when organizations comply with the necessary structural requirements, have adequate personnel and adopt the necessary methodologies, they may still run into difficulties. Such difficulties are attributable to a lack of networking among the different services that provide support to people with ASD, and to the lack of clear and shared procedures, especially in those situations at risk of abuse or of actual abuse.

3.2 Section 2: Staff Training

2.1 The question relates to the training of operators and the most appropriate methods to be used in order to manage problematic behaviours.
All the organisations (14/14) involved claimed they provide refresher courses for their experts, who receive training on how to perform behavioural functional analyses. These analyses aim at shedding light on possible antecedents of problematic behaviours, and on the consequences brought about by the surrounding environment, which can often reinforce such behaviours. Some organizations stress the need of offering supervision groups on a more frequent basis. This would allow to lower the risk of emotional overload for the group of caregivers, as they find themselves dealing with behavioural crises every day. Reference is made to the importance of leading experiential groups where the acquired knowledge can be put in practice, thus improving the ability of being together and increasing the theoretical knowledge.

2.2. The question investigates whether organizations follow common procedures when dealing with problematic behaviours, and whether experts are trained to perform them.
All organizations answered positively (14/14). It appears evident that some organizations follow internal protocols aimed at identifying and managing problematic behaviours. These are shared within the organization, where registers are kept to record and analyse information regarding such behaviours.
The professionals are frequently involved in training pathways, but the main difficulties seem to be related, at least for some organizations, to the scarcity of personnel who often feel overloaded with work and responsibilities. It is considered important to invest in continuous professional training, one that also includes team building, and to obtain funds to hire additional personnel in order to best address and analyse in depth those problematic behaviours. Several organisations report that among the causes that lead to the development of behavioural problems, sexual issues should receive particular attention, especially during the course of adolescence and even more in adult age. Those who deal with autistic spectrum disorders are aware that young people have sexual urges, just like other people do. Nevertheless, individuals with low-functioning autism in particular find it challenging to understand the dynamics of masturbation or show atypical sensory and perceptual responses.

2.3. This question relates to the training of personnel as for the identification of physical pain. Most of the organisations (10/14) report that they have conducted proper training for raising awareness among personnel on identifying pain as one of the possible reasons behind a behavioural problem. Some organizations indicate the presence of a doctor in their staff. Most organisations acknowledge that, due to the complexity in detecting pain in people with atypical sensory responses and sometimes with reduced or absent language abilities, it would be appropriate to provide further training and to have easy-to-use standards for a more accurate assessment and quantification of pain.

2.4. and 2.5. These questions aim at investigating the ability to identify whether physical pain is the cause of a behavioural crisis, as well as the assessment and pain management procedures performed by the organisations.

In particular:

2.4. Asks if operators are trained to identify physical pain as antecedents to problematic behaviours. 10 organizations out of 14 answered positively. In most cases, the need to resort to professionals who received proper training on Autistic Spectrum Disorders is pointed out. As for this, the importance of a training oriented towards recognising signs of pain, expressed through signs of nonverbal communication, or the variation in behaviour, is underlined. It is also deemed important to implement networking practices among organisations and families, so to raise awareness about the different ways used by patients to express physical pain.

2.5. The question asks whether an internal procedure is available within the organization for the assessment and management of physical pain. Only 1/3 of organisations answered affirmatively (5/15). Several organizations highlight the lack of a clear procedure to assess and, if necessary, address the physical pain of patients. In some organizations no doctors are available. In addition to that, and for some countries in particular, general practitioners lack the necessary knowledge about autism so to ensure a correct assessment of the possible causes of pain and the selection of a proper therapy. In several countries it is also reported that outpatient healthcare, and sometimes hospital healthcare too, provide inadequate assistance to people with autism, as the characteristics and peculiarities that go along with ASD are not given the necessary consideration. Individuals with ASD, in fact, find it challenging to wait for their turn in a crowded waiting room. They can also experience a sensory discomfort when coming into contact with some medical devices, or they may be unable to understand what is going on and, as a result, they can get scared.

2.6 This question investigates the main reasons why service users receive a pharmacological treatment.

2.7 The question investigates an important issue, pharmacological abuse, and asks whether clear procedures are available within the organization to detect and report this form of abuse. Half of the organisations (7/14) provided a negative response, pointing out that the lack of clear procedures is ascribable to internal issues, and to a greater extent to more general aspects. More specifically, some countries lack guidelines that provide counselling to families and caregivers on evidence-based practices, namely those therapies based on recent scientific research studies. The lack of these guidelines expose people with ASD to the risk of pharmacological abuse, as they may take ineffective and/or potentially harmful medicines, or may take medications that are excessively used for behavioural control.

3.3 Section 3: Health workers stress and burnout self-assessment

3.1 This question asks whether the working time is organised so to ensure a fair distribution of workload, and if the staff rostering is effective. 13 organizations out of 14 answered affirmatively.

3.2 This question investigates the availability of specific measures for the prevention and reduction of stress risk factors. In this case, 11 out of 14 organisations answered positively.

3.3 This questions asks if operators are provided with the necessary information so to be able to recognise burnout signs and symptoms, 9 organisations out of 14 provided an affirmative answer.

3.4 This question asks if the caregivers are able to recognise burnout signs and symptoms, and if they are aware of the effects that this can have on their work, with both patients and their families. Nearly all organizations answered affirmatively (13/14).

3.5 The question investigates the procedures adopted by the organisations to face the risk of burnout. Being aware of the high risk of burnout, most organisations declare that they put in place strategies oriented towards the prevention of burnout. This is done by supervising the team of operators. In case of burnout, some organisations declare not to have a staged procedure for intervention yet. Several organizations report that their limit is linked to the fact that the counselling group and the coaching service are managed by the personnel employed by the organization, while having such services managed by personnel from outside the organization would prove more effective and functional.

3.4 Section 4: Cases

3.4. The question asks if, within the organizations, there have been cases of suspected/actual abuse; 7 organisation out of 14 report that one case has occurred. Questions 3.4.1 and 3.4.2 ask to explain how such case has been managed and what were the difficulties connected to it.

More specifically, 4 out of 7 cases were connected to the use of medicines. In two of such cases, due to prejudice or disinformation, families categorically refused the pharmacological therapy, even when the clinicians who were following the patients had declared that administering a pharmacological therapy was important. In such cases, the organisations acted as mediators between families and clinicians, suggesting frequent checks on the improvements made by means of strategic and timely observations, which have later showed a positive response to the therapy. Another case reports an example of pharmacological abuse. In this specific case, the therapy served the purpose of a pharmacological restraint, in terms of pharmaceutical dosage and combination of drugs, causing heavy side effects instead of improving the life of the person with

ASD and the one of his family. In the last case reported of pharmacological abuse, the medicines administered to the patient were deemed inappropriate and even harmful by the scientific community. The main difficulty in this case was ascribable to the lack of a clear procedure to be applied in situations alike.

Another case relates to a suspected case of abuse by a therapist. The difficulty encountered in this specific case was to reconstruct what happened because the child was nonverbal.

Another case reported concerns a case of neglect and negligence within the family context. After a long period of training aimed at raising awareness among the members of the family of the patient, which did not produce the expected results, the organization decided to seek the assistance of local social services, that are currently still trying to find appropriate solutions.

The last case refers to a case of unintentional violence perpetrated by an adolescent with ASD towards his family. The boy was reported to the competent authorities when, following one of his behavioural crisis, the police was alerted by the family neighbours. The organisation points out that it was unable, due to the limitations imposed by the law in force, to perform a preventive home visit. The lack of training among public security organs is also pointed out. They encountered great difficulties in simply understanding what was happening, and they were unable to put in place effective measures.

4. Final Considerations

The data collected from the questionnaire do not allow to draw exhaustive conclusions. Indeed, the sample of cases was too small and the organizations and the countries that participated in the survey were very different from one another.

The data analysed and the answers provided to the open questions show that great differences exist among the different organizations, particularly as for the differences existing in the ways the services provided are organized within each country. Most of the organisations that took part in the questionnaire pointed out the existence of a gap between the knowledge and the awareness of the needs of people with ASD and their families in terms of prevention and management of the abuse/maltreatment, and the real possibilities and solutions available at the local level. Some considerations on the data obtained from the questionnaire will follow, in light of the data from the bibliography. Again, the analysis will be carried out by following the structure of 4 sections the questionnaire is divided into.

4.1 Service organization for the detection and prevention of violent behaviours

As the questionnaire results show, most of the organisations state that they have the sufficient structural requirements to provide a support service to families, but the major issue seems to be connected to the lack of a network and to a poor longitudinal planning of the needs of patients and their families (Life Project). We actually believe that the problem of autism, in its complexity, can be faced only by means of an integrated organisation of the Services that are being provided. Such services should be tailored to the age groups and the different needs of the patients who are receiving support.

However, as it emerges from the analysis of the answers provided, the greater fragility behind the development of an effective exchange network among the different institutions responsible for the care of the individual is the scarcity of funds. Another element that has been pointed out relates the lack of shared practices. The adoption of shared practices could be a clear reference point for the implementation of effective policies for the prevention of the abuse and/or maltreatment. The network mentioned above is also all the more important in all those situations where a suspected abuse shall be dealt with. It is further reaffirmed the difficulty, especially for nonverbal people with autism and individuals with ASD with self injurious behaviours, to detect evident signs of abuse/maltreatment. These signs, in some cases, can be the consequence of self injurious behaviours perpetrated by individuals with ASD themselves, so there is a risk of drawing the wrong conclusions.

This basic difficulty makes the activation of standard procedures burdensome. Such procuderes are needed to take the necessary action in case of abuse towards minors with typical development or who are able to express/recount events. Standard procedures need to be tailored to the specific characteristics of people with ASD.

The guidelines provided by Autism Europe (1998) recommend that the entire staff working within an organization who provide services to people with autism receive appropriate training in reference to the following: the legislative framework of reference, the procedure to be followed in case of suspected abuse, awareness-raising practices in the field of abuse of patients with ASD, the development of adequate communication skills.

It is advisable to involve the families of patients in the training process, especially as regards awareness-raising practices, key indicators of abuse and complaints procedures.

In addition, it is also imperative, as it has been done within the several countries involved in the research, that the different bodies responsible for the protection of people's rights (the police forces, the judiciary) receive a proper training on how to properly address those cases where disabled people are the victims of abuse.

A succesful example of the implementation of proper prevention strategies can be observed in Great Britain, where a report has been drafted following the work carried out in this field by an interdepartmental working group. Legislative modifications and additional improvements in the field of social services and healthcare services have been suggested.

The report is more than a simple list of political proposals, and provides specific suggestions as for those who should be responsible to ensure that specific policies are put in place. Even more significantly, the report stresses the need to consult people with ASD who have been victims of abuse, while also pointing out that their needs should be taken in consideration. Guides are available in order to support the members of the English justice system in case they should come in contact, within their profession, with people with ASD. (http://www.autism.org.uk/working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx).

Specific training courses were delivered to police forces. A proposal for the development of an alert card for people with high-functioning autism was also brougth forward. The alert card is designed to tell people about the condition of autism, and asks them to show respect, tolerance and to adapt their behaviour and their communication accordingly.
(http://www.autism.org.uk/card).

Another important element that emerges from the analysis of the answers refers to the difficulty of individuals with ASD to have early access to diagnosis and rehabilitation. This difficulty is due, on the one hand, to the financial costs that families must face. On the other, individuals with ASD experience a traumatic impact when undergoing invasive examinations within the centres. Such centres are not always able to meet the specific needs of their patients. As for this, the team of the MICHELANGELO project ("Patient-centric model for remote management, treatment and rehabilitation of autistic children") has put forward an interesting proposal. The project is financed by the EU and over the last five years it has been working on solutions for the evaluation and therapy for autism, for the provision of care services in the home of people with ASD, outside the hospital environment. The aim of the project is to overcome the main weaknesses existing in the current practices for the management of services to people with ASD. The "artificial context" of laboratory environment generates results that do not reflect real life behaviours. Also, when the therapy program is not intensive and when the intervention protocol is not tailored to the specific need of patients, there are limited benefits for them. For all the above reasons, it is believed that patients’ and families’ needs are best met when the care services are provided within domestic contexts. This allows for an ongoing contact with parents and educators, and for an improved cooperation between them and the professionals. Health professionals therefore act as "co-therapists" within the MICHELANGELO project, and are provided with the chance to actively participate in the health care process (Cordis Europa, 2015).

The importance of a proper exchange of information between families and professionals is well known among all those who work in the field of ASD. The families of people with intellectual disabilities and problematic behaviours seldom fail to receive practical support, as well as the necessary training and information. All this can lead patients to go through a tough, deeply isolating experience (Davies K. e Honeyman G., 2013). In 2013 the Italian Institute of Health published an evaluation manual for communication in rehabilitation settings. The manual was developed by the CARE Group (Communication, Care, Respect, Empathy). The manual is directed to health professionals and caregivers who wish to increase their knowledge in communication with patients and their families, in all its aspects. Initially designed as a guideline for rehabilitation professionals (doctors, physiatrists, physiotherapists, occupational therapists, professional educators, neuropsychometrists, speech therapists, etc.), this manual allows operators to self-evaluate their own communication skills (Italian Institute of Health, 2013).

Another important element is the relationship with schools. As it has emerged from the answers provided in the questionnaire, it is not possible to ensure an ongoing exchange of information among organisations, schools and families due to the scarcity of funds. That would allow for a global care of the individual with ASD, and would ensure a mutual support network, especially for the management of problematic behaviours. Because of the different school regulations in force in each different country, and because of the differences existing between the countries involved, it is not possible for school institutions to adopt common strategies in order to ensure the highest possible level of social inclusion for the child. Basically, minors with autism or severe disabilities do not always benefit from specific measures that are adequate to their disability, and this is fundamental for them in order to fully enjoy their right to education (Autism Europe, 2006).

The relationship with peers is a further pivotal factor. Children and young people with ASD are generally less accepted by other individuals. They experience social exclusion more frequently than others and they are victims of bullying in a greater measure than their peers with typical development (Frederickson N., 2010). This can lead to negative consequences, even in adolescence and adult life (Hebron J., 2011). For this reason, it is important to develop strategies to support and improve the social interaction skills of children with ASD, to allow them to develop and maintain meaningful relationships with their peers (Rowley E. et al., 2012). The available data suggest that emotional modulation and self-representation ability can play an important role in the prevention of bullying (Autism Eye, 2011). It is also essential, in line with the statements provided from the organisations involved in the research, to ensure a better communication flow with school institutions, so to provide adequate support to teachers who, through adequate didactic strategies, can create an inclusive context where the needs of students with ASD are met.

4.2 Staff Training

As far as the staff training is concerned, all organisations report that they put considerable financial resources in the promotion of theoretical and practical knowledge of their staff.

Differences exists between recently established and long-established organizations that are well rooted in the territory, although all organizations underline the need for ongoing refresher courses and supervision.

Adequate professional training is essential for the prevention of several types of abuse, as it can guarantee access to correct, early, multidisciplinary and ongoing diagnosis and treatment, as well as to adequate communication modalities between staff and families.

These factors play an essential role when delivering complete, specialized care to people with ASD, also in view of enabling them to reach the highest possible level of well-being.

The aim of the second section of the questionnaire was to detect those factors that, according to the organisations involved, could constitute the basis to develop a model of professional knowledge that is able to respond to the requests and responsibilities directly connected with those jobs involving patients with ASD.

The organizations participating in the questionnaire underline problems connected to the scarcity of funds, and, as a consequence, to the inability to employ additional internal staff and to recruit external staff, although they work hard in order to ensure that their personnel is appropriately and constantly trained about the most efficient treatment methods available.

Another problem is connected to the contents of specific training courses, especially in reference to the management of problematic behaviours. As also reported in the literature, far too often the

training in autism is conceived as a method that trains on how to take intervention when crises occur, and not as a way to prevent crises from developing (Jordan & Jones, 1996). When it comes to behavioural problems, it is fundamental to make a clear distinction between symptoms and causes. Treating behavioural problems without taking their causes into account is a form of violence or negligence, even more in the cases where educators resort to punishments.
To ensure the quality of intervention, socio-healthcare professionals should have access to relevant training programmes in the field of ASD. Such programmes should provide the tools to make early and accurate diagnoses, to prescribe proper treatments, and to successfully operate in relation to the rights of disabled people. The lack of adequately trained staff can lead to unsuitable interventions, as well as to an improper, inadequate, or excessive use of medicines, which often happens without the informed consent of parents, or even against their will (Autism Europe, 2007).

Among the behavioural triggers, the role played by medical conditions involving somatic pain is particularly important. There is an increasing interest towards this topic, and there is significant evidence that show that pain is an important variable. Nevertheless, this element is largely overlooked in the evaluation procedures of people with ASD. Pain detection should be considered as being fundamental in the clinical practice for people with ASD. Few studies are available on the relation between pain severity and pervasiveness of behavioural problems in people with ASD (Van Dijk M, 2009), and this is also because it is difficult to carry out such studies. The tools that are currently available for pain assessment require a level of cognitive and communication abilities that the majority of people with ASD lack (Carminati et al., 2011). In line with such difficulties, the organizations involved in the research stress the need to provide to healthcare professionals a training that focuses on nonverbal communication, as this could be useful to better understand their patients' needs.

Lastly, a further issue raised by some organisations relates to aspects of sexuality of people with ASD.
False beliefs on autism have led for a long time to the misconception that boys and girls with ASD were not interested in social relationships, nor to affective or sexual relationships. The first studies conducted on sexuality in people with ASD excluded the possibility for people with ASD of any interest towards others and towards affective relationships. According to such theories, sexual behaviours and masturbation in people with ASD were interpreted as stereotypical behaviours that served no functional purpose.

Recent scientific research and clinical experience indicate the opposite. The few studies conducted over the last twenty years, indeed, have shown that people with ASD not only search for a repertoire of sexual behaviours, first and foremost masturbation, but they also have an interest in establishing social and affective relationships with a partner. This data is even the more evident in those individuals with a typical cognitive functioning level and adequate verbal skills.

Professionals (Henault, 2006; Hellemans et al. 2007) as well as people with ASD themselves (Segar, 1997; Gerland, 1999; Lawson, 2006) have written about the topic of sexuality and its affective implications in people with high functioning autism or with Asperger Syndrome. Forming a couple, cohabiting with a partner and parenting still remain unresolved issues in the discourse on sexuality of high functioning people with autism. In other words, the issue revolves around the social acceptance and the social recognition of an affective and sexual relationship when one or both partners are labelled as being bearers of a “disorder”. Excluding high functioning people with autism from the education process on such topics equals to preventing them from fully achieving important rights in their lives.

The available literature on people with low functioning autism generally focuses on sexuality-related behavioural problems (Realmuto & Ruble, 1999). Some of these behaviours are developed during prepubertal age, such as genital self-stimulation, and they are seldom considered highly problematic when displayed by children. Yet, they cause profound discomfort to caregivers and to those who live closely to them when these behaviours are displayed during adolescence. Once it has been developed, intervention is taken to diminish the frequency of behaviour, including pharmacological interventions (Nguyen & Coskun & Mukaddes, 2008).

These issues are extremely frequent within the clinical practice, and both doctors and healthcare operators have to deal with situations where parents are worried, unprepared and scared by the sexual behaviours displayed by their children. The development of sexuality in young people with ASD can determine some relevant changes in the family equilibrium and dynamics. Therefore, parents and families should receive adequate support. Simply removing the shackles of prudery attached to sexual issues is the first, useful step to be taken in order to ease parents’ anxieties and worries. However, doctors and healthcare operators themselves are not capable of providing adequate responses, as the organizations involved in the project have also pointed in their answers to the questionnaire.

A recent American study has highlighted that pediatricians, who usually provide medical care for children with autism, are not sufficiently trained to provide support and guidance to parents and families of children with autism as for their sexual development is concerned. It is strikingly important to intervene in a timely manner, and to offer specific and tailored educational pathways to young people with ASD. The reasons for this are twofold. On the one hand, promoting a healthy sexual development for young people with ASD is imperative. On the other, it is necessary to protect them.

Such situation raises ethical concerns, above all. The first one relates to the way in which the legitimacy of sexuality (which hopefully will not be questioned) can be combined with the need to express sexuality in a socially acceptable way. The second one has to do with the correct educational approach to be adopted by those in charge of teaching what constitutes proper sexual behaviours.

Since several years already, specialized professionals who offer sexual services to people with ASD upon payment are available in some countries. The position of sexual assistant is not recognized under the law and may be prosecutable according to the law. Recognising that sexuality is a fundamental right of human beings, as enshrined by the World Health Organisation 50 years ago, equals to enable all individuals to have the possibility to exercise that right. Therefore organisations, in their answers, wonder what their role should be in reference to such issue.

In relation to the data emerged from the analysis of the answers provided in the questionnaire, special attention needs to be paid to pharmacological abuse. Eliane Corbet (1994) defines violence within institutions as all that goes against the laws of development, all that privileges the interests of the institution over the interests of users. In this view, she also includes pharmacological abuse as one of the several types of violence. She adds that patients with ASD can be subject to "*inappropriate pharmacological prescriptions, for the peace of mind of the staff more than the well-being of patients*".

The document issued by Autism Europe (*Draft Code Of Good Practice On Prevention Of Violence Against Persons With Autism, 1998*) underlines that a pharmacological therapy for autism is currently not available, intended as medicines that can have an impact on the natural history of the disorder. As a result, in the majority of cases the available pharmacological therapies aim at managing the symptoms, that is to say the behaviours that cause most difficulties to families. The difficulties related to the prescription of an adequate pharmacological therapy, as it also emerges from the analysis of the answers provided in the questionnaires, are mainly connected to the lack of clear and shared guidelines, especially in some countries, and to the scarcity of information available in reference to evidence-based treatments. In this light, an adequate training of staff and an effective communication between the organization providing care to patients with ASD and their families seem to be the main elements to ensure prevention and protection from abuse. In principle, it can be useful to stress the need for a pharmacological prescription that takes into account the side effects for patients and the consequences on their lives, the evolution of symptoms throughout the life of patients, one that does not replace educational or social methods.

4.3 Burnout

It should be stressed out that problematic behaviours elicit negative emotional responses from the staff, and therefore they should be considered as stress factors. Notwithstanding this evidence, few studies have been conducted until present on the development of tools that allow operators to foster a positive communication, one that allows to remove feelings of stigma towards patients, thus improving the quality of interactions.

On the basis on this hypothesis, Hutchinson and his collaborators from the Department of Psychology of Bangor University (UK) have developed a training tool for operators who work in this field. The tool is called WCW – Who's Challenging Who. It focuses on the experiences of individuals with problematic behaviours, and evaluates the attitudes and empathy of operators.

The results achieved were encouraging. In the short run, positive and meaningful changes have occurred in the attitudes, awareness, empathy and in the perception of self-efficacy of staff (Hutchinson L. et al. 2012).

The need to support the human resources that are available within organizations is constantly increasing. Moments of personal discomfort, work distress and dissatisfaction often affect the job performance, and slow down the process of educational growth of individuals (Italian Institute of Health, 2011).

In order to limit the problems related to burnout, the Italian Institute of Health (2011) recommends that organizations offer specific training programmes to their healthcare operators. Such training programmes should be aimed at increasing their levels of resilience through the implementation of life skills. This target can be reached by means of the following:

- individual interviews to provide support in conflicting and distressing situations, to facilitate the decision-making process, to provide help in moments of crisis and to improve relations with others, to strengthen coping strategies at the workplace by respecting the values of others, their personal resources as well as their self-determination skills.
- group activities, designed to better involve individuals and develop their group-work abilities, to share projects, to improve cohabitation approaches, to increase motivation at the workplace and organisational cohesion, to support the management of conflicts during processes of change.
- counselling and training activities that increase the well-being of people by helping individuals to recognise their own limitations, reactions and abilities to identify workplace stressors, and that lay the ideal foundations to develop teamwork skills.

These indications appear to be in line with the needs expressed by the organisations involved in the research. These needs mainly focused on the necessity of having a space where work-related difficulties can be shared and where workers can receive adequate supervision, also by resorting to the services offered by external personnel.

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Appendix: The questionnaire

With the financial support from the "DAPHNE III" Programme of the European Union

SPEAK UP Project

System for Protection and Empowerment of Autistic Child as victim of abuse or Unintentional Perpetrator (JUST/2012/DAP/AG/3192)

Survey for the exchange of ideas and Valid Actions for protecting children and young people with ASD in assisting and caring organisations

Il Cireneo, in collaboration with other organisations in Europe, is working on a project that aims at developing initiatives and tools for the prevention of violence suffered or unintentionally perpetrated by children with Autism.
In order to develop effective prevention tools the starting point is the collection of reliable information, through this survey, about initiatives already implemented, on the theme object of the project, by assisting and caring organisations
That is why we please ask you to help us in the collection of information.
Data regarding the person filling the questionnaire, as well as the ones regarding the organization in which s/he is employed, will be used only for developing the study and will be never given to any other third party, and are necessary only for the survey reliability. The data collection will be processed in anonymous way.
If you would like to have more information about the project aims and findings you can contact us

Thank You for your collaboration

I declare I understood nature and aims of the survey

Name and Surname of the person filling the questionnaire: ______________________________

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Institution to which the person belongs: ____

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Role in the institution:____

Signature of the person filling the questionnaire________________________________

The protection and safeguarding of children with ASD really represent a challenge for any assisting and caring institution. The aim of this research is neither evaluate the organisation nor detect the efficiency of its staff but the aim is the collection of information about standard procedures developed in caring institution in order to prevent as much as possible the incurrence of maltreatment and or abuse and violent acts as well as the research about good practices together with ideas and useful comments for improving existing prevention services. For this reason the following questionnaire is a semi structured one, and we please you to add as much information, comments and ideas you think might be useful for a better development of prevention strategies and services to prevent any possible case of maltreatment or abuse against children and adolescents with ASD.

SECTION 1. Service organization for the detection and prevention of violent behaviours

1.1. Within the Centre there is a figure that deals with the reception and information to families in particular for what regards protection and safeguarding of children with autism?

Yes No

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the effectiveness of the service?

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1.2. Within the Centre operates a multidisciplinary team formed by (specify the skills

available) in order to detect any possible aspect regarding internal or external problems of suffered and/or unintentionally committed violence by children

Child Neuropsychiatric
Psychologist
Educator
Speech Therapist
Neuro Psychomotricity Therapist
Physiotherapist
Nurse
Social Assistant

None of the above reported figures is present
Also if some of the above reported figures are present, they do not work together as a multidisciplinary team

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.3. The caregiver of the child (family member or other) has a direct contact (phone number, e-mail, other) that allows him/her to track down the reference person and the time in which s/he can contact him/her

Yes No

How would you "grade" the service?							
Badly implemented							Very well implemented.
O	O	O	O	O	O	O	O

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.4. There is, within the center, a welcoming and comfortable space for meetings between users / family members and the center's team which ensures confidentiality and reduces interruptions

Yes No

How would you "grade" the service?							
Badly implemented							Very well implemented.
O	O	O	O	O	O	O	O

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.5. Procedures for taking charge of users / family members are well-defined and constant during time

Yes No

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.6 There is a figure (team) that takes care of the family-school connections and interactions

Yes No

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service

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1.7. The Centre promotes initiatives to explain autism spectrum disorder to families offering also psychological support (specify how):

Individual meetings Parent training Self-help groups

Reception desk listening Other____

How would you “grade” the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.8. In case there are some difficulties in managing violent behaviour of the child at home, parents receive support (specify how):

through meetings with the team

getting in contact with the external reference specialist for the disorder

through supervision at home

Other ______________________________

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.9. If any evidence of negligence / carelessness at home appears, there is, within the organization, a specific procedure to address the problem

Yes No

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	O	O	O	O	O	O	O

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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1.10. If any evidence of physical / mental abuse at home appears, there is a clear procedure to make a report to the competent authorities

Yes No

How would you "grade" the service?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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SECTION 2. Staff training

2.1. The Centre organizes seminars, conferences and conventions that ensure operators continuous update on the issues related with the management of violent behaviours (functional analysis, specific tools and data collection procedures, etc.)

Yes No

How would you "grade" it?							
Badly implemented							**Very well implemented.**
O	O	O	O	O	O	O	O

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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2.2. Common strategies are in place within the structure to cope with severe problem behaviours and the staff is well trained about these strategies

Yes No

How would you "grade" them?							
Badly implemented							**Very well implemented.**
O	O	O	O	O	O	O	O

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve their quality?

2.3. Operators are trained to recognize a possible physical pain

Yes No

How would you "grade" the level of training?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

What do you think could be done to improve the quality of the training?

2.4. Operators are trained to recognize if among the antecedents for a behavioural crisis there is a physical pain

Yes No

How would you "grade" the level of training?							
Badly implemented							**Very well implemented.**
O	**O**	**O**	**O**	**O**	**O**	**O**	**O**

Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the training?

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2.5. There is an internal procedure within the Centre for the assessment of a physical pain and its treatment

Yes No

How would you “grade” it?							
Badly implemented							**Very well implemented.**
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Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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2.6. The main reason to prescribe a pharmacological treatment within the Centre is:

☐ **problem behaviour management** ☐ **mood stabilization** ☐ **hyperactivity**

☐ **sleep disorders** ☐ **other (specify)**____________________________________

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2.7. If you feel that there may be a condition of pharmacological abuse, there is a procedure for reporting such abuse

Yes No

How would you "grade" it?							
Badly implemented							**Very well implemented.**
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Can you briefly describe pros and cons of the service or any comment you think useful in order to better implement, in relation with the above mentioned aspect, the protection and safeguarding of children with autism within your organisation?

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What do you think could be done to improve the quality of the service?

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SECTION 3. Health workers stress and burnout self-assessment

3.1. Working time is organized to ensure a fair distribution and rotation of operators Yes No

3.2. Specific measures are implemented to prevent or reduce risk factors for stress Yes No

3.3. The Organization provides effective information (courses, brochures, questionnaires ...) to identify burnout signs and symptoms Yes No

3.4. Operators are able to recognize burnout signs and symptoms (fatigue, apathy, nervousness, isolation, and feeling of failure) and to understand the bad effects of such condition on their work with users / families Yes No

3.5. In the evidence of a burnout of a worker, which is the procedure? (Please describe)

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SECTION 4. Cases

4.1. Were there cases of suspected abuse in your Center? Yes No

IF YES

4.1.1 Can you briefly describe how the situation was managed by the Centre?

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4.1.2 Which were the greatest difficulties you noticed?

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stampato nel Maggio 2015
da **idea**stampa - Vasto