

**DRAFT CODE OF GOOD PRACTICE ON PREVENTION
OF VIOLENCE
AGAINST PERSONS WITH AUTISM**

September 1998

The European DAPHNE initiative, adopted in 1997, is aimed at supporting the activities of Non Governmental Organisations (NGOs) who are combating violence perpetrated against children, adolescents and women. We welcome the European Commission's suggestion to implement a four to five year action programme of the Union to follow on the first initiative. Such mid-term action programme is most needed to meet the crucial needs identified during the implementation of the first phase and to promote a better co-ordination of actions of prevention at European level. (September 1998)

Acknowledgements

On behalf of Autism-Europe, persons with autism and their families, I should like to single out for special thanks Yvette Dijkxhoorn of the University of Leiden (NL), André Foubert, director of a *Maison d'Accueil Spécialisée* (special residential care centre) (F), Dr. Paula Freitas, a child psychiatrist with APPDA of Porto (P), Bill Meldrum of the Scottish Society for Children with autism (UK), Dr. Donata Vivanti, President of ANGSA Lombardia (I) and Dr. Christopher Williams of the University of London (UK) for having accepted to draft this Code of Good Practice and thus share with us the fruits of their experience. Their task was on a par with the expectations voiced by many parents, that is, arduous and tricky. Despite some very short deadlines, the Experts Group accomplished its mission with the support of Anne-Sophie Parent, Autism-Europe Administrative Director and project co-ordinator, and I should like to thank them from the bottom of my heart for their enthusiastic support for our Code of Good Practice project.

I should also like to thank the speakers who, through their presentations at the seminar, will give our project a broader dimension. Let me mention in particular Dr. Joaquim Fuentes, a psychiatrist working with children and teenagers at San Sebastian Hospital (E), Professor Ernesto Caffo, President of the Italian association to control violence against children, Telefono Azzuro, Dr. Theo Peeters, Director of Opleiding Centrum Autisme in Antwerp (B), Dr. Rita Jordan, of the University of Birmingham (GB), and the "consortium" that worked on the unacceptable procedures project: Pat Matthews, Vice-President of Autism-Europe and Director of the Irish Society for Autism (IRL), Isabel Cottinelli-Telmo, Vice-President of Autism-Europe and President of the APPDA (P), Dr. Paul Shattock, Honorary Secretary of Autism-Europe, University of Sunderland (GB) and Gloria Laxer, a specialist in Education and Communication Sciences (F). Special thanks are also in order for all the participants in the seminar; their comments and contributions will help us greatly to forge ahead with this Code.

Many thanks as well to the many individuals and associations who sent us their testimony and documents to help us with our work and without whom this project would never have seen the light of day. We took on this difficult task for them and their children and to respond to the urgent demand of the many parents who want to see an end to poor practices and the creation of the necessary foundations to guarantee all persons with autism a fitting future. We are all fully aware that this Code of Good Practice is only a step towards better recognition of the rights of persons with autism. It does not claim to lay down immutable grand principles once and for all. However, I hope that it will help lay the first foundations of European co-operation to improve the lives of the particularly vulnerable individuals who are struck by autism and spare them useless suffering. This Code of Good Practice comes in the wake of the Charter of Rights for Persons with autism that was presented at Autism-Europe's 4th International Congress in May 1992 and the European Parliament's written Declaration that was adopted on 9 May 1996. Each step we take in our action brings us a little closer to better respect for the rights of persons with autism.

Finally, I would like to thank the European Commission DAPHNE Initiative for its support to our project and I wish to thank in particular Mr Anthony Simpson and his team of the Task Force "Cooperation on Justice and Home Affairs" for their valuable help and friendly advice.

Gilbert Huyberegts
President of Autism-Europe

CONTENTS

INTRODUCTION.....	5
CHAPTER 1 : GENERAL OVERVIEW	
Christopher Williams	7
CHAPTER 2: WHAT IS AUTISM	
Yvette Dijkxhorn.....	15
CHAPTER 3: THE RISK FACTORS OF MISTREATMENT IN THE FAMILY	
Donata Vivanti	23
CHAPTER 4: RISK FACTORS INHERENT IN THE STRUCTURES OF INSTITUTIONS AND STAFF WORKING IN THEM	
André Foubert	29
CHAPTER 5: PREVENTION OF VIOLENCE / INTERVENTION ON THE PERSON WITH AUTISM	
Paula Pinto de Freitas.....	37
CHAPTER 6: PREVENTING MISTREATMENT IN THE FAMILY	
Donata Vivanti	43
CHAPTER 7: PREVENTION WITHIN AGENCIES & CARE SETTINGS	
Bill Meldrum.....	51
CHAPTER 8 : THE IMPORTANCE OF TRAINEE IN THE PREVENTION OF VIOLENCE AND ABUSE AGAINST PEOPLE WITH AUTISM	
Theo Peeters & Rita Jordan	57
CHAPTER 9: A CODE OF PRACTICE FOR THE APPROPRIATE USE OF MEDICATION FOR PEOPLE WITH AUTISM	
Paul Shattock	75
CHAPTER 10 : EUROPEAN DIMENSION	
Dr Christopher Williams	81
CHAPTER 11 : POSSIBILITIES FOR CHANGE - A CASE STUDY OF THE UK	
Dr Christopher Williams	89

INTRODUCTION

Concern about harm suffered by people with disabilities has increased in recent years.¹ Lifestyle often creates particular vulnerabilities, and in some cases intellectual difficulties can make reporting and giving formal evidence problematic. Suffering is usually 'invisible' to the public, policy-makers and politicians.²

The documentation currently available is nationally based, because law is a central aspect and most of the relevant legislation is at the state level.³ So far there has not been a European perspective. In addition, most research considers people with learning disabilities as a single group, and there has not been any specific consideration of what might be unique in relation to people with autism.

This Code has been drafted by an international team of experts composed of Yvette Dijkxhoorn of the University of Leiden (NL), André Foubert, director of a residential care centre (F), Dr. Paula Freitas, child psychiatrist with APPDA and lecturer at the University of Porto (P), Bill Meldrum of the Scottish Society for Children with autism (UK), Dr. Donata Vivanti, President of ANGSA Lombardia (I) and Dr. Christopher Williams of the University of London (UK). Other experts participated in the project: Dr Rita Jordan, University of Birmingham (UK), Dr Theo Peeters, Opleiding Centrum Autisme (B) and Paul Shattock, University of Sunderland (UK). The project was co-ordinated by Anne-Sophie Parent, Autism-Europe Administrative Director.

Chapter One outlines the problem in general terms. Subsequent chapters identify the risk factors in relation to autism, measures of prevention and recommendations in terms of good practice. Finally, the concluding chapters give an overview of the areas in which a Europe-wide approach could add a new dimension and analyse an example of new legislation which will take on board the needs of vulnerable people. (A glossary and a bibliography will complete the final document).

¹ Sobsey, D. (1994) **Violence and abuse in the lives of people with disabilities - the end of silent acceptance**, Paul H. Brookes Publishing: Baltimore.

² Williams, C. (1995) **Invisible victims: crime and abuse against people with learning disabilities**, Jessica Kingsley: London.

³ For example: Brown, H. Stein, J. & Turk, V. (1995) 'Report of a second two-year incidence survey on the reported sexual abuse of adults with learning disabilities: 1991-1992,' **Mental Handicap Research**, 8, 1.

CHAPTER 1 : GENERAL OVERVIEW

Christopher Williams
Institute of Education, University of London

1.1 HARM AND SUFFERING - THE EUROPEAN DIMENSION

Thinking on a European level about a problem that is usually identified in terms of state legislation, is not straightforward. Actions that are unlawful in one country may not be unlawful in another. Terms such as 'violence' are widely understood, but omit many significant forms of harm arising from neglect. The term 'abuse' is often used, but this can distort the perception of serious acts which should be seen as unlawful. Calling rape 'sexual abuse', an assault 'physical abuse', or theft 'financial abuse' softens the perception of the suffering, and hides the fact that these acts are against the law. When a harmful act against someone with a disability is unlawful it is important to say so clearly, just as we would if the harm were suffered by anyone else. Put simply, the concern of this book is about circumstances in which

individuals suffer harm because of the acts or omissions of others.

Specific acts or omissions may or may not be unlawful in different countries, but within this definition it is possible identify categories of harm and suffering which are generally applicable throughout Europe.

1.1.1 Crime.

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

Crimes experienced by people with developmental disabilities include:

Killing - homicide, murder, manslaughter, death arising from a failure of duty to care.

Abduction - being taken away, without consent, by force or threat, without lawful reason to do so.

Assault - technically any form of unwanted touch is an assault, and some acts that do not involve contact such as threatening phone calls might be classed as assault.

Poisoning - suffering or death caused by a harmful substance, including medical drugs if given without consent.

Sexual offences - being touched in a sexual way without consent.

Verbal abuse that is likely to cause fear of violence.

False imprisonment - being kept in a place by force or threat, unless there is lawful reason to do so or in the case of an emergency to prevent immediate harm to an individual or others.

Loss of property - an unlawful removal of property with intent to deprive the owner permanently - theft, burglary.

Deception - money or property is taken without the owner fully understanding and agreeing to the purpose - 'confidence tricks', fraud.

Damage - breaking or harming personal property.

Incitement - being told and prompted to do something wrong, such as breaking a shop window.

(NB: There will be small differences in specific countries.)

1.1.2 Civil Offences.

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

Civil offences suffered by people with developmental disabilities include:

Failure of a duty to care, e.g. a professional care worker does not provide medication or food.

Avoidable mistakes which cause harm or suffering.

Administrative mistakes, e.g. failure to pay a state benefit to which an individual is entitled.

Defamation - includes unfounded accusations that a person has committed an offence, for example if a staff member said incorrectly, "John hit Marie". A UK newspaper was successfully sued for calling a 6 year-old child with behaviour problems arising from meningitis, 'The worst brat in Britain.'

1.1.3 Bad practice.

Much of what is suffered by people with developmental disabilities is neither a criminal nor civil offence, but is still clearly unacceptable. Many care organisations, and most professions, will have formal codes of practice which set standards (e.g. the *British Psychological Society, Code of Conduct*⁴). If an act or omission breaches a code (national or international), or does not match up to the norms of professional behaviour that could reasonably be expected of a trained professional (e.g. what could be found a standard textbook), there are usually procedures which may result in disciplinary action such as loss of a job, small fines, or loss of membership of a professional body. Some forms of bad practice do not contravene professional codes, but are contrary to human rights statements⁵ or accepted norms of behaviour, for example clinical experimentation without the consent of the patient.

⁴ BPS (1985) **Code of Conduct for psychologists**, British Psychological Society: London.

⁵ Gunn, M.J. (1986) 'Human rights and people with mental handicaps' **Mental Handicap**, 14, September, pp116-120

Bad practice suffered by people with developmental disabilities includes:

Failure to respect human dignity, e.g. letting a person go out shopping dressed in pyjamas.

Failure to assess needs, e.g. education or medical.

Failure to ensure proper medical checks and treatment - dentist, optician female hygiene.

Pharmacological abuse - the improper or inappropriate use of medical drugs.

Failures of state care which lead to abandonment of disabled children because parents cannot cope.

Experimentation - clinical, psychological or educational research without consent. In 1994 it was revealed that people with intellectual disabilities in US institutions had been used for research about the effects of radiation which included injecting them with plutonium.

Failure to identify and diagnose autism and other impairments, which leads to inadequate care and sometimes the improper detention of people who behave in an "anti-social" manner that is misunderstood.

1.1.4 Harassment.

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

Harassment suffered by people with developmental disabilities includes:

Name calling - "stupid", "imbecile" "cretin", "debile", "defect"

Teasing - unpleasant remarks about physical appearance or personal habits.

Racial comments - unpleasant remarks based on a person's race or ethnic group.

Sexual comments - unpleasant or unwanted comments relating to a person's sex.

Alienation - being forced away from the main group of people.

Workplace harassment, which often leads to people leaving or losing their jobs.

1.1.5 Abuse of power

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

Abuse of power suffered by people with developmental disabilities includes:

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

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

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

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

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

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

Film exposes lives of ‘unlucky ones’

Kamal Ahmed

The programme, *Innocents Lost*, presents a catalogue of complaints about institutions set up by Greek authorities in the 1960s to deal with children expelled by their families because they were thought to be mentally or physically disabled.

Using secretly shot footage, Brain Woods and Kate Blewett show children and adults who spend their lives tied to beds and are force-fed a diet of bread and milk. Children considered untreatable are sent to the institutions because many Greek families are concerned that having a disabled child can bring bad luck to the family. Called Kepeps, the institutions are known locally as institutes for the unlucky ones.

The children often receive no specialist care for the rest of their lives. In a institute in Sarrai...they found two children locked in large cots with bars over the top. One child, aged 10, was wearing a nappy, the other was naked.

A woman, Anastasia, has lived in the same bed for 15 years, Since she was aged 10. Although she is able to communicate, staff have ignored her pleas for a wheelchair.

Another patient, Stelios, has been tied to a bed in a children’s ward for nearly all his 35 years. No specialist has seen him since he was admitted as a young child...

Greece, a signatory to the United Nations Convention on the Rights of the Child, was one of the largest recipients of European Union aid, but the institutions’ requests for physiotherapists had been turned down.

(*The Guardian*, December 4, 1997 p.14.)

1.1.6 Other forms of harm

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

The **causes of disability** often stem from unlawful or improper acts or omissions. Assaults or poor medical care during pregnancy can cause impairments in the unborn child. Redress through the civil courts in relation to medical negligence can achieve large compensation payments in some European countries, but not in others. Acquired Brain Injury often arises from poor child care, for example if children are dropped or fall on their heads. Environmental causes of intellectual disabilities are increasing (e.g. pollution such as lead, mercury, PCBs, radiation).⁶ Redress is rare because environmental law does not protect human-beings, and it is not clear in most European countries whether unborn children, who are usually most vulnerable to environmental impacts, have full legal status as victims.⁷

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

⁶ Williams, C. (1997) **Terminus brain: the environmental threats to human intelligence**, Cassell: London.

⁷ Williams, C. (ed.) (1998) **Environmental victims: new risks, new injustice**, Earthscan: London, p11-12.

Children seek refuge from a city gone mad

Alfonso Rojo in Sarajevo

Every night they ask about their parents. When the shells begin to fall, more than 40 children crowd round Vasilija Veljkovic in a shelter in the middle of Sarajevo. The children have not been outside of their underground refuge for 25 days.

Before the fighting started, they lived at the Educational Centre for Subnormal Children. "When the fighting began, we rang their parents and asked them to come and collect them." "Some of the parents turned up. Forty-four children were left" "We got all the children into the basement. Every five seconds a mortar would go off and everything shook..." "Nothing remained of the Centre. I've seen many painful sights in my life, but one of the saddest was the look of desolation on the faces of those 44 children when they found that their home had been razed to the ground."

The children now live in a nuclear shelter built in the days of Marshall Tito. It has two big rooms with bare concrete walls and three small bathrooms dripping with damp. The only furniture was some metal shelving.

Stipo, is a strapping boy who looks about 13 and has to close his eyes and twist his tongue to make the words come out. "Why are you here?" "Because they're shooting at us." he replied. I ask him if he knows why they are shooting. Stipo looks at us with his huge blue eyes and says very seriously: "There isn't a reason. They've gone mad." (*The Guardian*, June 5, 1992, p1)

1.1.7 The unique aspect - the “chain reaction”

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

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

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

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

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

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

CHAPTER 2: WHAT IS AUTISM

Yvette Dijkxhorn
University of Leiden (NL)

INTRODUCTION

The autistic spectrum disorders are developmental disorders of a neurobiological origin, of which the specific cause is still unknown. The disorders manifest themselves in early childhood, and are not curable. The Autistic Disorder is relatively rare; the prevalence is 4:10.000 births. The prevalence of the entire group, officially called the Pervasive Developmental Disorders, however, is estimated 6 to 7 times higher. This implies that in the European Community with an estimated population of 375.000.000 about 1.000.000 have a pervasive developmental disorder. The prevalence in boys is 4 times higher than in girls. The disorders are found on all levels of intelligence. 75-80%, however, is functioning on a significantly low level of intellectual and adaptive functioning. Other associated problems are for example epilepsy, that is found in over 30% of the people with a pervasive developmental disorder (Berckelaer-Onnes & Engeland, 1986).

Descriptions of the syndromes are formulated on the biological (the brain), the psychological (the mind) and the behavioural level. There is a general consensus on the behavioural symptoms on which the classification of the syndrome is based. The behavioural descriptions of the two main classification systems, the International Classification of Diseases (WHO, 1977, 1992) and Diagnostic and Statistical Manual of Mental Disorders (APA, 1980, 1987, 1994) are almost identical. They are roughly based on the 'triad of impairment' which is formulated by Lorna Wing (1993). The theories on the biological and psychological level are still hypothetical. The results of the research on the genetic links, however, are getting close to being proven.

In the following chapter we will give a description of the syndromes and discuss the implications of having this syndrome on a person through the life-span.

A historic view on autism

The first descriptions of eleven children who showed a condition that 'differs so markedly and uniquely from anything reported so far, that each case merits-and, I hope, will eventually receive- a detailed consideration of its fascinating peculiarities' (p. 217) are attributed to Leo Kanner (1943). He thought that social withdrawal was the primary feature and hence chose the name 'autism' (derived from the Greek word *autos* (=self).

In Europe, Asperger (1944), published a similar article that did not get widely known until the 1980's. He also described a group of boys with specific social problems.

Although these descriptions are now considered to be the first official articles, anecdotal reports had occurred long before the 1940's. For example Victor, the Wild Boy of Aveyron is now considered to have been an child with autism abandoned by his parents (Brauner & Brauner, 1978).

Mainly due to the work of Creak (1961), Rutter (1978) and Wing (1979; 1993) there nowadays are clear diagnostic criteria. Both the classification system more or less agree on the basic diagnostic features. They both have the category 'Pervasive Developmental Disorders', which incorporates five diagnoses (Autistic Disorder, Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder and the Pervasive Developmental Disorder not otherwise specified or atypical autism, in the ICD 10). In Appendix I these diagnoses are listed.

The term 'Pervasive Developmental Disorders' is rather vague and meaningless. Most practitioners and parents associations prefer the term 'Autistic Spectrum Disorders (Wing, 1993).

The Triad of Impairments

Lorna Wing (1993) has formulated the 'triad of impairments'. People with an autistic spectrum disorder show impairments in social interaction, communication and imagination. As a consequence of these impairments they manifest a rigid pattern of behaviour, including insistence on sameness, stereotyped movements, limited interests etc.

Impairments in social interaction

Both Kanner (1943) and Asperger (1944) were struck by the social impairments of the children they described. The interaction problems of people with an autistic spectrum disorder are the main diagnostic criteria. Sometimes there is hardly any interaction possible, sometimes there is interaction but it lacks the reciprocity. Wing (1996) has formulated 4 subgroups according to social interaction.

- the *aloof* group does not initiate and react to social interaction
- the *passive* group does respond to social interaction, but does not initiate contact
- the *active but odd* group makes contact but it lacks reciprocity; it can often be characterized as one-way-interaction
- the *stilted* group initiates and sustains contact, but it is often over formal and rigid.

These subgroups are helpful in describing the social functioning of the individual. During development the person with autism can shift from one subgroup to another e.g. from active but odd to passive in high-functioning people after puberty. This subgrouping also show that although they can all have the same classification, the appearance of the social impairment can differ immensely.

Because of the different developmental path, especially the social development, people with a disorder in the autistic spectrum often fail to reach full understanding of emotions, lack the ability to engage in reciprocal relationships in adulthood and also fail to reach the full development of conscience.

Impairments in communication

The communication problems of people with an autistic spectrum disorder, manifest themselves both in the verbal and nonverbal components of communication. Being able to use communication is, on whatever level, the main condition to be able to function in society.

Pre- and Non-verbal communication

The problems in communication occur very early in childhood. Children with an autistic spectrum disorder have great difficulty acquiring joint attention behaviours. These include pointing in order to request objects or to comment to someone else about an object or event, and showing and giving objects to others to share interests. People with an autistic spectrum disorder seldom initiate social interaction (Lord & Magill, 1989). People with no verbal communication do not develop alternatives spontaneously. Teaching them augmentative communication is necessary.

Verbal communication

Although the percentages differ slightly, it is estimated that about 50% of the people with an autistic spectrum disorder never develop any useful speech. They are functionally mute. The group that do develop speech displays a variety of unusual features like echolalia, pronoun reversal, neologisms, metaphorical language, literal use of language. They show also problems with the language systems: language form (phonetics, prosody, syntaxis) in semantics and in

pragmatics. Even high functioning persons with autism have language problems, in particular with the pragmatic aspects (Fay & Schuler, 1980; Tager-Flusberg, 1989).

Teaching people with autism to communicate, with whatever means, helps diminishing challenging behaviours (Van Berckelaer-Onnes, Dijkxhoorn & v.d. Ploeg, 1996).

Impairments in imagination

Children with an autistic spectrum disorder do not develop imaginary play spontaneously. Their play is repetitive and the main goal often seems self-stimulation; e.g. spinning with objects, hitting two objects together etc. (Van Berckelaer-Onnes, 1994). Lack of imagination leads to a rigid pattern of behaviour and lack of understanding of others (lack of Theory of Mind). Although this impairment is most striking in children, it remains a problem through life.

As Lorna Wing (1996, pg. 99) stated: 'The value of true imagination and creativity is in associating past and present experiences and making plans for the future, ranging from the mundane what to do tomorrow to the grand plans for the whole of life'.

Cognition in people with an autistic spectrum disorders

Since the pioneering work of Hermelin and O'Connor (1970), the general notion has been that people within the autistic spectrum suffer from a specific cognitive deficit. As mentioned earlier, 75-80% has also a learning disability, but the people with normal intelligence show specific deficits as well. There are three theories formulated, searching for this specific deficit.

The first is the *Theory of Mind* (Baron-Cohen, Leslie & Frith 1985). Theory of mind is the capability of people to impute mental states to themselves and to others. Measures of theory of mind are false belief tests, appearance/reality tasks and story sequence tasks. It is clear that people with an autistic spectrum disorder have a deficient theory of mind, but it is not so obvious that this theory can explain autism. Theory of mind does not occur in normal childhood before the age of four years, autism is clearly visible before that age.

The second one is the theory from Ozonoff (1995) that implies that people with an autistic spectrum disorder have a deficient *executive functioning*. Executive functioning refers to the ability to free the mind of the immediate situation, and the context to guide behaviours through mental models or internal representations. This means the ability to plan. It is clear that people with an autistic spectrum disorder often fail executive functioning tasks, but this is not exclusive for autism.

The third is the *central coherence* theory (Frith, 1989). According to Frith, people with autism lack the 'built-in form to coherence over as wide a range of stimuli as possible and generalize over as wide a range of context as possible'. People with an autistic spectrum disorder experience the world in fragments and are not able to see the parts in relation to the whole. The integration problems affect all senses. Some people with autism experience a touch as painful, others can react totally indifferent to extreme stimuli (e.g. heat, sound, pain).

The central coherence theory seems at this moment, the most plausible explanation for the observed behaviours in these people.

Insight reports

Some people with an autistic spectrum disorder are able (and willing) to share their personal accounts of living with the specific problems as described above. Their insights are probably the most important source of knowledge which enables us to understand these disorders.

Most striking in these personal accounts is the way they describe their perception. Donna Williams writes in her book *Autism and Sensing* (1998): 'Up to the age of four, I sensed according to pattern and shifts in patter. My ability to interpret what I saw was impaired because

I took each fragment in without understanding its meaning in the context of its surrounding'. I'd see the nostril, but lose the concept of nose...'.
Kees Momma (1996) describes the difficulties he faces with meeting new people: 'Although someone may seem nice or interested at first glance, his or her character remains unpredictable to me'.

All these people describe that they have been teased and hurt, because of their behaviours that were not understood and their lack of understanding of the social rules and communication of the world they are living in. Temple Grandin described in an interview with Oliver Sacks (1993) that she could understand 'simple, strong, universal' emotions but was stumped by the more complex emotions and the games people play. She feels often bewildered and as she stated 'Much of the time I feel like an anthropologist on Mars'.

The aetiology of the autistic spectrum disorders

The autistic spectrum disorders are considered to be of a neuro-biological origin. At this moment worldwide genetic studies are going on. The first suggestions that genetic influences play a role in the pathogenesis of autism are found in the pioneering twin-study of Rimland (1964). The hereditary factor is important, but not exclusive.

There are also a number of specific genetic disorders e.g. fragile-X and Tuberous Sclerosis that display a high percentage of autism.

Another line of research is focusing on finding specific disfunctions in the brain. All kinds of disfunctions are found in different regions and systems of the brain. Dawson (1996) stated that it is almost certain that different neuropsychological impairments in a wide range of domains play a role, because autism involves disfunctions in multiple regions rather than only one cerebral region.

In conclusion we must state that people with an autistic spectrum disorder suffer from a lifelong handicapping disturbance, characterized by impairments in socialisation, communication and imagination. Although no specific cause has been found yet, there is a general agreement on the classification of the disturbances.

Caring for people with an autistic spectrum disorder

The above mentioned 'triad of impairments' and the underlying cognitive deficit can result, if they are not understood, in challenging behaviours. Their impairments implicate a specific need for care. Unfortunately most people with an autistic spectrum disorder need guidance through the life-span.

Kok, a Dutch pedagogue, developed a treatment model (1972, 1978) which has proven to be very useful in the field of the autistic spectrum disorders.

He classified interventions in three groups:

- The **first-level strategy** is directed towards the living conditions. Living conditions should be adapted to the needs of a person, to achieve optimal development.
- The **second-level strategy** are the individually directed therapies.
- The **third-level strategy** incorporates individual variations within the first and second strategy.

Rutter (1985) formulated four general treatment strategies: one directed to the family and three directed to the individual with an autistic spectrum disorder. Those goals are:

- alleviation of family stress (through practical and psychological support and training)
- promotion of normal development (i.e. socialization, communication, play, motor skills, cognitive skills etc.)
- reduction of autism-specific problems (i.e. rigidity/stereotypy)
- elimination of non-specific maladaptive behaviours (i.e. temper tantrums, eating and sleeping problems).

These goals can be primarily achieved in the first-grade strategy. People with an autistic spectrum disorder need a structured environment in which they can reach their optimum. The goals have to be functional, based on being to function in everyday life. Individual therapies (second-grade), for example speech therapy, play-training or sensory-integration therapy can be an excellent supplement, but must always be incorporated in a total plan.

The third-grade strategy is actually the most important one. Every person with an autistic spectrum disorder is a unique individual and so is the setting in which he lives. The individual nuances must do right to the individuality.

Within this framework an individual plan for care can be made, and it is applicable to all ages and all the levels of functioning and in both home-situations and (semi)-residential settings.

Vulnerability of people with autistic spectrum disorders

The above described triad of impairments makes people with an autistic spectrum disorder extremely vulnerable for all forms of abuse. Because of the problems in social interaction they have problems with friendships, and an even bigger problem with understanding who is not a friend. This makes them often a victim of exploitation (Howlin, 1997).

They also fail to understand the emotions and feelings of others, including ill intentions of others. Women with an autistic spectrum disorder are extremely vulnerable for sexual abuse, because of their inability to read social cues.

On the whole one must conclude that people with an autistic spectrum disorder have a gross communicational handicap; most of them are unable to communicate feelings, emotions and fears, or even physical pain. One of the most striking problems is the frequent use of echolalic speech. The 'skill' of repeating what has been said to them has led to gross exploitation. An example has been reported from France where able people were asked to repeat key words suggested by professionals, to promote the psychogenetic origin, or to cover up neglect or abuse or to blackmail parents that were considered to be disturbing.

Because of their communication problems people with an autistic spectrum disorder are not able to share feelings and experiences; so if harm is done to them they are not likely to share that with others. This does not mean that they can't be hurt! On the contrary.

People with an autistic spectrum disorder probably never obtain the skill of deception. Howlin (1997, p.74) states that 'the notion of innocence may have its attractions, but in a world that is far from innocent, the vulnerability and honesty of people with autism can be too easily exploited or abused'. Although people with autism will have troubles to hold up in court, they are very unlikely to tell a lie.

There is little evidence that people with an autistic spectrum disorder are more prone to criminal behaviours, but some anecdotal reports exist (Howlin, 1997). The lack of social understanding, the obsessional interests and a failure to understand the consequences of their behaviours can lead to offences.

Howlin (1997) suggests that the main intervention strategy to help people with this disorder to communicate should be training non-autistic people to communicate with them. There lies a big task to educate health-care-workers, teachers, policemen and judges!

References

American Psychiatric Association, *Diagnostic and Statistical Manual*. Washington DC. APA, DSM III, 1980; DSM III-R, 1987; DSM IV, 1994.

- Asperger, H. (1944). Die Autistischen Psychopathen im Kindesalter. *Archiv für Psychiatrie und Nervenkrankheiten*, 117,76-136.
- Baron-Cohen, S., Leslie, A.M. & Frith, U. (1985). Does the child with autism have a theory of mind: a case specific developmental delay. *Cognition*, 21, 37-46.
- Berckelaer-Onnes, I.A. van & Engeland H. van (1986). *Kinderen en autisme*. Meppel: Boom.
- Berckelaer-Onnes, I.A., van (1994). Playtraining for children with autism. In: Hellendoorn, v.d. Kooij & Sutton-Smith (eds.). *Play and Intervention*. Albany: State University of New York Press.
- Berckelaer-Onnes, I.A. van, Dijkxhoorn, Y.M. & v.d. Ploeg, D.A. (1996). *Categoriaal en/of Integraal?* Leiden: Rijksuniversiteit Press.
- Brauner, A. & Brauner, F. (1978). *Vivre avec un enfant autistique*. Paris: Presses Universitaires de France.
- Creak, M. (1961). Schizophrenia syndrome in childhood: progress report of a working party. *Cerebral Palsy Bulletin*, 3, 501-504.
- Dawson, G. (1996). Neuropsychology of Autism: A report on the State of the Science. *Journal of Autism and Developmental Disorders*, 26, 179-184.
- Fay, W. & Schuler, A. (1980). *Emerging language in children with autism*. Baltimore MD: University Park Press.
- Frith, U. (1989). *Explaining the Enigma*. Oxford: Basil Blackwell.
- Hermelin, B.A. & O'Connor, (1970). *Psychological Experiments with children with autism*. Oxford: Pergamon Press.
- Howlin, P. (1997). *Autism: preparing for adulthood*. London & New York: Routledge.
- Kanner, L. (1943). Autistic Disturbances of affective contact. *Nervous Child*, 2, 217-250.
- Kok, J.F.W. (1972). *Structopathic Children*. Rotterdam: University Press.
- Kok, J.F.W. (1978). *Specifiek Opvoeden*. Amersfoort: Acco.
- Lord, C. & Magill, J. (1989). Methodological and theoretical issues in studying peer-directed behaviour and autism. In: Dawson, G. (Ed.). *Autism: nature, diagnosis and treatment*. New York: The Guildford Press.
- Momma, K. (1996). *En toen verscheen een regenboog; Hoe ik mijn autistische leven ervaar*. Amsterdam: Prometheus.
- Ozonoff, S. (1995). Executive function in Autism. In: Schopler, E. & Mesibov, G.B. (Eds.). *Diagnosis and Assessment in autism*. New York: Plenum Press.
- Rimland, B. (1964). *Infantile Autism*. New York: Appleton.
- Rutter, M. (1978). Diagnosis and definition of childhood autism. *Journal of Autism and Childhood Schizophrenia*, 8, 139-161.

Rutter, M. (1985). The treatment of children with autism. *Journal of Child Psychology and Child Psychiatry*, 26, 2, 193-214.

Sacks, O. (1993). *Een antropoloog op Mars*. Amsterdam: Meulenhoff.

Tager-Flusberg, H. (1989). A psycholinguistic perspective on language development in the autistic child. In: Dawson, G. (Ed.). *Autism: nature, diagnosis and treatment*. New York: The Guildford Press.

Williams, D. (1998). *Autism and Sensing*.

Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11-30.

Wing, L. (1993). The definition and prevalence of autism: a review. *European Child and Adolescent Psychiatry*, 2, 61-74.

Wing, L. (1996). *The Autistic Spectrum; a guide for parents and professionals*. London: Constable.

World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems*. Geneva: WHO, ICD 9, 1977, ICD 10, 1992.

World Health Organisation. *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research*. Geneva: WHO, 1993.

CHAPTER 3: THE RISK FACTORS OF MISTREATMENT IN THE FAMILY

Donata Vivanti

President ANGSA Lombardia

I wish here to thank the parents who in the letters we exchanged or during discussions we have had in the past shared with me their problems and concerns and who are the true authors of this text.

INTRODUCTION

We can never repeat too often that the family is not at all responsible for the autism of its child. Similarly, no parent can unfortunately prevent a child being affected by autism. Having said this, we must add that the child with autism obviously is not safe from mistreatment in the family.

On the contrary, the very characteristics of autism are a risk factor of mistreatment in the family, since they create additional stress for the parents as of the child's first months of life.

The physical beauty of children with autism is more a myth than a rule. Indeed, while most children with autism do not have appearances out of the ordinary, some of them combine autism with one or more other handicaps that have physical manifestations.

Whilst the handicap itself exacerbates the risk of violence - the wider the gap between what the child is and what the parents hoped for, the greater the risk the child runs - **the absence of physical manifestations of a handicap in an child with autism can foster expectations in the parents that far exceed the child's actual possibilities.** This leads to an increased risk of mistreatment. Indeed, it is even harder for parents to mourn their imagined child when the child with autism is beautiful, despite her/his difference and does not always exhibit visible signs of physical handicaps, as is the case with most handicaps.

Another risk factor is the difficulty that family and friends have identifying the signs of abuse in children with autism because of their communication problems, strange behaviour, and very frequent episodes of self-mutilation. That is why it is all the more important to prevent abuse by reducing the stress factors that the child with autism represents for her/his family.

The family is the first social environment in which the lives of any and all children take place. Integrating the child into the family environment must thus be the first educational goal for the autistic child, too. Helping the child with autism to develop her/his social skills and interests in the family environment must be the first step towards her/his rehabilitation. The aim must also be to improve the quality of life, for the well-being of child and family are indissociable.

I) STRESS FACTORS IN THE FAMILY ENVIRONMENT

1) SOCIAL INTERACTION PROBLEMS

In the beginning, we didn't know our son had autism. He was so cute, so quick and agile, he seemed to understand everything at least when it suited him because when he didn't want too he was as deaf. We had to shout to make him listen. My husband and myself had to get angry at him to make him pay attention. We thought he was lazy and stubborn. We didn't know he had autism (oral testimony by parents of a young child with autism).

The autistic child's real or apparent indifference towards parents who have already placed their love and devotion in this small, apparently perfect being is a true emotional tragedy for the parents. The parents feel rejected by this child, who does not respond to their feelings, but cannot and do not want to abandon it.

Some children with autism are visibly greatly attached to their parents, but even in such cases the feeling of responsibility for a being whom they feel is defenceless against the world and whose suffering they soon start to understand prompts the parents to search for help in any event, without succeeding in translating the child's affection into emotive participation in family life or into learning. The parents may sometimes impose excessive social promiscuity on the child, guided by the laudable aim of helping and stimulating her/him. They do not realise that the child's failure to understand the environment and the complex rules that are implicit in our relationships expose her/him to suffering, humiliation and a feeling of inadequacy. These failures are not just psychological violence. They also increase the risk of physical mistreatment, for the child who does not respond to her/his parents' care and attempts at education may be considered lazy and stubborn and become the victim of unjustified punishment.

2) COMMUNICATION PROBLEMS

The infant's relationship with its parents develops through non-verbal communication as of the first months of life: Everyone knows the code, made of glances, gurglings, and still clumsy motions, that arises spontaneously between mother (parents?) and child from the very beginning. Similarly, the child's language develops spontaneously through contact with her/his close contacts, enabling her/him to become a person among similars. The infant's ability to learn a language is something truly extraordinary.

But here we have a child who is deprived of the possibility of receiving and sending out messages of love, of expressing her/his needs and feelings, right from birth. Here is a naive, defenceless child whose life is marked by solitude from the very outset. The child is autistic. The parents quickly notice their child's communication problems, but they often try to quell their fears by clutching at their friends' words of consolation, even at incompetent professionals' lack of understanding ("Each child develops at his own rate... There's nothing wrong with him, you're the one who needs to be treated for anxiety..."), as if they were life preservers. Their unsuccessful attempts at rearing the child upset them and poison the family's relations, whilst the child's apparent unwillingness to co-operate, which is misinterpreted, exposes the child to an increased risk of punishment for disobedience, for which s/he is not at all responsible. In a word, the child is punished because of her/his handicap.

Verbal children with autism are not safe from misunderstanding, either, because of very frequent echolalia and because, to understand a message one has to be able not only to decode words and sentences, but also to put them in present and past contexts. This is

something that children with autism, even verbal ones, do not always manage to do. They cannot understand messages that appear very clear to us. The presence of verbal language exposes them, on the contrary, to a greater risk of mistreatment because their parents may expect too much from them.

3) BEHAVIOURAL PROBLEMS

The family's life is soon upset by the autistic child's behavioural problems, especially if an aggressive attitude or self-mutilation develops. Nothing is more painful for parents than to witness, powerless, the spectacle of their child beating her/himself, scratching her/himself, or knocking her/his head against the wall, or to accompany the child, their hearts full of hope, in a group of children of the same age and see her/him drive them off aggressively (kicking, biting, etc.). Even less serious manifestations - screams, bursts of laughter or tears without obvious reason, throwing objects, and all other stereotyped activities - can sometimes push the exasperated parents to use punishment. There, too, the child will be punished because of her/his handicap.

Behaviour problems thus carry an additional risk of throwing in the child-rearing towel or using punishment abusively. Actions that are ordinarily considered violence when applied to an adult - locking up or punishing a person physically because of troublesome behaviour - can be considered a means of education or necessary action when a child is concerned, even though a child is even weaker and defenceless.

4) FRAYING THE FAMILY'S NERVES

Life with an child with autism is very hard. Often hyperactivity and sleep or eating disorders compound the behaviour problems that are already so difficult to handle. The hyperactive child is unaware of the danger and never lets up. The house looks more like a bare prison than a home, with its barricaded doors and windows, bric-a-brac hidden away, and hazardous substances placed out of the child's reach. Yet that is not enough: you still have to keep your eyes on the taps, cooker, larder, drinks, and so on. Going outside offers no relief, either. A walk in the park can quickly turn into a breathless chase; a second of distraction can prove fatal. Even the parents of calm, albeit autistic, children are not protected from frayed nerves. Their child's isolation, the hours s/he spends looking at her/his hands or playing with a string worries them, forces them to get the child involved in an activity at all cost, even though their efforts as a rule lead to only more frustration. Holidays do not exist, falling ill is a luxury, resting impossible, you are crushed by fatigue. Family relationships are soon strained, the child's brothers and sisters are neglected as a matter of course, the family lives in a situation of chronic stress and the risk of mistreatment is greatly increased.

II) RISK FACTORS LINKED TO THE ENVIRONMENT

1) ERRONEOUS BELIEFS ABOUT AUTISM

The belief that autism can be attributed to a poor mother-child relationship is an additional factor of stress. Even in the best-informed, most competent families, doubt creeps in. The parents brood over the past and the feeling of guilt wears down the couple and undermines the already problematic relationship with the child, for it is difficult for parents who have been ousted from their parenting roles to tackle such a major problem with the necessary serenity. Even when the parents are not explicitly blamed, the psychogenetic view of autism can result in increasing their expectations of the child by encouraging the belief that the child her/himself refuses to blossom and you merely need to find the key to her/his refusal for her/him to become a "normal child", but also by getting parents to give up their educational

roles for fear of having a negative impact on this improbable healing process. The same risk is obviously triggered by the mistaken belief that all children with autism are extremely intelligent. One must remember that three out of four autistic subjects also have intellectual deficits.

2) FRIENDS' INCOMPREHENSION

The family's friends and acquaintances very often consider children with autism's bizarre behaviours to be signs of impoliteness for which the family is responsible. Remarks such as, "If that were my child I'd know how to raise him..." are familiar to almost all parents of children with autism. Even the most tightly-knit, competent family must thus cope with not only the difficulties inherent in living with such a difficult child, but also the judgements, criticism, and intolerance of neighbours, friends and relatives, whereas, on the contrary, they greatly need such people's solidarity and support.

3) UNCERTAINTY ABOUT THE FUTURE

"What will become of my child when we are no longer around to take care of him, to love him?" This question, which is linked to the fact of normal life expectancy, haunts the parents of children with autism to the very end. It is possible to have surmounted your despair, understood your child's handicap, learnt how to deal with him, but your fear about his future is there every morning, every second of each passing day, day after inevitable day.

I would like to contribute my sad testimony to your project. In 1994, I preferred to put an end to the suffering of my daughter (who has autism) rather than let her endure once again the horror of being confined in Montepellier psychiatric Hospital, or any other hospital, because in France we have nothing else to offer adults who are experiencing an acute anxiety crisis than the chemical straight jacket and full time confinement in a room with nothing more than a mattress on the floor. After my terrible act on 7th August 1994, I went to the police, I was judged in the Assizes. I spent six weeks in prison just after the tragedy and I was given a five year suspended sentence. I have been judged and sentenced but the hospital has not been judged for failure to assist someone in danger. (M-J Prefaut wrote a book on her tragedy : « Maman, pas l'hôpital », published by Editions Laffont, in june 1997).

The family is not only gnawed by the uncertainty of the lonely future that awaits the person with autism when her/his parents are too old, ill or dead, but also the uncertainty of the near future, that is, what may happen tomorrow or in the next few minutes. Even when everything seems to be going smoothly they know that a new problem can arise at any second.

The lack of a prospect of a suitable, dignified adulthood for one's child with autism can quickly turn the stress into despair, and there is not a single parent of an person with autism who has not wished to outlive her/his child, to never have to leave the child to a life of solitude and marginalisation.

These feelings merely strengthen the parents' feelings of guilt and powerlessness. In extreme cases of families that have been abandoned by specialised facilities, they can even lead to a real risk for the autistic person's life. Indeed, there have already been cases of parents who preferred putting an end to their children's lives rather than leaving them to their unhappy fates.

4) ISOLATION

The fear and anxiety that are generated by the autistic person's wierd, incomprehensible behaviour, the shame of being considered incapable parents, and the feeling of inadequacy

can lead parents to shut themselves up in their home with their child and abandon their child-rearing roles, thereby plunging the child into chaos and the family into social isolation. The consequences of friends and neighbours' incomprehension are all the more devastating when the child is rejected by institutions because of her/his problems or the lack of specialised services or trained, motivated personnel. Indeed, most children with autism are refused the right of each child to develop her/his potential. Their parents must often beg, as if for a favour, to get what is an unchallenged right for others. The parents sometimes even have to apologise for their child's handicap. That is why the parents themselves feel rejected and driven into isolation, alone against the world.

The child's mother is often forced to give up working for lack of qualified assistance and finds herself, little by little, imprisoned with her child with autism in an exclusive relationship that separates her from all other interests and isolates her from the rest of the world, which doesn't understand her problems.

CHAPTER 4: RISK FACTORS INHERENT IN THE STRUCTURES OF INSTITUTIONS AND STAFF WORKING IN THEM

André Foubert
Director of Maison Spécialisée d'Accueil (F)

INTRODUCTION

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

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

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

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

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

1. TYPES OF ILL TREATMENT IN INSTITUTIONS

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

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

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

She lists the following practices:

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

To this list we would add the following abuses which occur all too frequently in provision for people with autism:

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

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

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

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

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

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

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

Special vulnerability of people with autism

Perhaps we should start by accepting the fact that the first act of violence a person with autism suffers is being born with autism. Surely the first injustice is to be imprisoned by this disability which scientists tell us is incurable.

For a person with autism, every tiny detail has its importance. The unforeseen absence of an educator, changes in a programme of activities, unpredictable use of time: all real situations which for a person with autism can take on a huge significance. Difficulties inherent in starting and organising an activity, the problem of generalisation, the lack of verbal expression or inappropriate language use complicate the relationship between him and the people around him still further.

When symptoms of autism are incorrectly interpreted, the person's solitude and distress are compounded. He usually finds himself placed suddenly in an institutional environment with a

whole set of rules most of which he cannot understand. It is not surprising that his reaction should be a marked increase in behavioural problems, making his acceptance by his companions and indeed by professionals that more difficult.

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

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

2. RISK FACTORS - SITUATIONS WHICH CAN LEAD TO VIOLENCE

a) Lack of proper structures

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

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

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

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

An article in *Le Monde* of 23 May 1998 provided details of the physical restraint techniques which were used in a specialised hospital on people with autism who had symptoms of self-

injury. According to the psychiatrist in charge, these methods were “a cruel choice, but often the only way to protect people from themselves”.

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

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

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

b) Lack of training for professionals

There was no dialogue with parents. The diagnosis of autism which had been confirmed by our family doctor was always denied whenever we mentioned it. After a few months, G. was forbidden to use the swimming pool. We were amazed, because he had always loved water. But “it would give him too much pleasure and could damage communication development” (sic).

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

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

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

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

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

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

b) Psychological and social patterns

In a paper submitted in 1988 to the Créteil Faculty of Medicine (University of Paris Val de Marne) Dr Michel Preel expounded his "ideas on aggression by educators against children suffering from intellectual disabilities in a medical-educational institute". He sets out to study the reasons behind acts which were morally wrong but not actual offences in the eyes of the law and which could be seen by their perpetrators as being unfortunate and abnormal. He also suggests a neurological approach, carries out a comparative analysis with animal ethology, and includes a sociological assessment. Some of his conclusions are relevant to our discussion. "Neurobiology tells us that aggressive behaviour cannot be perceived in isolation: it forms part of all kinds of behaviour. Animal ethology shows us that aggression is a normal phenomenon and is present in all group structures. It ensures the cohesiveness of a community and enables individuals to earn respect. If an educator is aggressive, it means he is trying to defend his territory against an intrusion or himself against perceived domination by the child he is caring for. Sociological research also shows that increased aggression or aggression control can both be attributed to the environment. Specialised research into relationships in a therapeutic context reveal the notion of defence

mechanisms. It would appear that, in their relationships with children who are mentally disabled and who may therefore also lack the capacity to show affection and suffer from personality disorders, educators experience a feeling of unhappiness..." In this way, "aggression very often becomes the symptom of the loss of all hope concerning the children". Preel's general conclusion is that there is no easy way out: the underlying causes of this kind of aggression are to be found in a whole range of factors. It is necessary to go back further and look at the phenomena which trigger acts of aggression.

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

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

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

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

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

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

3. RISK PREVENTION

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

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

No person with a disability should be deprived of the freedom to develop his or her own way of life in an independent way. To make homes and institutions more human, this aspiration must underlie all objectives which are pursued, even if only symbolically. Regardless of the

disability and the level of understanding, every disabled person must be allowed to see what is happening around him, why he is no longer living with his parents, why he must face up to his responsibilities as an adult. Activities must be appropriate and designed to give his life a purpose and develop his skills and interests. He should be enabled by appropriate methods to make choices concerning work and leisure.

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

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

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

Conclusion

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

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

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

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

- understand that the only well-intentioned therapy is to understand better the world of the person with autism and the way he operates, which differs so greatly from our accepted standards and codes,
- train ourselves to adopt an active approach so that we can make specific choices about the levels of support to provide in order to achieve objectives which may be modest but whose very realism will be a guarantee of success,
- be actively aware of the difficulties encountered by the family and give priority to any course of action which enhances the position of the person with autism in the family unit,
- work in close cooperation with families in order to learn from the insight they provide into their children and to exchange with them freely information and results,
- remember that working alongside a person with autism may mean learning to live with failure but also means being able to celebrate a tiny step forward.

CHAPTER 5: PREVENTION OF VIOLENCE / INTERVENTION ON THE PERSON WITH AUTISM

Paula Pinto de Freitas
University of Porto, APPDA (P)

I INTRODUCTION :

We believe that due to their disabilities children, adolescents and adults with autism, constitute a « group at risk » and may be submitted to negligence or abuse.

In order to prevent violence, it is important to recognize and to define it, and in the case of persons with autism to define it in relation with the person with autism. Violence can be active (mistreatment) and passive (negligence, abandonment) - corporal/physical, psychological or social.

II VULNERABILITY :

The triad of disorders at the level of communication, social interaction and imagination which are characteristic of autism, the challenging behaviours, especially auto and hetero-aggressivity, the learning disabilities which are associated in 75-80 % of the cases, the non development of the language (50 % of the cases) or their difficulties to use the language to communicate with others (absence of functional language), their hyperselectivity to some sensorial stimuli which make them perceive some stimuli (for example resonant) as very aggressive, make the persons with autism a group at risk particularly vulnerable to mistreatments.

The cognitive impairments of people with autism, particularly their difficulties in developing a theory of mind make them mindblindness. They have great difficulties in understanding the feelings, intention or thoughts of other persons. Uta Frith calls them « behaviourists » because they do not catch the meaning hidden behind behaviour and, thus, the evident behaviour is for them prevalent. Due to the fact that the persons with autism have difficulties in understanding the hidden meaning of other persons' acts, they are often very naïve. The risk of being abused is for them very high.

Other aspects to be considered are the difficulties they have to give a weak drive for central coherence. For example, the valorisation of an attitude or a special behaviour in different contexts. In our opinion, they are, in consequence, very vulnerable. Any pedagogical intervention to teach them what constitutes abusive behaviour, keeping in mind that this can vary according to the relational and social context, is thus very difficult.

Disorders related to executive functions affect skills necessary to define strategies to solve problems. Skills include the abilities of : shutting one-self out of the external context, inhibiting wrong responses, planing sequences of actions wished, checking the execution and use of feedback, flexibility of attention.

These disorders can explain the difficulties persons with autism have to evaluate behaviours in different social contexts and especially abuses and to give the appropriate answers to allow them to protect themselves against abuse.

III - PREVENTION

We think that it is important to enhance prevention against violence by allowing the person with autism to grow and develop in the least restrictive environment

It is possible to achieve these goals by respecting the Rights of Persons with Autism.

1 - The right of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment

The diagnosis should be done as soon as possible.

It is quite difficult to diagnose autism before three years of age, and we must be cautious with early diagnosis because of the risk of wrong diagnosis (positive and negative). It is however possible to identify children with disabilities related to communication, social relation and imagination from 18 months of age. The Checklist for Autism in Toddlers (CHAT) from Baron-Cohen and others, is a useful tool for an early diagnosis. Children who experience problems in two or more developmental areas (pretend play, shared attention, pointing, social interest and game) constitute a group with high risk for a futur diagnosis of autism.

Children with autism should always have a medical assessment to diagnose possible associated organical diseases (35 % of children with autism have an organical disease which could be diagnosed - C. Gillberg et M. Coleman - 1992). The neuropsychiatric evaluation proposed by Gillberg (1992) can be a very useful guide.

The importance of an early diagnosis is not only the diagnosis in itself but the fact that it enables carers to define a programme of care and early intervention.

2 - To respect the right to accessible and appropriate education in freedom

Autism is a pervasive developmental disorder which means that several fields (communication, social understanding, imagination) are touched by qualitatives troubles of development. Most persons with autism will therefore need care and specialised education all life long.

A child with autism has the right to receive a specialised, planned education, including active participation of the family and taking into account specificity, needs and potentialities of each child who will have had a personal evaluation.

A individualised package should be designed to meet the needs of the individual. This could include full integration into normal systems possibly alongside with special programmes.

In any case, teachers should be aware of the particular needs of the individual and the family. The range of available options should include special classes or schools for people with autism.

Parents and other family members should be actively involved in the education programme since evidence suggests that such participation is particularly beneficial to the person with autism.

Each educational care should be planned, should explain its reasons, the benefits forseen, the ways to obtain them and should be submitted to periodical evaluations.

The provision of adequate facilities for education and development should not place a severe financial burden on the families involved, that should enjoy the same rights for education than those enjoyed by families of children without disabilities.

Aims of the educational treatment

To encourage the development of verbal and non-verbal communication, social understanding, social skills, social interactions and cognitive abilities.

To encourage learning of functional abilities that can be used in different contexts.

To maintain a normative, ecological approach, that provides people with autism a way of life as close as possible to that of non disabled people of the same age. The choice of curriculum, leisure activities, and even the running of specialised institutions should reflect this spirit.

Pre-school : promotion of global development

School aged children : implementation of an adapted curriculum

Adolescence : planing for the future, the life in community and the transition to adult age.

Prevention of violence towards people with autism

We particularly recommend, in the field of prevention of violence, the investigation and development of educative programmes of prevention of violence that can help people with autism to develop abilities and strategies in order to defend themselves against violence.

3 - To respect the right to be educated in the least restrictive environment, to participate in and benefit from culture, recreation and sport.

The fight against withdrawal of people with autism in themselves, isolation within the family or the institution is one of the major means to prevent mistreatments (in an open environment, mistreatments will be more visible and, thus, will have less opportunities to occur and will be easier to denounce.

4 - To respect the right of equal access to and use of all facilities, services and activities in the community

Most people with autism will need support in order to encourage them to be independent, to help them advance their rights and face their responsibilities.

Although it is not always easy for them, people with autism are concerned about their looks, their achievements, their abilities and their independence, the same way non disabled people do. By developing all these fields, the person with autism gains more confidence and more dignity.

5 - The right to freedom from pharmaceutical abuse or misuse

There is no specific medication for autism : medications are used to control syndroms (for example : restlessness, stereotypy, irritability, auto and hetero-agressivity, depression, isolation...).

There are also diseases associated to autism that need specific medication (for example, epilepsy).

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

It is useful here to remind the 10 principles of Pharmautism by J. Fuentes (1998) aimed to promote good practices :

1. No, there is no drug to treat autism. Many drugs were tested, but none has solved the main problems related to what is called autism.
2. Yes, some drugs can efficiently treat psychiatric disorders or behavioural problems experienced by people with autism.
3. No, in the case of people with autism, drugs should not be used if we are unable to achieve, through other methods, the necessary progress. For the time being, there is no treatment for autism and drugs are likely to complicate even more the situation.
4. Yes, drugs can supplement a multimodal treatment and make other interventions more efficient.
5. No, drugs cannot substitute for other social or educational treatments and cannot offset structural shortages, i.e. a lack of qualified staff.
6. Yes, one should bear in mind that drug prescription is an attempt without any certainty as to the result. In principle, a drug should not be given all life long.
7. No, psychotropic drugs should not be given without the certainty that behavioural problems are not of physical origin, more especially in the case of children or non verbal people (restlessness can be due to a toothache, a headache or otitis, etc.).
8. Yes, the instructions given by the medical staff must be adhered to : the dosage should no be increased or reduced without permission ; the treatments should no be shortened or prolonged without necessary control.
9. No, there are no psychotropic drugs without side effects. Nearly all drugs have either positive or negative effects. Generally speaking, one has to weigh the pros and cons.
10. Yes, people with autism, to the best of their abilities, the families and the professionals concerned must be involved, warned about the limits, the potential risks and the beneficial effects of drugs. People with autism and/or their legal guardians are entitled to give their informed consent and it is up to the prescriber to provide the necessary information so that a decision can be made with full knowledge of the facts.

6- The right to meaningful employment and vocational training without discrimination or stereotype

Training and employment should have regard to the ability and choice of the individual.

People with autism should have the opportunity to perform a variety of tasks and share in a variety of work experiences. Only when such a variety exists and people are aware of them can there be any choice of activity. People with autism, because of their inherent difficulties, could require considerable help in performing relevant duties. Efforts should be made to teach and encourage them to attempt some new tasks which may, at first sight, appear challenging and beyond their capabilities. Ultimately tasks must be found which are appropriate to the abilities and accord with the desires of the individuals concerned.

The activities of any individual must be reviewed regularly to ensure that they reflect the developing aspirations and abilities of the individual and to prevent him from being exploited. Even when a person with autism is apparently satisfied with her/his occupation, it may be appropriate to consider experience with an alternative. It may be that the person still prefers the original occupation and so the possibility of returning should exist.

7 - The right to appropriate counselling and care for their physical and spiritual health.

This includes the provision of appropriate treatment and medication administered in the interests of the patient with all protective measures taken.

People with autism are liable to the same range of health problems as anybody else. Because people with autism are often unable to articulate any feeling on unhealthiness or express it in an inappropriate way (for example, instability, auto or hetero-agressivity), family and carers must be particularly alert for any evidence of health problems. Routine health checks should be performed and the results (checks on eyesight, hearing, dentition) recorded. Such monitoring should cover all the areas which would be covered in normal life. Where problems are identified, the treatment should be applied with a particular attention to potential side-effects (desirable or secondary).

People with autism experience the same problems as the other members of society and often in a more severe form. Problems such as bereavement, separations and movement from familiar surroundings are stressful for all of us but the effects can be devastating for those whose understanding is incomplete. Counsellors with an understanding of autism should be available to help, advise and support the person through the difficult periods.

8 - The right to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution

The threat of incarceration is a psychological violence and unwarranted incarceration is an aggression and a violation of individual dignity and freedom, fundamental rights of the individual.

The lack of adapted services and institutions to the needs of persons with autism could lead to unwarranted incarceration.

9 - The right to be involved in all decisions affecting their future must be encouraged.

The wishes of the persons with autism must be, as far as possible, ascertained and respected.

No effort should be spared in explaining the options available even though this may be time consuming and the explanation, perhaps, unintelligible to the subject. No attempt should be made, by enquirer, to obtain particular responses by deception or by the omission of significant details.

Even those people with the severest forms of handicap can usually make their preferences evident. Even when unable to verbalise, their behaviour, equanimity, pleasure or distaste can be observed and their preferences determined by those who know and understand them (parents, carers)..

It is recognised that it may not be in the best interests of the person with autism that all his/her wishes be acceded to but where such wishes, expressed or not, are over-ruled explanations should be provided.

All records of agreements, statements and minutes from such meetings should be subject to the approval of the person with autism and/or their representatives.

10 - The right to access of people with autism to all information contained in their personal, medical, psychological, psychiatric and educational records.

The personal information stored in such records should not be made available to outside agencies, including researchers, without the express permission of the person with autism or if this is impossible their representative.

11 - The right to freedom from abusive physical treatment or neglect.

It is to implement this right that this Guide of Good Practices is being developed, but, it is always crucial to remind that physical punishments are non acceptable procedures in children education.

The use of violence leads to increased violence, the victim of today becoming the agressor of tomorrow. Controlling auto or hetero-agressivity which raises in this context by pharmacological or physical means will lead to a new cycle of violence.

Lack of care is another aspect which can be prevented, but, it is also useful to remind that lack of care can also induce an alteration of behaviour that can lead to the use of pharmacological or physical controlling means which will lead to another cycle of violence.

The spiral of violence must be stoped with the implementation of good practice.

Bibliography

Autism-Europe Charter and Schedules

Pharmautism, J. Fuentes 1998

Autism. Explaining the enigma - Uta Frith, 1993

Autism - an introduction to psychological theory - F. Happé, 1994

Autism and Learning - A guide to good practice - Stuart et Rita Jordan, 1997

L'autisme. De la compréhension à l'intervention - Theo Peeters, 1996

Autism - preparing for adulthood - Patricia Howling, 1997

The biology of the autistic syndrome - C. Gillberg, M. Coleman, 1992

A. Bailey, W. Philips, M. Rutter, 1996 : Autism : towards an integration of clinical, genetic, neuropsychological, and neurobiological perspectives. J. of Child Psychology and Psychiatry, 37, 89-126

Invisible victims - crime and abuse against people with learning difficulties - C. Williams, 1995

CHAPTER 6: PREVENTING MISTREATMENT IN THE FAMILY

Donata Vivanti

Président ANGSA Lombardia

I) ACTION ON THE FAMILY

1) INFORMATION

To be able to relieve parents of their fears and uncertainty when confronted with such a different child and to reduce the risks of mistreatment in the family accordingly, the diagnosis of autism must be accessible and be made early. The parents must also receive accurate information on the origins and characteristics of the autistic syndrome as soon as possible so as to help them understand better and cope with their child's specific problems.

Today it is unacceptable not only to make the mother feel guilty, but also to suppress the doubt that the diagnosis of autism can engender. Professionals must be very explicit about this and start by freeing the parents of all feelings of guilt and preconceptions.

Still, the idea that one's child has a permanent handicap - often with mental developmental delays - can be difficult to accept, whereas the hope of being able to solve all problems by changing oneself is so much more tempting. You must explain to the parents that the diagnosis of a mental handicap is not a life sentence, that correct care will be able to improve the child's abilities significantly, that the child in turn has a right to have everyone's respect and confidence. What is more, because of the heterogeneity of the manifestations and levels of development, the diagnosis of autism does not explain enough about the child. The parents must also be given an individual assessment of the child's abilities and possibilities to protect her/him from over-expectations and child-rearing failures.

2) TRAINING

"My child doesn't look at me, he doesn't obey, he acts as if we didn't exist, he seems not to care about any of us. How are we supposed to behave?" To this question many professionals answer, "Simply act like parents." But being the parents of a child with autism is not simple at all. You have to know the diversity of autism, the strategies employed to attract the attention and co-operation of the person with autism, the difficulties underlying the behavioural problems, and learn how to behave with her/him.

When the various services and facilities do not offer enough information right from the start, the family is forced to get information itself in order to survive. In its concern not to overlook anything that might help the child it runs the risk of losing itself in a maze of confusing messages, caught in a constant tug of war between hope and disappointment. This is the "one-shot treatment" period. On the contrary, once the professionals have informed the family of the characteristics of autism and evaluated the child's abilities, it is advisable that they take charge of training the family through either courses for the parents alone or parents and professionals together or active participation in individually-tailored care and

skills-enhancement programmes conducted in the home in the form of joint working sessions.

3) INVOLVEMENT IN CARE

The family have a primordial role in educating their children and no parent can accept to be a passive bystander of his child's development. A programme of treatment or care must be created that takes account of the in-depth knowledge that any family have of their child, of his priorities and lifestyle. One must also provide for the parents' participation as active partners in the educational plan.

Unfortunately, all too often the parents, especially the mothers of children with autism, lose their identities and dignity as persons in the professionals' eyes. Everything they've done in their lives, their very humanity, no longer counts. As the parents of disabled children they feel incapable themselves. Getting the family actively involved in a care programme increases the child's chances of development. At the same time, by restoring their parenting roles and restoring their confidence in their abilities, it is also the most effective means of relieving the parents of their feelings of guilt and inadequacy. The parents will thus understand, little by little, that "being better" does not necessarily mean "being more normal" and after the first successes they will soon start to love and respect their child as s/he is. The risks of the family's mistreating the child will thus decrease greatly.

II) ACTION ON THE ENVIRONMENT

1) PLANNING CARE AND CO-ORDINATING SERVICES' ACTIONS

A diagnostic unit is of no use if it cannot evaluate the child and devise a custom-tailored programme of care that is adapted to the child's needs and environmental resources under regular supervision. The family's fears before an uncertain future could thus be dispelled by early planning of how to take care of the child all day and for the rest of her/his life. This obviously calls for co-operation amongst the various services, institutions, and families to ensure that all of the people involved are consistent in their approaches. It also requires a political programme to create facilities that are suitable for taking on adults with autism, regardless of their level of disability, for example, sheltered workplaces, living spaces, etc. Moreover, it is logical for such an all-encompassing disorder as autism, that affects many areas - education, psychology, medicine, etc. - to require integrated treatment. Any person who works with the person with autism without collaborating with the other people involved, including the parents, will be responsible for not giving her/him all possible chances of development.

2) SOCIAL AND EMOTIONAL SUPPORT

The parents of children with autism must be helped to conserve the lifestyle and social contacts they had before the child's birth. This means that they must have access to organised, accessible services and trained, competent staff to enable them not only to keep their jobs and circle of friends, but also to find time for each other and to take care of their other children. Indeed, you must not forget that the family is not spared the problems that everyone has, such as financial difficulties, sickness, and obligations to elderly parents. One thing is certain: the risk of mistreating the child will decrease if the child is not the pivotal member of the family, but merely a member of the family with an additional problem.

Moments of respite, that is, a chance for the parents and brothers and sisters to take short holidays, safe in the knowledge that their child/sibling is in the care of competent individuals in an appropriate environment, give the family a chance to recharge their batteries and find

new energy to cope with the difficulties of daily life. The solidarity and understanding of other parents of autistic children within associations likewise offer some emotional relief, but should not replace friends and interests cultivated outside autism, on pain of becoming a new source of marginalisation.

The tangible aid given by services to maintain the family's social contacts and relational networks both outside and inside its bounds, prospects of a dignified future for the child, the professionals' confidence and consequently confidence in oneself and in the child's abilities provide the most effective emotional support when the professionals involved are truly motivated and specialised in autism.

3) THE ROLE OF PARENTS' ASSOCIATIONS

INTRODUCTION

In serving as a bridge between families and services, parents' associations have a very important and at the same time tricky role to play in preventing the abuse of children with autism. Beyond the influence that these not-for-profit associations have in each country, they are the parents' spokesmen and can help prevent mistreatment by working with the various services, facilities and institutions.

Yet autism is a rather unknown area, especially as concerns its causes and, consequently, intervention strategies. Unfortunately, there still is no definitive solution or recipe that works for everyone. This gives associations of autistic children's parents the additional task of trying to help the parents and care facilities to make the right choices about the best way of caring for their children, given their specific disabilities, without trampling on their human rights.

I) ACTIONS ON THE FAMILY

1) INFORMATION ABOUT AUTISM

It is advisable that the parents be informed first by the facilities that take charge of their children, even though the associations may help clear the field of false beliefs about autism through publications, the dissemination of informative materials for the general public, the organisation of conferences or seminars for parents, and private talks, with the purpose of increasing the parents' expertise and thus improve the quality of life of the child and family. When the social environment is still influenced by the psychogenic theories of autism, information and the solidarity of other parents will be of invaluable assistance in dispelling the families' guilt feelings. Yet the parents themselves may prove reluctant to give up old beliefs about autism, especially when the child is very young and talented. It is very logical for people who have already invested so much love in their child to prefer to take on the role of the guilty party rather than giving up hope of seeing their child blossom and become normal. It will be easier for them to accept the truth if it is uttered by other parents who have already lived with the same anguish and fears.

The associations should hold informal get-togethers where the parents have the possibility of finding the warmth of understanding and solidarity but also of gleaning more knowledge from the testimony of more expert families, of being reassured as to their own abilities, and of re-appropriating their child-rearing roles whilst respecting their children's multiple facets.

Information about autism should keep up with changes in current theories as closely as possible so as not to confuse the family and plunge it in the period of "one-shot treatment". Still, it is logical for parents who are under the strain of living with autism and all its problems

and bowled over by their child's suffering to grab the first solution that comes along; making them the easy prey of vendors of illusion. The association can help these parents by keeping abreast of all new developments and providing them with all useful information, without prejudice but without encouraging the market of illusions, if need be with the help of a scientific committee of competent, influential, selfless professionals.

2) INFORMATION ABOUT THE CHILD'S RIGHTS

All too often the parents of children with autism, who are worn down by people's intolerance, humiliated by professionals and institutions' refusals to help, and exhausted by day-to-day problems, are reduced to begging, as if for a favour, for what are a so-called "normal" child's rights. They too often accept unjustified negligence. They have trouble finding their way in the maze of bureaucracy and laws, of which they are sometimes unaware. What is more, the weaker the people whom the laws are supposed to protect, the more complicated the laws seem. Proper information channelled through the association and the advice of more competent parents can help the families not to lose heart and defend their children's rights better.

3) INFORMATION ABOUT FACILITIES

When parents cannot find facilities that are willing to take on their children, they may be tempted to look for any recipe or entrust their children to no matter what "method" or novelty offering a miracle cure. It is known that while the child will have autism her/his whole life, appropriate care can improve her/his autonomy as an adult considerably. Parental disappointment can thus lead to negligence and jeopardise the child's chances of developing.

The associations may be the most selfless sources of addresses of reputable, effective services that the parents can find, since they rely on parents' testimonies and checks of specialised facilities (see "Working with the facilities").

4) SUPPORT

As we have already seen, the feelings of guilt and the misunderstanding of autism are likely to trigger over-expectations of normality or shift the blame for the autistic behaviour onto the child and thus stoke the illusion that s/he could be like others if s/he wanted to. The exasperation that results from this alleged attitude of opposition and feeling of inadequacy leads to completely unwarranted punishment. Now, a cruel truth may be easier to accept if it comes from another parent who has already been down the painful road of realisation, despair, and acceptance and knows how to listen with empathy and find the right time and best words to share the truth in order to relieve the parents and bolster their self-confidence and faith in their child's potential for development. The solidarity of the other parents in the association can restore the parents' self-pride and give them the strength to fight proudly against intolerance towards a child who gives everyone an opportunity to learn and to grow.

5) RAISING PARENTS' AWARENESS OF THEIR RESPONSIBILITIES

Parents' associations are the best institution for reminding parents of their responsibilities vis-à-vis their child with autism without being suspected of minimising the family's hardships or saying they are to blame. However, it would be too simple to recommend that people whose lives are devastated by autism respect their child's difference, continue to have faith in her/his abilities, be proud of her/his efforts to adapt to an incomprehensible world, and defend her/his rights. On the contrary, in the absence of support from the immediate environment, this could increase the feelings of frustration and inadequacy and

consequently the risk of mistreating the child. The associations can, on the contrary, make the parents conscious of the practical tasks that can improve the child and family's lives noticeably and protect the child from mistreatment by making the following recommendations:

- Do not count on yourself alone and do not give up on care outside the family solely in order to spare the child suffering. No one can tackle as vast a problem as autism alone. What is more, the child will soon become an adult, with all the attendant rights and demands to participate in society.
- Encourage the siblings to pitch in, but set as your goal teaching the child with autism to respect their living spaces, if necessary with the help of a programme drawn up with professionals. S/he needs their sympathy rather than forced tolerance.
- Try not to keep the child locked up at home for fear of criticism. Try to react calmly to expressions of intolerance without humiliating the person, for example through a simple, brief brochure on autism provided by the association that you can offer the person with a brief statement such as, "Unfortunately, my child has autism. Do you know what autism is?"
- Don't be afraid of asking for help, even physical assistance, from strangers when needed (for example, giving the child a hand to board a bus or cross the street). A person who is asked directly will rarely have the courage to refuse and this can provide an opportunity to make her/him aware of the problems of autism.
- Encourage relatives, friends, neighbours and truly motivated volunteers to help, even if they are not competent. The less suitable people will soon drop out on their own, but you may come across some precious helpers.
- Be ready to work with the professionals unbiasedly and to meet with them whenever necessary to inform them of your child's problems or discuss the family's aims.
- Keep and make available to the professionals all documentation about or assessments of your child.
- Settle upon a system of regular information exchange between the family and professionals and their reciprocal roles right at the start of treatment.
- Ask for a programme to put the skills that are learnt outside into general practice at home and strive to implement them.
- Trust in the professionals who give evidence of their desire to take the child to their bosoms and truly want to work with you, even if they have some problems doing so in the beginning, but be ready to ask for outside opinions if the facility seems to lack experience or expertise.
- Pay attention to the child's rejection of the professionals to whom s/he is entrusted and report all suspicions of mistreatment to the unit's head as soon as possible.
- Pay attention to the presence of overly frequent bruises or injuries, even if the child is subject to self-mutilation, for proper care should reduce the frequency of aggressiveness towards oneself.

II) ACTION ON THE ENVIRONMENT

1) RAISING PUBLIC AWARENESS

Disability is not a family affair. No one wished autism on her/his child and while the family have primary responsibility for making choices concerning their child's life, no one can say that s/he is safe from these difficulties.

The families sometimes find invaluable help in their immediate environment, *i.e.*, relatives, friends, and neighbourhood volunteers. This situation is the best chance for the child to surmount her/his isolation and truly participate in social life. It should thus be encouraged by raising awareness of and teaching people in simple terms about the positive aspects of autism, such as naiveness, attitudes toward work, etc. On the other hand, intolerance of the autistic person's behaviour often gets the better of solidarity, so that all the family's efforts to integrate the child into the social environment are soon frustrated. In addition, because of her/his naiveness, the child can become the victim of jokes by her/his "normal" school- and playmates and be humiliated because of her/his strange behaviour.

Sometimes, if the child's handicap is not well understood, s/he may not be protected enough and the best intentions in the world can subject her/him to the dangers or suffering of intolerable social promiscuity or a chaotic, incomprehensible environment. Everyone is familiar with the cases of children with autism who, finding themselves in the middle of a noisy party without appropriate preparation and landmarks, are seized by behaviour fits or tantrums.

Parents' associations can improve the autistic person's participation and integration in the environment by raising public awareness of autism and its characteristics, asking that the media broadcast information about autism, giving informative lectures for the general public, and offering courses for the children's classmates and their families in the schools or any other of the child's environments. One has to explain that autism is not contagious and gives those who do not have autism a chance to develop their sense of responsibility and respect for diversity, that is to say, to become responsible citizens.

2) GATHERING INFORMATION: A TOLL-FREE NUMBER FOR REPORTING ABUSE

Parents' complaints about professionals often are not taken seriously. Sometimes the parents themselves prefer to remain silent about the mistreatment of their children for fear of losing the facility's assistance, to protect the child from reprisals, or out of fear that the child will be put away. Similarly, even the most diligent professionals can forget their duty to protect those who are weakest and confuse complicity and solidarity with their colleagues or loyalty towards their institution or facility by taking advantage of the communication problems, *i.e.*, the very disability, of people with autism. Sometimes the fear of being isolated, criticised, or fired prevents them denouncing episodes of mistreatment that they have witnessed, although they are well aware of their responsibilities.

Parents' associations could pressure public institutions to set up a toll-free number to collect all complaints anonymously and promote the objective verification of all reports of mistreatment.

3) WORKING WITH THE FACILITIES

We encourage parents' associations to create committees of parents who are not directly involved in order to keep watch over care facilities, participate in the drafting of house rules, and monitor their enforcement. These parents' committees could fulfil the following tasks in working with the various care facilities and services:

- help guarantee competent care that respects the needs and rights of the person with autism and protect the child from all physical and psychological abuse.
- check that medication is administered to improve the person's well-being, not to calm behavioural problems that are due to inappropriate treatment.
- check that the family has access to all documentation concerning their child and all information about all treatment strategies and research. In this case, it is necessary to ascertain that the parents have given their written authorisation.
- encourage the collaboration and impartiality of professionals vis-à-vis the family in order to improve the care that is provided and the parents' feelings of adequacy.
- avoid having the parents interrogated about their lifestyles. If the parents feel that they are under suspicion or criticised they may decide not to let others take charge of their child.
- help the care facilities to build up a network of professionals who are up on the difficulties of autism and can be consulted by the parents for all sorts of medical problems: feeling out of sorts, illness, dental problems, etc., since people with autism are not immune to disease.
- participate in the thankless work of managing waiting lists and deciding on admissions priorities.
- participating in staff hiring.

4) SUPPORT FOR THE PROFESSIONALS

The professionals who are involved in caring for persons with autism also have their own problems. These are due to the difficult nature of the disability, but also to their colleagues lack of understanding. "You are lucky to have a kid like that one": once again, the child's normal appearance is misleading and ignorance of the seriousness of autism does the rest. Colleagues sometimes pooh-pooh at strange teaching strategies or criticise singular approaches to handling the child. The care facilities' very directors may occasionally find it difficult to understand how such an apparently normal child needs so much care. Finally, such children often make very modest progress and rarely show any gratitude to their "teachers".

Parents' associations' understanding and appreciation of the professionals' work can then encourage and motivate competent professionals who are respectful of the person with autism. The associations can also join in the political struggle to get institutions to recognise the work of qualified professionals and competent facilities as they deserve, to demand financing in line with the needs for continuous training and the difficulty of taking on such individuals, and to raise the necessary funds. Last but not least, they can help motivate personnel by organising exchange visits or joint projects with specialised facilities from other countries.

CHAPTER 7: PREVENTION WITHIN AGENCIES & CARE SETTINGS

Bill Meldrum
Scottish Society for Autistic Children (UK)

I. ORGANISATIONAL ISSUES

1. Organisations and public agencies working in the field of autism should have a Code of Good Practice which takes account of the particular difficulties associated with autism.

Each organisation/agency should adopt a brief statement setting out its policy on safeguarding the welfare of the children and adults with whom it works. This policy should state clearly the duty of all those employed or involved in the organisation to prevent the physical, sexual or emotional abuse of all people with whom they come into contact.

Any such policy statements should be brought to the attention of all existing and any new staff or volunteers, who should also be informed of any guidelines or training which will enable them to implement the policy statement. The policy statements and guidelines should also be brought to the attention of parents or guardians.

2. The work of the organisation should be planned in such a way as to minimise situations where abuse may occur.

This includes the following measures:

- Activities involving a single child working with an adult should take place in a room with some means of observation or monitoring.
- Staff/volunteers should not meet with children/adults away from the organisations base unless a parent or other adult is present.
- Where it is necessary to have adults working with children or young people in unsupervised settings (eg befriending schemes for people with autism), organisations should take every step possible to assure themselves that people in such high risk positions have no record of, nor potential to abuse. This may involve more thorough recruitment procedures, the procurement of additional references and very close supervision.

3. The organisations child/adult protection procedures should be regularly scrutinised and evaluated by independent assessors who have a satisfactory knowledge of autism.

II. STAFFING ISSUES

There are 2 main considerations:

1. How can staff be involved in minimising the risk for the service users.

2. How to minimise the risk of staff themselves being involved in the abuse of service users.

Staff must be aware of and understand the relevant policies and guidelines on abuse and the implication these have for working practices.

Staff require opportunities to consider what activities may constitute sexual abuse.

Staff require an awareness of which people are potentially most vulnerable and what behaviour should raise questions and be reported to their line manager. They must know the procedure to follow if they have suspicions. They must be clear on the limits to confidentiality if allegations come to their notice. They must also be aware of their duty to inform their line manager (or other appropriate person) of such allegations.

Employers must ensure that references and police checks are followed through and should avoid placing staff, about whom they have little knowledge in situations in which the possibility of abusing service users is relatively easy.

Where possible, consideration should be given to the balance of male and female staff when preparing staff rotas.

Employers should also have clear policies relating to the use of volunteers in relation to supervision, training and vetting procedures.

Clear individual guidelines should also be available to all staff regarding procedures and safeguards to be taken when staff are providing intimate personal care. It is recommended that intimate personal care is most appropriately provided by a person of the same gender.

III. CLIENT ISSUES

Service Users as Victims

It must be recognised that there can be additional vulnerability where clients are dependent on others for basic toileting and dressing functions and therefore their notions of personal privacy may be affected.

Similarly where clients have communication difficulties, as in autism, which would make it difficult for them to clearly indicate abuse, this again increases vulnerability. It is of crucial importance that every effort is made to understand any client who is suspected of having been abused. There should be particular awareness and close monitoring of any client who has previously been abused as there may have been particular factors which made them an easier target in the past.

Where staff are concerned about the vulnerability of a client, this should be highlighted in their individual care plan and, ideally, this should lend to a safety plan being developed for that individual. Such a plan is recommended for all clients identified as particularly vulnerable. This could include those who have previously been abused, those who seem to be vulnerable because of inappropriate social or sexual behaviour, or people who are living with someone who had a history of offending.

It is important that services try to develop an ethos of empowerment for clients through self advocacy, assertiveness and wherever possible encouraging clients to question staff and to

communicate with staff in order to facilitate disclosure. This is particularly important as most research suggests that the majority of disclosures of above are made by clients themselves rather than staff or families.

Perpetrators With a Learning Disability

The fact that a perpetrator does not fully understand the nature of abuse does not alter that fact that the abusive act has occurred and appropriate action **must** be taken. Ignoring abuse by service users does not help perpetrators or victims in that abusive behaviour may be reinforced if it goes unchallenged or is not taken seriously. Staff should be aware that victims can become abusers and this aspect should be considered in the personal safety plan for individuals. Where an individual has been involved as a perpetrator this should be included in their individual care plan, addressing the need to safeguard them and other people.

IV. MAXIMISING SYSTEMS TO LIMIT ABUSE

The general focus here must be to ensure that service systems, within the bounds of confidentiality, are open rather than closed. It is important that there is good collaboration between agencies and linked to this is the need for good record keeping and reporting, both with regard to perpetrators and victims, and the development of a system to ensure a flow of information between agencies where appropriate.

Cases of abuse within agencies should be regularly reviewed to see what can be learned about prevention and whether procedures for reporting and investigation are adequate. Services need to create a climate where the disclosure of abuse, or concerns about abuse is encouraged, both by staff and service users or their families. This should incorporate good systems of support and training (see below). Clients and their families should be made fully aware of their rights under the complaints system of service providers and of their rights to contact appropriate external agencies.

Support Services Following Incidents

When an incident of abuse of a person with autism occurs, this can very often lead to a great need for support for a number of people involved. This will vary according to individual circumstances and may include a range of practical and emotional support.

Support For Victims

The immediate work with a victim will involve ensuring their safety and comfort. It is crucial that the victim needs to know that they are believed. There should be clear identification of who will be the main support worker to minimise confusion.

The amount of change for the victim should be minimised, although they must be made to feel safe. Support must be provided at the level of need indicated, including behaviourally, by the client.

It is important that the support is provided by someone who is technically skilled and emotionally equipped to do so.

Support For Staff

Support is likely to be required for staff who:

- report abuse.
- work in settings where abuse has occurred.
- have themselves been accused of abuse.

Staff who report abuse should be seen to be supported by management. Given that some well publicised cases of abuse have only come to light after having been reported by staff members who had left the service, consideration should be given to 'exit' interviews for staff leaving services, with the option of the interviews being carried out by someone outwith that direct care setting.

Services should be aware of the need to provide support for staff following incidents, particularly if this has involved a member of staff. All such support should be made available on a pro-active basis rather than requiring staff to request help.

Support For Other Service Users

Just as staff can be affected by abuse within their environment, the same consideration must be given to other service users and full consideration given as to how best to provide support. It should be acknowledged that, particularly where major incidents come to light, the needs of the staff going themselves may preclude them from providing an appropriate level of support to service users.

In such circumstances additional staff should be drafted in, in consultation with the existing staff group.

V. TRAINING ISSUES

Clearly, in order for many of the recommendations to be applied effectively, organisations will have to commit to providing appropriate levels of training for their staff.

Joint Training

A number of benefits are likely to be gained from the development of some joint training initiatives, which would involve staff from Social Work, Health, the Voluntary Sector, Advocates, the Police and other professional in the Criminal Justice System being involved together in training. This would facilitate an understanding of the different roles, an awareness of difficulties in different settings, sharing of expertise and exchange of information.

Training For Staff

It is recommended that all staff providing a service to people with autism should receive training in the following:

- policy guidelines
- key indicators of the possibility of abuse
- what to do if they suspect abuse

- clear guidance on acceptable and unacceptable socio-sexual behaviour and interactions with clients
- general awareness-raising in relation to abuse of clients with autism
- communication skills

It is also likely that relevant staff would benefit from training in the following areas:

- risk management
- support skills
- therapeutic intervention skills
- interview techniques

Training For Clients

Whilst it is recognised that empowering clients to disclose abuse is no easy task, this can be facilitated through the promotion of self-advocacy opportunities. Sex education as part of wider social skills training should also be available - it can offer people an understanding of what is usual acceptable behaviour and provide a vocabulary for sexual activities and body parts. Assertiveness training to enable clients to say 'no' and make them aware of their rights is also likely to be beneficial. Clients should be provided with information on who to report abuse to and on the importance of reporting concerns about others being abused. These should be part of an ongoing programme and not a one-off training event. It is also important that clients are aware of complaints procedures.

Training For Families/Carers

It would be good practice to make training on the policy available to carers and the families of clients, particularly in relation to awareness-raising, key indicators of abuse and complaints procedures. It is recognised that this would have to be presented very carefully and sensitively.

Training For Managers

It is absolutely crucial to the effectiveness of the policy that all managers, from first line managers upwards, are up to date with the policy and the actions to be taken and that a clear system is in place to ensure that new managers are made aware of this.

Ongoing Training

It is recommended that training initiatives be developed on an ongoing basis in addition to any initial training events run following the introduction of the Code of Good Practice. An ongoing programme of training would ensure that new staff would be made aware of appropriate practice and existing staff can maintain and develop their knowledge base. It may be appropriate for such training initiatives to be monitored by an appropriate committee.

CHAPTER 8 : THE IMPORTANCE OF TRAINING IN THE PREVENTION OF VIOLENCE AND ABUSE AGAINST PEOPLE WITH AUTISM

Theo Peeters, Opleiding Centrum Autisme (B)
& Rita Jordan, University of Birmingham

I INTRODUCTION

The principles of training staff to work with individuals with autism in positive ways are the same as the principles of intervention in which they are being trained. Such training should be based on the understanding of autism, the situation, and the individual.

It is only logical that carers who choose autism as their profession should receive a full training in autism. Parents, on the other hand do not have the choice, but it is only logical that they also, as the most concerned persons, as persons who have the ultimate responsibility over their child, should receive the best possible training, since no one is born with an innate knowledge of autism. Yet this training is seldom provided.

Parents and professionals living and working with individuals with autism risk living under circumstances of extreme stress, because they love the persons they care for and have so many difficulties understanding their behaviours and emotions. Loving someone who suffers and having no means or ideas of how to help them is one of the most exhausting situations one can imagine. In many cases the use of violence is a desperate attempt at controlling a behaviour one does not understand and one has not really learned to treat or prevent.

We think that the use of violence is more likely to occur where training (and understanding of autism) is not available or where society does not make available the necessary resources to put the insights of training into practice. So the training of professionals as an important factor in the prevention of violence is not only an educational affair, it has an inherent political dimension that will also have to be dealt with.

All too often training in autism is exclusively seen as a kind of crisis-intervention and not enough as the most important factor in the prevention of a crisis (Jordan & Jones, 1996). It often happens -and it is understandable- that professionals from the very first day of training try to find short term solutions for long term problems, leading to a 'recipe-approach' to teaching (Jordan, 1996a). It is essential in dealing with behaviour problems (and preventing violence as a desperate reaction to the "uncontrollable" behaviour problem) to make a clear distinction between symptoms and causes.

II - UNDERSTANDING AUTISM

High functioning individuals with autism (such as Gerland, 1997; Grandin, 1986; Segar, 1996; Sinclair, 1992) write about their extreme efforts to understand our neurotypical communications and social interactions. They also speak of their feelings at conferences or on the INTERNET:

'The fact that so-called normal people, or whatever I should call them, have thought that they know exactly how all human beings function, has been one of the most harmful things in my

life: that all those people have had a model into which they have tried to fit me. And that they also have been absolutely convinced that this model of theirs is the only existing model. That's why they've told me to behave myself, and not to be different. They have never imagined that I would function differently from them, and they have never been able to guess what I felt. Lack of empathy, or what?' (Gerland, unpublished, 1996 conference)

'..approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you could never have imagined'. Yes, that takes more work than relating to a non-autistic person, but it CAN be done - unless non-autistic people are far more limited than we are in their capacity to relate. We spend our entire lives doing it. Each of us who does learn to talk to you, each of us who manages to function at all in your society, each of us who manages to reach out and make a connection with you, is operating in alien territory, making contact with alien beings. We spend our entire lives doing this. And then you tell us we can't relate!' (Sinclair, INTERNET, 1998).

Through their writings we understand better than before how difficult it is to "survive" among us and how many adaptations they have to make. It helps us also to be more respectful to persons who have a combination of autism and mental retardation and who are less able to speak up for themselves.

Many forms of echolalia, echopraxia and repetitive behaviours need to be interpreted more positively than one used to do (Jordan, 1996b; Schuler & Prizant, 1985). The history of the understanding of autism at the same time seems to be the history of the growing of our respect for their attempts to be with us. For most people with autism and mental retardation, happiness may depend more upon our adaptations than upon the development of their skills (even if the two should go together). The relationship between a person with autism and us can be compared to the myth of Procrustes. Procrustes had a strange concept of hospitality; he adapted the length of his visitors' legs to the size of his bed by cutting them off or stretching them out. We also seem to have such a strange concept of hospitality: Without training, we adapt persons with autism to our non-specialised knowledge. In such a relationship, a climate of violence seems to be inherent, even if not always deliberate or visible.

Thus, understanding autism becomes the cornerstone of the training needed to avoid violence and abuse in treatment. Judging and responding literally to behaviour leads to frustration because it takes no account of the base of that behaviour within the understanding and perception of the person with autism (Jordan & Powell, 1995a). This has become known as 'the iceberg theory' of autism (Gillberg & Peeters, in press; Peeters, 1997; Schopler, 1995; Schopler & Mesibov, 1994) which suggests that behaviour problems in autism are like the tip of an ice-berg. The tip is the symptom, but the most important part of the iceberg is invisible; the tip is 'caused' by the biggest part hidden under the water.

When someone with autism throws objects, for example, hits himself or someone else, we see the symptoms. To make the symptoms disappear or diminish, we have to treat the causes. If an adult with autism feels bored to death because he has to deal with seven or eight hours of non-organized free time each day and he hits his head against the wall because he has not learned any other way to ask for attention, then it is obvious that he needs educational help in the development of communication and leisure skills. If, on the other hand, we 'treat' his behaviour problems in a symptomatic way, disregarding the causes, this is itself a form of violence, perhaps of neglect but perhaps worse, if the carer resorts to punishment. It is impossible to accept ethically that one is going to 'punish' someone because he is not able to communicate like us.

An education specialized in autism is the best form of treatment for behaviour problems, since it is a treatment where the main focus lies in prevention. The first thing professionals have to

understand is that persons with autism treat information in a different way. 'Autism thinking' is the key phrase in preventing behaviour problems and violence, not a 'recipe' approach. What it comes to is attempting to put ourselves into the brain of someone with autism and trying to see the world the way he or she does. The more we succeed in understanding what causes so many difficulties, the more we will be able to remove the obstacles and in this way prevent behaviour problems (and the violence which often comes as a desparate reaction).

III - POSSIBLE CAUSES OF VIOLENCE IN THE TREATMENT AND CARE OF INDIVIDUALS WITH AUTISM

Just as it is necessary to understand autism if we are to treat individuals with autism effectively and with respect, so it is necessary to understand the causes of violence in the carers and educators of those with autism, if we are to deal effectively with that. It is that understanding that must inform the training we give. There are special factors in autism which may lead to such violence in addition to the normal pressures of family or institutional life that sometimes result in violence.

The transactional nature of autism

This leads to the frustration and de-skilling of both parents and professionals. Autism is essentially a disturbance of the relationship with others (Kanner, 1943; Hobson, 1993). This has two important sequelae. One is the effect on the individual with autism who, contrary to all other groups of individuals, will be disturbed and confused rather than consoled and comforted by the proximity and social overtures of others. What is intended as a gesture of affection or comfort, or a placatory attempt following conflict, will not be perceived as such by the individual (Attwood et al., 1988) and indeed may be experienced as at best further confusion and at worst intrusion and aggression. The person with an autistic spectrum disorder may then react in turn with distress and panic and this too may be perceived as aggression by others.

The second of the sequelae is the effect on the person who is caring for or working with the person with autism. Even when they understand the condition at a theoretical level, but especially if they do not, they will experience the reactions of the person with autism as rejection and even aggression. This will make them feel helpless and angry. Their natural instinctive reactions do not work, nor do their previously successful professional strategies - they feel demoralised and de-skilled. The natural consequence of those feelings is frustration and anger.

The literal reading of behaviour

As mentioned above, even when autism is understood at a theoretical level, our normal intuitive 'reading' of the behaviour we see in autism is liable to mislead. In particular, the attempts that the person with autism does make to communicate are not recognised or understood and we naturally impute an intentionality to the behaviour we see which may not in fact be the case.

It is natural that the behaviour of others is processed unthinkingly. We do not 'work out' the motivations of others as a kind of theory (as the 'theory of mind' theorists - Baron-Cohen, 1995; Leslie, 1987; 1991 - would have us believe); real-time processing is too short for that. We reserve such conscious analysis for our deconstruction of written and dramatic texts or for a post-hoc analysis of events. At the time, we respond instinctively to the emotional subjective 'meaning' of events as conveyed through the behaviour of others. We can discipline ourselves to recognise that what we see in autism does not mean what our subjective reading of events tells us, but this is something we need to be trained to do. If we respond intuitively, we will misinterpret the behaviour we see, reading it literally according to our subjective experience and our understanding of normal development and motivation. Thus, behaviour will be

misinterpreted to mean just what it would mean if we were doing it and we will assume a kind and level of intentionality that is not really there.

There may, for example, be an incident in which the person with autism is asked to do something quite unexceptional such as get into the back seat of the car and reacts with apparent unprovoked aggression, screaming and throwing her skates at the person making the request. Yet, if we analyse the situation from the point of view of the young lady with autism, a different picture emerges. When asked later, she cannot remember what she did and reports being in a panic and reacting blindly to that. The cause of the panic? She has been told that she will be picked up from the station by one person but now, when she goes to enter the car she is confronted unexpectedly by someone else sitting there and, even more disturbing because even less predictable, it is a child. It is no good punishing the person with autism because they have reacted in panic, since the behaviour is not under conscious control at the time. We need to prevent the behaviour (as indicated below) by our prediction of the likely reactions of someone with autism to such events.

Fear.

Just as it is difficult for the person with autism to understand and predict our behaviour, so it is difficult for us to understand and predict what they will do. They are following a different developmental path and show many very idiosyncratic behaviours, which can lead to fear of loss of control in those who are living and/or working with them.

Thus, it is not always the behaviour itself of someone with autism that can provoke an angry and violent reaction, but the fact that the different developmental path and the consequent different and idiosyncratic behaviour makes it hard for others to predict that behaviour. Just as the person with autism is confused and fearful of us because it is hard for them to predict and understand our behaviour, so we experience fear and confusion when faced with behaviour that we can neither understand nor predict. A common response to such feelings is the desire to inhibit and control the behaviour and so our demands on the person with autism may become coercive and even violent. It must be remembered that the person with autism will be experiencing the same need for control for much the same reasons, so there is then a clash whereby both participants in an interaction are seeking control of the other. The experience of this conflict may increase the fear in the carer or professional and the extremity of the measures used to re-establish control.

Short term success reinforces long-term exacerbation of problem

Using violence may bring about short-term success for the carer or professional in terms of stopping unwanted behaviour or coercing the individual with autism to do something. The immediate effect will be to reward the person for using this violent act as a strategy in similar situations in the future. The unease the person may feel about using violence may be counterbalanced by self justifications such as 'It is the only thing that works' or 'It allows him/her access to a better learning situation or environment'. Such positions may even be taken in text books or in approaches meant to guide professionals (Kraijer, 1997; Lovaas, 1981). In such a way, the person is able to feel vindicated for the use of violence and even to gain in self esteem because they feel they have a strategy that 'works'.

Over time, of course, the short term 'solution' leads to longer term problems, but the pathway to this is seldom recognised unless it is pointed out in training. To begin with, for example, the professional may slap the child for pinching as they sit together to do a task. This appears to work; the child is upset but stops pinching and can be re-directed to the task in hand. The adult is relieved and feels successful overall, in spite of some initial feelings of discomfort at slapping the child. But what has the child learned? In a situation that the child finds disturbing (perhaps because of the confusing nature of the task or the way it is presented, perhaps because of the proximity of the adult at the table) the child performs an action (pinching) that in

the past has led to others leaving him in peace. This is not the effect this time; instead, the adult slaps the child, there is a pause in the activity as the child is distressed and then the adult gives the child something concrete to do by positive re-direction to the task. This works for a while because the child's pattern of behaving has been disrupted. But now the uncomfortable situation re-asserts itself; the task may still not be clear (maybe the adult has reduced his or her level of guidance at this stage) and the adult is still uncomfortably close. So the child tries pinching again and this too is followed by a slap. Gradually, a new pattern is established. It is true that pinching now no longer leads to being left alone, but now it leads to the even more clearly predictable reaction of being hit. This may be intended as a punishment, but in a confusing world any predicted response is preferable to unpredictability so the child comes to seek the predictable pattern of the pinch followed by the slap. For the adult this is infuriating and frightening. The hitting becomes harder in an attempt to re-establish control and a vicious (metaphorical and actual) circle is established.

Some methodologies based on control and reward/punishment

The short-term effectiveness of some measures have meant that some programmes have incorporated them as part of the training advocated. In spite of Skinner's (1957) own strictures against punishment, they have, for example, often been advocated as part of behavioural training techniques. The following objections to punishment are based on Skinner's original points:

- ineffective in the long term (for the reasons given above)
- causes unwanted side effects such as fear
- indicates what an individual should *not* do, not what s/he *should* do-
- justifies inflicting pain on others
- being in a situation where previously punished behaviours can be 'indulged' in without being punished may 'excuse' that behaviour (e.g. the child learns not to jump on the sofa when daddy is there because he will hit you, but will jump on it even more when daddy is not around)
- elicits aggression towards the punishing agent and/or others (aggression may be used against more vulnerable others, if the punishing agent is seen as too powerful)
- replaces one undesirable response with another (if the causes are not tackled, a behaviour may be suppressed but another will take its place and that one may be even worse)

A very influential book in the UK in the 1970s (Copeland, 1973) had parents in particular hitting their children with autism regularly in the hope that this would bring about the 'cure' promised by the author. Lovaas and his colleagues (Lovaas, 1966; 1967; Lovaas et al., 1965; Lovaas & Simmons, 1969) was regularly using aversive techniques to eliminate all manner of unwanted behaviour and even, it was claimed, to train pro-social behaviour. Although the current educational and ethical climate means that aversives are no longer promoted as part of the Lovaas treatment, the basis of the home training programme (Lovaas, 1987) was not only based on the use of aversives but saw these as an essential part of the programme.

'...In the within-subjects studies that were reported, contingent aversives were isolated as one significant variable. It is therefore unlikely that treatment effects could be replicated without this component'. (p.8)

Even without specific advocacy of aversive techniques, however, it is likely that methodologies that stress control and manipulation of behaviour without an understanding of the underlying causes, and thus meaning, of that behaviour, will be more likely to lead to forceful (and ultimately, aversive and punitive) ways of establishing and maintaining control.

Vulnerability of people with autism

The lack of speech and/or communicative ability makes people with autism vulnerable and perpetrators of violence can 'get away with it'. Sadly, the most basic (and base) reason why violence may occur in the treatment of those with autism is simply that it can. In many cases the individual with autism will have little or no speech or alternative forms of communication. Even where there is speech, the person with autism will not understand about communication and will not be able to communicate what has happened to others or even to themselves, especially if the perpetrator of the violence is giving an alternative account. We have experience of situations where the person with autism has been taught to give a completely false account of his injuries by the very person responsible for them. We have also known of cases where an official policy of non violence has led to a culture of underhanded forms of violence - pulling of hair in the nape of the neck, nails dug into the skin underneath the child's own nails and so on. Violence has been shown to increase in situations where there is less chance of detection (Blunden & Allen, 1987). The short-term success of violence, as indicated above, may encourage its use and, if undetected, the cycle of abuse may continue.

With the possible exception of this last reason for violence, it should be emphasised that violence does not usually come from evil intent or from a perverted pleasure from other people's pain. We accept the helpful and hopeful doctrine of the Option philosophy (Kaufman, 1994) that everyone is doing the best they can with the resources available to them. This implies that carers and professionals resort to violence because of fear, misunderstanding and lack of knowledge about autism and alternative effective strategies to achieve the same ends (Harris et al., 1996). If that is the case, then these are all aspects that can respond to education and they provide the rationale for an effective and necessary training programme.

IV - PRINCIPLES OF TRAINING

The principles that should underlie a training programme, therefore, follow from an understanding of autism and the points made above, on the possible causes of violence and abuse in those who live and/or work with people with autism.

Developing a good understanding of autism

A teacher of the blind should know what blindness means, a professional for the deaf should know about the effect of hearing problems on development. If you have a profession in autism you should have a good understanding of this pervasive developmental disorder. Love and intuition are necessary, but not enough. The international criteria for diagnosing autism (APA, 1994; WHO, 1992) talk about 'qualitative impairments' and the different qualities of some behaviours are not always easy to understand. Here are some examples from the triad of impairments that underlie the diagnostic criteria (Wing, 1996).

'..other people's words, intonation, facial expression, body language and touch had no consistent meaning...(Williams, 1996 p2)

It is extremely important that professionals, in a culture where the accent often lies so heavily on 'verbal therapies' and the verbal mediation of education, realise from the very beginning that some uses of language and speech may be more a burden than a help for persons with autism.

Or one other example, is the realisation that children with a combination of autism and mental retardation who have a general developmental age of two (a mental age that allows normally developing children and those with severe learning difficulties, to 'speak') still may have to learn the use of expressive communication through pictures or even through objects, because

their capacity to abstract meaning from perceptions and their symbolic knowledge is much lower than their developmental age suggests (Happé, 1995; Jordan, 1996b; Peeters, 1997). The development of communication in autism is very important in finding openings towards our world, yet the misuse of communication may be a source of much suffering, abuse and mental violence.

Gerland (1997) talks about the difficulties she experiences in getting along in a social world in spite of her high levels of intelligence.

'...You have such complicated rules in your world! And all the time I have to think and think and think about them' (Gerland, 1996 p 225).

Or when she had to go to her new school for the first day:

'...250 unpredictable voices and all these arms and legs' (Gerland, 1996p).

People with autism have been said to be suffering from 'mindblindness' or 'social blindness' (Baron-Cohen, 1995). They may have extreme difficulties reading our eyes, faces, behaviours, and even more when they are in group situations than in one to one situations (Lee et al., 1994). This is often misunderstood and people with autism (in a culture where so many therapeutic effects are associated with group situations, on the grounds that 'otherwise they may even become more autistic'), are sometimes pushed into group situations that lead towards intolerable levels of confusion and pain.

Repetitive, stereotyped, obsessional and other such behaviours may be an obstacle towards what we call educational progress, but sometimes they may also be the only possible defense people with autism have against cognitive and social overload in the environment (Grandin, 1995; Williams, 1996) a form of self-protection. Bringing up this respect for self-defense in persons with autism does not come automatically. An untrained professional may try to get rid of the only possible form of defense a person with autism is left with. This is cruelty and violence, resulting from ignorance and lack of training.

Assessment as a starting point for an individualized programme

Autism may be associated with all levels of intelligence, so knowing about autism in general is not enough, we have to know about their level of cognitive development as well; an educational programme for someone like Rainman is certainly going to be different from an educational programme for someone with a very young developmental age. Moreover, people with autism have very uneven learning profiles, which means that we need more detailed information in all the different areas of functioning. Starting from a general developmental age, and deducing an educational programme from it, is poor professional practice and is likely to lead to demotivation, a sense of failure and poor self-esteem. The aim of an educational project should be success, for without success staff develop high levels of stress and elicit negative reactions from other persons (Harris et al., 1996). Success will only be possible if detailed assessments have been made and individualized programmes developed, based on the assessment results.

Adapting the environment

Adaptation is a two-way process. Through the development of an individualised educational programme professionals try to 'adapt' a person with autism to achieve what we call a 'quality of life'. Yet autism is a pervasive developmental disorder, so all the adaptations cannot be expected to come from people with autism themselves. Is society able and willing to adapt to them in a 'pervasive' way?

How does one start adaptations when developing an educational programme? Therese Joliffe wrote that the hardest part of her life was trying to find a pattern behind the chaos (Joliffe et al., 1992). If finding a pattern in their lives seems so difficult, then this should be the first aspect of developing an educational programme for students with autism. Nobody is ready for programmes for communication, social interaction and so on, if they are still living in chaos or confusion. Being able to predict where and when things will happen seems to be the very beginning of independence and self-esteem. Without this predictability one is too powerless and too dramatically dependent.

If one still lives in a pre-symbolic world where perceptions are only perceptions (there is no meaning beyond the literal) then life must seem completely dominated by coincidence. It seems again one of these situations where violence may occur : extreme levels of stress leading to behaviour problems because there is no 'meaning', no predictability, no 'power' in life, and on the other hand the professional not understanding that the behaviour problem is the result of being powerless and thus reacting negatively. If the professional does not understand that the 'behaviour problem' is a desperate attempt to ask for power (or meaning) his or her unthinking and violent (or neglectful) response may make the client with autism even more powerless.

The use of educational strategies specialised in autism

The usefulness of an educational approach specialised in autism, that enables appropriate methods and strategies to be developed, is obvious. Imagine a school for the deaf where educational methods for the blind were used. Everyone agrees that this would be completely absurd. Imagine now a centre for persons with autism where the strategies for those with severe learning difficulties (without autism) were used. Absurd of course, but in a European context this situation may unfortunately be more the rule than the exception. Yet it need not be so; even in mixed settings, one author knows of very effective autism-specific practice, where the needs of those with autism are given priority (and co-incidentally, benefit a wider group within the setting for children with severe learning difficulties).

One of the very important strategies is to use visually-based augmentative methods of communication and education, especially since the majority of people with autism themselves are confirming what the international literature suggested: that they are visual learners (Grandin, 1995; Jordan & Riding, 1995; Sacks, 1995).

V - KINDS OF TRAINING

Continuing Professional Development (long-term courses)

It is desirable that initial training of all relevant professionals should include the principles we have outlined above. However, there should be no illusion that violence is restricted to untrained and/or inexperienced personnel. The sad fact is that training that is not autism-specific may do little to counteract the possible causes of violence we have given above. Individuals that are stressed and under pressure to achieve certain results with their clients or demonstrate certain levels of control with restricted resources, are at risk of resorting to violence. If such conditions prevail throughout a service, a culture of violence may develop in which violence is condoned and even seen as inevitable; in such situations, staff may support one another in their use of violence and conspire to protect one another from external inspection and intervention. In such situations also, training is resisted and the culture of the service remains unchallenged. Thus, there is a need for continued professional development and to ensure that workers in an establishment are exposed to other models of treatment and other ideas of what is necessary and acceptable in treatment. The role of continued professional development in this is crucial. Ideally, this would be in the form of mandatory training for staff, after a certain time period, but this is not currently the case in autism (at least in the UK).

It is also important that training moves from short-term crisis intervention to long-term strategic training that allows time for an understanding of autism to be developed and the development of positive strategies that look at change in the total situation and not just in the individual with autism. These principles are not unique to training in autism, but they are particularly relevant to it. serious and difficult endeavour, accepting that we also believe it can be a rewarding and enlightening one. Such professionals have a tremendous responsibility for the ultimate quality of life of individuals with autism and their families. If we understand the nature of the complexity of the task faced by professionals (and parents) in the education and care of individuals with autism, it is inconceivable that we could consider the undertaking of this task without adequate training.

There is evidence that attitudes are at least as important as knowledge as determiners of professional behaviour (Hall & Oliver, 1996). Short term skill based courses have a part to play in building expertise but without a deeper understanding of autism, mere techniques may be misunderstood and misapplied (Jordan, 1996a). An analysis of the way in which students on a long-term (1 or 2 year part-time) course evaluate their own change in practice shows the importance these professionals place on their own change of attitude (see figure 1 below) as a pre-cursor to their change of practice. One hundred students on a part time professional development course in autism run by the University of Birmingham, UK (all previously professionally qualified as teachers, social workers, nurses, psychologists or therapists, and all working concurrently with individuals with autistic spectrum disorders) answered evaluation sheets on the self assessed changes in their practice, following being on the course. A qualitative analysis of the responses to an open-ended question showed the percentage mentioning "attitude change" as the most important influence in improving their practice.

The importance of Practice

Alongside, or as well as, the opportunity to reflect on and analyse practice that comes from academic professional development courses, there is a need to help most professionals transfer that knowledge and understanding to their own practice. To some extent academic courses can help in this by including evidence of the application of theory to practice within the criteria for assessment (as is done in the Birmingham courses), but many will not be eligible for this training and/or will find this process too abstract and will need training in the actual situation in which they work. In the UK, certain kinds of special need (namely sensory difficulties) carry the mandatory requirement for teachers of such children that they receive training within 3 years of starting to work with such children and, furthermore, that such training include evaluated practice. Unfortunately, the UK government is against the extension of such mandatory requirements to areas such as autism and the costs of evaluating practice are too high to include it within professional development courses without the support of such a mandatory requirement.

There is a need, therefore, for additional practical training courses such as are provided by Opleidingscentrum (based in Antwerp). The virtue of such courses is that they do not attempt to give staff "tips", that will be open to misapplication, but rather that they deal with principles and with practical supported experience of applying those principles to practice.

The best approach to training is the long-term one mentioned above that incorporates the principles of reducing and preventing challenging behaviour in people with autism. However, even the most highly trained staff will continue to make mistakes occasionally, or there will situations that lead to difficult behaviour that cannot be entirely controlled. One object of practical training, therefore, is to give staff ways of avoiding their own violent reaction to difficult or challenging behaviour. Such techniques will incorporate:

recognising their own symptoms of stress and tension and developing ways of defusing these (breathing exercises, humming, aerobic exercise, music and so on). As an example, one of the authors attributed the lack of visible tension and stress, found at the end of the autumn term in a particular specialist school for children with autism, to the fact that staff were also engaged with the pupils in a daily session of aerobic activity.

training an alternative behaviour that serves the same function, just as one would teach a child with an unwanted behaviour. This would involve prior training on the functional analysis of one's own behaviour, which requires more analytical skill and honesty than when applying this to the behaviour of others. Thus if the main function of the violence is to stop the behaviour of the person with autism, then other ways of modifying the person's behaviour are given (or brainstormed) and (if this is unlikely to be effective early enough to satisfy the immediate need of the professional) ways of removing the professional from the triggering context (in actuality, or in imagination) are given as a stop-gap until the person with autism's behaviour can be better controlled or managed. If the main function is to relieve tension and frustration, then some of the techniques suggested above may be tried.

Finally, there is the issue of motivation. Very often in such situations, the problem is perceived by the staff to lie within the person with autism and they are reluctant to be diverted from attempts to change the behaviour of the person with autism to attempts to change their own behaviour. Sometimes the acceptance of the need for change can come about by making the professional aware of the way that their own behaviour is having long-term effects that are making the situation worse. Sometimes, even this revelation is insufficient to get the professionals to change their behaviour and the attitudes that underpin it. They may feel resentful of the effort to be expended for perhaps a single individual (if they think that others in their care are not a problem and are thereby being neglected, for example) or they may be trapped into this pattern of behaviour.

It is a feature of violent behaviour that perpetrators may recognise that there are other ways of behaving in the abstract but not feel that they themselves can behave differently (Harris et al., 1996). In such situations, attempting to force a change of behaviour is liable to make the situation worse (since they feel further de-skilled and helpless) so it can then be best to try a therapeutic technique derived from Kelly's (1955) personal construct theory. In this technique, staff are not asked to alter their personality or permanent ways of behaving, but rather to imagine themselves as the kind of person that would react differently. For example, they think of themselves (through a process of imaging) as someone who is not made uncontrollably angry by the behaviour of the person with autism but who is able to be more tolerant than they can currently manage and to behave more rationally. Another important element, is that the professional does not have to commit themselves to a permanent change of behaviour (which they may find threatening) but to a trial of a few days, or a week, as is appropriate. It is usually the case that such a person is enabled to notice the beneficial effects of behaving differently during this "trial" and is then motivated to effect a more permanent change in their behaviour. At the very least, they will have challenged their own idea that they are helpless in the face of their own anger or lack of ability to change, and they can be persuaded to extend the "trial" to the point where they do feel confident enough to change. After all, it is frightening to change a "technique" that has become part of one's repertoire in a situation, even if one recognises that it is not effective in the long-term, especially (as is invariably the case in autism) when there can be no guarantees of the immediate success of alternatives.

Empowering

This relates to the issue of motivation raised above. A vital of all training is that (like the education of individuals with autism, or indeed all individuals) it needs to start with the skills, experience and personalities of the learner. Effective training does not impose a method that is alien to the learner or it will be difficult for the learner to incorporate this into practice on any long term basis. The person must be able to take on the approach as their own, and thus to feel empowered to act in a new way, rather than just feeling prevented from acting in an old way. Legislation alone is seldom responsible for changing behaviour (Lyon, 1994) unless there is already cultural acceptance of that change and a change of ideology within the individual. Attempting to impose a change of attitude or behaviour may just result in "reactance" (Short & Carrington, 1991) whereby the alien views are rejected and the violent culture reinforced. Training should not emphasise the violent behaviour in an attempt to get rid of it but rather should concentrate on building on the positive interactions and skills the person already has begun to show and so empower the person to behave in ways that are their own. A short (10 week, 2 hours a week) training programme using such empowering techniques with parents showed how parents can improve in confidence to act positively (Jones & Jordan, 1997).

Supporting change

As Haracopolous (1975) has shown, we cannot train individuals alone and then leave them in a culture that does not support their new skills and understanding, if we expect the effects of the training to last. It is important that institutions are committed to non violent approaches and that that commitment extends beyond lip service to practical strategies for supporting staff (Harris et al. 1996.). This should include strategies and resources for reducing staff stress and for debriefing staff after stressful incidents. Staff should be encouraged by institutional policies to support one another rather than to be in competition, so that staff can admit at an earlier stage when they are not coping and need help, rather than waiting for a crisis to develop. In England and Wales, for example, the system of inspection for quality in schools (OFSTED: DfE, 1993) should look for collaborative practices in schools as a mark of quality, rather than seeking to identify grades of teachers as at present. If admitting the need for help is seen as a sign of poor quality teaching and weakness, then the culture of hiding one's difficulties and passing them on (by whatever means), rather than dealing with them, will be inevitable.

Jordan and Powell (1995b) have detailed the weaknesses of professional education and training (especially in autism) that relies on each practitioner learning from his or her colleagues "on the job". This kind of approach (which in industry was known derogatively as the "sit by Nellie" approach to training, and has long been discarded as ineffective) might work if the model is one of good practice, but even then, copying what someone else does, without understanding why, only leads to a form of "echopraxia". It is no longer acceptable at a time when professional training courses in autism are available.

VI - CONTINUITY OF SERVICES AND SUFFICIENT PRACTICAL RESOURCES TO PREVENT VIOLENCE AND NEGLECT

In the previous section the training and educational aspects of enabling professionals and others to work effectively (without abuse and neglect) with autism were emphasised. One should, however, not forget that there is an important political dimension involved in the prevention of violence and the care of persons with autism and their families.

The practical experience of the authors is that teachers and other carers are very positive about their course of practical training, immediately following its completion. They often report that they have learned a lot and have a far greater understanding of autism, assessment,

adapting the environment, using augmentative strategies, and so on. But then they go on to talk about their work situation and how it would be impossible to do everything they should do (for example, one teacher existing in a classroom for four pupils with autism and additional severe learning difficulties without additional help, one nurse in a psychiatric ward with 20 'patients'). They talk about the stress deriving from knowing what to do for someone you care for and not having the resources, and the consequent risk of giving up and neglecting all they had learned.

Thus, it is very important to provide appropriate services when aiming to avoid the risk of behaviour problems and violence in services for people with autism. Appropriacy in this context means a continuity of lifelong services specialised in autism (either as specialised services, or with special practices within mixed services). The following conditions should prevail:

Creating horizontal continuity

A person with autism does not have autism part time, but full time. That means, for instance, that 2 hours a week of "therapy" or even 2 hours a day, is ridiculous if s/he cannot be full time in an environment where people can adapt to her/his autism in a coherent way. This asks for good coordination between the different environments where an individual spends her/his time: home, classroom, boarding school, respite care, vocational training unit, social skills group and so on. Good collaboration between parents and professionals who have similar realistic ideas and expectations about autism is necessary.

Creating vertical continuity

A person has autism as a lifelong condition, even if he or she is able to make remarkable progress; they do not stop having autism at 12 or 16, or 32 years of age. Services should offer protection accordingly, allowing for the large proportion of adults with autism (especially with additional learning difficulties) who will need life-long care. Services that seem necessary for persons with autism and their families are:

- diagnostic and home-training services,
- pre-school, primary, secondary school services,
- university studies where enough adaptations to autism can be made so that a person with autism may live a life balanced between protection and challenge,
- work and living facilities for persons with autism,
- leisure facilities for persons with autism and their families.

Not all people with autism will need all of these services, but they are all needed for at least some people with autism and their families. In all these services staff should be sufficiently trained in autism.

The role of the creation of this continuity of services in the prevention of behaviour problems and violence cannot be exaggerated. During practical training (conducted by on the authors) participants are offered a theoretical and practical model where the emphasis is on the prevention of stress problems. At the end of the week "the biggest behaviour problem" of the week is analysed and discussed. A treatment plan is formulated. In the beginning of the discussion, however, it is necessary to emphasise that the discussion is a bit hypocritical if this continuity of services, adapted to persons with autism, has not been realised.

Imagine one child with autism whose family has had an early diagnosis, early home-training services and afterwards he has been accepted in a pre-school, primary school and secondary school and all the time he has been surrounded by persons who were trained in autism, able to

adapt the environment, make assessment and individualised programmes and who used teaching strategies specialised in autism. Even though there are exceptions, it is very likely that this person with autism will not have many behaviour problems.

Imagine this child with a late diagnosis, parents who are perplexed by the lack of specialised help, the child going from one "facility" to another where there was little of nos specialised knowledge of autism. And then this child has severe behaviour problems at fifteen. Isn't an analysis without considering the role of the lack of appropriate services hypocritical? It is reminiscent of this poster in a zoo "Attention. This animal is dangerous. When attacked he bites". Perhaps there should be another notice for service providers: "Attention. This person has autism. I you do not adapt to his autism he will have behaviour problems".

VII - THE PROFILE OF A 'CARETAKER' FOR SOMEONE WITH AUTISM

Extraordinary people require extraordinary professionals. Thirty years of (joint) experience in training, forces us to formulate another insight: in order to help these different individuals with autism, professionals themselves must be a little bit "qualitatively different" themselves. Some caretakers will never be able to develop individualised educational programmes, even though they have followed the best possible theoretical and practical training. It is useless to "force" someone to work with children with autism (we know examples where directors randomly appoint teachers, but it just does not work). Professionals must choose autism themselves. They do not choose "in spite of autism", but "because of autism".

What is the secret? Until now we have always said, for want of another explanation, that one needs to be "bitten by the bug" of autism. For insiders this is perfectly clear, yet we know professionals who will never be bitten by the microbe, who are "immune" form the bug. The problem is that bugs are invisible to the authorities. So we think that developing a professional profile for caretakers in autism is necessary. Here is what we think are the most important characteristics:

Be attracted by differences

We think that it helps to be a 'mental adventurer' and to feel attracted to the unknown. Some people fear differences, other people are attracted and want to know about them.

Have a vivid imagination.

As was explored above, it is almost impossible to understand what it is like to live in a literal world, to have difficulty in going "beyond the information given" (Burner, 1975), to love without inborn social intuition. In order to be able to share the mind of someone with autism, who suffers from a problem in imagination, we must have enormous levels of imagination in compensation.

Be able to give without getting (ordinary) thank you's.

We need to be able to give without receiving much back in return, and not to become disappointed by a lack of social reciprocity. With experience, the person will learn to detect alternative forms of thank you, and the gratitude (whether or not warranted) of many parents often provides ample compensation.

Be willing to adapt one's natural style of communication and social interaction.

The style needed is more linked to the needs of someone with autism than to our spontaneous (logorrhoea-like?) levels of social communication. This is not easy and requires many efforts of adaptation, but it is important to consider whose needs we are serving.

Have the courage "to work alone in a desert"

Especially at the beginning of the development of appropriate services in an area, so few people understand autism, that a motivated professional risks being criticised instead of applauded for his or her enormous efforts. Parents experienced this kind of criticism much earlier: "all he needs is discipline", "if he were mine", "refrigerator mothers" and so on.

Never be satisfied with how much one knows.

Learning about autism and educational strategies is continuous, as knowledge of both expands continuously. The professional who thinks s/he has found it, has, in fact, "lost it". Training in autism is never "finished".

Accept that each bit of progress brings a new problem.

People have a tendency to throw away crossword puzzles, if they cannot solve them. This is impossible in autism. Once you start, you know that the "detective" work is never over.

Extraordinary pedagogical and analytical capacities.

The professional in autism needs to take very small steps, to use visual support at very individualised levels. There are so many evaluations to be made constantly, that one has to adapt all the time.

Prepared to work in a team.

Because the approach needs to be coherent and coordinated, all professionals need to be informed about the efforts of others and the levels of help they provide. This includes parents, especially when the child is young.

Humble.

We may be "experts" in autism in general, but parents are the experts about their own children and we need to take into account their wisdom and experience. The professional who wants to remain "on his pedestal" is not needed in autism. When collaborating with parents it is important to talk about successes, but also to admit failures ("please help me"). Parents also need to learn that an expert in autism is not an Olympic god.

Some will wait for the word "love" in this list. Love is of course essential, but, as one parent warned: love is not a miracle cure. Parents and professionals who count too much on the effects of love, will become disappointed. If the child does not make enough progress, is it because he has not been loved enough then? Or perhaps we have loved enough, but he has not accepted our love sufficiently. Such attitudes are destructive and create an abyss there where what is necessary is optimal collaboration. Amor NON vincit omnia. Autism is different.

VIII - CONCLUSION.

Prevention of violence and stress problems in autism depend on the individual characteristics of the child, but also on the level of training that is offered to parents and professionals, on the

attitudes we use to weaker persons, and on the continuity of practical resources that are available.

The degree of civilisation of a society may be measured by the level of protection that is offered to the most vulnerable.

REFERENCES

AMERICAN PSYCHIATRIC ASSOCIATION (APA) (1994) *Diagnostic and Statistical Manual of Mental Disorders IVth Edition* Washington, DC, APA

ATTWOOD, A., FRITH, U. & HERMELIN, B. (1988) The understanding and use of interpersonal gestures by autistic and Down's syndrome children *Journal of Autism and Developmental Disorders*, 18, 241-257

BARON-COHEN, S. (1995) *Mindblindness: an Essay on Autism and Theory of Mind* London, MIT Press

BLUNDEN, R & ALLEN, D (1987) *Facing the Challenge: an ordinary life for people with learning difficulties and challenging behaviour* London, Kings Fund Centre

BRUNER, J.S. (1975) The Ontogenesis of Speech Acts. *Journal of Child Language* 2, 2-19

COPELAND, J (1973) *For the Love of Ann* London, Arrow Books

DEPARTMENT FOR EDUCATION (1993) *Handbook for the inspection of schools*, London; Ofsted

GERLAND, G. (unpublished) Paper to Autism Conference, Gottenburg, March 14-15 1996

GERLAND, G. (1997) *A Real Person* London, Souvenir Press

GILLBERG, C. & PEETERS, T. (in press) *Autism: Medical and Educational Aspects* London, Whurr

GRANDIN, T. (1986) *Emergence, Labelled Autistic* Tumbridge Wells, Costello

GRANDIN, T. (1995) *How people with autism think* In E. SCHOPLER & G.B. MESIBOV (Eds) *Learning and Cognition in Autism* New York, Plenum

HALL, S., OLIVER, C. (1996) Differential-effects of severe self-injurious-behavior on the behavior of others *Behavioural Psychotherapy*, 20, 355-365

HAPPE, F.G.E. (1995) The role of age and verbal ability in the theory of mink task performance of subjects with autism. *Child Development*, 66, 843-855

- HAROCOPOLOUS, D. (1975) The myth of the hero innovator In C.C. KIERNAN and F.P. WOODFORD (Eds.) *Behaviour Modification with the Severely Retarded*. The Hague, Associated Scientific Publishers
- HARRIS, J., COOK, M & UPTON, G. (1996) *Pupils with severe learning disabilities who present challenging behaviour: a whole school approach to assessment and intervention* Birmingham BILD
- HOBSON, R.P. (1993) *Autism and the Development of Mind*, London. Erlbaum
- JOLIFFE, T., LANDSDOWN, R. & ROBINSON, C. (1992) Autism: a personal account, *Communication*, 26, 3-4
- JONES, G. AND JORDAN, R.R. (1997) Working with parents of preschool children with autistic spectrum disorders, in G. Linfoot And P. Shattock (Eds) *Living and learning with autism: perspectives from the individual, the family and the professional*, Sunderland: Autism Research Unit/National Autistic Society
- JORDAN, R.R. (1996a) Educative Strategies in P. SHATTOCK & G. LINFOOT (Eds.) *Autism on the Agenda* London, NAS
- JORDAN, R.R. (1996b) Teaching Communication to Individuals within the Autistic Spectrum. *REACH - Journal of Special Needs Education in Ireland*, 9,95-102
- JORDAN, R.R. & JONES, G. (1996) *Educational provision for children with autism in scotland: Final Report of a research project for the SOEID*, Birmingham, School of Education, University of Birmingham
- JORDAN, R.R. & POWELL, S.D. (1995a) *Understanding and Teaching Children with Autism* Chichester, Wileys
- JORDAN, R.R. & POWELL, S.D. (1995) Factors affecting school choice for parents of a child with autism *Communication, Winter*, 5-9
- JORDAN, R.R. & RIDDING, R.J. (1995) Cognitive style in autism in LINDFOOT, G., SHATTOCK, P., FINNIGAN, R. & SAVERY, D. (Eds) *Psychological Perspectives in Autism : Proceedings of Durham Conference 5-7 April 1995*. Sunderland, Autism Research Unit/National Autistic Society
- KANNER, L. (1943) Autistic disturbance of affective contact *Nervous Child*, 2, 217-250
- KAUFMAN, B. (1994) *Son rise: the miracle continues*, California; Kramer
- KELLY, G.A. (1955) *The Psychology of Personal Constructs*, New York, Norton
- KRAIJER, D. (1997) *Autism and Autistic-like Conditions in Mental Retardation* Abingdon, Swets & Zeitlinger
- LEE, A., HOBSON, R.P. & CHIAT, S. (1994) I, you, me and autism: an experimental study *Journal of Autism and Developmental Disorders*, 24, 155-176

- LESLIE, A.M. (1987) Pretense and representation: the origins of " theory of mind " *Psychological Review*, 94, 412-26
- LESLIE, A.M. (1991) The theory of mind impairments in autism: evidence for a modular mechanism of development? In A. WHITEN (Ed) *The Emergence of Mindreading* Oxford, Blackwells
- LOVAAS, OI (1966) A program for the establishment of speech in psychotic children In J.K. WING (Ed) *Early Childhood autism* London, Pergamon
- LOVAAS, OI (1967) A behaviour therapy approach to the treatment of childhood schizophrenia In J.P. HILL (Ed) *Minnesota Symposium on Child Psychology*, 1, University of Minnesota Press
- LOVAAS, OI (1987) *Teaching developmentally disabled children: the me book*, Baltimore: University Park Press
- LOVASS, OI (1987) Behavioural treatment and normal intellectual and educational functioning in autistic children, *J. of Consulting and Clinical Psychology*, 55, 3-9
- LOVAAS, OI, SCHAEFFER, B. & SIMMONS, J.Q. (1965) Experimental studies in childhood schizophrenia: building social behaviours by use of electric shock *Journal of Experimental Personality Research*, 1, 99=109
- LOVAAS, OI. & SIMMONS, J.Q. (1969) Manipulation of self destruction in three retarded children *Journal of Applied behaviour Analysis*, 2, 143-150
- LYON, C. (1994) *Legal Issues Arising from the Care, Control and Safety of Children with Learning Disabilities who also present Severe Challenging Behaviour*, London, Mental Health Foundation
- PEETERS, T. (1997) *Autism: from Theoretical Understanding to Educational Intervention* London, Whurr
- SACKS, O. (1995) *An Anthropologist on Mars* London, Picador
- SEGAR, M. (1996) *Coping: a Survival Guide for people with Asperger's Syndrome* Nottingham, Early Years centre
- SCHOPLER, E. (1995) *Parent's Survival Manual* New York, Plenum Press
- SCHOPLER, E. & MESIBOV, G.B. (1994) introduction to behaviour management in autism In E. SCHOPLER & MESIBOV, G.B. (Eds) *Behavioural Issues in Autism* New York, Plenum Press
- SCHULER, A. & PRIZANT, B.M. (1985) Echolalia in E. SCHOPLER 1 G.B. MESIBOV (Eds) *Communication Problems in Autism* New York, Plenum Press
- SHORT, G. CARRINGTON, B. (1991) Unfair discrimination - teaching the principles to children primary-school age *Journal of Moral Education*, 20, 157-176

SINCLAIR, J. (1992) Bridging the gaps: an inside-out view of autism (or do you know what I don't know?) In E. SCHOPLER & G. MESIBOV (Eds) *High Functioning Individuals with Autism* New York, Plenum Press

SKINNER, B.F. (1957) *Verbal Behaviour* New York, Appleton Century Crofts

WILLIAMS, D. (1996) *An Inside-Out Look at Autism* London, Jessica Kingsley

WING, L. (1996) *The Autistic Spectrum: a guide for parents and professionals* London, Constable

WORLD HEALTH ORGANISATION (1992) *10th. International Classification of Diseases and Disorders* Geneva, WHOI

CHAPTER 9: A CODE OF PRACTICE FOR THE APPROPRIATE USE OF MEDICATION FOR PEOPLE WITH AUTISM

Paul Shattock
University of Sunderland (UK)

INTRODUCTION

As well as the need to consider the actual choice of the drug there are other factors which are of equal importance in treating people with autism. Since the means of communication and the understanding for the need for communication are either lacking or impaired, it is especially important that those responsible for the supply of medicines to people with autism are very vigilant. Some of the considerations which must be applied to the use of medicines are listed below.

Care and Storage of Medicines

Drugs should always be stored in lockable containers which are kept locked. Suitable cabinets are used by Pharmacists to store controlled drugs. It is usually possible for a local Pharmacy to obtain a suitable cabinet, at cost price, from his supplier.

It is not unknown for drugs to go astray or otherwise disappear from the system. A completely accurate system of recording all medications is an absolute must. Even 'Over the Counter' (OTC) and 'herbal remedies' must be recorded as they can sometimes have very pronounced effects. Records should be inspected on a regular basis to confirm that they are complete and reliable.

Dosages

The dosages and the timing of these dosages must be adhered to as rigidly as possible. If the requirement is for 'three times a day' the dosages should be spaced out as evenly as is reasonably convenient. For example, antibiotics are often given '*three times a day*' If given before breakfast, at lunchtime and before tea this would mean that all three doses have been given over perhaps a nine hour period of the day. The other 15 hours will be medication free and any bacterial infection will have an opportunity to 'recover' during this period. It is equally stupid to wake people up in the middle of the night in order to give medication.

It has been estimated that only 13% of dispensed medicines are taken exactly in accordance with the prescriber's instructions.

One of the difficulties is in ensuring that the people with autism actually take their medication. Some people are very clever at hiding medications in their mouths for subsequent expulsion. With most medicines, a liquid formulation is available for those who find it difficult to take solid forms. Even when no such commercial product exists, it is usually possible to arrange for the production of an acceptable liquid formulation.

Following Instructions

There are often other subsidiary instructions on the labels. 'Avoid milk'. 'Take before meals or with food'. Such recommendations should be regarded as instructions rather than mere advice. For example, most antibiotics should be taken on an empty stomach. In other words they should be supplied at least half an hour before a meal or an hour after one. 50% of their potential activity could be completely lost if such instructions are ignored. Some antibiotics (such as oxytetracycline) are completely inactivated in the presence of calcium such as is found in dairy produce and in many antacid preparations. In other cases, it is preferable to take the medication with food. In general, taking a medicine with food results in a less dramatic but more prolonged action; the food is also helpful when taking medicines which could otherwise physically damage the stomach wall for example. Aspirin is a prime example of such a product.

Taking with Water

On the whole medicines should be taken with water. The oesophagus, down which the medicine travels between the mouth and the stomach, is not a solid piece of pipe through which the tablet drops. The medicine is actively transported down the oesophagus by peristaltic waves. At least 100 ml of water (a cup full) are required to ensure this process. The practice of taking tablets 'dry' is wrong, potentially harmful and cruel, and yet still unforgivably common when people with disabilities are concerned. Many tablets are acidic and will physically burn the throat for example.

In many schools or units for people who cannot with special needs there is a perceived difficulty in persuading clients to take their medicine. This may be a result of an unpleasant taste or the awareness of the appearance of unpleasant side effects or, more frequently, it is because the medication is not given with adequate amounts of water so that an immediate consequence to taking tablets is pain. It is not surprising that under these circumstances there is reticence about taking medication.

Drug Interactions

Once again, carers must be ever vigilant for such possibilities. Nowadays Pharmacies and Physicians keep records of all medicines prescribed for each individual client. It should, therefore, be a simple matter of spotting potential difficulties. Most modern computers (in the Pharmacy) will indicate potential problems which can, therefore, be avoided. Even OTC and herbal remedies should be checked out in this way. If there are any special peculiarities about a particular subject, for example a sensitivity to penicillins or wheat, this could be notified to the Pharmacist for entry on the computer. This could be a life preserving process in some cases.

It is clearly impossible to relate every possible example of drug interactions but some more obvious examples are given below.

Tetracyclines and antacids have already been mentioned. The same applies to iron supplements (which may be present in tonics or multi-vitamin products). These would react together in the stomach to form a totally inert complex. Thus the beneficial effects of both the antibiotic and the supplement will be lost.

Warfarin and Aspirin (and other Non-Steroidal Anti-Inflammatories). Both of these products have effects which under certain circumstances are beneficial. Both will thin the blood down and thus prevent the blood clotting **in** inappropriate circumstances. The amount of warfarin taken for this purpose is critical for each patient. The taking of apparently innocuous aspirin could enhance these effects and result in internal haemorrhaging.

Anti-fungal drugs such as metronidazole (Flagyl) and others (usually with the suffix -azole) are justly infamous for their interactions with even very small quantities of alcohol. Ignoring the stricture 'Avoid Alcohol' would almost inevitable lead to nausea, vomiting and severe pain.

Drugs with similar structures and modes of action will, when taken together, have an additive effect and thus an increased potential for side effects. For example diazepam taken during the day for anxiety whilst temazepam taken at night to encourage sleep are both members of the same group of drugs (the benzodiazepines). Although their activity profiles are slightly different there is an obvious increase in risk.

Antibiotics are, on the whole, very safe drugs but they can have unexpected interactions. For example, many types of contraceptive pills will lose their efficacy during a course of antibiotics. During such a course of treatment, those who are sexually active must be encouraged to use additional methods of birth control.

Many people with autism also suffer from epileptic attacks and these were (and still are to a considerable extent) controlled by means of phenytoin (Epanutin). The side effects of phenytoin are many and various and include, for example, such unexpected effects as the enlargement of gums and the production of excess hair. In addition, it can drastically affect the breakdown of other drugs so that their effects are either enhanced or diminished. Phenytoin is one of many drugs whose circulating levels are not necessarily closely related to the doses taken. It will be necessary, particularly in the early stages, to monitor the circulating levels by means of blood tests.

There are many other examples of interactions. If anything abnormal is suspected it should be reported to a competent authority for evaluation and consideration.

Side Effects

*The drug without side-effects does **not** exist.*

Minor side effects of medications are extremely common and may often be trivial compared to the health problem being treated. However, many can be life threatening in certain individuals. A read through, for example, the '*Datasheet Compendium*' (1997/98) which lists all the commercially available drugs in the UK and includes descriptions of all the possible side effects, can be a fairly traumatic experience. For the Doctor or Pharmacist supplying the medicine there is always the dilemma of how much to say to patients. Should the patient be warned about every possible side effect? When patients are told of potential side effects they could very well experience what are actually non-existent effects. However, at the same time, a patient may be suffering unnecessary side effects without knowing the cause and being able to associate them with the medication.

For example, many patients claim to be sensitive to penicillin when, in fact they are not in the least. However, because the potential consequences are so severe, such suggestions must be treated at face value. Clearly, carers and parents should be alert to these possibilities and be vigilant for any untoward effects. People with autism are often totally dependent upon their carers for protection against such harm. Nowadays, there are many good reference books which deal with the use and abuse of medication and such material should be available for reference. It is a good idea to ask the Pharmacist or the prescriber for information or clarification if unsure.

Examples of Side Effects

Every drug has its own complement of side effects but a few classical examples are listed here.

Antibiotics, as described earlier, are usually taken in the form of a course which last about a week. Bacteria, if sensitive, are killed but fungi and yeasts will flourish. Bowel motions will probably become more liquid and thrush and itching around the genitalia and anus are very likely to occur. Many parents and carers have noted that these problems are particularly apparent in people with autism. There is a school of thought which relates the presence of these yeasts (particularly *Candida*) with the causation of autism. The connection remains unproven but there is no doubt that people with autism seem to be particularly prone to these sort of problems.

Diuretics are often given to reduce raised blood pressure. Diuretics remove excess liquid from the blood but they can also remove other substances and, in particular, the element potassium. Potassium supplements are often, but not invariably, given. Additionally, if diuretics and water are removed from the blood, the concentration of the other drugs will be increased and side effects may become apparent. Warning signs would be dryness of the mouth (apparent as increased thirst); irregular heartbeat; mood or mental changes; nausea, muscle cramp; unusual tiredness or weakness.

Virtually all drugs which affect the brain are pretty non-specific in their action. Their effects are more related to the blunderbuss than to the rapier. However, by careful observation and an awareness of the side effects they can be minimised to the point of eradication by variations to the dose.

Neuroleptic drugs such as Chlorpromazine (Largactil) and Thioridazine (Melleril) are frequently, and largely inappropriately, given to people with autism. In some cases, perhaps because of the biochemical abnormalities which may underlie the condition, people with autism seem to be particularly prone to side effects from these drugs. Effects such as drowsiness, abnormal movements, increases in stereotypic behaviours, inability to keep still are **common**. Many of these so called 'dyskinetic' movements are typical of people with autism in any case but are greatly increased when such medications are used. In some cases the effects of such medication are sufficiently severe as to produce very severe catatonia (rigidity and inability to move) or an effect where the eyeballs appear to be rolled up in to the tops of the sockets. Fortunately such effects are quickly reversed when the medication is stopped or when other medications are taken to alleviate these effects (see below).

Of much greater significance could be the development of permanent and irreversible effects known as 'tardive dyskinesias'. Such effects will develop when these medications are used over a period of time and, as yet, there is no cure except to give increased doses of the same drug. When the drug is withdrawn, 'withdrawal dyskinesias' will follow. Many of the strange trunk movements and movements of the mouth, the tongue protrusions for example, which are seen so often in long term hospitalised patients are drug induced. In some parts of the world it is illegal to give such medications to people with autism. The United Kingdom is not one of those parts.

Very often, drugs such as procyclidine (Kemadrin), orphenadrine (Disipal), and benzhexol (Artane) are given together with the neuroleptic drug to minimise these effects. Sometimes the neuroleptic drug is stopped but the drug to take away the side effects is forgotten and continues to be prescribed. Such occurrences, although totally avoidable, are not uncommon and clients may have been taking such drugs and experiencing their side effects (dryness of the mouth etc.) for years.

While discussing neuroleptics it may be relevant to comment that amongst their more unexpected but well documented side effects is the possibility of the initiation of lactation, ie production of milk, even in males.

Significance of Effects and Side Effects of Drugs

Whenever there is a change in the behaviour, mood, appearance or functioning of people with autism one should automatically check the medication and in particular, whether there have been any changes. In addition to grosser effects such as nausea, sickness or diarrhoea, look for evidence of the following:

- increased restlessness or drowsiness;
- skin rashes;
- high temperature;
- weakness;
- mood changes/ confusion/ dizziness;
- dryness of the mouth or thirst;
- unusual colour or smell to the urine;
- pains;
- persistent cough.

Such symptoms as a persistent cough could, of course, be a consequence of many situations but one which must be checked is the medication. Some drugs used to reduce blood pressure, known technically as ACE inhibitors, are noted for this effect. Checks should be made and records kept not only for the officially prescribed drugs but also the 'Over the Counter' and herbal products.

Always check:-

- Is the medication being taken correctly? When a person is based at home this is, on the whole, unlikely.
- Could the reaction be due to too much or too little medication?
- Are there any other additional clues?
- for example, a perception of a yellow halo around objects (excess digoxin).
- a ringing in the ears (aspirin).
- sudden production of milk or unexpected hair (see above)

Elderly Populations

As the population ages so side effects will become apparent. Medications which were previously completely safe with respect to these effects will start to produce side effects. There are a number of reasons for this.

- a) The size of the individual decreases;
- b) The liver and kidneys, which are responsible for the break down and excretion of waste products, become less efficient;
- c) The fat to muscle ratio decreases so that less drug is stored in the fatty tissues and more is available and circulating in the blood stream.

In the community as a whole, the correct use of medication is comparatively rare. Much avoidable suffering is caused by the misuse of medication and neglecting simple procedures.

In residential settings those responsible for the selection of medication are frequently remote from those actually responsible for administering it. Staff in the front line complain that they are kept in the dark about the reasons for giving the medication, and how they should be administered. They also voice the complaint that they are not given the opportunity to comment, or to have input into discussion about medications. Management and senior staff will advise physicians about medication regimes, but they are frequently not in a position to be aware of the effectiveness of the programme, the problems which may occur, or of the incidence of side effects, particularly some of those which are unexpected.

Clearly systems should be in place to implement a system of constant monitoring. Most Pharmacies will offer a variety of aids to ensure the correct supply of medicines to the individual patient. This service **is** aggressively marketed by certain chains of Pharmacies, and they will probably be keen to encourage the use of their own particular system so as to tie all future purchases of drugs and dispensing of prescriptions to their company. Most Pharmacies will, if asked, be happy to provide such a service and would be willing to discuss and provide a system to fit your needs rather than the other way round. If a company wishes to retain custom it must provide a service which entirely satisfies our needs.

CHAPTER 10 : EUROPEAN DIMENSION

Dr Christopher Williams
University of London (UK)

I A GUIDING PRINCIPLE - THE UN DECLARATION ON VICTIMS

Much of the harm suffered by vulnerable people is therefore outside the remit of national law. The UN *Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power* (1985) is therefore very relevant.¹ It makes three key points.

First, the Declaration clarifies that victimisation is not solely defined in terms of national legislation, and that it is appropriate to conceptualise victim *groups* in some cases:

18. Victims means persons who, individually or collectively, have suffered harm, including physical or mental injury, emotional suffering, economic loss or substantial impairment of their functional rights, through acts or omissions that do not yet constitute violations of national criminal laws but of internationally recognised norms relating to human rights.

Second, there is a demand for a response at state level:

19. States should consider incorporating into national law norms proscribing abuses of power and providing remedies to victims of such abuses. In particular, such remedies should include restitution and/or compensation, and necessary material, medical, psychological and social assistance and support.

21. States should periodically review existing legislation and practices to ensure their responsiveness to changing circumstances, should enact and enforce, if necessary, legislation proscribing acts that constitute serious abuses of political or economic power, as well as promoting policies and mechanisms for the prevention of such acts, and should develop and make readily available appropriate rights and remedies for victims of such acts.

Third, there is a demand for an international response:

20. States should consider negotiating multilateral international treaties relating to victims, as defined in paragraph 18.

The European Commission provides an appropriate forum for addressing Article 20.

II THE EUROPEAN DIMENSION

A European approach cannot provide a complete framework for a response, because many of the key strategies require legislative change and improved professional practice in individual nation states, as proposed in the final chapter. But the European perspective creates the potential for significant change in two ways: (i) through specific actions at the

European level that are not possible at the level of individual member nations, and (ii) through achieving greater consistency across nations.

II.1 Actions at the European level

II.1.1 Mobility of offenders

Some nations have systems for checking criminal and other records of professional carers who wish to be employed to work with vulnerable people and children. But these checks are not Europe-wide, so it is a simple matter for people with a record of relevant offences, who may have been dismissed for victimising vulnerable people, to move to another country and gain further employment that creates the opportunity for them to continue to abuse vulnerable people.

Police checks of care professionals should eventually be Europe-wide. Meanwhile, they should include checks of police records in the country of the proposed employment, country of origin, and any known countries of previous residence. These checks should be available to government *and* non-government employers.

II.1.2 Cross-border prosecution

Mobility within Europe is increasing for people with disabilities, particularly holidays. This creates situations in which offences are committed while victims are outside their home country. In many instances the perpetrator is a care worker accompanying a party of disabled people, and offences are often not discovered until the victims have returned home. Usually, prosecution is not possible through the courts in the home country. The logistics of returning to the country in which the event happened for investigation and prosecution are complex. Success at pursuing a case in a court using another language, on behalf of victims who may have difficulties communicating in their own language, is very unlikely. At the present time the opportunity for evading the consequences of wrongdoing, provided by the absence of cross-border prosecution, is recognised by perpetrators, many of whom have clearly planned to abuse their position of trust when outside their home country.

There are two routes to ensuring cross-border prosecution on behalf of vulnerable people:

(i) developing legislation similar to that which now permits prosecution of paedophiles in their home countries, for offences committed in other countries (e.g. as in UK and Australia)

(ii) using mobile courts, i.e. a court from the country in which the offence happened sits in the country in which the victim lives, and perhaps uses the language of the victim and defendant. Technically, this is probably already possible, but the possibility has not been explored. The system could relate to other situations, for example people with severe health problems or paedophile cases, and could be administered at European level.

II.1.3 Pornography and prostitution

There are indications that people with developmental disabilities are being used in the production of pornographic videos, INTERNET and other material. Similarly, it is suggested that vulnerable people are sometimes taken to other countries and used as prostitutes.

European anti-pornography and prostitution initiatives should be aware of the possibility that people with mental disabilities are being exploited, and compile a data-base of relevant national legislation that specifically addresses the exploitation of vulnerable people for sexual purposes (e.g. UK Sexual Offences Acts).

II.1.4 Mobility and immigration.

Levels of public service provision for people with disabilities vary greatly between nation states, which creates a fear, within nations with better provision, that people with disabilities will be brought to those countries in order to obtain public services. Immigration practices that can be used to discriminate on the basis of disability can lead to the mobility of people with disabilities being impeded.

The belief (true or false) within families that immigration authorities will not permit entry because a family member has a disability can lead to people with disabilities being 'dumped' with unsympathetic carers in the countries of origin. This problem seems most prevalent among legal immigrants/refugees from outside the EU, either because of myths that entry will be denied (e.g. Hong Kong immigrants to the UK have put their disabled children in orphanages in mainland China), or because nation states give varying degrees of citizenship to these groups in an inconsistent way (e.g. Bosnian or Turkish people in Germany).

The immigration rules, in relation to disabled people, in all member states should be examined for technical consistency and correct application, and the criteria communicated in an open and clear manner to all potential immigrants.

II.1.5 Countries administered by European nations

Some European Nations still administer a few of their former colonies, and are therefore responsible for any harm suffered by disabled people in those countries, particularly if it arises from a lack of public services or abuse within those services. Standards of public services overseas are sometimes much lower than in Europe, and the principles of the European Convention on Human Rights are not extended. At the time when Portugal still administered Macau there were press reports of the 'Forgotten cage-kids', which told of

severely retarded young men and boys who spend their lives locked inside a pathetic, out-dated human zoo...Most of these spend a great part of their life in cages, the remained usually pitiful vegetables lying in 40-year-old metal framed cots...a frightening noise comes from the corner of the large dimly lit

room where a naked, young mute swings ape-like on the bars demanding bread as best he can.ⁱⁱⁱ

Problems of a less extreme, but still significant, nature are still reported.

European minimum standards of service provision and the principles of the European Convention on Human Rights should be extended to overseas countries administered by European member states.

II.2 Consistency across Europe

II.2.1 Identification and diagnoses of autism

Currently there are no standard criteria for identifying and diagnosing autistic spectrum disorder, and terminology is inconsistent. This leads to

- (i) unequal service provision between nation states.
- (ii) a difference in whether or not someone with autism is held responsible for criminal acts.
- (iii) a lack of reliable statistical information about autism.

There should be a Europe-wide agreement about the identification and diagnoses of autism.

II.2.2 Inconsistent services and abandonment

It seems that children with disabilities will sometimes be sent to or abandoned in countries in which service provision is perceived to be better.

Nation states should aim to achieve a minimum level of care provision for people with disabilities, especially children, throughout Europe. The criteria for this should, in part, stem from research about the reasons why families might decide to abandon their children in other nations to achieve better care.

II.2.3 Medical negligence

European citizens are entitled to basic medical treatment in member states, but there is no consistency about redress if a person suffers harm as a result of that treatment which may result in a disability. This is particularly relevant in relation to post-natal care and childbirth, and the protection of the unborn child.

This also extends to dentistry. There has been recent concern that the mercury in dental fillings could be linked to birth impairments. Action was quickly taken in Sweden and Germany, and later the UK. An individual from a country with a high level of protection may not be aware that such high standards do not apply in the country in which treatment is being given. If a consistent high standard cannot be

achieved across Europe, the difference in standards should be made explicit to patients from other countries.

Vaccination of infants and children very occasionally causes mental impairments. There is inconsistency in

(i) the type of vaccinations used throughout Europe (e.g. the UK has used forms of vaccine banned in Germany and Sweden),

(ii) whether or not childhood vaccinations are compulsory (as in France where it is a requirement of school entry) or can only be given with specific parental consent (as in Netherlands), and

(iii) whether or not compensation is payable for resultant injury, e.g. the UK has specific legislation.

This gives rise to inconsistencies for mobile families. A Dutch child living in France does not enjoy the protection of parental consent that s/he would have had at home. A UK child vaccinated in the UK but living elsewhere when the condition was diagnosed could not claim compensation through the UK law, because the victim must still reside in the UK to claim under the UK Act. But a non-UK child who was vaccinated in the UK, and lives in the UK, *could* claim compensation under UK law.

A European policy about childhood vaccination should be developed: (i) the type of vaccines used everywhere should reflect the highest European standards of safety, (ii) the parental right to withhold consent should be defined and applied consistently, (iii) compensation schemes should be consistent across Europe.

II.2.4 The status of the unborn victim.

Disabilities are often caused while a child is in the womb, by identifiable factors. The causes can be physical (e.g. a pregnant woman is assaulted), arise through clinical practice or medication use, stem from drug or alcohol abuse, or, increasingly stem from environmental impacts such as heavy metal pollution, radiation, or micro-nutrient deficiencies.ⁱⁱⁱ It is unclear within European nations whether or not an unborn child has full victim status, and can therefore benefit from claims for compensation. (In the US this has been clarified). In the case of babies harmed by the Thalidomide drug, a claim was never brought to court because it was uncertain if an award for damages could be claimed on behalf of an unborn child. The resultant out-of-court settlement has proved completely inadequate, and UK legislation intended to redress the problem has proved unworkable.

The relative status of the unborn victim throughout member states should be investigated, and if possible a consensus reached.

II.2.5 Responsibility for wrongdoing

Punishment for wrongdoing is ethically improper if the person concerned does not understand that an act is wrong, and punishment is unlikely to have any effect if a

person does not comprehend the link between the act and the punishment. In some member states, there are sophisticated systems for screening defendants and offenders who have mental impairments to ensure that those who should not be held responsible for their actions are diverted from the normal court processes and receive appropriate help. In some cases a 'trial of the facts' is held to ensure that any resultant detention under mental health legislation is not excessive in the light of the offence committed. (There have been cases in which people have been forcibly held in psychiatric hospitals for decades, when the offence was minor and would not usually attract a prison sentence, for example stealing a bottle of milk.) Currently there is no consistency between member states. A person who steals a bar of chocolate might be handed directly to a social worker in one nation, could be sent to prison in another (as a result of not paying the fine), or detained for many years in a hospital under mental health legislation elsewhere.

Europe-wide consistency needs to be achieved about the concept of mental capacity and criminal responsibility.

II.2.6 Racist and "disablist" harassment

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

"Let's go and hit that black monkey. We don't want people from the jungle around here."

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

"Let's go and hit that stupid imbecile. We don't want people from the asylum around here."

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

The European Commission should provide guidance and encourage nation states to extend laws about racial harassment to people with disabilities.

II.3 European Convention on Human Rights

Many aspects of the European Convention on Human Rights are very relevant to redressing and preventing harm suffered by people with developmental disabilities.

Disability organisations throughout Europe should be encouraged to use the Convention.

The European Convention on Human Rights

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground...(Art.14)

Everyone's right to life shall be protected by law (Art.2)

No one shall be subjected to torture or to inhuman or degrading treatment or punishment (Art.3)

No one shall be required to perform forced or compulsory labour (Art.4,2)

Everyone has the right to liberty and security of person (Art. 5,1)

Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him (Art.5,2)

Everyone who has been the victim of arrest or detention in contravention of the provisions of this Article shall have an enforceable right to compensation (Art.5,5)

Everyone one charged with a criminal offence has [the right] to have free assistance of an interpreter if he cannot understand or speak the language used in court (Art.6,3e)

Everyone has the right to respect for his private and family life, his home and his correspondence (Art.8,1)

There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law...(Art.8,2).

Everyone has the right to freedom of thought, conscience and religion...and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance (Art.9,1.)

Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority...(Art.10,1)

Everyone has the right to freedom of peaceful assembly and to freedom of association with others...(Art.11.1)

No restrictions shall be placed on the exercise of these rights other than such as are prescribed by law...(Art.11,2)

Men and women of marriageable age have the right to marry and to found a family...(Art.12)

Everyone whose rights and freedoms as set forth in this Convention are violated shall have an effective remedy before a national authority notwithstanding that the violation has been committed by persons acting in an official capacity (Art.13).

Every...person is entitled to the peaceful enjoyment of his possessions. No one shall be deprived of his possessions...(First Protocol Art. 1.)

No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions (First Protocol, Art.2)

Everyone...shall have the right to liberty of movement and freedom to choose his residence (Forth Protocol, Art.2, 1)

Everyone shall be free to leave any country, including his own (2)

Copies of the Convention and a brief guide to its implementation can be obtained from

European Commission of Human Rights
Council of Europe
BP 431 R6
67006 Strasbourg Cedex
France.

CHAPTER 11 : POSSIBILITIES FOR CHANGE - A CASE STUDY OF THE UK

Dr Christopher Williams
Institute of Education
University of London

In some regions of Europe, the possibility of achieving appropriate changes at government level may seem very limited. The purpose of this chapter is to show that change is possible. Britain is used as a case study, not because it is more advanced than other nations, but because at the time of writing the British government is taking the problem seriously. There are proposals from the UK Home Office for significant changes, in a report, *The Treatment of Vulnerable or Intimidated Witnesses in the Criminal Justice System*.^{iv} (The term 'witness' applies very broadly to anyone who might give evidence - the victim, someone who saw the event, or the defendant.)

The Home Office report derives from an *interdepartmental* working group, and it makes proposals for legislative change *and other necessary developments*, for example within social work and health service practice. In the past, the intent of legislation has often been frustrated because law alone cannot create changes on the required scale. Interdepartmental co-operation has helped to overcome this problem. The report goes well beyond a simple list of policy proposals, and covers precise details of exactly who should be responsible for ensuring that specific policies are implemented. Most significantly, the report constantly reminds that victims with disabilities should be fully consulted and their wishes taken into account.

It is also stated explicitly that the report 'took account of the United Kingdom's obligations under the European Convention on Human Rights.'

*.1 Background to the report

The circumstances of victims with intellectual disabilities came to public and government attention through various activities during the 1990s - academic research, parental activism, political concern, and press interest. At the start of the 1990s two pieces of research^v were funded by an independent British charity, the *Joseph Rowntree Foundation*.^{vi} This Foundation has an excellent reputation for supporting work that concerns people with disabilities, especially intellectual disabilities, which would otherwise not be a mainstream interest for academic researchers. The UK Home Office then commissioned its own research, which came to very similar conclusions,^{vii} but was taken more seriously by the government (probably because they had paid for it). At the same time, a parent-led organisation, *VOICE*, was set up by parents who had successfully achieved a prosecution on behalf of their daughter who had been sexually assaulted.^{viii} These parents had overcome the initial prejudices of the police, prosecution service, and courts, with the help of a very enlightened police-woman, and they thought that they could share their knowledge. A lively British MP, Edwina Currie, became the chairperson of *VOICE*, which led to regular meetings with other MPs at the House of Commons. In 1998, the House of Commons *All-*

Party Working Group on Disability heard evidence from a range of interested parties and experts.

A British newspaper, *The Independent*, started to show a specific concern about the victimisation of people with intellectual disabilities. On one notable occasion the paper pointed out how a story about an abduction of an attractive, female Oxford student had been given front page coverage, while an almost identical story about a woman with Downs' Syndrome had been ignored. The long-established parents' organisation MENCAP, publicised the problem of crime against people with learning disabilities in its newsletter *VIEWPOINT*, which is written in a manner that is accessible to people with reading difficulties, and then commissioned its own research. The specialist magazine for social workers, *Community Care*, ran a major campaign, over a three month period, which culminated in a petition to the government and meeting at the House of Commons, a major conference at which the Director of Public Prosecutions was directly challenged, and ensuing radio and TV coverage.

***.2 The proposals**

The UK Home Office proposals cover ten broad areas:

- *Definition of vulnerable or intimidated witnesses*
- *Encouraging the reporting of crime.*
- *The identification of intimidated and vulnerable witnesses*
- *Communication between the police and prosecution service about witness' needs.*
- *Ensuring appropriate interview methods are used*
- *Investigative and pre-trial support measures*
- *Procedures for applying for special measure to be available at the trial.*
- *A range of measures available for use at the trial to assist vulnerable or intimidated adults and children.*
- *Continuation of necessary measures after the trial.*

1. The problem of defining a vulnerable or intimidated witness is difficult because specific circumstances can have as much influence as personal status - we could *all* be vulnerable and intimidated in certain circumstances. The report clarifies that:

Witnesses who are vulnerable as a result of personal characteristics which may relate to the effects of a disability or illness should automatically attract the provision of special measures.

The court should be required to make available one or more of a range of measures, if the witness by reason of significant impairment of intelligence and social functioning/mental disability or other mental or physical disorder, or physical disability, if the witness requires the assistance of one or more special measures to enable them to give best evidence.

The report adds that,

When considering applications for special measures to be available for a witness the court must have regard to the views of the witness on behalf the application has been made.

2. The report recognises that it is not sufficient to restrict necessary action to the justice system. Social Services, Health departments and other professional bodies must respond.

Consideration should be given to providing better education for professionals, carers and service users involved in the care of those who are potentially vulnerable or intimidated witnesses about recognising the symptoms of victimisation to enable them to be better able to recognise acts that may be criminal.

3. The need for inter-agency co-operation, particularly between police and social services, is recognised.

National guidelines should include a recognition that when abuse occurs a crime may have been committed and that there should be clear policies about reporting such incidents to the police as soon as practicable and in consultation with the victim.

Crime reporting policies should include the following components:

*clear definitions of abuse and types of mistreatment and criminal offences.
indicators of abuse.*

what should be reported to the police and at what stage and assisting the client to do so.

outline of the purpose and conduct of any internal investigation and arrangements for assisting a police investigation.

clear policies and procedures for reporting and dealing with allegations of abuse/offences by a member of staff.

4. A common excuse for not responding to the needs of victims with intellectual disabilities is that police have not recognised their disability. This is understandable. It is sometimes not easy for non-professionals to distinguish between disability, and people who have abused drugs or alcohol, in the difficult circumstances of investigating a crime.

The police should aim to identify a vulnerable witness as early as possible in the investigation process.

Police forces should identify individuals who would have responsibility for either making the identification of a vulnerable witness and/or seeking assistance in doing so.

To assist police in identifying a potentially vulnerable witness a series of prompts should be developed. These should not be used as questions to be put to the witness but be regarded as a guide only. The prompts should be used as an aide in making an overall assessment of an individual witness' needs.

5. Ensuring effective communication, by witnesses, from the start of an investigation, and throughout the trial, is seen as crucial.

In the first instance, the police should consult the vulnerable witness and those who know the witness best to seek advice on communicating with him/her provided that they are not party to the crime under investigation.

The courts should have statutory power to require use of means to assist the witness in communicating, whether through an interpreter, a communication aid or technique, or communicator or intermediary where this would assist the witness to give their best evidence at both pre-trial hearing and the trial itself, provided that the communication can be independently verified.

(These proposals reflect Article 6,3e of the European Convention on Human Rights.)

6. There is a clear need for emotional and practical support for the victim, and an appropriate location for interviewing which may not be the police station, or, in some circumstances, the victim's home or place of work.

While being interviewed vulnerable witnesses, particularly someone with learning disabilities, should be able to benefit from being accompanied by someone, preferably someone familiar to them. This "supporter", whose role would need to be clearly defined, would need to be independent of the police and not a party to the case being investigated. The police should have responsibility for ensuring that a support person is present

Vulnerable or intimidated witnesses should not be denied the emotional support and counselling they may need both before and after the trial.

When deciding where interviews with vulnerable or intimidated witnesses should take place account should be taken of the needs and wishes of the individual.

The witness' own views on pre-trial measures should be obtained, with the assistance of their supporter where relevant..

Consideration should be given to the need to provide an escort for the witness to and from the court.

7. Often witnesses have to wait many hours in the court before giving evidence, and by the time they are called they are tired and confused.

Consideration should be given to the use of pagers so that witnesses can wait outside the court building and be called only when they are needed to give evidence.

8. Avoidable bad practice has often occurred simply because of poor communication between police and the prosecution service.

While recognising the distinction between the role of the police, who have responsibilities as the investigator, and the role of the prosecution service, there should be an early strategy meeting between the investigating officer and the prosecution service to discuss and agree the form in which the statement should be taken, and what measures might be needed to assist the witness before and during the trial, taking into account the witness' own views and preferences.

Meetings between the Prosecutor and certain vulnerable or intimidated witnesses could benefit the conduct of the case and provide reassurance to the witness.

The court service should appoint a liaison officer to ensure that measures ordered by the Court to assist vulnerable or intimidated witnesses at Court are in place on the day of the trial.

Information about the needs of the witness and the witness' own views on the requirements for assistance in court should always be passed on by the police to the prosecution service

9. Already, the UK Home Office has funded experts to create learning materials to help victims with intellectual disabilities prepare for going to court. An excellent series of books exists, which uses pictures without text.^{ix}

The Home Office should develop further material to assist vulnerable or intimidated witnesses prepare for their attendance in court.

10. Video links are already in use with child witnesses, and this practice could be extended to vulnerable adults.

Live CCTV links should be available to enable vulnerable or intimidated witnesses to give evidence to the court, either from another room within the court building or from a suitable location outside the court.

A vulnerable or intimidated witness should have the option, if they wish, of being accompanied in the CCTV link room by a supporter.

Video recorded interviews conducted by police officers, social workers or those involved in the investigation of crime and/or appropriate defence representative should be admissible as evidence.

11. In the past, victim-witnesses have found it difficult to give evidence in sight of the defendant and public. Screens can be placed so that the jury and other court officers can see the witness but the defendant and public cannot.

Screens should be available on a statutory basis to be used as a measure to assist vulnerable or intimidated witnesses.

12. There have been many instances in which lawyers have bullied, demeaned or intimidated vulnerable witnesses, sometimes with the result that witnesses break down and cannot continue to give evidence. This has included congratulating witnesses on using long words, leaving very long silences, repeating the same question many times, telling a woman that it is impossible that anyone would want to have sex with her because she has a disability.

Witnesses are performing a public duty and should be treated with dignity and respect when giving evidence in court. While recognising the need to ensure that defence counsel is able adequately to test the evidence against their client...guidance should be given to barristers and judges on the need to disallow unnecessarily aggressive and/or inappropriate cross-examination

13. British courts can appear very bizarre because lawyers dress in the same way that they have done for the past three centuries. This can upset witnesses.

The court should have statutory power to require the removal of wigs and gowns when the court considers that this will assist a vulnerable witness give best evidence.

14. Many cases have failed because witnesses with intellectual disabilities cannot say the formal oath or cannot explain the meaning of "truth". Defining "truth" is something that has eluded philosophers for centuries, yet a witness with intellectual disabilities is supposed to give an instant and convincing definition in front of a court - a test no other witness is expected to take. There is no research demonstrating that people with mental disabilities are more likely to lie in a court than, say, a financier or politician. If they do, their disability is likely to make it easier for a court to detect - it is highly intelligent people who make the best liars. As mentioned earlier in this book, people with autism are less likely to lie than others, because their disability specifically affects the intellectual skills needed to tell lies.

The law on competency should be changed along the lines of one of the following 3 options:

(i) Unsworn evidence should be admitted in respect of all adults with learning disabilities.

(ii) Unsworn evidence should be admitted if the witness is unable to understand the oath.

(iii) Evidence could be given unsworn if necessary, but the need to tell the truth would be explained to the witness who would need to acknowledge this.

15. Traditionally the police expect a 'complainant' when a crime has been committed, i.e. someone who will say, to the police and in court, for example, "He hit me?". This expectation arises even if there were a dozen reliable witnesses, and forensic evidence. In law a complainant is not necessary - in a murder case there is no complainant, and in a case in which the victim stayed unconscious after a serious assault there might not be a complainant. The police would still prosecute in these circumstances, but they do not extend the logic to a circumstance in which a victim cannot complain because of intellectual disability.

In the case of vulnerable or intimidated witnesses the police should pay particular attention to obtaining forms of evidence with a view to reducing the need for such witnesses to attend court to give evidence.

In addition to these proposals from the Home Office, a *Public Interest and Disclosure Bill* is currently being considered by parliament. This will support "whistle-blowers" - employees who wish to disclose and give evidence about abuse or bad practice by their employers. In the past this has often led to people losing jobs, ruined career prospects, or other forms of retaliation. The new law will protect "whistle-blowers", provided their disclosure was made in good faith. This legislation stemmed from the work of an NGO, *Public Concern at Work*,^x which showed that major accidents involving loss of life could have been prevented if employees had been given the chance to disclose dangerous practice.

In 1215, the *Magna Carta* declared, *To no-one deny or delay right or justice*. It did not add, "Except for people with disabilities". Hopefully the current government action in the UK will ensure that the original intent of the 13th century law-makers is restored and upheld.

***.3 The process of achieving change**

Whether or not these current UK Home Office proposals eventually become legislation remains to be seen, but the process itself provides two very important lessons for those wishing to influence the law-making process in their own countries.

1. The topic is not politically contentious. Few politicians would question that something should be done to achieve equitable justice for people with disabilities - in the words of a UK minister, "You are pushing at an open door". A small number of politicians

are likely to take the problem very seriously, usually because they have direct involvement with someone with a disability, and it is important to identify these politicians as allies.

BUT

2. Although the problem is very important to people with a direct concern, in the context of a whole nation it is marginal. The main hope for adequate legislative change is that the issue “piggy-backs” on a broader policy-making debate.

The Home Office civil servants have very skilfully brought together areas of current public concern, which seem unrelated. The first is that witnesses in major cases concerning terrorism or organised crime have been intimidated, often on a life-threatening scale, and this has made it problematic to get witnesses to testify. (This situation would probably be well-recognised in Italy.) The second area is that victims of rape have experienced revictimisation in the court room through forms of intimate and intrusive questioning, sometimes by the defendants themselves, which has little bearing on achieving justice. The third concern is long-standing - child abuse. And the fourth area is how the courts respond to the needs of disabled people *in general*, but specifically those with mental disabilities.

The two concepts common across these four areas of concern are that the witnesses (both defence and prosecution) are all potentially *vulnerable* - albeit for very different reasons - and this puts them in a position in which they might be *intimidated*, inside or outside the courtroom - albeit in very different ways. By addressing these two generic problems, the government could propose relatively simple measures that will affect and please a wide spectrum of the public, and probably attract all-party support. And this outcome is very appealing to any politician. Addressing the problems of disabled people alone, would probably not have seemed so attractive.

The sometimes unique circumstances of people with autism must be identified but then put in the context of all people with mental disabilities. The circumstances of people with mental disabilities must then be seen in the context of all people with disabilities. And the circumstances of people with disabilities must then be considered in the context of everyone. If the reverse happens, history shows that special laws about mental disability can further marginalise people who are already, all too often, seen as not fully part of the community.

ⁱ Fattah, E.A. (1992) **The plight of victims in modern society**, Macmillan: London, see chapter - 'On some neglected types of victimisation - victims of abuse of power'.

ⁱⁱ op cit 6, p27.

ⁱⁱⁱ op cit 6.

^{iv} Home Office (1998) **Speaking up for justice: report of the Interdepartmental Working Group on the treatment of Vulnerable or Intimidated Witnesses in the Criminal Justice System**, Home Office: London.

^v Brown, H., Stein, J. & Turk, V. (1995) 'Report of a second two-year incidence survey on the reported sexual abuse of adults with learning disabilities: 1991-1992,' **Mental Handicap Research**, 8,1.

Williams, C. (1995) **Invisible victims: crime and abuse against people with learning disabilities**, Jessica Kingsley Publishers: London.

^{vi} *Joseph Rowntree Foundation*, The Homestead, 40 Water End, York YO3 6LP. Details of research projects, etc. are on the Home Page - <http://www.jrf.org.uk>

^{vii} Sanders, A., Creaton, J., Bird, S. & Weber, L. (1996) **Witnesses with learning disabilities, research findings no. 44**, Home Office: London.

^{viii} VOICE, P.O.Box 238, Derby DE1 9JN UK, fax (0)1332 521392.

^{ix} Hollins, S. et al (1994) **Going to court**, Sovereign Press, St Georges Mental health Library: London. (Division of Psychiatry of Disability, St Georges Hospital Medical School, Cranmer Terrace, London, SW17 0RE.

^x *Public Concern at Work*, 42 Kingsway, London, WC2B 6EN.