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## Quality of Life and Physical Well-Being in People with ASDs

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### 1. Introduction

The term Quality of Life (QoL) started to be used in relation to disability in the 1980s. Persons with disabilities have the right to a good quality living. In the 1990s it became a goal to be achieved, verified and measured. The next step was mandatory: if progress is to be made towards achieving QoL for people, then it is necessary to specify what QoL is. In 2002 Schalock and Verdugo published 12 basic principles for conceptualising, measuring and implementing it. They defined a multidimensional concept that is influenced by personal and environmental factors, and their interaction, and is improved with self-determination, resources, life purpose and a sense of belonging. They translated their multidimensional proposal into eight dimensions: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. The importance of the concept of QoL lies in the fact that it provides: a conceptual framework from the individual's perspective; 2) a guide to action; 3) a criterion for assessing both strategies and results. QoL becomes the goal to be reached for the person, the organisations, the politicians and the funders concerned. It is a guarantee with regard to objectives, procedures and quality outcomes.

To improve an individual's QoL we must focus on their point of view, their needs and their context. The QoL model helps us, in the first place, to know where to look. We have eight dimensions, but might there not exist a hierarchical structure among them? Kreuger et al., (2008) conducted a study to identify the priority needs of persons with severe intellectual disabilities. One of their findings was that the physical well-being dimension is of crucial importance for these persons. Chou et al., (2007) carried out a study in Taiwan in which they assessed the QoL of adults with intellectual disabilities. They found that of the eight dimensions in the model put forward by Schalock & Verdugo (2002), the one singled out as most important was the physical well-being dimension.

The eight dimensions of QoL are inter-related and it is likely that improving one will result in an improvement in one or more others. Of course, the converse is also true. This is particularly evident in regard to the physical well-being dimension. Physical well-being and emotional well-being are closely related. Indeed, in populations with communication difficulties, one of the ways pain or physical discomfort may be manifested is through displays of anxiety, increased motility, crying and even tantrums with acts of aggression and/or self-aggression (Nieto et al., 2008). Physical well-being becomes a key item for

generating the motivation that leads individuals to set themselves goals to do with social interaction, personal development and so on. Moreover, in general, physical discomfort will affect the other dimensions. This is how the results of the studies by Kreuger et al., (2008) and Chou et al., (2007) can be interpreted. Perhaps it is not quite accurate to say that physical well-being is what contributes most to individuals' QoL, but it does seem that lack of it has an extremely deleterious effect on the other dimensions. In short, actions aimed at ensuring a healthy state must be a priority objective of persons, organisations, politicians and funders.

## 2. What is the health of persons with Autism Spectrum Disorders like?

Autism spectrum disorders (ASDs) are heterogeneous and multifactorial neurodevelopmental disorders. They are neurobiological disorders for which genetic aspects appear to have a decisive influence in interaction with environmental factors (Sigman et al., 2006). This complex interaction shows up clearly in studies of monozygotic and dizygotic twins in which the concordance ratio between the former is 88%, whereas between the latter it is 31% (Rosenber et al., 2009). It is possible to speak of a syndrome in which there is a phenotype with common underlying general features caused by different biological mechanisms (Coleman & Betancur, 2005). There is no specific local problem in the brain; rather, various neuronal systems are probably affected (Akshoomoff et al., 2002; Schultz & Robins, 2005), especially those involved in regulating neuronal connections during development (Minshew et al., 2005); or underconnectivity (Just et al., 2004; Cassanova, 2006; Dosenbach et al., 2010).

Autism spectrum disorders are associated with different biological conditions. Epilepsy is one of the most frequent comorbid disorders of autism (Canitano, 2007; Tuk et al., 2009) and it is even mentioned in The Diagnostic and Statistical Manual of Mental Disorders Fourth Edition [DSM-IV] (1994), although it is not included as a diagnostic criterion. There is a high degree of variability in respect of its prevalence. According to Tuchman & Rapin (2002), about 30% of persons with autism develop epilepsy as adults. The risk of epilepsy varies also depending on the subtype of autistic spectrum. The lowest prevalence (4%) is associated with Asperger syndrome (Cederlund & Gillberg, 2004) and the highest (77%) with childhood disintegrative disorder (Mouridsen et al., 1999). Amit et al., (2008) found that the risk of epilepsy increases as a function of two factors: intellectual disability and female gender.

Gastrointestinal problems are also frequent in this population (Nikolov et al., 2009). Buie, et al., (2010) carried out a wide-ranging study from which they concluded that the prevalence and best treatment of these conditions are still incompletely understood. A key problem is the difficulty this population has in recognising and characterising gastrointestinal dysfunction because of their communication difficulties. Many parents report improved behaviour following medical or nutritional intervention. In this connection, some studies have reported improvements associated with changes in diet (Knivsberg et al., 2002). The high frequency of gastrointestinal problems in persons with autism has made this the focus of a number of studies investigating the aetiology of the disorder. Cassanova (2008) looked for connections between gastrointestinal symptoms and failures in neuronal architecture, in particular, minicolumnar disturbance. Kimberly et al., (2009) carried out a comprehensive review of studies investigating the association between autism and viral infections (Rubella, *Toxoplasma gondii*, Varicella, etc.), neuroimmune studies (including gastrointestinal factors)

and the role of vaccines. It is important to point out that so far no data have been found to support a possible causal relation between the triple viral vaccine and the appearance of autism, and this hypothesis has been ruled out on the basis of strong scientific evidence (D'Souza et al., 2006; Rutter, 2005).

Another crucial aspect of the health of persons with ASDs is the high proportion that are treated with psychotropic medication. There are no medicines that improve the core disorders of autism, but treatments are often prescribed with the aim of alleviating certain symptoms such as aggression, self-injury behaviours, stereotypes and hyperactivity (Hollander et al., 2003). Aman et al., (1995) found that 30% of children with ASDs were using some psychotropic medication. Green et al. (1996) conducted an internet survey of 552 parents of persons with autism in which 52% reported habitually administering psychotropic medication. Recently, Mandell et al., (2011) investigated a sample of 60,641 children with ASDs in the USA. In their sample, 56% were treated with at least one psychotropic medication, 20% of whom were prescribed three or more medications at the same time. The use of these drugs was common even in children aged 0 to 2 years (18%) and 3 to 5 years (32%). Neuroleptic drugs were the most common (31%), followed by antidepressants (25%) and stimulants (22%). In their conclusions they stress that the effects of these treatments on development are not yet known and argue the need to assess the risks, benefits, and costs of the use of this type of medication. Fuentes et al. (2008) develop PHARMAUTISME TR, a protocol to administrate psychotropic medication to people with mental disabilities and ASDs. This protocol is followed in Gipuzkoa, País Vasco (Spain) and the use of these drugs in this population is less than 30%.

There are also other problems commonly found in persons with ASDs that can have negative repercussions on their health and need to be taken into consideration. These include issues to do with the lack of a balanced diet due to food selectivity (Ventoso, 2000) or overeating; difficulties in maintaining suitable hygiene habits, especially oral and dental hygiene (Shapira et al., 1989; Dias et al., 2010); sleeping problems (Berthier et al., 1992; Polimeni et al., 2005; Allik et al., 2006); the lack of physical exercise, with prolonged stress and anxiety (White et al., 2009; Green & Ben-Sasson, 2010) and the difficulty of foreseeing and controlling risks.

Lastly, there is another fact showing that the health of persons with ASDs is worse, or more threatened, than that of other people, namely the mortality ratio data. The different studies conducted on this (Shavelle & Strauss, 1998; Shavelle et al., 2001; Mouridsen et al., 2008; Gillberg et al., 2010) have revealed that persons with autism have a shorter life expectancy than the rest of the population and a higher mortality ratio. High mortality ratios have been reported for circulatory disorders (2.3) and cancer (1.9), which leads to the formulation of the hypothesis that the higher mortality from these causes may be due to late diagnosis of the disease as a consequence of the communication difficulties present in persons with autism. Recently, Gillberg et al., (2010) have published the results of a longitudinal study which was completed in 2008. It was carried out in Sweden with a sample of 120 persons with ASDs born between 1962 and 1984 who were followed up between the ages of 13 and 22. They report that the main causes of death were associated with medical disorders and accidents. They also found that the mortality ratio was higher in women.

As can be seen, persons with ASDs are at greater risk than the population with typical development of suffering various problems affecting their health. In addition, they are at a disadvantage in recognising and expressing their discomfort, and in allowing themselves to be examined. It is common for persons with ASDs, even when they possess language (about

50% of them fail to develop spoken language), not to report on their internal state. So on many occasions we lack information on their psychological and/or physical condition. In addition, they may have difficulty identifying pain and discomfort as a result of altered sensory thresholds, so it is quite possible that they are unable to locate the source or nature of the discomfort (Boghashina, 2003; Ventoso & Osorio, 1997). They are people who do not usually ask for help or consolation consistently when they are in discomfort or suffer pain. Pain is often manifested in behaviour problems, irritability, etc. Relatives and clinical professionals formulate successive hypotheses about the cause of such behaviour and it is not always easy to find the real connection between cause and effect. On some occasions an extreme situation -such as a very high temperature, the discovery of major physical lesions that have become quite evident- provide the key to explaining -a posteriori- serious behaviour disorders that have been going on for years (Nieto et al., 2008). Medical professionals are faced with people coming to their clinics who do not use any means of communication to describe their symptoms, define them incompletely or even deny them, and who, moreover, do not allow an adequate examination to be performed, which means the practitioner tends to act on the basis of trial and error. To this must be added the fact that not all health care environments have sufficient information and training on the treatment and adaptations necessary to optimise examinations (Carbone et al., 2010; Merino et al., 2010).

Taking these factors into account, it is essential for health care education programmes to be implemented that are clear, simple and well-defined, and also demonstrate their effectiveness. The QoL model becomes a guide guaranteeing quality practice.

### **3. Towards an integral health plan for persons with ASDs**

The integral health plan put forward here comprises 12 aspects that have a direct connection with, and may have an influence on, physical well-being and, inseparably, on emotional well-being. Some of these factors depend on, or are more directly related to, the person with ASDs and require specific teaching programmes to be run for particular groups or individuals, according to their needs and level of competence. Others focus on the contexts and it is these that need to improve their knowledge and put in place specific assessment and monitoring systems, and action protocols.

The 12 dimensions of the integral health plan constitute, on the one hand, a proposal for 12 different programmes to be carried out and, on the other, offer a schema or basic outline for drawing up health assessment protocols that will help to determine needs, enable intervention goals to be set and serve as a monitoring tool. They provide information that helps to carry out specific intervention programmes for persons with ASDs depending on their particular disorders within the spectrum.

To help with these proposals, the main contents referred to in each of them are described briefly below

#### **3.1 Disease prevention and treatment**

The “physical” health problems of persons with ASDs may be no different from those of the rest of the population. However, the health care they receive may be different and of inferior quality due to the difficulty some of these persons have, especially in childhood, in allowing adequate examinations to be performed. That is why carrying out programmes designed to get persons with ASDs used to examinations and their contexts by employing specific



strategies, such as a routine maintained over time and providing information beforehand using analogous material (photographs or drawings), has proved to be useful (Nieto et al., 2008). Gradual, ongoing habituation from infancy prevents many health care problems, especially in persons with more pronounced disorders within the autism spectrum.

Another component of this prevention dimension is the advisability of carrying out regular “general” health check-ups (primary health care normally performed by general practitioners) and dental check-ups, especially in persons with more pronounced disorders. A regular check-up (for instance, every two months) enables the habituation learning to be maintained and also makes it possible to detect complaints in their initial stages and treat them appropriately and simply (Nieto et al., 2008). For example, a person with ASDs with serious communication limitations, even though they possess language, may, just like anyone else, have a wax blockage in their ear. The manifestations may be the expected lack of attention, in which case there is a considerable likelihood of this being misinterpreted. But it is also not infrequent for the discomfort to be manifested through maladjusted, even self-harming, behaviours that can lead to interventions far removed from what is really needed and, among other negative consequences, aggravate the original health problem. Routine, regular check-ups do not imply excessive “medicalisation” of this population and may have enormous personal and social benefits.

In high-functioning persons who may experience anxiety or rejection when being medically examined, anticipating and explaining such situations using Carol Gray’s (1994, 2010) social stories technique may be of great help.

### 3.2 Medication

The aspects to do with the medication dimension are diverse. On the one hand, as happens with the rest of the population, many children may reject the administration of drugs via the different routes and in the different formats. It is important to assess the child’s acceptance of the medication formats and administration routes to plan the intervention. Again, employing teaching procedures that include routine, successive approximations and prior visual information about what the child is expected to do and the consequences it will have for their well-being, is extremely useful.

In the case of high-functioning adults, it is advisable to review their ability to follow autonomous administration guidelines. If necessary, specific programmes can be carried out that include a scientific explanation of the effect of the drug and the need to use it at the appropriate times and in the appropriate amounts, the use of external reminding systems such as reminders in watches or diaries.

### 3.3 Food

Food problems are common in persons with ASDs in childhood and some authors have even suggested them as a diagnostic indicator (Ahearn et al., 2001). They appear with various manifestations, but usually present with food hyperselectivity as a common feature, the child accepting only limited ranges of food and completely refusing to eat or even try any others (Field et al., 2003; Martins et al., 2008). Some children display from the very earliest months of life problems in ingesting the necessary amounts, but the most common problem arises when the time comes to change the type of food from milk to baby food and then to introduce solids. Some children will only eat if they are offered a particular type of food, flavour or presentation. Various factors can affect this, one of which is the possible

existence of gastrointestinal disorders such as gastro-oesophageal reflux and other digestive problems (Lightdale et al., 2001; Fombonne & Chakrabarti, 2001; Horvath & Perman, 2002) that lead to the refusal of food. The presence of sensory disorders is also common. These tend to be specially pronounced and serious in the early years of development (Williams, 1996). It is likely that some children with autism have a basic sensory disorder problem affecting taste, smell, touch, sight, sensitivity to temperature, etc. (Field et al., 2003) so they find certain foods unpleasant or even unbearable, whereas others, with strong and strange tastes are among their favourites. In addition, changing flavours, smells and sensations, or even simply the visual stimulation conditions of the plate, cutlery, etc. may present a challenge for the cognitive system of a child with ASDs. Mental inflexibility is a central characteristic of autistic processing (DSM-IV-TR; Ozonoff, 1995; Ozonoff et al., 1991; Rivière, 1997) and may manifest itself in the absolute rejection of anything new to do with food. Parents and teachers generally fail to understand the reason for this rejection and often the only way they find to deal with this is by forcing the child to eat so that, by a classical conditioning process, the child comes to associate the intake of new food or the entire stimulation complex of the eating situation with a negative emotional state which the child rejects. Persisting in forcing the child to eat reinforces the association between negative emotion and feeding situations so that some children cry at the simple sight of food or an attempt to give them a little piece of food unleashes a strong temper tantrum.

The food programmes try to break this negative conditioning gently but firmly and gradually, and must be carried out in a personalised way bearing in mind the children's sensory characteristics and their previous history of routines during feeding. Ventoso's (2000) programme proposes a change of attitude in the people in charge of feeding and suggests they take into account various general considerations: turning meals into a pleasant and peaceful time, which requires the adult to display serenity and firmness at all times; associating food only with eating; creating and performing every day a meal ritual shaped by the adult, forcing slightly without entering into a "battle" with the child; requiring the child to eat a small pre-established amount.

The programme includes a number of steps to be followed to make the changeover from minced food to solid food:

- Collect information from the family about foods, the ways of taking them, cutlery preferences, bibs, etc.
- Create a routine and keep the physical conditions constant;
- Finish the meal with a highly gratifying situation such as playing an interactive game, letting the child see a favourite advertising brochure, etc., in other words an activity that is highly desired by the child;
- Begin the new programme in a different context from the usual one;
- Begin with a small amount of the food the child likes best offered in a small spoon. Insist in multiple tries with the utmost tranquillity and strategies of successive approximations plus reinforcement for each one;
- Gradually increase the amount of food accepted;
- Choose a totally new situation for offering new foods;
- Introduce new flavours by choosing a food of similar flavour to the child's favourite and the same texture and temperature;
- When moving from purés to solid foods, change textures, for example, extremely gradually and carefully, introducing a small spoonful of food in a slightly different form into the food in the form the child accepts.

She also recommends some methodological principles that should be adhered to: provide visual information beforehand about what the child is going to eat by showing it to them; present only an amount that one is certain the child is going to eat; always give the child's favourite dessert and do not change it at the beginning; prevent the child from getting wet or dirty and clean them gently and immediately if this does happen; do not mix different foods; do not offer a new spoonful until the child has swallowed the previous one; make sure the food is at the ideal temperature for the child; etc.

Other specific problems, such as the child's leaving the food in their mouth without swallowing it, swallowing without chewing, not accepting new foods, etc., require special adjustments.

At the opposite extreme, some persons with ASDs overeat and lack the comprehension and communication mechanisms that would make it possible to explain to them the reason why it is not good to eat all they want.

Strategies involving feeding at set times to a strict, but fairly frequent, routine –five meals a day- are a good idea. It is important for mealtimes to be set and be known in advance by the individual (Schopler et al., 1995). It is useful to include large amounts of dietary fibre in the food, especially at breakfast and tea time. It is important for persons who are overweight or have nutrition problems due to the limited variety of their food intake to be supervised by a doctor who is an expert in nutrition who can make suggestions about diet and monitor their evolution (Volkmar & Wiesner, 2004).

High-functioning persons with food problems may benefit from diet education programmes that include an intellectual explanation of the food pyramid, the need for a balanced diet and suggested examples of diets.

### **3.4 Physical exercise and posture control**

It is obvious that physical exercise and posture control are two fundamental aspects to be looked after, especially in adults, just as in the rest of the population. However, the high incidence of mortality due to circulatory disorders in persons with ASDs (Shavelle et al., 2001) makes it advisable to pay particular attention to this.

Moderately intense physical exercise is a useful tool in reducing stress. Doing moderately intense routine physical exercise is advisable. Individual sports such as swimming, skating, using exercise machines in a gym, trekking, etc., are particularly suitable. With low-medium functioning persons, visual or physical signs can be used to help them understand when an activity begins and ends, e.g. by means of warning devices, route signs in open spaces or indicators showing the number of times an exercise has to be done, eg passing a counter or washer from one container to another after every go (Peeters, 1997).

A much neglected aspect in this population is care in maintaining a suitable posture. There is no information on the effects this may have, but the existence of discomfort must be obvious. It is important, especially in adult care homes, that residents are helped to maintain appropriate postures and are provided with appropriately adapted furniture where necessary. Care and supervision by physiotherapists may also be highly advisable.

### **3.5 Hygiene**

Persons with ASDs fairly often lack an understanding of the need for hygiene and its benefits. Nevertheless, most of them have adequate hygiene habits or allow suitable hygiene procedures to be performed; many of them even avoid dirt and try to take their clothes off if



they do get dirty. In children, oral and dental health problems are often associated with deficient hygiene (Shapira et al., 1989; Dias et al., 2010). The mouth is a specially sensitive area in which sensory disorders can occur as a result of the brush, the toothpaste or the brushing action. To deal with this, programmes have been carried out to teach carers how to perform hygiene. These teaching programmes often employ a behavioural methodology known as backward chaining supplemented by visual information: drawings of the mouth with the number of times the teeth have to be brushed or numbers to be counted while using an electric toothbrush. Using an electric toothbrush may benefit some children, but it is aversive to others, so an individual assessment is needed. The taste and strength of the toothpaste are aspects that can help or hinder teeth cleaning.

Hand hygiene requires special care due to its implications for health. Hygiene programmes must include the need for the person to wash their hands after going to the toilet, always before handling food or after handling any substance that may be harmful. Here too visual information plus routine are two suitable complementary procedures. Action guides with analogous images are extremely useful, but an intellectual explanation using illustrations of the health consequences may also be of great help to many children and adults with autism with poor communication and comprehension ability.

Cutting nails and hair, especially in the case of children, are two other activities for which special programmes are commonly needed. Adults require special attention to be given to their feet, as they may have discomfort that causes them a great deal of pain. Procedures based on routine, successive approximations, contingent reinforcement and visual anticipation, in the same way as in the medical examination habituation programme, are extremely useful.

### 3.6 Sleep

Sleep problems are quite common in persons with autism and are of various kinds. Generally they include difficulty in getting to sleep, waking up during the night, sleeping for only a short time and waking up very early (Honomichl et al., 2002; Wiggs & Stores, 2004). In general, persons with ASDs appear to sleep for a shorter total time than control groups (Elia et al., 2000). Complicated rituals or strange behaviours for going to bed or getting back to sleep are common and force parents to go to bed with their children or perform complicated rituals to keep them asleep (eg having to leave one of the parents' arms on the child's body or let the child sleep while holding a lock of their mother's hair in their hand). There is a strong association between sleep problems and family stress (Schreck et al., 2004) and although a direct empirical relation between sleep problems and state of health in person's with ASDs has not been established, it is an aspect requiring assessment and intervention.

In some cases drug treatment can alleviate this problem (Filipek, 2005), but intervention via specific programmes is necessary. In such programmes the following kinds of strategies are useful: having the person do moderate physical exercise every day a few hours before going to bed, trying to keep excitement levels low as it gets near bedtime, creating rituals keeping to strict times, ensuring the stimulus conditions (bedroom temperature, weight of bedclothes, etc.) are optimum for the child in question depending on their sensory profile, and, of course, depriving the child of sleep during the day and keeping social attention and stimuli to a minimum if the child wakes up during the night (Durand, 1998).

PREVENTION AND TREATMENT OF ILLNESS
<ul style="list-style-type: none"><li>• Allow examination and use of medication by family members at home</li><li>• Become habituated to health care contexts and allow standard medical examinations (by paediatrician and dentist)</li><li>• Allow special medical examinations: medical tests</li></ul>
MEDICATION
<ul style="list-style-type: none"><li>• Accept taking medication when necessary</li><li>• Take medication autonomously</li></ul>
FOOD
<ul style="list-style-type: none"><li>• Take solid and varied foods</li><li>• Take an adequate amount of food</li></ul>
PHYSICAL EXERCISE AND POSTURE CONTROL
<ul style="list-style-type: none"><li>• Do regular physical exercise</li><li>• Maintain suitable postures in different situations</li></ul>
HYGIENE
<ul style="list-style-type: none"><li>• Perform appropriate oral and dental hygiene every day</li><li>• Maintain hygiene habits: shower and rinse off soap, wash hands before handling food, hygiene after using the toilet</li><li>• Cut nails, hair, etc. or allow them to be cut</li></ul>
SLEEP
<ul style="list-style-type: none"><li>• Suitable sleep habits: bedtime, appropriate length of sleep, appropriate strategies for getting to sleep at the right time, etc</li></ul>
HEALTH COMMUNICATION
<ul style="list-style-type: none"><li>• Recognise and express physical discomfort and pain</li><li>• Give and receive information in medical contexts</li></ul>
KNOWLEDGE ABOUT HEALTH AND THE HEALTH CARE CONTEXT
<ul style="list-style-type: none"><li>• Know and name parts of the body</li><li>• Know the meaning of the specific terms for illnesses, the course of an illness, etc.</li><li>• Get to know health care contexts: vocabulary and action guides</li><li>• Be independent in health care contexts</li></ul>
RELAXATION
<ul style="list-style-type: none"><li>• Have strategies for managing stress</li><li>• Keep healthy life habits to reduce stress</li></ul>
SEX EDUCATION
<ul style="list-style-type: none"><li>• Know the anatomy and appropriate vocabulary</li><li>• Know and use suitable ways of releasing sexual tension</li></ul>
INFORMATION TO HEALTH CARE CONTEXTS
<ul style="list-style-type: none"><li>• Have general information about ASDs</li><li>• Know the characteristics of the communication limitations and possible sensory peculiarities. Adapt the environment and forms of treatment. Use alternative information and communication systems</li><li>• Possess information on the associated biological conditions and the need for assessment using agreed protocols</li><li>• Possess up-to-date knowledge on the limits and benefits of psychotropic medication and its effects.</li></ul>
HEALTH ACTION AND MONITORING PROTOCOLS
<ul style="list-style-type: none"><li>• Draw up and periodically apply state-of-health assessment and recording protocols</li><li>• Protocols for periodical general and dental health check-ups</li><li>• Draw up protocols to ensure continuity between educational, social and health care services</li></ul>

Table 1. Integral Health Plan: Summary of the dimensions involved

### 3.7 Health communication

Communication difficulties are one of the basic criteria in diagnosing ASDs (DSM-IV). Programmes to improve communication by means of language or alternative systems are a priority and a central component of intervention. Prizant & Wetherby (2005) have pointed out that limited social communication is directly related to the appearance of behaviour problems. Many problematic behaviours, such as self-injury, tantrums, aggression, preservative use of speech, and so forth may be the only means by which an individual with ASD can exert social control. With such behaviours they may achieve certain goals, such as putting an end to unwanted situations, ensuring physical contact or attention, and initiating or regulating social interaction (Carr et al., 1994). But these maladapted behaviours may be the insidious manifestation of physical discomfort (Buie et al., 2010). It is difficult for persons with ASDs to convey pain and discomfort for various reasons: in the first place, they may not find it easy to identify or locate the sensation precisely due to sensory disorders and a lack of basic body awareness; in addition, their communication is clearly limited, which means they do not engage in spontaneous expressive behaviours or requests for help; and lastly, they often have limited vocabulary –whatever the code they employ– with which to describe specific ailments. In view of this, an important aim of health programmes is helping to express internal states, especially pain and discomfort, is.

A programme designed to help express pain may begin by teaching the person to understand what is happening to them and to express it simply by means of drawings when it is happening. There are situations in which pain is easy to detect: a fall, a cut finger, a grazed foot. At such a time it is appropriate to make a simple drawing of the situation and show it to the child so they can see it and at the same time understand that afterwards they will be helped to share the drawing and show it to people they are familiar with who can console and help them. Ventoso & Osorio (1997) suggest making one or two sketches, entitled “Important”, in red describing what has happened that can be shared by showing them to others and saying the appropriate words (eg “knee hurts”) if the child has spoken language.

This incidental intervention strategy may be backed up by a broader programme for the expression of sensations. Fun situations can be designed for children to learn, at particular times as part of the regular school activities in the area of communication, to express, by means of spoken language or any other alternative system, sensations, such as “my x itches”, “y cold”, “z hot”, etc., that do not refer directly to pain, but develop the ability to express frequently “what is happening” in their body precisely and accurately. At the same time, it may be useful to have a panel visible or handy by way of a dictionary with drawings depicting common bodily sensations or pains –“head hurts”, “tummy ache”, “want sick”, “hungry”, “thirsty”– so that when something happens to them they have a better chance to express it. Stick-on graphics that can be detached by the child and handed to an adult provide enhanced possibilities for communication (Frost & Bondy, 1994).

It is sometimes necessary to explain to high-functioning persons, especially during childhood, the difficulty of identifying sensations and naming them. It is a good idea to help them to recognise the internal parts of the body by providing them with some knowledge of anatomy while explaining the need to ask for help to make things better. Using the social stories format devised by Carol Gray (1994, 2010) can also help a great deal in understanding why it is necessary to express ailments, what consequences this can have and how to react to discomfort.

### 3.8 Knowledge about health and the health care context

As part of the school curriculum dealing with knowledge of the environment, it is extremely important for children with ASDs to be given information allowing them to:

Learn and name parts of the body.

- Learn the meaning of the particular terms for illnesses, the course of diseases, etc.
- Be aware of health care contexts: the different places, vocabulary and guides to action in each one.
- Be independent in health care contexts.

To achieve this, it is proposed to create a special image-based book dealing with these subjects. The format of double fold-out images that the child can match up while someone shows them and explains them to her or him may help the child gain a better understanding and make the knowledge stick (*Autismo Sevilla*, 2010).

This “Health Knowledge” book can be for general use, but personalised for particular children. For example, if a particular child often has diarrhoea, it will be useful to include a page explaining what diarrhoea is, what it implies, what to do about it and when it finishes. As already indicated, the presentation format should be simple, realistic drawings.

The section on health care contexts might cover learning what a health centre or hospital is like, getting to know the rooms and specialities, staff names and material, and brief descriptions of what doctors, nurses and patients do. Naturally, the level at which this is dealt with must be adapted to the different capacities and developmental ages. It is important to back up the theoretical lessons with actual visits to the places to give the child simple experiences in them in accordance with fundamental educational principles (routine, visual anticipation and the possibility of repeating the experience several times in a similar fashion).

Higher-functioning persons can be given more ambitious targets, such as making an appointment, keeping a calendar of visits to doctors, etc., but achieving this also requires teaching with clearly programmed goals and structured and repeated learning opportunities.

### 3.9 Relaxation

Many high-functioning persons with ASDs report that, because of their sensory disorders – hypo- or hypersensitivity- they sometimes feel exposed to excessive stimulation that overwhelms them (Grandin, 1992; Williams, 1994). Some of them may feel panic, for example, if they experience certain noises, touch, certain smells or combinations of stimuli they find too much for them.

On the other hand, limited communication competences, the constant need to adapt to social demands and rules they don’t understand, the perception of being different and limited social relations may cause persons who are less affected by such disorders to experience high levels of anxiety and stress and considerably diminish their emotional and physical well-being (Arick, et al, 2005). Each person must be assessed individually to detect the possible stressful stimuli or situations.

There are many strategies for preventing or reducing anxiety and stress in everyday life. One of the most useful is providing a routine with analogous visual information in advance about the activities to be performed and how to carry them out (Mesibov et al., 2005), and especially giving information beforehand when major changes in routine are going to be made. Two other important strategies are having the adult look out for subtle signs of discomfort and doing work on expressive communication.

Arick et al. (2005) made some concrete proposals for reducing stress in high-functioning children in a school setting: identifying one person as a reference and support figure to whom they can turn whenever they need to and who routinely makes sure to ask them how they are, as many persons with ASDs may have difficulty in recognising and expressing their fears and anxieties; making agreed plans for temporary “escape” from the classroom when they cannot stand the stress; combining, in daily life, more demanding activities of limited duration with others more to the child’s liking and with a positive value, and allowing “time-outs” in between activities to do relaxing activities, such as wandering around the classroom for a little while, going into another room to be alone for a few minutes or playing with an anti-stress ball.

Other strategies that work for some people with ASDs are routinely doing physical exercise (Grandin, 1992) and occupational therapy focusing on sensory integration (Myles et al., 2000). Harrington et al., (1991), and Baron et al., (2007) have devised programmes of special relaxation techniques for persons with ASDs. They have also produced visual supports to help them detect when they are starting to get nervous and which techniques to use to relax. It seems especially important to teach self-detection systems and immediate calming strategies that can be used by even low-functioning persons. So, for example, when an adult detects signs of anxiety in a child, they can gently guide the child to the bathroom to wet their face, if water has previously proved to relax them. After having done this on several occasions, steps can be taken to offer an alternative communication system with the image of a bathroom that the child can learn to pick up and hand to the adult.

Some organisations (eg *Autismo Burgos* in Spain) regularly employ a jacuzzi and hydrotherapy to reduce anxiety and stress levels.

### 3.10 Sex education

Sexual tension and the limitations on getting to know appropriate ways of relieving it are frequently a cause of discomfort and can give rise to behaviour problems in persons with ASDs. In persons with intellectual disability these are commonly associated with not being able to find any way of releasing sexual tension, the presence of autosexual behaviours without respecting the social environment, seeking release with inappropriate objects and failing to perform appropriate hygiene measures (Ruble & Dalrymple, 1993; Van Bourgondien et al. 1997). With high-performing persons the difficulties are of another kind and are usually associated with the need to have sexual relations with persons of the opposite sex, but not knowing how to achieve this or what to do if they succeed, which may cause confusion, sadness and frustration.

Sex education must begin in childhood, ensuring that the basic principles of privacy are respected. Particular objects can be used to associate moments of sexual release with a specific private place, such as the bedroom, at a particular time of the day and in comfortable conditions. Explanations employing drawings representing where and where not to engage in such behaviour are also of help. On occasions putting on tight-fitting clothes, combined with an offer of an incompatible activity limits the possibility of touching the genitals in inappropriate places and at inappropriate times. It is essential to teach hygiene routines. To do this, the person can be given visual guides to the steps involved by placing the materials to be used in order (eg wet wipes, clean clothes, etc.) or doing the same with drawings.

Sex education programmes for persons with a sufficient level of understanding usually include information on parts of the body and the correct vocabulary for private parts,



genital hygiene, the concept of privacy and the appropriate degrees of intimacy with strangers, sporadic acquaintances, regular acquaintances, sporadic dates, friends, boy/girlfriend, wife/husband, family, etc., adjustment of the intensity of the relationship depending on the context, masturbation, sexual relations with other people, emotions to do with sexual relations and the ways to express them, and any other issues particular persons need to clear up (Koller, 2000; Shea & Gordon, 1984; Aizpuru et al., 1998)

### 3.11 Information for health care contexts

In spite of its being presented as just another dimension of the integral health plan, the information given to health care contexts and adaptation of these contexts constitute an enormous programme in themselves because of their possible scope, but also because of the major positive repercussions such a programme can have on persons with ASDs.

In order for them to attend appropriately to persons with ASDs, healthcare professionals working in primary health care and the different specialities should have the following simple but accurate information:

- General information on persons with ASDs. Their behavioural and psychological traits which explain the need to be understood and cared for in a special way.
- Information on the biological conditions commonly associated with ASDs, such as epilepsy and the type of ailments the literature reports as being frequent, such as gastrointestinal disorders and allergies, and the need for assessment in accordance with agreed protocols.
- Detailed knowledge of the communicative limitations of persons with ASDs even though they may be able to speak, possible sensory disorders (hypo- or hypersensitivity), anxiety linked to lack of knowledge and the possible anomalous ways of expressing discomfort, making an accurate diagnosis difficult.
- Appropriate adaptations to the environment and ways of treatment. Use of alternative systems to provide information and facilitate communication.
- Up-to-date knowledge of the limits and benefits of psychotropic medication and its effects.
- Periodically updated expert knowledge for professionals in key specialities for ASDs: neurology, psychiatry, electrophysiology, genetics, digestive system, allergology.

These information programmes can be carried out in very different ways: campaigns with talks, the issuing of brochures, the appointment of volunteer professionals to spread the information, etc. Whatever the form in which the information is conveyed, it is advisable for it to be brief, clear and attractive, for the health care professionals to play an important part, for the information to be regularly updated, and for support to be provided

### 3.12 Health action and monitoring protocols

The last dimension concerns the necessary collection of data and the ways of keeping and sharing important health data (always respecting the relevant privacy laws) to ensure continuity and appropriate care, and the need for suitable prevention and care protocols. The following proposals are made in this connection:

- In both the educational and health care contexts, draw up questionnaires for the initial gathering of health data: present and past illnesses, tests performed, sensory disorders, ways of manifesting discomfort, behaviour during medical examinations, etc. as well as all the possible information resulting from the proposed integral plan.

- A protocol for the ongoing inclusion of health data: check-ups and tests and their results, and especially records of medication and its effects (in educational and health care contexts).
- Simple protocols for “fixed” routine periodical general health and dentistry check-ups, eg every two months. Less frequent routine physiotherapy, eyesight and foot health check-ups, eg once a year.
- Specific protocols for attending to persons with ASDs in various settings: at the health centre, at hospital, in accident and emergency, etc. setting out simply the person’s needs and how to respond to them.
- Protocols to ensure continuity between social, health care and educational services.

In this area it is important for there to be agreement among all the institutions involved, for all the professionals to be convinced of the need for such measures, and for the possibility of easily introducing small adaptations into other protocols that are already being used, for example, with persons with disabilities.

#### 4. Conclusion

The quantity and complexity of factors that can influence the health of a person with ASDs make it advisable to specially monitor and look after this dimension of QoL through comprehensive health care programmes (Volkmar & Wiesner, 2004).

We know that persons with ASDs can be very different from each other in regard to their degree of competence on various dimensions. Their health needs may therefore also be very different, but the highest-functioning persons may need special monitoring and care when it comes to certain aspects of their physical health (Belinchón, Hernández and Sotillo, 2008). That is why for a long time many organisations dedicated to caring for persons with ASDs have been running programmes dealing with different aspects of health care (e.g. Fuentes, 2010; Álvarez et al., 2007; Autismo Burgos, 2010; GAUTENA; Asociación de Padres de Personas con Autismo [APNA]; Autismo Sevilla; Autismo Galicia) and guides for good practices and action protocols have been published (e.g. The National Autistic Society; Merino et al., 2010)

The integral health plan presented here is based on an assessment of the health care context and the treatment it dispenses to persons with ASDs. It has been designed on the basis of the characteristics of persons with ASDs and what they need to ensure they have a healthy life. This action plan seeks to provide a framework that will serve as a guide so that those involved will know where to look, and offer guidelines on how to act with regard to the initial assessment, the intervention strategies and the final assessment recording the results obtained.

The physical health dimension deserves to be accorded the importance that belongs to it. For a long time the mistaken belief was held that, unlike people with other types of disability, persons with ASDs enjoyed good health. Some recent studies with the families of high-functioning persons with ASDs have verified that this mistaken belief about the latters’ general good state of health still exists (Belinchón et al., 2008). The health problems associated with this condition, the difficulties persons with ASDs have in identifying and communicating health problems, and allowing themselves to be examined, and the still scant information and training health care personnel have about these disorders produce an interaction of factors that diminishes these persons’ QoL and life expectancy.

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## **Autism Spectrum Disorders - From Genes to Environment**

Edited by Prof. Tim Williams

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Autism spectrum disorders are a major topic for research. The causes are now thought to be largely genetic although the genes involved are only slowly being traced. The effects of ASD are often devastating and families and schools have to adapt to provide the best for people with ASD to attain their potential. This book describes some of the interventions and modifications that can benefit people with ASD.

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