



NewsLetter

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Union is strenght

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On occasion of the 3rd European Down Syndrome Conference, some considerations can be made on the overall situation of the persons with Down Syndrome. The association movement is definitely alive. News coming from different parts of the world do confirm a fervour of initiatives aimed at ameliorating the clinical and social conditions of these persons. Self-sufficiency is no more an unattainable dream.

Advances in medical sciences have been noteworthy in this field: clinical, biological and genetic aspects have been thoroughly studied, so that today we can state that Down Syndrome, for its specificity, has become a model for researchers. Similar advances have been done in the fields of behavioural sciences, of learning, of development and of social sciences; as a consequence the quality of life has greatly improved in recent years.

Nevertheless, there are still too many persons who cannot take advantage of these benefits, simply because they have not been informed.

We must obviate this.

In 1991, in the Editorial of the first issue of the EDSA Newsletter, it was written that "it will be the voice that collects the experiences, the demands, the requests coming from the different parts of Europe, so that everybody can share the experiences of other people". Hence EDSA would have become the necessary reference for all the needs of persons with Down Syndrome in an enlarged Europe, extended to its eastern components.

The reality, after four years, is unfortunately not so. EDSA still lacks the indispensable support of many regional Associations. The fact of course is negative in that it deprives a representative organisation of the political weight necessary to obtain acknowledgements and benefits at the Community level. We all must understand that unity is strenght, because we want to obtain better conditions for the persons with Down Syndrome in our society. Only together we will succeed in obtaining what we strive for.

The first example of a common effort was the fifth World Congress, held in Orlando (USA), organised by the National Down Syndrome Society with the collaboration of EDSA, in 1993. The sixth World Congress will take place in Paris in 1996: it will be organized by EDSA and it will have the collaboration of the NDSS and the support of other important international Federations like the Australian and the Canadian ones.

All agreed on the essential subject of the specificity of Down Syndrome.

Today the Dublin Conference will certainly be an important moment for aggregation of most of the European Associations under the leadership of EDSA. We hope it will be another step towards the creation of a World Federation of Associations. A step towards the effective and total integration in the society of all the persons with Down Syndrome: for a life worth living.

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Down Syndrome Preventive Medical Check List

Prepared for EDSA by Alberto Rasore-Quartino with the collaboration of EDSA Scientific Board.

Introduction

In DS a progressive increase of life duration and a constant improvement of the quality of life has been experienced in recent years. One important cause of the reduction of mortality and morbidity was positively a more accurate medical care both in prevention and treatment. Many protocols have been devised for a correct evaluation of the health status of the persons with DS throughout their life. In order to indicate a common approach to the caretakers, we propose here a preventive medical check list for persons with DS from birth to adult age.

Some important points must be stressed: This is a general and comprehensive list and therefore individual problems must be accurately taken into account; a major concern is to avoid overdoctoring, so it seems reasonable not to emphasize the medical approach; the frequency of the suggested controls is the result of discussion, but can be modified by personal experience.

Newborn

The clinical diagnosis should be assessed as soon as possible after birth. This is easy in more than 80% of the cases. Attention must be paid to erroneous diagnoses based on the wrong opinion that single signs such as the oblique palpebral slant or the transverse palmar crease are pathognomonic. Since major and minor malformations are often present in DS, they must accurately looked for at birth. Congenital heart disease is the most frequent malformation (40-50%). It is represented by atrioventricular canal defect (36-47%), ventricular septal defect (26-33%), patent ductus arteriosus (8-10%), atrial septal defect, tetralogy of Fallot and by rarer complex anomalies. Other congenital malformations, although quite uncommon, are more frequent than in non Down infants. Gastrointestinal anomalies, such as oesophageal atresia, pyloric stenosis, duodenal stenosis or atresia, annular pancreas, imperforate anus and Hirschsprung disease and malformations of the urinary tract, such as hydronephrosis or obstructive uropathy can be present.

In trisomic newborns unefficient regulation of myelopoiesis is usual and is substantiated by different hematological abnormalities: polycythemia, thrombocytopenia or thrombocytosis, higher or lower leukocyte count. Another aspect of defective hemopoiesis relates to leukemia. In DS the risk of leukemia is 10 to 20 times higher than in normal children. The risk of developing leukemia is highest in the newborn: 25% of all leukemias in DS are evident at birth; 15% of congenital leukemias develop in DS newborns. In 17% of DS infants, a form of acute transitory leukemia, mainly of the myeloid type, can develop. Its clinical and hematological features are undistinguishable from those of the common acute leukemia, except for the complete and spontaneous remission within weeks or months from the beginning.

Newborn

- Clinical diagnosis and
- Communication to the parents by a competent pediatrician or a clinical geneticist
- Cytogenetic analysis
- Clinical and neurologic assessment
- Careful clinical and instrumental investigations for congenital malformations (echocardiography for congenital heart defects; abdominal echography for gastrointestinal tract blockage and urinary tract malformations)
- Ophthalmologic examination for congenital cataract
- Orthopedic examination for hips subluxation
- Laboratory: routine neonatal screening tests for congenital hypothyroidism, phenylketonuria etc.
blood tests for polycythemia, leukemia, leukemoid reactions

Infancy and childhood.

Ocular abnormalities are definitely more frequent than in other children. From a practical point of view, it is necessary to stress the clinical significance of strabismus and of refractory defects. They can really hinder a correct vision, so adding an organic defect to the preexisting mental disability. Cataract is also excessively frequent, both in the newborn and in the adult. More than 70% of persons with DS have a hearing defect, mostly of the conductive type. Often it is the consequence of common middle ear pathology developing in childhood. Dental anomalies are a common problem. A peculiar oral and dental anatomy, developmental anomalies and malocclusion are common in DS. On the contrary, caries is rare. Gingivitis and periodontal disease and subsequent early and total tooth loss can be the consequence of poor oral hygiene.

Infancy (up to 12 months)

- Clinical and neurologic controls for developmental milestones every 2 months
- Screening tests for hearing defects (auditory brain stem response) and ophthalmologic evaluation at 6 and 12 m.
- Echocardiography (if previously negative) at 6 months
- Laboratory tests for thyroid dysfunction, anemia, malabsorption... at 12 months
- Routine immunizations according to local programs
- Contact local DS parent group(s) for family support
- Enroll in early intervention program (psychomotricity, logopedic training, etc.)

Infections are still more frequent in persons with DS: although antibiotic treatment has dramatically changed the course and prognosis of the infections, nevertheless they still are the cause of major concern. The cornerstone of medical care in the prevention of infections is to provide careful immunization. Standard vaccinations are mandatory. Optional vaccinations are also indicated.

A high incidence of thyroid disorders is characteristic of DS. Congenital hypothyroidism in DS varies from 0.7 to 10% (0.015 - 0.020% in the general population); acquired hypothyroidism is also more frequent (13 to 54%, versus 0.8 to 1.1% in the normal population). Increased levels of TSH alone with normal T3 and T4 values are often observed, representing a temporary phase preceding a progressive decrease of function. Although this is generally the course of the disease, in DS TSH values often fluctuate without any modification of the thyroid function.

Hypothyroidism develops slowly, so that the clinical symptoms may go unrecognised at the beginning, or be mistaken for the common features of the syndrome itself (dullness, increased fatigability, loss of attention, etc), chiefly in adolescents and adults. Periodic controls of the thyroid function are therefore mandatory since childhood and during the whole lifespan.

Orthopedic disorders are chiefly the consequence of ligamentous laxity. Pes planus, subluxing patella, hip dysplasia, slipped capital femoral epiphysis and scoliosis are frequently observed. Atlanto-axial instability can occur in 10-15% of persons with DS. It is generally asymptomatic, but it can lead to luxation, causing cord compression whose consequences can be very severe: sensory disturbances, abnormal gait, torticollis and in rare instances even death. Persons at risk can be detected by lateral cervical radiographs in flexion, extension and neutral positions. If atlanto-axial instability is detected, restriction of field activities dangerous for the articulation as tumbling, diving, boxing or riding should be imposed.

Childhood (preschool age, from 1 to 6 years).

- Clinical and neuropsychiatric controls once/twice a y.
- Nutritional and dietary counseling once a year
- Auxologic controls once a year
- Dental controls once a year
- Ophthalmologic and auditory controls at 3 and 6 y.
- ORL controls (nose, throat, ears) once a year
- Routine immunizations
- Laboratory tests for thyroid dysfunction, anemia, malabsorption... once a year
- Continue developmental or educational programs, speech therapy and physical therapy
- Insert in maternal school with normal children

Childhood (school age, from 7 to 12 years)

- Continue yearly clinical, neuropsychologic controls, auxologic controls, orthopedic controls, dental visits, dietary controls.
- Ophthalmologic and audiological controls at 9 and 12 y.
- Laboratory tests for thyroid dysfunction, autoimmune disorders, anemia, malabsorption once a year
- Complete routine immunizations
- Insert in normal school (teaching support)
- Insert in sport activities
- Complete educational assessment
- Continue speech therapy
- Stimulate physical abilities
- Monitor for behavioural problems
- Periodical family visits for psychological support

Adolescence and Adulthood

Cardiac problems other than congenital defects occur in adults with DS. The most frequent anomalies found in asymptomatic persons are mitral valve prolapse and aortic regurgitation, with a prevalence of about 70%. Accurate cardiac diagnostic investigations are recommended in young adults, especially before dental and surgical procedures, for the presence of valve defects. Antibiotic prophylaxis for endocarditis should be taken into consideration.

Autoimmune disorders, with protean clinical manifestations, are frequently observed in DS; of these, most important are: hypothyroidism, celiac disease, diabetes mellitus, alopecia, chronic active hepatitis, autoimmune thrombocytopenia.

Neurological problems, including seizures, become prevalent with age. There is a constant, though slow and variable, decline of intelligence. A reduction in thought elaboration ability, in particular for the abstract thought and logical performances, both inductive and deductive, is likely to occur after the age of 30, but with great individual differences. Characteristic of aging in DS is also the dementia (Alzheimer's disease), appearing in 30% of persons of more than 30 years. Clinically, the affected patients show deterioration of mental and emotional responses, apathy or excitement, irritability, temper tantrums, loss of previously acquired vocabulary and a decline in personal habits of cleanliness. The progression is often very rapid. Seizures can be an early sign of Alzheimer's disease. At present there is not any procedure able to slow down this process.

Adolescence (12 to 18 years)

- The same periodic controls and laboratory tests as in childhood, plus
- Gynecologic examination at 16 -18 years
- Monitor school insertion, sport activities, behavioural problems, social and recreational programs with friends, health and sex education

Adulthood

- Complete medical control once a year
- Neuropsychiatric control every 2 y.
- Audiologic and ocular controls every 2 y.
- Orthopedic controls every 2 y.
- Cardiologic controls once a year
- Dermatologic controls once a year
- Odontoiatric controls once a year
- Gynecologic control once a year
- Dietary controls once a year
- Laboratory tests for hypothyroidism, autoimmune disorders, malabsorption... once a year
- Training for job insertion
- Prepare for community living or sheltered residence
- Monitor for recreational programs and behavioural problems
- Continue family and personal psychological support

Attention to people with Down syndrome today

Prof. Juan Perera

Things have changed radically in recent years for people with Down syndrome.

Scientific advancements in the identification and consequences of trisomy 21, the specialized educational treatment they receive, the change in social perception in relation to people with Down syndrome, the ever-growing involvement of families in the educational process and the powerful specialized associative movement mean that we are moving towards an ever more hopeful and positive future. However, one of the principal concerns of parents is to know if they are following the right course in the treatment and education of their children.

Without wishing to dogmatize - haven't forbid such a gross error - I would like, in the form of suggestions, to thread together some ideas on what attention to people with Down syndrome could be today.

In other words, to propose some criteria on the procedure for attention to people with Down syndrome.

SPECIFICITY

Today there is no longer any debate about the Specificity in Down syndrome.

There are numerous publications throughout the world outlining the Down syndrome's typical and singular aspects that do not occur in other types of deficiency (or occur in different proportions) and that therefore mark the limits with other types of cerebral pathology. The molecular structure of chromosome 21 reveals a series of genetic abnormalities that, in turn, cause a series of disorders in the brain and in the nervous system all through the life of people with Down syndrome and that determine their learning and behaviour. The more we know about these specific aspects, the better we will be able to design therapeutic methods and educational strategies that will prove to be more direct and efficient for their rehabilitation.

INDIVIDUALITY

No two persons with Down syndrome are alike. The chromosome 21 identifies its bearer, but the geneticists explain that chromosome 21 houses about a thousand genes, whose effects we know in only 25 of those. However, not all the genes are revealed in a certain individual and those that do manifest themselves do not do so in the same way. This explains the great variability, the differences existing between one person and another with Down syndrome. And this leads us to the need to study each one in particular and to design educational treatments and methods on the basis of their limitations and potentialities. Individuality leads us to diversity, that is to say, to the need to diversify the attention and to give each individual the specific help required.

INTEGRATION

Or, as the Anglo-Saxons better express it, inclusion. There

is no debate nowadays about this criterion either. Integration at all levels (in school, in the neighbourhood, in sport, in work, etc) is the priority system to achieve full normalization of people with Down syndrome. The Special Education Centre, the Special Occupational Centre are only justified when the limitations of the child or young person are so great that integration is impossible. Always bearing in mind that to integrate a child does not mean putting him or her in the classroom, but to give the supports, adaptations in the curricula and didactic methodology he or she needs, there is a very important role to be played here by the local Associations who should try to provide what the school lacks.

NORMALITY

In a statistical curve of normal distribution (the well-known Gauss bell), the mean (X) is the most frequent score occurring in a group and around that mean (1σ to the right and 1σ to the left) is agglutinated what is called "the normality", that is to say, 68% of cases. At each extreme there are approximately 14% of cases which are above or below the criteria of the normality. Frequently, in congresses and in the news media we are presented with cases of persons with Down syndrome who do not represent the "normality" of the Down syndrome. They are exceptionally gifted cases and have often had training facilities that are not available to everyone. This sometimes causes an enormous anguish in parents who ask themselves why their children are not like the ones who are seen on the telly. The normality in the Down syndrome is constituted by people with mental deficiency (8-10 years as an average MA), problems in auditory and visual perception, disturbances in perception of time and space, short and long-term memory difficulties, deficiencies in attention and awareness systems, difficulties in the mechanisms of input, processing and integration of information, failure in the consolidation of acquired knowledge, low response to stimuli, difficulties in processing logic, abstraction, deduction and generalization, language and communication problems, etc. And I feel it is important to stress that the educational programmes of language, reading and writing, job training, etc., should be addressed towards those 68% who form the "normality" in people with Down syndrome. However, as we have already mentioned, there are 14% above (who are obviously those who stand out because of their brilliant results) and another 14% below (who unfortunately are hardly ever mentioned).

HEALTH CARE

Good health is the fundamental base for intellectual development and, consequently, fully developing the capabilities of everyone with Down syndrome will depend to a large extent on their health. From that, the importance of preventive medicine. The FEISD (Spanish Federation of Down Syndrome Institutions) has paid special attention to

this matter and has published and circulated the "Spanish Health Programme for People with Down Syndrome". The main objective of this programme is that the most frequent problems encountered in Down syndrome are diagnosed and resolved early. This is the most effective way to prepare the future for people with Down syndrome.

ATTENTION IN THE FIRST STAGES OF LIFE

The basic objective of our attention to persons with Down syndrome is for them to become autonomous persons. This is being achieved when we work well from the beginning. Owing to the plasticity of the brain during the first years of life, we observe that early intervention and educational programmes are proving efficient because an ever-increasing number of children with Down syndrome are moving in a moderate rather than severe level of retardation. Our objective should be to convert passive individuals into autonomous and productive individuals, and that is achieved if good

work is done from the first stages of life.

FULL SOCIAL INTEGRATION BY WORKING

Work is a characteristic of adult life for all persons with or without disability. The kind of employment, the salary we earn and the opportunities we are given directly affect the way we perceive ourselves and the way society values us, as well as the degree of freedom we have at economic and social level. To give the individual with Down syndrome the opportunity to carry out a job means not only an earned salary, but also recognition of their social value on the part of the family and the community. People with Down syndrome now have a much longer life expectancy. It is possible that they will survive their parents and that brothers and sisters cannot or do not want to take care of them. The working person has stability and more probabilities of being self-sufficient, of living independently or in small supervised homes without being a burden to their families.

The cognitive development of children with Down syndrome. Theoretical approximation and practical implications

Prof. Isidoro Candel Gil

Introduction

The development of children with Down syndrome (DS) has traditionally been considered from a distinctive sign, mental retardation, and from one of its consequences, their institutionalization in Special Education Centres. In this way, the analyses of their behaviour and progress were based on nondeficient (ND) children, on the assumption that children with DS arose from Zigler's hypothesis on the development of deficient children, according to which they followed the universal sequences of development and did cognitive-linguistic tasks in the same way as ND children who had the same mental age (Zigler and Hodapp, 1991). Until the 70's the evaluation of the development of children with DS was made by scales of development based of maturational criteria. A lot of data was also obtained from informations given by the parents themselves. As a general rule, the principal conclusions derived from these studies were the following:

- Children with DS present an almost normal development during their first months of life, with a pattern of development very similar to that of ND children.
- The developmental quotient of children with DS progressively decreases with age.

-There are important interindividual differences between children with DS as regards their level of development. Equally, there are intraindividual differences in the various areas examined, some developing better than others.

-Children with DS who were living at home develop better than those who had been institutionalized.

It seems that the intellectual status of children with DS has improved considerably, and not because they are any more intelligent today than they were years ago, but because the conditions of rearing and education and the methods used are now more efficacious and allow the potential of these persons, although diminished through their chromosomic alteration, to manifest itself in a more complete way. Various factors have had an influence on this improvement: participation of children with DS in early intervention programmes, greater involvement of parents in the education of these children, the change in attitude of a good part of society towards deficient persons, integration of DS children in Infant Schools and in ordinary Colleges, improved knowledge about the characteristics of people with DS, etc. Nowadays it is assumed that the degree of mental deficiency in the majority of people with DS usually ranges between moderate and mild, without forgetting the severe and even

profound cases which are fortunately fewer in number.

Cognitive development in the early years

As can be easily deduced, all these data tell us very little about the real functioning of children with DS, as they persist in the general characteristics of their development, putting greater emphasis on the quantitative aspects.

However, we are rather more interested in knowing what that development in qualitative terms is like; that is to say, how children with DS develop; what their strong and weak points are; what typical aspects their development has; what relation that development keeps with biological or environmental factors; what styles of learning they use; what their cognitive strategies are, etc. In a word, to know their characteristics more deeply in order to teach them in a way more suited to them.

As a general rule, children with DS seem to develop in a rather similar way to normal children. However, the most recent studies are revealing the existence of a series of specific characteristics in children with DS which are already present from the first months of life, and which must be considered at the time of planning educational strategies.

Children with DS from 0 to 3 months take more time to fix their eyes on visual, moving or inanimate stimuli; their orientation responses to sound stimuli are slow and late; their defensive movements to aversive stimuli are not so strong nor so global as those of ND children; their habituation responses take more time to appear. In short, their capacity of response to and their interest in environmental stimuli are, as a general rule, lower than those observed in ND children. A behaviour as important as eye contact appears later in children with DS and, furthermore, develops in a different way. This is certainly going to cause some difficulties in the acquisition of cognitive patterns, alterations in the parent-child interaction, difficulties in communication and limitations for knowledge of environment (Berger and Cunningham 1986, Richard, 1986). So then, it appears that the development of children with DS, in their first months, is not almost normal and does not follow patterns similar to those of non-deficient children, as was previously thought (Candel and Carranza, 1993).

One aspect of enormous importance in the development of children with DS refers to the attention processes. Despite the presence of considerable similarities in general aspects among children with DS and ND children, the children with DS show a different attention pattern: they spend less time being occupied with toys, objects or persons; they show a more repetitive behaviour; they have less social contacts; they throw toys more without any visual control (Kasari, Mundy, Yirmiya, and Sigman, 1990). On the other hand, it is clear that they have more difficulties in joint their attention. This phenomenon of joint attention, as a process of learning to combine or share the visual attention with another person in relation to objects of the environment, is a very important means for the development of cognitive and communicative skills (Landry and Chapieski, 1990). With respect to the skill of manual exploration, although there do not seem to be great differences with respect to

ND children, typical exploratory behaviours in children with DS have been described, namely: they vocalize less while manipulating their toys, they explore objects for much less time and show more aimless behaviours (Ruskin, Mundy, Kasari and Sigman, 1994). On the other hand, Koop, Xrakov and Johnson (1983) found that children with DS at a developmental age of 24 to 30 months presented an impulsiveness leading them to less visual and manual exploration of the materials presented, as well as less interest towards the "spectacle" these materials can produce.

As regards the sensorimotor development of children with DS, although its acquisition is very similar to that of non-deficient children, apparently there are significant differences in the way in which children with DS learn those skills. Children with DS show a progressive delay in the acquisition of sensorimotor competences as their chronological age increases, except in "vocal imitation" where the speed of acquisition is even slower; this subarea of vocal imitation is the only sensorimotor competence that has some clearly different development patterns among children with DS. It has also been found that children with DS take longer than non-deficient children in passing from one sensorimotor stage to another, most of all when it involves passing from the IV stage to the V stage. But the cognitive development of children with DS is not only significantly slower; on considering the detailed pattern of success and failure, differences arise on comparing the two populations: in children with DS, the previous acquisitions are not well consolidated and the patterns of failure do not lead to developmental progress (Dunst, 1990).

We can say, therefore, that similarities do exist between the cognitive development of children with DS and ND children in the early years of life, although it is also evident that there are some significant differences:

- children with DS differ in the strategies used to assimilate and integrate information;
- they fail in the consolidation of recently acquired knowledge;
- they tend to avoid the more complex learning situations or those that are beyond the level of development;
- they present an insufficient degree of motivation;
- in some familiar situations, learning is produced in a very rapid way, not because of a high potential, but rather because of a dependence on the environment;
- children with DS usually under-use the skills they have acquired, by not generalizing their acquisitions in all contexts and showing a low level of spontaneity, which can become a serious developmental problem.

Recently, a series of neurobiological discoveries have been made which might explain some of the characteristics of children with DS. For a recent revision, any interested reader can consult the work of Florez (1994).

Cognitive development at the schooling stage

For a long time it was thought that persons with DS experienced a progressive decline in their intellectual quotients and had such low levels of development that they could not lead a full social life. The worst is that all these prejudices are based on a figure (the intelligence quotient) which

determines a static development of the intelligence. Furthermore, the data involved come from samples of institutionalized subjects with DS.

Nevertheless, there are results which appear to contradict this traditional affirmation. For example, Carr (1988) observed a certain recuperation in the intellectual quotients of children with DS starting from 11 years. Also, as a result of a work on reading in children with DS, we have had occasion to collect a set of data on 22 of them, of ages comprised between 7 years and a half and 16 years (average=11 years and a half); the average intellectual quotient of these 22 children with DS, obtained with the Terman-Merrill scale, ranged between 50 and 84.

The truth is that, once again, these intellectual quotient figures prove deceptive and do not contribute much on the real potential these persons might have. Molina and Arraiz (1993) indicated that, in the case of children with DS, the intellectual quotient does not seem very reliable as an indicator of their learning capacity. On the other hand, we have already pointed out that the intellectual quotient gives us a static concept of intelligence, and this has to be contemplated rather as a dynamic process and with a functional nature of planning and resolving problems in daily life. It would be convenient to remember here that in the last definition of mental retardation by the American Association on Mental Retardation (1992), very great importance is given to aspects related to the adaptive behaviour and not only to that concerning strictly intellectual functioning.

Let us then go over some of the characteristics in children with DS at their schooling stage.

1. It appears that children with DS have difficulties in processing auditory informations, while their possibilities of processing visual informations are more acceptable (Pueschel, 1988). We observed that the tasks the children with DS did worst were those connected with vocal-auditory communication channels. On the other hand, their "strong points" were in the visual social and visual motor modalities.

2. It seems that children with DS process simultaneous informations better than the sequential ones. However, this is a datum that is not absolutely clarified.

3. Older children with DS show significant memory impairments. They usually have short-term memory problems, whatever the presentation modality or controlled task. They also show less ability in memorizing recent events and have greater difficulty in remembering sequences of auditory informations than visual ones (Marcell and Weeks, 1988).

4. Older children with DS have difficulties attending, selecting from the stimuli presented to them and they tend to present a disperse behaviour. This leads them to concentrate on the least relevant aspects of the situation, forgetting the most significant ones. Also, they quickly pass from one stimulus to another without taking hardly any time to examine it. It seems that in persons with DS, habituation is slower than in normal persons. It has been proved that persons with DS are deficient in their ability to adapt and inhibit their responses to the repeated stimulation, with which there is an incapacity to adapt mental states with speed to the constant demands of the environment, and

also insufficient habituation before successive presentations of a stimulus.

5. The response of children with DS is slow (that is to say, their reaction time is longer), above all if an auditory sensorial modality is used. Furthermore, the newness of the task and its complexity prolong the reaction time. It appears that this slowness can be due, above all, to problems in the information processing and in the decision taking (strategical behaviour). It is as well to clarify that this slower reaction time does not in any way signify a reflexive cognitive style.

6. Difficulties have been described in the concept formation and in abstract thought (analogies) in children with DS. Their arithmetical problems have also been constantly reflected, even in those persons with acceptable levels of development. However, a recent work (Brito, Olmos and Serna, 1992) has shown that school-age children with DS are more flexible in counting than was imagined, and that their counting activity is not so routine as one would suspect. The individual differences in arithmetical abilities are very significant among children with DS.

Proposals for the intervention

Better knowledge about the psychological characteristics of persons with DS has a clear, practical consequence: it is possible to design educational strategies better adapted to their needs and to their strong points.

One of these strategies, much developed in recent years, is the application of a language-reading programme based on the hypothesis that domination of written language is easier for these children than domination of spoken language. As children with DS learn visual languages more easily, these can be used to promote their expressive and comprehensible language (Buckley, 1992).

From the middle 80's, we have been using a language-reading programme in ASSIDO (Navarro and Candel, 1992). It is a language-reading method, that is to say, teaching reading abilities is not its sole objective, but by means of strategies adapted to the impairments of children with DS the intention is to develop the children linguistic abilities and then, if it is possible, to tackle the teaching of proper reading. It develops a polisensorial stimulation, making the visual afferences work more. The effectiveness of this programme has been proved, both from the practical and empirical points of view.

Another strategy which has proved to be very effective is the use of the computer. Computers can be a powerful tool in the education of children with DS. Thanks to the incorporated graphics and to their sound signals, computers have a high capacity of motivation. Also, they allow children to have control of their surroundings and to be an active part of same, increasing their self-confidence and their self-esteem.

Computers offer something as important as the opportunity of repeated success. They enable children to learn at their rhythm, competing against themselves and not against others (Meyers, 1988).

Like other educational techniques, computer learning must be integrated in other learning experiences. Programmes

with computers can provide a very necessary cognitive base to help children with DS at pre-school and school age to learn language. These interventions do not cure the problems due to the genetic disorder, but they can help the children to participate more actively in the learning processes of language (Tanenhaus, 1993)

Summary and Conclusions

We have tried in these lines to revise some of the principal aspects of the cognitive development of children with Down Syndrome. It seems obvious that some of the contributed data discredit certain myths and stereotypes that were very deeprooted.

The notable individual differences between children with DS preclude extracting generalized conclusions. Although, in a certain way, this variability is already a conclusion itself to be taken into account. It is difficult, therefore, to try to encompass all children with DS in one single type.

But those individual differences also have much to do with the type of stimulation and education received in the different contexts of development. We know that children with DS

do in fact present some deficiencies and limitations in their capacity of adaptation to the environment, but we have also been able to show that the limits in that adaptation depend upon the sensitivity parents and society in general show on the need to offer them an integrated development. It seems that, as a general rule, children with DS have a series of developmental patterns quite similar to those of nondeficient children. At the same time, we have observed how these children show some special features in various aspects of behaviour and, consequently, some qualitative differences in their adaptative possibilities. A better knowledge of these specific qualities is fundamental because of their implications at the time of the intervention. Without this knowledge, as Gibson (1991) indicated in a graphic way, present-day intervention programmes are as deficient as the children they are trying to help. It is necessary, therefore, that we get to know more and more about how children with DS function so that our help can prove to be more effective from the very first days of their life.

References on request

Thyroid function in Down syndrome

Prof. Carlo Baccichetti

Characteristic	Down Syndrome	Hypothyroidism
appearance	dull, chubby	dull, chubby
head	microcephalic	normal
fontanels	delayed closure	delayed closure
hair	fragile, frequent alopecia aerata	fragile
eyes	slanted	not slanted
voice	hoarse and gruff	hoarse
tongue	large	large
neonatal		
icterus	persistent	persistent
neck	short	short
heart	murmur	murmur
abdomen	prominent	prominent
neuromuscular	hypotonia	hypotonia
feeding	difficulty	difficulty
skin	dry	dry
extremities	short	short
stature	reduced	reduced
development	retarded	frequently retarded

TABLE 1 Comparison of physical characteristics of children with Down Syndrome and hypothyroidism. The history of the connection between hypothyroidism and Down Syndrome (D.S.) initially arose from the observation of strikingly similar clinical findings between infants with thyroid dysfunction and D.S.

Some clinical symptoms of patients with D.S. and patients with hypothyroidism are reported in table 1. In 1866 John Langdon Down made his great contribution by differentiating children with cretinism (congenital hypothyroidism) from children with D.S.. Benda in 1960 found that at autopsy of D.S. patients the thyroid was small sized with underdeveloped histology. Hence the failure of routine thyroid treatment to improve either intellectual functioning or growth of the D.S. patients as demonstrated by Koch (1965). Following studies showed that there was an increased prevalence of abnormal thyroid tests and hypothyroidism in this population. With the advent of neonatal population screening for hypothyroidism this disease was described as occurring at a rate of 1/141 in newborns with D.S. (1/4000 in normal population), but hypothyroidism can affect a child with D.S. at any age. There are studies from many countries that have documented hypothyroidism in young children with D.S.. Cutler in 1986 documented that 3 out of 49 D.S. children less than three years of age had a hypothy-

roidism. Although it is very difficult to detect it just by physical examination, it is important that the clinician picks up developing thyroid disease in children. By the times that the prominent features of severe hypothyroidism (growth deviation from previous line of growth, plateau of intellectual growth, constipation, lethargy etc) are seen in the patient, the child with D.S. is already having major adverse effects of the disease process. Thus the annual preventive medical protocols for individuals with the syndrome of all ages always should include a blood test for thyroid disease usually T3 T4 fT4 and TSH.

With the advent of this population screening the prevalence of thyroid dysfunction was found relatively common in individuals with D.S.. About one thirds (32.5%) of D.S. persons have a high TSH level in the presence of normal levels of T3 T4 fT4, 1% have an overt hypothyroidism and 0.6% have hyperthyroidism. An autoimmune disease was proposed for explaining the pathogenesis of this disorder and all patients with hypo or hyperthyroidism have circulating antithyroid antibody. In a study of 201 patients who underwent prolonged follow up, a wide range of thyroid function variations was observed (it is reported on table 2)

TABLE 2

	first examin.	Within 1 year follow up			
		normal thyroid	TSH +	hypothy roidism	hyperthy roidism
TSH + A.T.A. +	14	0	11	2	1
TSH + A.T.A. -	56	12	44	0	0
normal TSH ATA +	13	8	3	2	0
normal TSH ATA-	118	114	4	0	0

	within 2 years follow up			
	normal thyroid	TSH+	hypothy roidism	hyperthy roidism
TSH + A.T.A. +	0	9	3	2
TSH + A.T.A. -	19	37	0	0
normal TSH ATA +	5	5	2	1
normal TSH ATA-	110	8	0	0

TSH+= elevated TSH with normal T3 T4 fT4

ATA+= with circulating antithyroid antibodies

ATA-= negative for circulating antithyroid antibodies

At first examination 30% of D.S. presented have elevated TSH with normal T3 T4 fT4: the mean age of this population is similar to the mean age of the population with normal thyroid function. The ATA prevalence was more than double in comparison to the control population. The ATA

are present at all ages also in very young patients. Consistent with these data D.S. appears to represent a risk condition for the development of autoimmune thyroid disease showing a characteristic pattern:

- 1) relatively frequent involvement of the male sex
- 2) disease onset at young age: acquired hypothyroidism is rare before 3 years in children without D.S. , and is reported to occur infrequently until adolescence.

An hypothesis proposed by Sharav explains the increased TSH level as a consequence of the delayed maturation of the hypothalamic-pituitary axis, it is worth noting that a considerable number (about 50%) shows at successive controls a decrease of the TSH level to normal range. However, two aspects should be pointed out:

- 1) this decrease is observed not only in children but also in adults;
- 2) in other patients the TSH levels remain unchanged.

Hormonal therapy of TSH + is still a matter of debate. On the basis of this observation it appears unlikely that the early administration of l-thyroxine could lead to same improvements in young patients with elevated TSH with normal T3 T4 fT4 in the absence of circulating ATA. At present a wait-and-see policy with frequent controls of thyroid function should be considered adequate, with the aim of avoiding chronic hormonal therapy in patients in whom TSH levels show a spontaneous tendency to normalization. On the contrary, l-thyroxine administration should not be delayed in patients with TSH + and ATA + due to frequent evolution towards overt thyroid disease.

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NEWS FROM EDSA SCIENCE ADVISORY BOARD

A very important event will take place next year, organized by the European Down Syndrome Association with the National Down Syndrome Society (USA):

LE 6^{me} CONGRES MONDIAL A PROPOS DU SYNDROME DE DOWN THE 6th MONDIAL CONGRESS ON DOWN SYNDROME

Paris (France)

27-28-29-30 Août/August 1996

Programme Préliminaire/Preliminary Program

Séances Plenières/Plenary Sessions (27-28-29 Août/August)

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Désordres neurologiques chez les personnes porteuses de trisomie 21/Neurologic disorders in persons with DS
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Conséquences de l'hypotonie sur les troubles statiques/Consequences of hypotonia on static disturbances

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Ateliers/Workshops (27-28-29 Août/August)

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6) Trisomie 21 et troubles de la personnalité DS and personality disorders	L. NADEL	16) Langage écrit, lecture, écriture Written language, reading, writing	J. PERERA
7) Diagnostic - Bioéthique Diagnosis - Bioethics	J.F. MATTEI	17) Développement moteur Motor development	P. GARDES
8) Image de la personne porteuse de trisomie 21 Image of the person with DS	D. VAGINAY	18) Accompagnement familial Family support	D. VAGINAY
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		21) Actualités scientifiques Scientific trends	Md LONDON

Journée des Associations/Associations Day (30 Août/August)

Présentation des et par les fédérations spécifiques trisomie 21 des différents pays représentés/ Presentation of and by the specific federations trisomy 21 of the different represented countries.

Présentation des textes constitutifs de l'Association Mondiale/Presentation of the constituting texts of the World Association.

Pour tout renseignement s'adresser à:/For further informations, please contact:

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GOALS AND OBJECTIVES OF EDSA

1. To spread throughout all European nations the principle that every person with Down's syndrome has the right to receive the health care and educational services demanded by his (her) condition, in order to achieve the best of his (her) possibilities.
2. To stimulate the implementation in each European country of a network of local groups, made up of parents and professionals. These groups should be able to better attend and resolve local needs, so that the families of every newborn with Down's syndrome may immediately receive the required support and advice.
3. To promote the principles of normalization in order to transform, humanize and dignify all human services upon which persons with Down's syndrome rely.
4. To encourage the development of programs and services that may be appropriate for persons with Down's syndrome.
5. To exchange information among the European countries on those programs that have proved to be effective. It is EDSA's conviction that the cultural pluralism of the European nations will enrich the personal and communal actions on behalf of the persons with Down's syndrome.
6. To introduce in all nations specific and comprehensive health programs for persons with Down's syndrome.
7. To encourage the constitution and convening of scientific groups, to share their study and research on:
 - a) The biology of Down's syndrome and its pathological consequences.
 - b) The mental development at different ages.
 - c) Programs of education and intervention that are suitable for the specific conditions of each person with Down's syndrome.
 - d) Integration in his (her) environment, in the community and at work.
8. To study and recommend legislation adapted to each European nation, in order to guarantee and ensure the services for the person with Down's syndrome during his (her) adult life.

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Organizations of the countries that belong to the European Community, which are involved in the promotion of the rights and welfare of persons with Down's syndrome.

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