European Down's Syndrome Association

NewsLetter

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De l'adolescent à l'adulte trisomique 21

Observation et réflexions

R. BONJEAN [1]

Les personnes trisomiques 21 deviennent un jour "adulte". Ce mot "adulte" a exactement la même signification qu'il soit utilisé à propos de la personne trisomique 21 ou de n'importe quelle autre personne.

Une personne ne devient pas "adulte" parce qu'elle a un jour 18 ans, 20 ans ou 21 ans.

Elle devient progressivement "adulte". Cette accession à un statut reconnu par la société se fait au long de son éducation familiale, scolaire et professionnelle.

La personne doit y est preparée dès son plus jeune âge en acquérant des compétences, des aptitudes tant physiques qu'intellectuelles. Elle se forme une personnalité, une manière d'être, de penser et d'agir qui la font devenir un "adulte unique".

C'est cela éduquer.

Chaque adulte trisomique 21 est un être unique et la présence d'un chromosome surnuméraire ne change rien à son droit ni à sa capacité d'accéder à un statut d'adulte à part entière. Les limites sont différentes. Nous devons permettre à la personne trisomique de vivre en "adulte" avec ses capacités et ses limites MAIS non en ignorant sa différence.

ESSAI DE DEFINITION DE L'ADULTE

Lambert définit l'adulte comme "une personne qui réalise au mieux de ses capacités une évolution lui permettant d'atteindre la maturité la meilleure dont il est capable".

Cette maturité lui confère un certain statut social, un certain nombre de droits et de devoirs devant lui permettre de rencontrer des situations dans le respect des contingences matérielles et sociales afin d'en retirer le plus de plaisir possible".

Devenir adulte n'est donc pas un aboutissement. La personne trisomique va poursuivre son développement.

L'objectif ne sera pas qu'il soit capable de se prendre en charge seul ou encore d'avoir une activité professionnelle. Ce sera simplement qu'il puisse vivre le mieux possible avec ses capacités et ses compétences comme membre à part entière de notre Société.

Pour y arriver il est de la première importance que la personne trisomique soit un partenaire à part entière, quelque soient ses difficultés ou le peu de capacités qu'elle présente. Elle aura comme autres partenaires ses parents (sa famille) et les professionnels des services utilisés (éducateurs, psychologue, travailleurs sociaux...). La société dans laquelle la personne vit devrait devenir le quatrième partenaire. Il y a à ce niveau encore un long chemin à faire. Dans ce partenariat la personne trisomique adolescente et surtout adulte a la place prépondérante. Son opinion sera écoutée et discutée avec elle. Chacun des partenaires ne peut agir sans tenir compte des autres, pas plus les professionnels sans les parents que les parents sans les professionnels ou la personne adulte sans ces deux composantes qui forment son environnement immédiat. Les actions entreprises doivent correspondre aux besoins de la personne, à ce qui lui est nécessaire, à ce qu'elle se souhaite. Je pense qu'il est de première nécessité que tous ceux qui sont partenaires de la prise en charge de la personne trisomique 21 dialoguent et réfléchissent ensemble à la perception qu'ils ont de la personne et définissent ce qu'ils permettent ou ne permettent pas.

J'ai choisi de développer uniquement deux aspects: 1. la capacité de penser et d'agir par soi-même, pour soi-même. 2. la normalisation et la relation aux pairs.

Je tiens à associer à ces réflexions Madame A. BASTYNS, psychologue à l'APEM et Madame A. MONTULET, psychologue au Centre de Santé Mentale qui par leur expérience et leur compétence ont grandement contribué à la pertinence de certaines réflexions. Ces réflexions proviennent d'observations que nous avons faites dans notre centre de jour "la fermette", dans le cadre de notre "service d'aide pour l'intégration" et dans le cadre d'un club d'adolescents.

Mon unique objectif est de vous inviter à m'accompagner et d'aller à la rencontre de nos adolescents et adultes.

(à suivre)

1) *Directeur du Centre de Jour "la fermette"*
Secrétaire général d'EDSA (Association Européenne du Syndrome de Down)

avec la collaboration de:
Madame A. BASTYNS, psychologue, service d'aide pour l'integration (SAPI) (APEM-Belgique)
Madame A. MONTULET, psychologue, centre de Santé Mentale de Verviers, animatrice du club d'adolescents (Club "J") (APEM-Belgique)

The risks of sport in children with Down syndrome

Marijke J. G. Cremers M.D., Ph.D.

Many children participated in a study on the risks of sport in children with Down syndrome. For those who are curious about the conclusions of the study this report has been written.

Why a study on the risks of sport?
Since the eighties people worried about the high frequency of atlantoaxial instability in persons with Down syndrome. In such case, especially after certain movements of the neck, the spinal cord can be injured and hemiplegia or diplegia might be the result. These movements in the neck may occur during sport activities. Should therefore be advised that sport is not safe for a child with Down syndrome?

The study on the risks of sport in children with Down syndrome.
In this report the main results and conclusions will be presented; information about atlantoaxial instability, about the children in this study, about the diagnosis, is laxity a predictor for atlantoaxial instability, and last but not least about the risks.

Atlantoaxial instability
Atlantoaxial instability is present when the connection between the first and second vertebra of the cervical spine is not stable. The fixation of the axis of the second vertebra in the ring of the atlas by a ligament is not firm enough. This ligament often is too lax in people with Down syndrome and therefore it is sometimes possible that the axis moves towards the cord lying next to the axis. In the worst situation the nerves that are part of the cord can be disrupted with paralysis as a result. In less severe situations a doctor can find abnormal reflexes.

The subjects in this study
The children in this study were all between 6 and 17 years of age, all had Down syndrome and all went to special schools. So these children had a similar programme during daytime and had an equal level of functioning. (In The Netherlands, where this study took place, children with Down syndrome with a low level of functioning visit day-care centres and children with a high level go to a normal primary school). At the start of the study all children were active in sports. The physical education lessons at school were also considered as sport in this study. One group of children with atlantoaxial instability was asked to stop for a year with risky sports. These sports were diving, wrestling, judo, gymnastics, high jumping, trampoline jumping, soccer, skiing, and horseback riding. The other group went on with their regular sports programme.

The diagnosis of atlantoaxial instability
The diagnosis is based on an X-ray of the cervical spine. All participating children had an X-ray made in the nearby hospital. At the institution were this study took place all X-rays of 282 children were assessed by one radiologist. The conclusions of this part of the study were:

1. In our study 91 of 282 children were found to have an atlantoaxial distance of more than 4 mm (32%), mostly in boys younger than 11 years (48%). In older boys and in younger and older girls the frequency was lower but about the same. The longest distance found was 6,5 mm. The number of children with Down syndrome who have atlantoaxial instability depends on the threshold of the distance of displacement of the atlas and axis. For normal children this threshold is 4 mm. We used the same distance as threshold. Other authors use 4,5 mm.
2. Because the X-rays were made in several hospitals the difference in the atlantoaxial distance that we found could be the result of different degrees of magnification on the X-rays. Therefore we used a method to calculate the magnification. We used a marker (a paper clip), affixed on the nape of the neck, and afterwards this marker was affixed in the X-ray. In this way we were able to calculate the magnification from the rate of the two measured distances of the paperclip. After correction for the magnification, with the same threshold of 4

mm, we found 15% with atlantoaxial instability. Again especially in boys under 11 (26%).
3. No relation was found between the atlantoaxial distance and neurological abnormalities as a result of cord compression. These abnormalities were found but in an equal rate in children with and in children without atlantoaxial instability.
4. We also studied the accuracy of the results because it is difficult to measure 4 mm., or even less, very exactly. After nine months a number of X-rays were assessed again by the same radiologist and by another. They had no access to the previous results. The outcome was that the longer the measured distance the more exact the assessment was. From about 4 mm. the assessments proved to be correct.

The conclusion is that in children with Down syndrome atlantoaxial instability is more frequent, especially in boys under 11.
Because the assessment of the X-ray is not reliable enough in atlantoaxial distances of less than 4 mm. screening of normal children with Down syndrome is not useful. Only in case of symptoms, a radiograph completed with other diagnostics (CT scan or MRI) can make sense.

The relation between laxity and the atlantoaxial distance.
At the start of the study we supposed that practising sport could be risky. If this would be the conclusion, the result would be that children with Down syndrome should have regular check-ups. X-rays are expensive and not without certain harm. We therefore studied if the assessment of laxity in the children could predict the outcome of the measurement of the atlantoaxial distance and therefore the possibility of atlantoaxial instability. If so, a laxity assessment, not so expensive and without harm, could be used as a method for screening. Only children with a doubtful outcome are then indicated for radiographic screening.
All children had a laxity assessment and these results were compared with the outcome of the X-rays. Although some of the children showed an excessive laxity, no correlation was found with the atlantoaxial distance. It seems that excessive laxity is a local sign that infrequently occurs in all joints in the same person. The conclusion is that the laxity test can not be used to predict atlantoaxial instability.

The risks of sport
One group of 38 children stopped with risky sports during a year and stopped certain risky movements during physical education lessons. Another group of 43 continued their usual sports activities. Children of both groups had atlantoaxial instability. A third group of 38, without atlantoaxial instability, also continued their sports. All children had a neurological examination five times during the year to find out if they had signs of cord compression. The teacher also completed a motor function test at the start and after a year. If the results of the group that stopped with risky sports should be different from the group that continued their normal sports activities this could only be the result of the difference in sporting practice if this practice was different indeed. Therefore parents completed weekly forms with information about the kind of sport their child had practised and for how long the physical education lessons were observed. From this information we could conclude that the children with sport restrictions were less active in risky sports than the children of the control group.
After a year we found
- no difference in neurological signs or symptoms, - no difference in motor function,
- no difference in atlantoaxial distance,
- and no difference in the alterations of this distance.

From this we may conclude that for children with Down syndrome and atlantoaxial instability sport means no extra risk.
Some remarks have to be made. In this study about 25% of all such children in The Netherlands participated (age between 6 and 17 and all from special schools). None of the children had an atlantoaxial distance more than 6,5 mm. In literature also distances of 11 mm are described. But as our group was about 1/4 of the total group, a longer distance than 6.5 mm is rare indeed.
The study focused on sports as they are practised at this moment; no top level training and no weekly competition. This study does not exclude that if someone has a very wide atlantoaxial gap, or somebody is practising sports on top level, he or she could have a higher risk. But in the way sport is practised at this moment a higher risk is not to be expected.

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Working memory Down syndrome

Jean A. Rondal [1]

It is customary to hear that Down syndrome (DS) persons have particular difficulties with memorizing particular items, names, nouns, arrays, patterns, and other information, and retrieving them from memory stores. Such difficulties may certainly be expected to interfere with the acquisition of knowledge and skills, and wich various aspects of language and cognitive functioning. The memory problem, therefore, is a serious one for DS persons, and it should be given careful consideration in psychological assessment and intervention with these people. An interesting by-question is whether the memory systems can be boosted in DS persons, perhaps starting specialized training early in life.

Current models of human memory [cf., for instance, the one developed by Alan Baddeley (Baddeley, 1990)], conceive of the human memory system as constituted of at least two major subsystems, one with strictly limited capacity and a strong temporal-ordering component (short-term memory -STM- or working memory -WM- in the terminology used by Baddeley), the other one with illimited (or, at least, extended) capacity and several properties of network systems (long-term memory -LTM-). There is also basic agreement that the memory systems are subdivided and organized into specialized stores with particular processes, corresponding to the specific nature of the mental material to be treated and stored (e.g., verbal or propositional, iconic-visual). In Baddeley's WM system, speech-based information are momentarily held in a phonological store equipped with an articulatory control process (based on inner speech) - both constituting the phonological loop -, the function of which is to refresh memory traces by reading them off and feeding them back into the store. Short of this, the traces become unretrievable after a few seconds. Visuo-spatial information, on the other hand, are held momentarily in a specialized visuo-spatial store. Topping the two subsystems, and controlling them, is an attentional device, the so-called central executive, one of the roles of which is to direct conscious attention on, to plan, and to assist the functioning of the components of the WM system (cf. Figure 1 for a schematic representation).

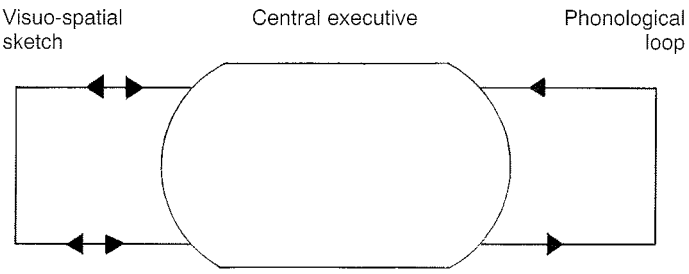

Figure 1. A schematic and simplified representation of the working memory model (after Baddeley, 1990).

Long-term memory does not seem to constitute a homogeneous system, either. Current theorizing define several subsystems, each one with its particular properties and characteristics, involved in long-term storage, organization, and retrieval. Several systems serve to accumulate various sorts of information - related to the sensory modalities - (very likely in a separate manner). They are responsible for the continuous updating of past events with new events. Episodic memory is another LTM system, the function of which is to allow the mind to recollect specific events. Semantic memory is yet another LTM system (probably intimately related to the episodic memory system - Baddeley, 1993). Its function is to regroup specific events into generic (and, therefore. "more meaningful") patterns.

Mentally retarded (MR) persons, in general, and DS persons in particular, have significant limitations in this functioning. I will restrict myself in what follows to the WM subsystem for speech-based information.

MR and DS persons are severely limited in (1) the capacity (span) of their working memory system as well as in (2) the inner articulatory process normally used for purpose of maintaining the otherwise evanescent memory traces in the phonological store, and yet in (3) the ability of the central executive to efficiently monitor the functioning of the WM system. Preliminary data gathered in my Laboratory (cf. Rondal, 1994) indicate that the overt speech rate of DS adult subjects varies from 37 to 79 French words per minute (i.e., one word - 4 to 5 phonemes - per second and less) versus around 200 French words per minute (i.e., approximatively 3.3 words - 12 to 15 phonemes - per second[2]) for normal controls (males and females) of corresponding chronological ages. The capacity of the phonological store is defined as the quantity of the verbal material that can be articulated in about 2 seconds (Baddeley, 1993). Speech rate may be seen as an index of the speed with which information can be rehearsed within the articulatory loop. The WM word span of DS subjects can be predicted to be 2 items, or 3 items in the best cases, versus 7 or 8 items for nonretarded adult subjects. And this is what is actually observed (Rondal, 1994). Also, the inner articulatory refreshing process of WM is largely deficient (or, perhaps, even inexistent to any significant extent) in DS subjects. They can be trained to rehearse in a loud voice in experimental learning situations, but such strategies are not or only little used spontaneously. This probably means that, in these subjects, the central executive component of the WM system (keeping up with Baddeley's terminology) is not appropriate, in the sense that it fails to monitor the volontary and conscious use of rehearsal and mediational mechanisms.

In general (i.e., beyond and besides memory questions), the lack of an efficient mechanism of inner speech and mediational propositional representations is a most serious cognitive problem for DS subjects (and, probably, for most, if not all, moderately and severely MR subjects). This problem should be given high priority in the cognitive intervention with these persons, for, judging from the present-day specialized literature (e.g., Baddeley, 1990 ; Gathercole & Baddeley, 1993), it seems that WM may play an important role in language development, particularly early lexical development. And one knows the cumulative nature of the language acquisition process.

Although the necessary experimental work on this problem with MR subjects is mostly lacking, there seems to be indications that the WM functioning of moderately and severely MR subjects can be improved. In a pioneering study, Hulme and Mackenzie (1992), trained short-term memory rehearsal strategies in a group of moderately MR adolescents. Each subject in the experimental group was given an overt rehearsal consisting of one daily session lasting approximatively ten minutes over a period of ten days. Materials for the rehearsal training consisted of lists of words of increasing length. The subjects repeated successively longer sequences as each individual word was spoken by the experimenter. The rehearsal training succeeded in producing an increase in memory span of approximately .50 (more with some subjects). The Hulme and Mackenzie study is only a beginning study. Many theoretical as well as practical problems remain to be solved. For example, it is possible that more spectacular gains in WM memory spans could be obtained with younger MR subjects, as well as from using more systematic and longer training procedures. Also, the longer-term benefits of training WM skills in MR children for language development as well as for cognitive abilities such as reading, reasoning, arithmetic, information processing, have yet to be established.

Annick Comblain, doctoral student in psycholinguistics and logopedics, at the University of Liège, is currently documenting the WM functioning of children, adolescents, and adults with DS and its relationships with language development in these subjects. She has designed and is currently testing ways of training memory span, rehearsal, and inner speech, in young DS children, based on suggestions from Hulme and Mackenzie (1992) and Broadley and MacDonald (1993). This work, as well as other urgently needed fundamental and applied studies in this area, hopefully should help us to design and implement efficient ways of promoting memory development in MR subjects, and from there onto improving significant aspects of their basic language and cognitive functioning.[3]

Notes

1) EDSA Vice-President, Professor of Psychology and Psycholinguistics, University of Liège, B-32 SARTTILMAN, 4000 LIEGE, BELGIUM.

2) This figure is about the normal rate for continuous speech, according to Caron (1989).

3) A short summary of Comblain's procedures for training working memory in Down syndrome children is presented in the file card n°1 of EDSA Newsletter.

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European Down's Syndrome Association
NewsLetter
FILE CARD • FICHE N° 1

How to make a child with Down syndrome talk?

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Question 1: *What are the major language problems of children with DS ?*
Answer: - DS children have difficulties with every aspect of language, but particularly with the sound system and the grammatical organization. Difficulties with the words (learning the words meaning and learning how to use them, organizing them in ways that make it easier to retrieve them from the mental lexicon), and difficulties with the social uses of language (taking into account the interlocutor's knowledge and point of view; taking turns in the verbal exchange; structuring information according to its relative importance in text organization, etc.) are usually commensurable with cognitive (intellectual) deficit. Problems with the sound system (sound discrimination, articulation, and co-articulation) and with the grammar of the language (particularly the morpho-syntactic rules) may and most often do go beyond what can be expected on the basis of cognitive development.

Question 2: *Can these problems be improved and if yes, how ?*
Answer: - Yes, these problems can be significantly improved. However, there are some conditions to be fulfilled for the intervention procedure to have a good chance to meet with success. These conditions are, in major part:
(1) Language intervention must start early (prelinguistic stimulation and training before proper language training);
(2) It must be conducted in a developmental way (i.e., follow the sequence of steps and the path of normal language development);
(3) Language intervention must be conceptualized and organized in a modular way (i.e., divide the intervention according to the major components or modules of the language system - sound system, lexicon, semantics, morpho-syntax, pragmatics, because each one of these components follows its own course of development, has its own time-table, its specific characteristics and specific difficulties;
(4) Language intervention must be systematic and carried over in close connection with current state-of-the-art technical knowledge. Only in this manner, can language intervention have marked and long-lasting effects on the retarded child's development and ultimate level of functioning.

Question 3: *What do you mean by precocity in language intervention ?*
Answer: - By early language intervention - I should say "very early intervention" -, I mean, first, prelinguistic stimulation and training from the first few months onto approximatively twenty months or two

years. The objective is to foster through appropriate educational manoeuvers:
(1) sound (and particularly language sound) discrimination;
(2) the child's babbling and pre-speech expression;
(3) practical knowledge of the environment (physical as well as human); this knowledge will supply the basis from which the semantic dimension of language will emerge;
(4) the grasp of the mechanism of symbolization on which the whole language system rests. This is followed by receptive and then expressive lexical training, choosing lexical items in the language that have a concrete meaning, are frequently produced, and correspond to entities that are frequently encountered in the child's familiar environment. When the DS child is well on his (her) way in motor development and understands and uses a few dozens of concrete lexical items, one may envisage systematic articulatory and grammatical training.

Question 4: *What is grammatical training and how should it be conducted ?*
Answer: - Grammatical training means giving the child access to the formal regulations of the language; those regulations that allow for expressing more complex ideas through multiword utterances correctly patterned in such a way as to minimize ambiguity. This is a difficult area for moderately and severely mentally retarded children, including Down syndrome children. Grammatical development must be fostered on its own through specific procedures. It is not likely to happen as a simple by-product of semantic or pragmatic training or just through everey day use of simple forms of language. Grammatical training should proceed according to the following major principles:
(1) Selecting grammatical aspects of the language that are both easier and most useful to language practice - very often languages offer several alternatives of varying degrees of structural complexity for expressing a given semantic relation;
(2) Analysing the composing parts of a grammatical rule or set of rules, and training them in order of increasing difficulty, advancing to the next step only when the preceding one has been acquired and stabilized; and
(3) Making sure, when training grammatical regulations, that the semantic relations underlying syntax are well understood and the lexical items used in training are mastered.

- Details of this intervention program as well as the major justification for it may be found in my books:

1 . *Le developpement du langage chez l'enfant trisomique 21. Manuel pratique d'aide et d'intervention*. Brussels: Mardaga, 1990 (in Spanish translation and adaptation, Buenos Aires, Nueva Vision, 1993).

2. *Comment faire parler l'enfant trisomique 21 et améliorer son langage. Un programme d'intervention psycholinguistique*. Verviers: European Down Syndrome Association, 1993.

3 . *Eduquer et faire parler l'enfant Down. Un guide à l'usage des parents et des professionnels*. Mexico, D.F.: Trillas, 1993, (in Spanish).

European Down's Syndrome Association
NewsLetter
FILE CARD • FICHE N° 2

Alzheimer's disease and Down syndrome

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Alzheimer's disease is a progressive degenerative neurological disorder, which destructs the neurons and their connections in the brain. Alzheimer's disease is far more common in individuals with Down syndrome than in the general population, affecting them at an earlier age. Clinical diagnosis at onset is not easy and other conditions can mimic the symptoms.

Question: *What are the symptoms of Alzheimer's disease?*
Answer : Alzheimer's disease is a progressive disease with an enormous impact on cognitive capacity, personality and motor skills. Early symptoms include disturbances of short term memory and mild personality changes. With the progression of the disease long term memory capacity is also affected and personality changes become more severe. Motor skills are involved with changes in coordination, gait and a decline in daily living skills. Seizures occur frequently and there is a loss of selfcontrol regarding bladder and bowel habits. In a final stage the patient is completely depending on nursing care.

Question: *Aren't these symptoms common to some other diseases and conditions?*
Answer : Especially the early symptoms are rather aspecific and can also occur in other diseases. It is important to be sure that these early symptoms do not arise from other conditions as thyroid disorders, depressive illness, sensory impairment, brain tumor etc. Although all the individual symptoms can also be present in other illnesses, the course of Alzheimer's disease is rather specific.

Question: *How is the final diagnosis ascertained?*
Answer : The clinical diagnosis of Alzheimer's disease can only be made with a certain probability, based on the clinical history with progressive memory impairment, decrease in cognitive function and in personality changes. A variety of tests will contribute to the evidence: electroencephalogram, brain stem auditory evoked response, computerized tomography, magnetic resonance imaging and neuropsychological tests, but none of them is specific. As there is no specific test for Alzheimer's disease, the final diagnosis can only be made at post mortem investigation of the brain.

Question: *Is there a test that can be done at intervals to determine the decrease in cognitive function?*
Answer : Social Competence can be assessed in questionnaires done by psychologists. The questionnaires have to be repeated at certain intervals. However, if there is a decline in social competence scale ratings, this may be caused by other conditions, like depression. In the case of a Alzheimer-type dementia memory problems and personality changes are almost inevitable prior to a decline in social competence. To detect onset of dementia you better use a checklist with possible early symptoms of dementia. Social competence scale

ratings are suitable afterwards to measure progression of dementia, but they are quite useless in the detection at onset.

Question: *Is there an objective laboratory test that could be helpful in diagnosis?*
Answer : Although aspecific, EEG changes occur almost without exception in Alzheimer's disease and, favourably, at a rather early stage. However, the changes can be interpreted correctly only if there is a possibility to compare them with a base-line recording. The EEG represents the functioning of the brain and EEG facilities are usually available and applicable on mentally handicapped individuals.

Question: *Is Alzheimer's disease a common disorder in individuals with Down syndrome?*
Answer : There seems to be a difference between "clinical" and "neuropathological" Alzheimer's disease in Down syndrome. Autopsy of all the brains of individuals with Down syndrome show after the age of 30 the Alzheimer caracteristics and already 95% after the age of 40. Figures about "clinical" Alzheimer's disease vary a lot, depending on the age of the investigated group, level of intellectual functioning and criteria for the diagnosis. Between 30 and 40 years, 8% to 33% of the individuals with Down syndrome show the clinical symptoms of Alzheimer's type dementia. Between 40 and 50 years the percentages vary between 10% and 50% and after that age the percentage seems to rise. In the general population Alzheimer's disease is rare before the age of 50, but the prevalence rises with age till 5-10% after age 70.

Question: *What information has research yielded thus far about a link between Alzheimer's disease and Down syndrome?*
Answer : There are a couple of links between Alzheimer's disease and Down's syndrome. At first: the neuropathological characteristics are identical. Even so are the neurochemical alterations. Further: a gene, responsible for a familiar form of Alzheimer's disease is located on chromosome 21, the same chromosome that, in triplicate, is responsible for Down's syndrome. The extra "gene dosage" effect caused by this third chromosome may have a causative relationship with Alzheimer's disease and the premature ageing of the Down-brain.

Question: *Can research in Down syndrome help to find the cause of Alzheimer's disease?*
Answer : If Alzheimer's disease occurs in Down syndrome so often it seems speculative to consider Down syndrome as a kind of "model disease" to study Alzheimer. As research progresses it is more likely that Alzheimer's disease is a multi-genetic disease with various causes and forms. Study of Alzheimer's disease in Down syndrome may at least help to clear obscurities in this very specific form of it.

Question: *Is Alzheimer's disease treatable?*
Answer : As far as we know, there is no treatment available against Alzheimer's disease. There are some preliminary reports about drugs with a possible positive effect on memory disturbances. What we can offer to individuals with Down syndrome is the possibility of a rather firm clinical diagnosis of Alzheimer's disease with the possibility to create appropriate help in the various stages of it. What is also important: not everyone with Down syndrome, who shows a cognitive decline, suffers on Alzheimer's disease. Be alert on other, sometimes treatable diseases.

Summary

* Individuals with Down syndrome are far more likely than the general population to develop Alzheimer's disease. Onset of Alzheimer's disease is 20 to 30 years earlier than in general population.
* Symptoms of a variety of other diseases and conditions can mimic the symptoms of Alzheimer's disease: memory disturbances, personality changes and a decline in daily living skills, in coordination and gait. Some diseases and conditions like depression, thyroid disorders, sensory impairment, brain tumor and metabolic imbalances must be ruled out.
* It is recommended that individuals with Down syndrome take a baseline test of cognitive function before age 30 and that these tests are repeated annually. Is is also helpful to make a baseline EEG-recording, creating a possibility for comparison in the case of cognitive decline.
* Current research suggests a causative link between the extra chromosome 21 and Alzheimer's disease. This specific form must be explored further.

NEWS FROM EDSA SCIENCE ADVISORY BOARD

V World Down Syndrome Conference in Orlando, Florida (August, 11-14th 1993)

Co-organized by the National Down Syndrome Society (NDSS) of New York and EDSA, this important scientific event was attended by 800 people from 47 countries. On behalf of EDSA the following persons participated at lectures: Richard Bonjean (Belgium), Valerie Bradley (UK), Sue Buckley (UK), Erik de Graaf (Netherlands), Anna Zambon (Italy), Juan Perera (Spain), Alberto Rasore-Quartino (Italy), Jean A. Rondal (Belgium), Montserrat Trueta (Spain). The lectures are going to be published by JOHN WILEY & SONS, INC.

VI World Down Syndrome Conference

This conference will be held in PARIS under the organization of EDSA and the French Federation FAIT 21 from 20 to 23 August 1996. **Further information to follow.**

- **1994 Conference Canadian Down Syndrome Society.**
  Vancouver, British Columbia. March 3rd-5th. CANADA. 204-12837-76th Avenue, Surrey, B.C. Canada V3W2V3.

- **First International Down Syndrome Conference.**
  Biomedical advances. Monterrey, Mexico. 7-8-9th March 1994.

- **First National Down Syndrome Congress.**
  Buenos Aires from 8th to 11th August 1994. Organized by ASDRA (Down Syndrome Association of the Republic of Argentina). Vera, 863 (1414). Buenos Aires, Capital Federal, Argentina.

- **International Conference on Cognitive Development in Down's Syndrome.**
  22nd to 25th Sept. 1994 at the University of Portsmouth (UK).
  Keynote speakers: **Professor Jon Miller, Dr. Anne Fowler, Dr. Robin Chapman, Dr. Sue Gathercole, Dr. John Clibbens, Dr. David Messer, Sue Buckley.**
  The aim of the conference will be to bring together all the leading international researchers to discuss the current state of our knowledge and identify areas for future research. To this end it will be a large seminar (200-300) for professionals (mainly psychologists, speech and language therapists) but we may urge the keynote speakers to set aside time for a more specialised seminar/discussion either before of after the main conference.

- **Third International Down Syndrome Symposium.**
  Subject: Psychology of Down Syndrome. Organized by EDSA ASNIMO. Palma de Mallorca (SPAIN). 24th-25th February 1995. Information: ASNIMO, km 7'5 Carretera Palma-Alcudia, 07141, MARRATXI, SPAIN.

- **European Down Syndrome Congress.**
  21st to 23rd August 1995. Dublin, Ireland. Organized by the Down's Syndrome Association of Ireland. 5 Fitz William Place, Dublin 2, Ireland.

JOURNEES NATIONALES SUR LA TRISOMIE 21 F.A.I.T. 21-G.E.I.S.T.21 9 et 10 Avril 1994 NIMES (France)

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An International Conference on

Growth in Down's Syndrome

will be held in Troina, Sicily Italy on September 27, 1994 followed (on September, 28-30, 1994) by the 3rd International Symposium on Brain Dysfunction whose topic will be

Down Syndrome, Alzheimer Disease, and Chromosome 21

For further information please contact the Organizing Secretariat: R. Mascali, M. Schillaci - Tel. 39-935-653001 / Fax 39-935-653327

EUROPEAN HEALTH PROGRAMME FOR DOWN SYNDROME

The Science Advisory Board of EDSA is working on the adaptation of a European health programme for persons with Down Syndrome. In 1981 the "Children's Brain Research Clinic" in Washington D.C. proposed a first programme of preventive medicine for persons with Down Syndrome. Since then, every two years in the USA this programme has been revised and adaptations have been made in other countries in accordance with the specific possibilities and needs of each nation. The European programme, whose head is Prof. Alberto RASORE-QUARTINO, Dept. of Pediatrics Galliera Hospital, Mura delle Cappuccine, 14. Genova - ITALY. Tel.: 39-10-5632464, Fax: 39-10-5632699, is open to the participation of members of the EDSA SCIENCE ADVISORY BOARD.

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AFFILIATION FORM

This affiliation form has to be sent by ordinary mail to the General Office. It's necessary it will be completed and signed by the qualified members so say the law of the Association if this affiliation form concerns effective member or adherent member.
It will be signed personally if it concerns an affiliate member. The affiliate form means the adhesion to the law of EDSA.

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I. The undersigned: (name, first name and function)
   1.....
   2.....

II. Representative of the Association:
   .....
   .....

III. Official address:
   .....
   .....

IV
   Phone: .....
   Fax: .....

seek to join EDSA as:
   1. Effective member* 2. Affiliate member* 3. Associated member*

We join a copy of the law of our Association.
* Cross out the wrong information.

INFORMATION FOR CORRESPONDENCE

Name and address:
.....
.....

Action of the Association (or brochure):
.....
.....

Number of members: .....
Down's syndrome people's age (if personal affilation) .....
Representative parent: .....
Representative professional: .....
Phone: .....
Fax: .....

Date Signature

EDSA EUROPEAN DOWN'S SYNDROME ASSOCIATION

Rue V. Close 41, B 4800 Polleur - Verviers Belgium

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I'd like to help the European Down's Syndrome Association to attend its goals and objectives in favour of the persons with Down Syndrome

Je désire aider dans la poursuite des ses objectifs en faveur des personnes atteintes par la trisomie 21.

Name / Nom _____

Address / Adresse _____

City / Ville _____

State / Nation _____ Zip / C.P. _____

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.

EFFECTIVE MEMBERS

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.

AFFILIATE MEMBERS

Organizations of the European nations that do not belong to the European Community, which are involved in the promotion of the rights and welfare of persons with Down's syndrome.

ASSOCIATE MEMBERS

Persons and organizations who provide advice and any kind of support to the persons with Down's syndrome and/or to the members of EDSA.

EDSA

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