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# **Early intervention in the Netherlands: The struggle of a syndrome specific organisation**

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**As a country the Netherlands is generally known for its superior services for people with learning disabilities. However, in recent years, the introduction of early support for very young children has proved to be very difficult and time-consuming.**

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## **Early intervention, a definition**

For the purpose of this article, early intervention will be defined as individualised, early, structured, long term support, either at home or in a centre. In the great majority of cases it will be carried out in accordance with a specific early intervention program. Next, this definition will be explained and successfully extended.

In the foregoing attempt to define early intervention the word *individualised* is included because every child is different. The *support* itself is necessary because there is much research evidence to indicate that children who have been enrolled in an early intervention program 'do better' than children who have not. *Early* is included because parents generally cope better when they learn about optimum support of their child as early as possible after the diagnosis. (For that purpose, a great number of intervention programs offer suggestions for useful activities during the first months of life!) Furthermore, if the condition of the baby is such that early intervention is indicated, in the great majority of cases the same arguments that hold at a very early age still do at a later age. Therefore, early intervention has to continue in the *long term*. Finally, the word *structured* is included to emphasise the step by step precision teaching approach of early intervention. This means that one first has to assess whether the child has mastered the step he was supposed to learn before one can move on to the next one.

Apart from purely educational support, usually seen as early intervention in a *strict sense*, medical support and even mere information, general as well as syndrome specific, are, in the view of the author, important constituents of the total concept of early intervention. The resulting type of support could be indicated as early intervention in a *broad sense*.

## **The 'typical' situation**

Below a brief description will be given of the 'typical' situation in the Netherlands in the field of the care for children with a mental handicap towards the end of the eighties, just before the Stichting Down's Syndroom (Down's Syndrome Foundation, or SDS for short) was founded. This typical situation still heavily dominates the present field, although the pattern is rapidly changing, as will also be indicated.

## **The medical profession**

Immediately after the diagnosis, parents of a child with a disability need support from either their family doctor or their paediatrician. However, generally speaking, both of these will have only extremely limited experience in that field. Let us take the most frequently occurring disability with the same etiological diagnosis, Down's syndrome, as an example. From the annual total number of live births and the number of family doctors it can be computed that an average Dutch family doctor may welcome a new-born baby with Down's syndrome in his practice only once in every 20 years! On the basis of estimated prevalence figures for the Netherlands, purely statistically speaking, and disregarding the patients' ages, he continuously will only have about one person with Down's syndrome in his practice. The average Dutch paediatrician is consulted about a new child with Down's syndrome once in about every three and a half years. Therefore, he has to take care of six children with Down's syndrome simultaneously at most. As a consequence, medical care for children with Down's syndrome in the Netherlands over the years has been far from optimum, resulting in missed oppor-

tunities for breast feeding, missed heart defects, under reporting of hypothyroidism etc., while being even further away from the ideal for children with other handicapping conditions. In addition, it emerges that, although individual paediatricians perhaps might closely follow the developments in their own specialism, they are not aware of non-medical advancements with respect to Down's syndrome. Generally speaking, professionals out of the medical field tend to see the diagnosis as a purely medical problem for which there is no solution. As a consequence, they are only very reluctant to refer parents to other organisations which could provide help. In the field of Down's syndrome this has all led to a form of specialised medical care being brought in to existence, which will be described below.

### **Social Pedagogic Agencies**

The country is covered by a web of Social Pedagogic Agencies, or SPD's in Dutch. One of the tasks of their social workers is to lead the way towards helping parents of children with a mental handicap. The national policy in this respect is that parents still have to take the initiative and apply to their local SPD for help, and not the other way around. The SPD workers are able to give information, e.g. about the entire educational system for children with very severe learning disabilities, starting off at the special day care centres.

A problem, the importance of which cannot be overemphasised, is the difficulty parents experience in finding their local support organisation. Right after hearing the diagnosis of their child in actual practice they may merely remember the name of the syndrome, while the abbreviation 'SPD' doesn't make any sense to them if they are not clearly directed to make contact. Small scale enquiries by the author amongst parents of children with Down's syndrome have yielded the result that on an average it takes two years for parents to find the SPD's and to make actual contact. On the other hand, the average age of the children from the 'lower three quarter', the 75% of the parent members of the SDS with the youngest children, at the moment of their registration sometime in 1992, was four months. In addition, it can be stated that the SDS has reached more than half of the concerned parents within the last six birth cohorts. In the opinion of the author, this illustrates very clearly in how far the SDS, as a typical syndrome specific organisation, plays an important 'porch function' to the professional support system instead of the other way around, as is the present government policy.

### **Special day care centres**

As soon as they are three years old the children are allowed to attend the special day care centres for children with learning disabilities, called KDV's in Dutch. There are more than a hundred of these in the Netherlands. Without exception, they are very well equipped. Many even have indoor swimming pools etc. Likewise, they are very well staffed. The children are looked after in groups of about eight, all with disabilities of variable degrees. If necessary, their group leaders can draw on the specialised knowledge of the physiotherapist, doctor etc., mostly employed (as part time) by these centres as well.

At the present time, every individual day care centre more or less follows its own curriculum, not particularly directed towards actual education. Rather, self care is emphasised. Even at the present time there still appears to exist a fair amount of resistance against the use of structured educa-

tional programs emphasising precision teaching at the KDV's. The question is often asked whether the children concerned retain the right of simply being learning disabled. Many professional helpers are even afraid that the children are not allowed to remain children anymore, because they have to be involved in 'such an extensive training'. Furthermore, it is often thought, that the children will develop behavioural problems if the requirements are too highly directed. Yet, if considered necessary, the children are subjected to psychological assessment. However, the intervals between two successive assessments are fairly often considerably longer than a year. In addition, relieving the parents from the task of educating their handicapped children, traditionally, has been seen as an important primary task by many of its workers and, most probably, by parents as well.

Carrying the example of children with Down's syndrome a bit further, towards the end of the eighties the great majority of children went to such special day centres. From a very recent nation-wide inquiry, under about 1000 parents of mostly young children with Down's syndrome with 732 respondents, it appears that at the present time, apparently only about half of the concerned children 'begin their educational career' there (Velde, 1993). The remaining children visit regular play groups in preparation for integrated regular education, at least during the initial years.

### **Educational support at home**

Upon their request, the possibility exists for parents of a child with a learning disability to receive practical support with their children's education, called practical educational family support, or PPG in Dutch. However, this kind of support is quite different from the foregoing definition of early intervention. Very generally speaking, the Dutch PPG worker will only come for a limited number of, in most cases, weekly visits, with a maximum of twenty (although there are exceptions). Furthermore, she will only come in cases of real ad hoc problems, e.g. a child that is consistently throwing away everything he gets in his hands. As soon as that problem is more or less eradicated, that support stops. PPG workers do not use a structured program. They insist on calling themselves pedagogic workers instead of teachers. Their training and attitude do not allow for the point of view that achievements of the individual child are taken as a measure of the child's possible future placement. They believe each child should go to a special day care centre, while parents who are considering a regular play group simply have not accepted their child's handicap. However, especially in the last two or three years, more and more PPG workers are becoming convinced that a more structured, early intervention type of approach could be beneficial and that mainstream education might be a serious consideration.

### **Physiotherapy and speech therapy**

From a certain age on, many paediatricians recommend physiotherapy, while some do not. If physiotherapy is given, it is mostly of the Bobath type. As long as it is recommended by a doctor, it will be paid for by the health insurance companies. The physiotherapist will visit the child at home. In the course of the last few years many of them have begun using the Macquarie Program (see below) as a guideline for their work. However, the number of children supported by ergo therapists is negligible.

With speech therapy the situation has been much less favourable. Speech therapy for children, with special refer-

ence to children with a learning difficulty, e.g. Down's syndrome, is only included in some two of the eight speech therapy colleges in the Netherlands. In addition, few speech therapists are familiar with pre-verbal speech therapy. Parents regularly complain that their speech therapist rejects their child because he or she is not speaking as yet, whereas this was the main reason for the parents' request for help. Until only a few years ago, many health insurance companies only started to pay for speech therapy for three years olds onwards, meaning that most of the pre verbal speech therapy was not covered. However, at the present time, the situation has greatly improved. In most cases, the speech therapist will visit the child at home. In the course of the last few years many of them have begun using the Macquarie Program and related materials, as a guideline for their work.

### Parent organisations

The parent organisations in the Netherlands have traditionally been organised very broadly, differentiating on the basis of religion rather than type of disability, meaning that they are umbrella organisations for all types of disability. On a national level, they have joined forces with the Federation of Parent Organisations, or 'the Federation' for short. As such, until very recently, they did not have at their disposal, specific information about Down's syndrome, that parents urgently need in the first few months after the birth of their children. They still merely teach parents to accept, but simultaneously work on topics like e.g. respite care, the acceptance of children with disabilities in general, the attitude of the general public, and fiscal, as well as legal aspects of having such a child. Very close relations have been established between the Federation and the Ministry of Welfare, which is responsible for the care of children with a learning disability.

During the course of 1990, following a suggestion from the Dutch Parliament, the Federation, originally a very strong opponent of syndrome specific organisations, and the SDS, have begun to co-operate. Since then, this co-operation has been gradually growing closer and closer to the benefit of both (de Graaf, 1991).

### Recent developments

#### Macquarie and Portage

In April 1986, the author and his wife, parents of a boy with Down's syndrome born in 1984, visited the third International Down's Syndrome Congress in Brighton, England, where they came across early intervention in a broad sense for their first time. They heard many presentations about the subject and had discussions with proponents of specific programs from various parts of the world. One of these was Moira Pieterse, Director of the Down's Syndrome Program, School of Education, Macquarie University, Sydney, Australia, and the first author of the Macquarie Program. Back home in the Netherlands, they ordered several early intervention programs and studied them, including Portage and the Macquarie program. They were particularly impressed by the 'parent friendliness' of the latter program, not in the least because of the very high quality and very clear instructional videos that came with it. Furthermore, the program not only prepared children for school integration, but for real mainstreaming, because of the inclusion of academic skills like reading, writing and numbers at a very early age. As a consequence, the present author and his wife started to work with the program for the benefit of their own child, thereby gaining very valuable and, for the Netherlands, very unique

experience. Simultaneously, they embarked on a translation of the Macquarie Program into Dutch.

Notwithstanding the apparent advantages of the Macquarie Program, the author and his wife also retained a keen interest in developments around what might be the world's most widely used early intervention program: Portage, not in the least after having read 'Jacob's Ladder' (Lloyd, 1986). Within that framework, in the winter of '86-'87, they came into contact with the Faculty for Special Education at Groningen University. Researchers there were planning a study into the effectiveness of the Portage program, at that time for children with only mild educational problems. In February 1987, the author participated in a Portage workshop in England, together with the researchers from Groningen University, which resulted in his being asked to comment on the first concept of the Dutch version of the Portage checklist. As a result, he received a copy of the adapted semi-definitive version with the explicit stipulation that he would never hand the translation over to other parents of children with Down's syndrome. The planned research studies would first have to be conducted and reported. The unresponsive attitude at Groningen University towards parents of children with a learning difficulty, presented the author and his wife with a further incentive to produce a Dutch version of the Macquarie Program as soon as possible. (At the time of writing, six years later, the official Dutch version of the Portage program is still not on the Dutch market).

#### The Down's Syndrome Foundation of the Netherlands

Very fortunately, in the fall of 1987, Mrs. Pieterse announced her intention to spend three weeks in the Netherlands in May 1988, and she proposed to do some workshops etc. At that time, on several occasions, the author and his wife had suggested the introduction of early intervention in the Netherlands to professionals, as well as to parent organisations. In general, they received rather negative reactions. Therefore, they set to work towards establishing a specific Down's syndrome organisation. As such, they gladly accepted Mrs Pieterse's proposal. In March 1988, the SDS was founded. Its objectives were copied from those decided by the European Down's Syndrome Association, EDSA, in November 1987. Not surprisingly, one of the main goals of the SDS-Committee was the introduction of early intervention in the Netherlands.

During the visit of Mrs. Pieterse, the SDS arranged several workshops and visits to scientists interested in the care of children with disabilities. Thanks to her experience, these were all very successful and provided extensive impetus to the spreading of the concept of early intervention in the Netherlands. Moreover, her presence was of great importance for the recognition of the SDS in its initial phase.

In the summer of 1988, the core of the Macquarie Program, notably the handbook, the Developmental Skills Inventory and the Manual was finished. Because no publisher in the field would take on such a novum as early intervention, the SDS had to publish the program. It did so, by simply photocopying the originals it had made. From the outset, the SDS organised a continuous series of workshops and presentations on early intervention for parents as well as professionals, so helping the former to be able to use the program themselves, while very gradually changing the attitude of the latter. The result has been that the use of the program has

spread over the country like wildfire, first reaching parents, but more and more also the professionals at Practical Educational Family Support, the Special Day Care Centres etc. Understandably, the program is now used for the benefit of an increasing number of children with disabilities other than Down's syndrome. In 1990, the aforementioned video 'Small Steps' was likewise translated and became widely available. In the Dutch version, it has proved to be a very valuable instructional asset, for parents as well as for professionals.

### **Frequently used objections against early intervention**

During the many workshops the SDS has given, there has often been strong opposition to the concept of early intervention, mostly from professionals. Recently, the opinion of professionals became somewhat more positive. Some of the most frequent arguments are listed below.

#### **A. General theoretical arguments against stimulation of the development**

1. Why should one go to all this trouble to encourage developments that will occur of their accord at a later date?
2. Couldn't one better wait until the children themselves indicate when they are ripe to learn the next step?
3. As a result of early intervention, the development of these children might proceed well, but, of course, they still have their limits!
4. Has there ever been any kind of scientific proof of effect?

#### **B. Restrictions of early intervention programs with regard to their content**

5. Your program is no good. Its steps are far too big.
6. Early intervention programs are directed too much towards stimulating cognitive development. As a result the social-emotional development of the child stands less chance.
7. Isn't such an early intervention program only suitable for the brightest (the better functioning children)?

#### **C. Educational objections**

8. Aren't expectations raised too high with early intervention?
9. Early intervention implies unremitting training.
10. Isn't such an intensive training program too much for parents? I have heard of entire families breaking up because of it.
11. Early intervention takes away the spontaneity of the education.

#### **D. Restricted applicability in professional support**

12. What early intervention? Please start off by accepting your child!
13. Such a program might work in the home, or at least in a one to one situation, but it is not acceptable in the group situation at our special day care centre.
14. We are reluctant to apply early intervention, because what should one do when the child has outgrown the program?
15. Early intervention is OK, but only as a support system in the short term. As soon as the situation in a family with a child with a handicap has been accepted and is back to normal, the support will have to be decreased. In most instances this is the case after some six or seven months.

discussion of these points. This is done elsewhere (Anonymous, 1993).

### **The Pilot Project**

In the fall of 1988 the SDS was asked to give a presentation of the Macquarie Program at a very high level in the Dutch Ministry of Welfare. It had a very positive response: the SDS was asked to produce a policy document which it would elucidate how, in the view of the SDS, early intervention could be implemented nation-wide. In the resulting document the SDS outlined its plan to gradually introduce home based intervention with weekly professional assistance, for many years at a stretch, on the basis of the Macquarie Program. Gradual introduction was considered necessary, because of manpower limitations within the Practical Educational Family Support (PPG) services. (In the meantime, of course, the SDS would continue its own efforts to enable parents to help themselves without professional support). The SDS proposal led to the establishment of a working party of professionals in the Greater Rotterdam area, which was to set up a local pilot project in the form of a feasibility study. It was designed to support 75 young children with a developmental disability for a period of two years, on the basis of the Macquarie Program. At the same time, a scientific study into the effect of the intervention would be conducted. However, just as the grant necessary for this project was to be applied for from the Ministry of Welfare in the summer of 1990, the Federation of Parent Organisations, which in the meantime had also developed a keen interest in the concept of early intervention, took over the leading role in the project.

In the course of that year the Ministry proposed that the original project be split up into three sub projects. This led to the SDS in Rotterdam using the Macquarie Program (with a planned 40 children annually), the SDS in Alkmaar using the Portage program (with 20 children annually), and that of Uden applying 'typical' PPG (with 20 children annually). A scientific comparative evaluation would have to be part of the project. In conjunction with the Federation, the national umbrella organisation of the SPD's, SOMMA, was involved in the project as was, of course, the SDS, its originator. As such, the author participated as a member of the scientific as well as the practical support committee. In addition, the SDS was largely responsible for the training of the professionals in the Rotterdam area, using the Macquarie Program. In the summer of 1991, the first intakes of children took place.

Very briefly, the protocol of the pilot project is as follows:

- intake
- first Bayley test
- 2 months without support
- second Bayley test
- 6 months support by a home visitor (once per week) or longer, up to 10 months with less frequent visits.
- third Bayley test
- 6 months without support
- fourth Bayley test

In addition to the four Bayley tests, many child and family variables are recorded simultaneously in the various phases of the protocol.

The ministry of Welfare originally intended waiting for the results of the pilot project before deciding to give the green light (for extra money) for nationwide implementation of

Unfortunately, the scope of this article does not allow for

early intervention. However, in the meantime, two opposing tendencies have emerged. On the one hand there are fewer children than originally anticipated, due to unforeseen reasons, which has necessitated prolongation of the pilot project in order to arrive at adequate numbers from a statistical point of view. On the other hand, the attitude at the Ministry has changed. The latter appears now willing to give the go ahead, most probably per January 1st 1994, even if the results of the pilot project are not yet then available.

### **Present figures**

To keep things in perspective, it is as well to know that at the present time the annual number of live births with Down's syndrome in the Netherlands can be estimated at 230 (1989). Assuming that the Down's syndrome population is about one quarter of the number of potential candidates for early intervention, this latter number might be estimated at 1000 annually. Knowing, furthermore, that the Macquarie Program is dealing with the first five years of nominal development, a rough first estimate of the total number of children which could simultaneously be enrolled in whatever phase of the aforementioned early intervention program (or another long term program) for children with a mental handicap in the Netherlands, is about 7500.

Against this background, some figures of the present situation might be helpful in judging in how far the concept of early intervention has rooted in the Netherlands after more than six years of extensive promotion, at first by the SDS and its predecessor only, and, latterly by others. When making a rough estimate, we have to distinguish the following four levels of support with the related number of enrolled children:

#### **1. Children participating in the separately funded Pilot Project in the three regions.**

At the present time the total number is estimated at about 70, while it is expected that the prolonged program will support 120 participants. Great care is taken not to have a majority of children with Down's syndrome in the project.

#### **2. Children supported by an early intervention program within the normal PPG budget.**

As a result of the nationwide inquiry among about 1000 parents of mostly young children with Down's syndrome, it appeared that 686 of the 732 respondents reportedly knew what early intervention meant. Of these 17% (119) were working intensively with an early intervention program, or had been doing so since 1988, whereas 43% (294) reported to do so every now and then. Only 38% of the parents actually working with a program ( $0.38 \times 119 + 294 = 156$ ) received (or had received) support from professionals [1]. During a course on early intervention for special educators of the PPG, the author received the impression that the number of children presently supported was very much lower than this figure, with the number of children with Down's syndrome being of the same order of magnitude as that of the children with other handicaps.

#### **3. Children supported by an early intervention program under the guidance of physiotherapist or speech therapist.**

From the inquiry it is known that 65% of the 732 children received physiotherapy and 69%, speech therapy at one time during their lives. It is not known, however, how many of these were using an early intervention program. The only thing that can be said is that this type of professional support

is probably predominantly motor or speech development directed, and can hardly be considered complete support.

#### **4. Children supported by an early intervention program without professional assistance.**

This is the remaining 62% of the  $119 + 294 = 257$  children with Down's syndrome. Only very few parents of children with handicaps other than Down's syndrome are aware such a thing as an early intervention program exists in the Dutch language. Therefore the number of children in that group, whose parents are working with a program, but receiving no professional support, is probably negligible.

From the foregoing figures, however incomplete, it becomes clear that the backbone of the total group of children with developmental delays supported by an early intervention program is made up of the group of children with Down's syndrome whose parents work on their own. The group receiving professional support is a minority, whereas that support is often only relevant to one specific developmental domain.

In the opinion of the author, the main problem in the future situation in the Netherlands is dealing with the preferred duration of the intervention. Time and money restrictions for the pilot project dictated a protocol with only a short term intervention from the outset. This has led people in the Netherlands to believe that early intervention is a short term way of support, whereas the author, on the basis of the experience gained within the SDS and elsewhere, strongly believes in the advantages of support in the long term. In defence of that, it is good to draw attention to all the changes that have taken place in the last few years in the Dutch Down's syndrome scene. Undoubtedly, the introduction of early intervention to young parents has been one of the most important factors. It has enabled much more mainstreaming (also heavily promoted by another syndrome specific organisation, the Association for an Integrated Education of Mongoloid children, or VIM for short), at least in the early years, and therefore resulted in much less use of expensive special facilities. It can fairly easily be computed that this has saved the Dutch tax payer millions of Dutch guilders so far!

#### **The Down's syndrome Team**

After an original suggestion by the author to initiate a Down's syndrome Preventative Medicine Clinic in the Netherlands, the co-ordinators of the local branch of the SDS in the Rotterdam/The Hague area managed to organise the first operational Down's Syndrome Team in the Netherlands in the course of 1991. Its purpose is to offer the possibility of regular, syndrome specific health check ups, as well as the resulting recommendations for treatment to their local practitioners at home, to young children with the syndrome, right from birth. The medical professionals and therapists, who are most important for children with Down's syndrome, work within the team. It is presently on duty every first Saturday of the month. As a result, a continuous co-ordination of the health check up takes place. In the first year of its existence almost 100 children between 0 and 11 years of age visited the Team, in which two paediatricians are playing the central role. To the author this seems a fine example of syndrome specific early intervention in a broad sense. For organisational reasons, it was decided to organise the Down's Syndrome Team within a separate foundation with very close ties with the SDS.

### Information

A final example of syndrome specific early intervention in a broad sense is the availability of good quality information. Since its foundation the SDS itself has published, amongst others, a Dutch version of an entire early intervention program, notably the Macquarie Program, together with the accompanying instructional videos, a book on speech and a book on reading and writing for children with Down's syndrome. At the present time the successor of the Macquarie Program is in production. Further, there is the quarterly SDS newsletter, which has appeared for five years, steadily increasing in volume and circulation. Furthermore, the SDS has co-operated in the compilation of the Dutch version of the book on Down's syndrome by Cunningham (1991) and in a brochure on breast feeding by La Lèche League (Good, 1991).

### Conclusions

In conclusion, it can be said that the introduction of early intervention in the Netherlands is a fine example of the important role that syndrome specific organisations can play. Much of the research justifying early intervention, has been conducted with children with Down's syndrome. In the Netherlands it could have remained undiscovered for many years by a non syndrome specifically oriented care system. Once early intervention had been introduced by the relevant syndrome specific organisation, it appeared to hold clear promises as a way of support for children with all types of handicaps. Extrapolating this experience, one can postulate that the example of the Down's Syndrome Team will serve a comparable purpose. In due course special teams for other handicaps will be successfully established. The same arguments hold for the production and distribution of syndrome specific information. Sooner or later particular treatments and particular ways of support, developed for one particular condition or syndrome, will prove to be ben-

eficial to other conditions or syndromes as well, while initially needing a substrate of its own, to allow for its discovery and development.

Furthermore, early intervention in a strict sense has proved to be a very delicate subject to introduce into the Netherlands. However, after many years of struggle, now, finally, there is a light on the horizon.

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## Computers and Children with Down's Syndrome: An Introductory Guide for Parents

by Rebecca Stores

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