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### The development of children with down syndrome: the influence of maternal adaptation, mother-child interaction and early forms of support

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# The development of children with Down syndrome: the influence of maternal adaptation, mother–child interaction and early forms of support

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## ABSTRACT

In this paper, we present a longitudinal case study involving four dyads with babies with Down syndrome from birth until the age of 7 years – the moment at which the children were observed for the last time before they began compulsory schooling. At each data collection point, the mother was given a semi-directive interview and we filmed a free interaction situation. The objective of our study was to carry out an in-depth analysis of the ways in which mothers adapt to the birth of a ‘different baby’, the evolution of their expectations in relation to the child’s development, mother–child interaction and early support for both the child and the family, and the way in which these aspects of the overall situation relate to the children’s development. The data of our longitudinal study show that there is an interaction between children’s development and family characteristics and patterns, particularly mother–child interaction and the way in which the mother deals with the stress factors associated with the fact that she has a disabled child. We found that the four dyads experienced different models of early support, which to some extent reflect what really does happen in Portugal in cases involving children with disabilities, and that the programmes’ impact was not identical in every situation. The most successful was the one which best suited the family’s wishes, and involved both the mother and later on the kindergarten teacher.

## KEYWORDS

Down syndrome, mother–child interaction, maternal adaptation

## INTRODUCTION

Whether children are at risk or disabled or in a normal developmental situation, it has been shown that their development cannot be studied without looking at the particular contexts in which they live and are brought up.

According to the ecological model (Bronfenbrenner, 1989, p. 191), development is defined as: *the set of processes through which properties of the person and the environment interact to produce constancy and change in the characteristics of the person over the life course*. This author views the context of development as a hierarchy at four levels – micro-, meso-, exo- and macrosystem – from the most proximal to the most remote. In a transactional perspective, development of the child is defined as: *a product of the continuous dynamic interactions of the child and the experience provided by his or her family and social context* (Sameroff and Fiese, 2000, p. 142).

Within this theoretical framework, and considering mainly the more proximal system – the family – two other models seem of interest to our study, as they point out the importance of the quality of the parental function in the development of children. Belsky (1984) describes a parenting model in which he considers that the parental function is directly influenced by factors that are intrinsic to the particular parents involved (i.e. each one's personality), by the individual characteristics of the child him/herself and by the social context into which the parent-child relationship is incorporated.

Guralnick (1997, 1998) offers us a similar model in which he also considers that children's development is directly related to their family's characteristics. According to this model, the various influences engendered by those characteristics are mediated by family patterns. The parents' personal characteristics, family and conjugal relationships, the support the family receives from society, financial resources and the child's temperament are just some of the aspects that influence family patterns. In the case of children who are disabled or at risk, family patterns are also influenced by stress factors derived from the situation itself – especially added needs for information and resources and personal and family feelings of unease which, in turn, result in diminished self-esteem and feelings of competence.

When working with disabled children, it is particularly important to study the process via which mothers adapt to the birth and development of a 'different baby', parents' perceptions of their children and the interactive processes that arise between the two.

Where the first of these aspects is concerned, several authors talk about the different phases parents go through in their adaptation process – initial shock and denial, feelings of loss, anger and depression and, ultimately, acceptance of the situation – explaining them through linear models (Brown, Thurman and Pearl, 1993; Crnic, Friedrich and Greenberg, 1983; Hodapp, 1988; Peterson, 1988; Roll-Petersson, 2001; Tanaka and Niwa, 1991) and inspired by the classic work of Solnit and Stark (1961).

The interaction that parents establish with their children appears to be influenced by the former's perceptions (Skinner, 1985). The studies reviewed by Smith *et al.* (1985) have concluded that the mothers of disabled children differ from those of normal children in the way in which they see their offspring, their expectations in relation to milestones in the children's development and their own feelings of effectiveness and competence.

Mothers' perceptions of their children's characteristics, their self-perceptions of their own competence, the assistance provided by the family and the social support network also all seem to have a decisive influence on mothers' feelings of stress (Sarimski, 1996).

Some studies on mother-infant and mother-child interactions have concluded that mothers of handicapped children show a higher degree of directiveness, trying to

stimulate their child and compensate for their lack of responsivity (Crnic *et al.*, 1983; Marfo, 1988; Peterson, 1988). Mahoney (1988a, 1988b) and Mahoney, Fors and Wood (1990), present us with a new approach concerning maternal directiveness showing that it only has positive effects if it is simultaneously responsive and contingent with children's behaviour.

Moving on to Early Intervention, we must point out the importance of the work by Meisels and Shonkoff (1990) and Shonkoff and Meisels (2000). One outstanding text on research into the effectiveness of early intervention is Guralnick's book (1997). Especially important where our current work is concerned is the chapter by Spiker and Hopmann (1997), who not only address the issues surrounding studies on the specific characteristics of Down syndrome children, but also offer transversal and longitudinal research on their development, along with some results of the implementation of early intervention programmes.

In the same field of research, Shonkoff *et al.* (1992) and Hauser-Cram *et al.* (2001) offer us a model with which to evaluate the changes that take place in disabled children's development and the adaptation process that their families go through during the first ten years of the children's lives. In doing so they address many of the issues we refer to above.

In Portugal there is a great lack of research concerning all of the above. As far as we know, there is no empirical work studying the attitudes of parents to children with disabilities, and although in the past 30 years the trends are towards the inclusion of children with special needs into mainstreaming (Bairrão *et al.*, 1998; Costa and Rodrigues, 1999), no work has been published on the feelings of parents regarding this issue.

In what concerns Down syndrome children, it is worth mentioning the studies conducted by Coutinho (1999) and Leitão (1994). These authors have carried out major reviews of the literature on Down syndrome and have respectively presented the results of research in the parental training and mother-child interaction fields, using sample groups of children with Down syndrome.

In previous work (Pimentel, 1997),<sup>1</sup> we conducted a longitudinal research with 12 children and their mothers in the first year of life (five Down syndrome, three pre-term and four normal children). Our objective was to carry out an in-depth analysis of the ways in which mothers adapt to the birth of a 'different baby', the evolution of their expectations in relation to the child's development, mother-child interaction and early support for both the child and the family, and the way in which these aspects of the overall situation relate to the children's development.

It was a qualitative case-study research (Yin, 1984), and most of the data were collected from interviews with mothers and video tapes of mother-child interaction. Although we used an adapted Codrenau's *Scale of Maternal Child Care Attitudes and Feelings* (1984, quoted in Engfer and Gavranidou, 1986), as it had not been adapted to our population, we looked at the quantitative data purely as indications of the variation of maternal feelings.

The qualitative research described in this paper refers to the same Down syndrome children<sup>2</sup> as in our previous work. We present data about the children and their families from birth until age 7 years – the moment at which the children were observed for the last time before they began compulsory schooling.

## METHOD

The participants in this study were four children with Down syndrome (three with free trisomy and one with a translocated chromosome 14), all of whom were born

between February and April 1994, and their mothers. All the parents were married or living together at the time of the children's birth.

In the first year of the children's lives the dyads were observed during the first 48 hours and then at months 1, 3, 6, 9 and 12. In their second year they were observed at months 15, 18 and 24. In the third and fourth years they were observed twice during each year – half-way through and then on a date near their birthday. After that, we saw them only once a year, close to their birthday. At each data collection point, the mother was given a semi-directive interview and we filmed a free interaction situation.

The objectives of the semi-directive interviews were:

- to study the ways in which the mothers had adapted to their children's temperament and development;
- to study the evolution of each child's competencies, and the mother's familiarity with and adaptation to that evolution and her expectations concerning her child's future development;
- to study the mothers' emotional state and the way in which their feelings, educational attitudes and parental practices had evolved.

Although the objectives of the interviews remained constant, in order to cover the developmental aspects of older children the scripts were altered as more data were collected (especially from the fourth year onwards).

Each year the mothers graded their feelings and attitudes on a scale that was used from the first month onwards. It was adapted from Codrenau's *Scale of Maternal Child Care Attitudes and Feelings* (1984, quoted in Engfer and Gavranidou, 1986). From the second year onwards, we modified and reformulated a number of items concerning behaviour that is specific to babies and adapted them to older children, while retaining the same five focuses: Empathetic enjoyment of the child, Overstrain, Frustration, Overprotection and Depressiveness. On all five subscales, higher results signify more positive feelings.

The intention behind video taping a free interaction episode was to evaluate the interaction from a global viewpoint, albeit paying particular attention to both the maternal qualities referred to in the Goldman and Johnson-Martin (1986) adaptation of Crawley and Spiker's (1983) *Mother-Child Rating Scales* – Pacing, Developmental appropriateness of play, Readability of the mother and Intrusiveness – and an overall assessment of the adult's involvement with the child, based on five parameters from Farran *et al.*'s (1986) *Parent/Caregiver Involvement Scale* – Availability, General acceptance and approval, General atmosphere, Enjoyment and Provision of a learning environment. Each child's development was reviewed annually using Griffiths's *Mental Developmental Scale* (Griffiths, 1954).

As in our comparative study (Pimentel, 1997, 1998), for each dyad we have opted to present the main themes we focused on at each moment in the data gathering process: the mother's dominant feelings, the results on the feelings and attitudes scale, the characteristics of the interactive process, familiarity with the baby's development and expectations in relation to future development, the results on the Griffiths scale and the Early Intervention programme.

## DATA FROM THE LONGITUDINAL STUDY

### 1. Catarina and her Mother

Catarina is the couple's second daughter (she has a sister who is two years older) and was born when her mother was 29 and her father was 33. Both parents possess

university degrees. When Catarina was around 3.5 years, her mother gave birth prematurely and the baby did not survive.

When talking about Catarina's birth, her mother said:

'After they told me she was like that, that half-an-hour before I saw her was horrible and is still here inside. It is as though I don't feel fulfilled by being a mother. There is something wrong that I can't explain. There is a [feeling of] frustration.'

Catarina's mother made the first statement that we have chosen to quote here in the form of a commentary on one of the items in the *Maternal Child Care Attitudes and Feelings Scale* at month 6. It represents the only time that this particular mother admitted to a feeling of frustration during the first year of her daughter's life.

She maintained her denial of both her daughter's disability and her own depression until the interview at point 3;6 (inclusive). It was only during the fourth-year interview that she told us what had happened in the previous six months:

'After you had been here last time I fell completely apart...I started drinking...I don't even know if I want to keep on living with my husband...It was a lot of things all at once...I never cried when Catarina was born... Perhaps this should have happened earlier... Then I lost the baby... My parents, above all my mother, always thought I wasn't worth anything... I never do anything right and I'm not a good mother... I try to hide my suffering from everyone. However bad I feel, I still laugh and yet I'm still criticized on top of it all... The only thing they know is how to put a person down.'

The depression that we had been fearing since the first year of Catarina's life had finally appeared and her mother was now capable of talking about Catarina's late development and of facing up to it in the presence of others. It can certainly not have been a coincidence that it was only after this interview that the mother was able to send Catarina to kindergarten – a decision that had always been put off for the widest variety of reasons, but which from our point of view was simply explained by the mother's inability to face others. The truth is that for something like three years Catarina's mother had never talked to any of the couple's friends about her daughter's disability. She always used to say:

'I can't face other people and tell them what's happening yet. When the time comes, people will find out...'

In subsequent interviews the mother confessed that she continued to experience difficulty with the fact that everyone noticed her daughter's disability:

'The most difficult step was putting her in the kindergarten. It's still hard. If parents go there, they start looking at her and at me... When I go out I never feel relaxed...The fact that the disease is so stigmatizing revolts me. I would like to have her operated on.'

It should be pointed out that the latter phrase was spoken during the seventh-year interview, which shows that the wound was still wide open.

It is curious to note that over the course of these seven years, Catarina's mother always used the statements on the *Maternal Child Care Attitudes and Feelings Scale*

on which she had to comment in order to express her own feelings, but that she rarely did so during the semi-directive interviews. This mother scored quite high results on the 'Empathetic enjoyment of the child' and 'Frustration' subscales throughout the period under analysis. Her results on the 'Overstrain' subscale were lower and varied over the years; and those on the 'Overprotection' and 'Depressiveness' subscales reveal the feelings that she always tried to cover up, and a substantial fall on the 'Depressiveness' subscale at the fourth year clearly reflects the situation she was going through at the time.

During all those years, we witnessed a mother-child interaction that was marked by a great degree of interactive harmony, in which both the mother and Catarina were completely available for social interaction. The play that the mother initiated matched Catarina's interests and was suited to her level of development, which meant that not only did the child adhere to her mother's initiatives, but also took new ones which the mother, in turn, accepted and responded to with sensibility and in a contingent manner. Catarina's prolonged attention spans made it possible for play to last a long time, to the clear delight of both mother and daughter. Despite the fact that the mother said that she did not want to teach Catarina anything, both her attitude and the materials and activities she chose during the interactive episodes provided her daughter with a stimulus that was suited to her state of development.

During the interview we conducted while she was still in the maternity wing, the mother stated that Catarina's development would be the same as that experienced by a normal child until she went to school. All the various aspects of the mother's dominant feelings that we have focused on here make it easy to see that she always talked to us about Catarina's development as though it would proceed normally. Her assessment of her daughter's competencies and acquisitions was always very poorly adapted to Catarina's real development in the areas that we observed when we applied the Griffiths scale.

During the first year of her life, Catarina possessed a Development Quotient (DQ) of 83. The successive Griffiths scale results show that it was between the second and third years of life that she experienced a substantial decline in her development, above all in the motor development and language areas. In subsequent years, the results in the various different areas of development were more homogeneous. At the age of 7 years, her overall DQ was 58.

In the month-1 interview, Catarina's mother immediately asked us for information about the services that were available to her, and before Catarina was 3 months old, she had already been assessed by an official service which offered domiciliary support that the mother apparently accepted. However, in practice, this support was rarely provided. When it came down to it, Catarina's mother either cancelled visits on the widest possible variety of pretexts or forgot them. When by chance they did take place, the early intervention provider who was responsible for the case found a mother who said that Catarina was very well and that she herself was not experiencing any difficulties in dealing with her daughter. It is also worth noting the very unusual attitude which this mother had towards early intervention:

'I stimulate her and teach her things as little as possible, because she has to manage by herself.'

It was obvious to us that Catarina's mother was teaching her all sorts of things, but she always wanted to make us believe that Catarina learnt everything as easily as her other daughter had done.

The decision to delay going to school was taken almost exclusively by the special teacher and the mother only 'agreed' to it with some difficulty. We also believe that

the clearly lower scores which the mother obtained on the 'Overprotection' subscale of the *Maternal Child Care Attitudes and Feelings Scale* were related to Catarina's going to school – an event which had originally been planned for the age of 6 years, but only actually took place a year later. The choice of her daughter's school was also a painful period, in as much as the plan to send her to the same one as her sister turned out not to be possible.

## 2. Helder and his Mother

Helder is the first child of a couple with nine years' schooling. His mother was 35 and his father 22 when Helder was born. The mother had a 12 year-old daughter who lived with them, and when Helder was around 5 years, his parents had a healthy daughter.

Anxiety, depression, a feeling of revolt, isolation and frustration were the mother's dominant feelings during the first years of Helder's life. Although her emotional state went up and down during the first interviews, some degree of depression and anxiety was always evident:

'The problem exists and no one wants to face up to the situation. When I say anything, my husband says "there you go with that obsession". We don't talk about the problem of Helder ... I'm very tired after everything that has happened this year ... I'm still very upset. I'm going to feel that hurt for ever ... I feel stressed. I don't have anyone to help me ... Sometimes I just feel like crying.'

The pain which the birth of this baby represents has persisted throughout all these years and is clear from statements like:

'When I think about the birth, the surprise, the disillusionment [2 years], only someone who has been through this knows ... it's something I can't get over ... it was difficult and it still is [3 years] ... there are times when I say that I have accepted it, but I see that I am fooling myself [4 years] ... I accept him 200 per cent, but I think that I am never going to get over it [7 years].'

When Helder was 12 months old, his mother scored very low on the 'Overprotection' and 'Depressiveness' subscales of the *Maternal Child Care Attitudes and Feelings Scale*. This reflected her feelings of great anxiety and depression at that time, and although there was some positive change in subsequent interviews, her average scores almost always remained below the mid-point on the scale. The results on the remaining subscales were always higher, although the 'Overstrain' subscale went up and down considerably. The mother often said that she felt very tired, but immediately added that this fact was not due to Helder, but rather to her work and domestic situation, in which she felt that she was making the greater effort.

At the end of the first year of life, this was the dyad in relation to which we felt that the adaptation process was most at risk. From 9 months up until the 3;6 interview, all the interactive episodes we witnessed were marked by signs of disharmony and very often a general atmosphere of conflict was manifest. During various interviews, we witnessed situations in which the mother was aggressive towards Helder and he responded by 'attacking' her, hitting her, trying to scratch her or pulling her hair. We did not feel that there was any availability for social



interaction on the part of either of the members of the dyad, and it often seemed to us that the games they played in our presence were not their daily norm. The mother's behaviour was very disorganized. She jumped from one activity to another without sequence, trying to capture Helder's attention and interest in ways that were unsuccessful except when she played with a ball or allowed him to ride a tricycle. Whenever she tried to read him a story or play games fitting things into one another, her response requests were completely unsuited to Helder's developmental competencies.

From the 3;6 interview onwards, there were some changes in Helder's behaviour and he was able to pay attention to the activities his mother proposed for a few minutes at a time, but the contents of the play never underwent any significant changes and the symbolic content of the activities was extremely poor. We think that the absence of a suitable teaching environment and the mother's poor stimulatory qualities, together with the interactive disharmony which characterized this dyad until Helder was 3.5 years, had a very negative influence on this child's development.

It was during the first year of his life that Helder's mother already began to realize that her expectations in terms of the age at which he would acquire given competencies were constantly being frustrated. When she was asked to describe Helder, the first things she mentioned were his negative characteristics:

'He doesn't stop for a minute, you always have to be after him... it's crazy, it drives me up the wall... when he doesn't get what he wants he raises his hand to hit and he bites people... I do the wrong thing, in that I let my arm be twisted and I do what he wants... I smack him and he smacks me too... he has to be the last one to give a smack...'

The evaluation with the Griffiths scale was a difficult time. The fact is that Helder rarely cooperated with the tasks that were proposed to him. When his mother was present – something that from a certain point onwards we tried to avoid – she interfered with the performance of the tasks, gave him orders, got angry and insisted too much, in an attitude that demonstrated the frustration she felt at seeing her son's difficulties. Although at 12 months Helder's overall Development Quotient was 77, there was a very substantial fall between the ages of 2 and 3 years. After that, there were smaller but systematic decreases in every subscale, especially in those related to hearing and speech, hand-eye coordination, performance and practical reasoning. At the age of 7 years, his overall DQ was 42, with a particularly low result in relation to hearing and speech (DQ 26).

Following an appointment at an official service when he was around 3 months old, Helder was placed on an Early Intervention programme, which began at home at the age of 6 months. The assistance was centred on the child, however, and took the form of 'competency training'. Despite the fact that before he was 1 year old, we called attention to the interactive disharmony that was manifesting itself, this aspect of Helder's situation was not adequately worked on. The only time specific support was given to the mother, it emphasized behaviour modification and providing educational competency training to the mother and so sufficient attention was not paid to her anxiety and latent depression.

From the moment when Helder started to go to kindergarten, the home visits ceased and the whole programme was conducted in the educational context. The mother took no further part and thereafter never again had regular contacts with any support specialist.

The decision was taken to put off going to school for a year and the programme continued throughout that period, but the mother remained completely uninvolved

in what was being done. When Helder's seventh birthday arrived he was still finding it enormously difficult to concentrate and the special teacher wanted him to go to a special school – a fact which the mother refused to accept. In the last interview, she heaped blame on all the work that had been done by the kindergarten and the support teachers, whom she held responsible for the fact that Helder was still behind and for his behavioural problems and instability. It was not easy to find a solution for Helder, especially when it came to complementary activities outside regular school hours, and once again, his mother felt completely alone and without assistance of any kind to help her resolve yet another problem.

### 3. João Paulo and his Mother

João Paulo is the first common child of a couple who only went to school for six years. The mother was 35 and the father 36 when João Paulo was born and both already had children from previous relationships. Only the siblings on the mother's side, who were already teenagers, kept in touch. In the second year of João Paulo's life his father left the country and over the years his contacts with the family became increasingly sporadic.

When she recalled the initial shock of hearing about João Paulo's disability, his mother said:

'What I went through was horrible, but it was above all during those moments in the hospital ... the shock was the news itself ... I didn't even want to see him ... They described him as though he was going to become severely disabled ... when I got home, I gradually got round to the idea ...'

When João was only 2 years old, his mother was already saying:

'I'm worried about the future, about school, but given that he is an attentive child who concentrates, listens and likes to do things, maybe there won't be a problem. I'm getting more worried ... I don't know if he will talk properly ... If I'm not there any more, what will he do?'

The difficulties she had to deal with in order to get a kindergarten to accept João and the point at which he first went to school were moments when she relived with anguish the feelings she had had when she had been faced with her son's disability:

'I feel like I did at the beginning ... I never thought I would go through this again.'

In the *Maternal Child Care Attitudes and Feelings Scale* it was the 'Overprotection' subscale that displayed the widest discrepancies between this mother's results. They revealed excessive levels of anxiety, but only at some of the data gathering points. It seems to us to be of interest to note that the lowest score, which occurred during the first month of João Paulo's life, reoccurred in the seventh year, probably as a consequence of the fact that it was then inevitable that he would go to primary school. Throughout the observation period, the mother's scores on all the other subscales were both higher and more homogeneous and always revealed positive feelings.

The most significant characteristic of the interaction between João Paulo and his mother was the great pleasure which both of them derived from the interactive

situation. The interaction was clearly led by the mother, but João Paulo followed all her proposals and collaborated in the games, in which she in turn allowed herself to become involved. His mother's responses did not always match João Paulo's initiatives – they were sometimes even anti-contingent – but we never witnessed any conflictual episode in any situation at any time. On most occasions the content of the activities proposed by the mother was not rich from a symbolic viewpoint – that is, we never saw her spontaneously pick up a book to tell João Paulo a story or show him the pictures – but there were sometimes doll's-house type games in which he understood and imitated all the activities his mother had begun.

The general atmosphere was very harmonious not only as regards the pleasure they both felt and which we mentioned earlier, but also because of the very complementary comments which João Paulo's mother made about him and the way in which she said:

‘He is a superman when it comes to learning ... He is a jewel of a child, a lovely João who makes me laugh and makes me happy.’

João's mother, who was always able to objectively assess his competencies, progressively became aware of the delay in his development and avoided making prognoses about the future.

Although there were always a few tantrums and complaints that João Paulo was very stubborn, it was only from the sixth-year interview onwards that his mother began to display a lot of concern about his behaviour. At the age of 7, the problems had not been overcome and the mother was beginning to doubt herself because she thought that this behaviour was due to the educational attitudes she had taken in relation to her son:

‘When he doesn't get what he wants he lies on the floor and attacks me and his siblings ... He's always getting smacked ... I don't know if it's due to his problem or if he's just like that ... I don't know if it's my fault, if I cuddle him too much or pay him too much or too little attention.’

During the data gathering sessions and particularly the evaluation with the Griffiths scale, João Paulo's behaviour was entirely suitable, he displayed interest in the tasks that were proposed, collaborated with them well and made an effort to carry them out. At 12 months, João Paulo possessed an overall Development Quotient of 82. However, the results of the ‘Hearing and speech’ subscale were substantially lower than those for the other subscales. What is more, they have since suffered a significant further decrease. The development quotients on the ‘Locomotor’ and ‘Performance’ subscales remained quite homogeneous until the sixth year of life, when they also underwent a significant fall. The reduction in the ‘Personal-social’ subscale occurred early on, during the first and second years of life, but the DQ values for this subscale then remained homogeneous until the age of 7. The ‘Hand-eye coordination’ subscale and the overall Development Quotient fell between the second and third years of life. The development of the various different areas thus displayed quite inhomogeneous values at different times in João Paulo's life and it was only during the seventh year that the figures for the sub-quotients came closer together. The exceptions were the ‘Hearing and speech’ and ‘Practical reasoning’ subscales, on which his scores were always considerably lower than those he obtained on the other subscales. At the age of 7 years, his overall DQ was 53.

João Paulo's situation was initially supported via home visits by a nurse with early intervention experience. The programme applied a family-centred perspective which, besides stimulating João Paulo, also addressed all the other issues that worried the mother: her husband's emigration, problems with her older children and a poor-quality housing situation. Once João Paulo started to go to kindergarten, this assistance began to be provided within the scholastic context and his mother only participated very sporadically. We think that this change in the way in which the support was focused – from the distinctly family-centred perspective pursued during the initial years to a child-centred programme – was not beneficial for either João or his mother. The fact is that it was during the transition year that more behaviour-related complaints began to arise, and it seems to us that they were clearly related to a less correct educational behaviour on the part of the mother.

#### 4. Mariana and her Mother

Mariana is the first child of a couple who both possess higher education. When she was born, her mother was 28 and her father 26. A healthy sister was born when Mariana was around 2;6. When she was 6 years, her mother had a miscarriage.

Two statements by Mariana's mother offer a good summary of the way in which her feelings towards her daughter evolved. They are both from the third-year interview:

'I have been learning to be Mariana's mother ... When I go to the school to fetch her, I always feel very happy because I see that they like her ... There are times when I feel very happy with both my daughters, with no distinction between them.'

The mother recognized that the birth of the younger sister was very important to the whole adaptation process and that having a normal baby was a 'good experience' to which she and her husband felt that they were entitled.

Where facing up to other people was concerned, the mother overcame her initial feelings of shame, but from time to time they came back:

'A few days ago, I got very worried about what other people thought of her. Then I felt remorse and was very irritated with myself. It was as though I had had a relapse, but it was only for one day ... I came home upset about it, but I talked to my husband and it passed.'

From the age of 4 years onwards, the mother began to worry about Mariana's going to school, although she also said:

'I learnt to do things in their own time without always thinking about the future ...'

The mother recognized that as the day when Mariana was due to begin primary school – something that took place when she was 6 years – drew nearer, her nerves really got on edge. She became pregnant and lost the baby at 7 weeks:

'I think it was the stress I was under about the two girls going to the new school.'

The results that Mariana's mother obtained on the *Maternal Child Care Attitudes and Feelings Scale* remained quite high and homogeneous over all these years. This is particularly true of the 'Overprotection' and 'Depressiveness' subscales, on which her scores were much higher than those of any of the other mothers in our study, thus revealing an absence of anxiety and depressive feelings.

The high degree of availability for social interaction, the quality of the stimulation she gave Mariana and the great harmony between mother and child are perhaps the main characteristics of this dyad's interactive process over the years. Mariana's mother displayed great sensitivity to and knowledge of her daughter's interests and always managed to interest her in tasks that were stimulating from the cognitive point of view, were always suited to her level of development and possessed a clear symbolic content. As soon as her sister was old enough to play with Mariana, their mother always involved both of them in the games and taught them to share and to respect each other's pace.

From the very first interview in the maternity wing, this mother was able to match her expectations about Mariana's development to the fact that the child had Down syndrome. During the interviews we conducted over the course of the seven years, she always displayed a detailed knowledge of both Mariana's competencies in the different areas and aspects of her development and the various types of evolution she had achieved since the previous interview. She was also able to rigorously assess her daughter's development compared to that of a child who did not have her disabling condition. The great majority of the successes that we obtained from Mariana during the evaluation with the Griffiths scale coincided with what her mother had told us she was capable of doing.

At the age of 12 months, Mariana's overall Development Quotient on the Griffiths scale was 83. We observed it decrease over the seven-year period, but the greatest fall took place between 24 and 36 months. After that, the various quotients either stabilized or increased slightly and, at the age of 7 years, her overall DQ was 65, albeit with substantially higher scores in the 'Personal-social' and 'Hearing and speech' areas. The level of Mariana's language is clearly superior to the norm for children with Down syndrome and is a factor that facilitates the whole of her social and scholastic integration.

During the first month of Mariana's life, her mother went to various services – some of which we had told her about during the first interview and others that she had discovered by herself – and made a conscious choice in relation to the assistance that satisfied her best: monthly support from a psychologist belonging to a private agency.

Although all the work, which continues to this day, was always carried out in the presence and with the collaboration of the mother, we cannot say that the assistance programme was family-centred, but we can state categorically that this mother saw herself as the decision-maker in the whole process. Some of the things she said over the years clearly denote this role:

'There was a time when I worried about stimulation a lot ... now I try to ensure that the moments when I play with her are pleasant for both of us ... I bought her some didactic games and we're teaching her ... The psychologist has insisted a lot on the "learn to read to learn to speak" programme, but we got really fed up with the job of reading the names, and so did she, so we haven't persisted with it ... The psychologist has been a great source of support, but sometimes she is not very flexible ... She has very set ideas and doesn't always adapt to what we want.'

The decision to begin compulsory schooling at the standard age without requesting a delay – an exceptional case in Portugal where children with Down syndrome are concerned – was taken jointly by all the people who were involved in the process. It was considered that Mariana possessed the competencies needed to begin a more formal style of learning, although her mother was fully aware that her scholastic acquisitions would never occur at the same rate as those of the other children.

The sensitivity of Mariana's mother, the complementarity of the roles which both members of the couple fully assumed and the suitable use of the various formal and informal support networks meant that the prediction we had made at the end of the first year of Mariana's life came completely true and Mariana was able to achieve and maintain a level of development that is entirely acceptable, given her disability.

## DISCUSSION

The longitudinal study shows that the development of these four children was influenced by several variables, namely those of the micro- and mesosystem: familiar context, mother-child interaction and forms of support.

As we reported earlier, due to the lack of research in the field, we can not compare these four mothers' dominant feelings and attitudes to those experienced by Portuguese mothers having a disabled child or a Down syndrome child. Each of them reacted in different ways to the birth and development of a 'different child', but a feeling of discomfort regarding the way other people looked at their child was common to all four mothers. Although there is no empirical evidence that the Portuguese population does not accept inclusion, the difficulties that João Paulo's mother faced to include her son both in pre-school and in elementary school show that inclusion is still a difficult issue.

Even in such a small sample group, it is possible to discover a considerable degree of variation in the intellectual and psychological characteristics of the children. According to Mahoney, O'Sullivan and Robinson (1992) and Spiker and Hopmann (1997), this contradicts the way in which the stereotypes with which children with Down syndrome have been labelled in the past emphasize their homogeneity. Still, there are some similarities between the four situations we studied and we shall begin by analysing them.

Just as Cicchetti and Beeghly (1990) found, the developmental sequence that the children in our study followed was similar to, albeit slower than, that experienced by normal children, and displayed an organization that was coherent in overall terms, with a close relationship between the various areas of development.

When evaluated using the Griffiths scale, the data on the children's development also show that although their Development Quotients averaged around 80 at the end of the first year of life, in every case they experienced a considerable decline over the years – something that has proved to be the case in every study conducted on children with Down syndrome.

It should also be noted that the child with, by far, the highest Development Quotient at the age of 7 years was the only one who does not have free trisomy 21, but rather a translocated chromosome 14 – another habitual finding (Coutinho, 1999). But we do think that not only genetic factors contributed to the higher DQ of this little girl. In fact, as we noted earlier, the sensitivity of Mariana's mother, her acceptance of her daughter's disability, the quality of her interaction with her child and the quality of the early intervention programme she was involved in were probably other important factors of a lower decrease in the rate of her development.

The differences between the various families, the individual characteristics of the mothers and their parenting styles were not only immediately clear from the interviews we conducted during the first year of the children's lives, but indeed became more accentuated over the seven years during which we studied them. We think that all these variables – particularly mother–child interaction and the way in which the mother deals with the stress factors associated with the fact that she has a disabled child – provide support to Belsky's (1984) and Guaralnick's (1997, 1998) models we quoted earlier.

The various phases of the adaptation process through which all the mothers went are similar to those described by Tanaka and Niwa (1991), and some of the statements we transcribed are also similar to those quoted by Roll-Petersson (2001). However, there are some very significant differences between the ways in which these four particular mothers lived their situation on the one hand, and the models' descriptions of the different phases of mourning and adaptation on the other hand, which are said to appear one after the other in a linear and sequential fashion as the years pass. To us, it does not seem that these models are capable of explaining the diversity in the feelings these mothers experienced over a period of seven years of their lives: their 'need to live one day at a time' (Mariana's mother), 'the times when everything seems to go back to the beginning' (João Paulo's mother), 'the feeling of revolt at the fact that the disease is so stigmatizing' (Catarina's mother) and the 'impossibility of accepting the situation' (Helder's mother).

The excessive directiveness that some authors attribute to the mothers of disabled children (Tannock, 1988) was only apparent in Helder's mother. In this dyad, mother and child seemed to ignore each other's initiatives, and the activities initiated by Helder's mother were mainly to stimulate his development. It seems to us that this mother's directive style resulted from the type of early intervention programme they underwent, which had been centred exclusively on training the child's competencies within a behavioural approach with very directive instructions. To the extent that the interactive style prevented Helder's mother from being responsive to the child's initiatives, it had some quite harmful effects, similar to those found in the researches of Mahoney (1988a, 1988b) and Mahoney, Fors and Wood (1990). In complete contrast, we have Catarina's mother, who 'let herself be carried along' by her daughter's initiatives and followed them with sensitivity, albeit without elaborating on them much.

João Paulo and Mariana's mothers always led interactive situations, but none the less managed to maintain their children's interest and adhesion. But in regard to the content, the degree of symbolic elaboration and the stimulative qualities of the activities they proposed, there were enormous differences between the two mothers' styles. The type of interaction we observed between Mariana and her mother clearly shows that it is possible to employ a directive interactive style and, simultaneously, be sensitive and responsive to the child's activities and focus of attention (Marfo, 1990, quoted in Spiker and Hopmann, 1997) – something that Crawley and Spiker (1983) showed to be associated with higher Development Quotients.

If we look at the special support given to these families, we find that the four of them also experienced different models, which to some extent reflect what really does happen in Portugal in cases involving children with disabilities. All the families lived in the same county, and all of them were entitled to the same kinds of early intervention programmes. When we first interviewed the mothers, we gave them the same information about the private and public services that dealt with Down syndrome children. Perhaps because of our work, all four cases were signposted very early on and began early intervention programmes during the first six months of the children's lives, but Mariana's mother was the only one who took an active

role in choosing the kind of support she thought more suitable for herself and her daughter.

The programmes' impact was not identical in every situation. Whereas, as we have said earlier, in the case of Helder's mother the programme appears to have been completely mismatched to the mother's real needs, not only did the support that was given to Mariana's mother seem to have been that which best suited the family's wishes, it also involved both the mother and later on the kindergarten teacher as well. Catarina's mother rejected the early intervention services that were offered to her and the lack of professional support probably influenced the way she coped with the situation. As regards João Paulo, we have already highlighted the negative consequences of the fact that the family-centred support that the mother enjoyed until her son went to kindergarten was replaced by a child-centred programme provided exclusively in the pre-school context.

As a last point of this discussion, we would like to comment on the support we, as researchers, gave to those families. As we have said, after the first interview we gave to all the mothers, in the same way, information concerning the services that could support them and we think that without this information the intervention programme would have begun later for these four children and families.

During these seven years, all the mothers knew that we could help them, namely in some issues concerning the orientation to pre-school and school settings that were more suitable to their children, but only Mariana's and João Paulo's mothers asked us for advice. We believe that these two mothers (mainly João Paulo's mother), considered us an extra form of support, apart from the early intervention programme.

Given the small number of situations under analysis, the longitudinal study that we have been conducting cannot be compared to any of the work of the same type of which we are aware, namely that of Carr (1988), Crombie, Gunn and Hayes (1991) and Rynders and Horobin (1990), all as quoted by Spiker and Hopmann (1997), which followed large numbers of children until the age of 21 in the case of the first study, and until adolescence in the remaining cases. Although the research of Shonkoff *et al.* (1992) inspired, in some way, our research, the objectives of their work and the follow-up study by the same team (Hauser-Cram *et al.*, 2001) were much more ambitious than our own.

None the less, we think that the qualitative nature of this kind of work and the fact that it includes not only child-related data, but also factors within the micro- and mesosystem – mother's attitudes and feelings, informal and formal sources of support and early intervention programme – may constitute a source of added value in the overall panorama of research in Portugal, where we do not know of any longitudinal study involving this type of children and families.

We know that we cannot generalize our conclusions, but we hope that this study will help early intervention professionals to understand the process of maternal adaptation to a child with disabilities. We think that the improvement in the quality of early support to children and families depends on the ability of professionals to match the characteristics of the programme to those of both the family and the child. As much as the development, competencies and other characteristics of the children, familiar factors, mother-child interactive styles and parental attitudes and feelings, must be taken into account in a responsive way, if we want high-quality early intervention programmes.

#### NOTES

1. The research was conducted within our Master's thesis.
2. One of the children died when he was 13 months.



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