



# NEWSLETTER

Children of the 90s

Spring 1997

## You are the study



As a member of the Children of the 90s team who spends time talking on the phone or in person to hundreds of mums and dads in the study, I thought this was an ideal time to 'talk' to more of you through the newsletter.

Its been six years since our first Children of the 90s child was born and for all parents that fill in questionnaires it must sometimes feel like a lifetime!

We know how dedicated you all are and you realise that answering thousands of questions, some of them repeated, over a long period of time is the only way we can attempt to solve some of the problems our children have.

*But especially to those that are struggling occasionally, can I just make a few points*

If you are going through a desperately busy time at home when a questionnaire arrives, there are several solutions and throwing it in a cupboard is not one I would want to recommend!

- ◆ Just fill in whatever you have time to do and then send it back. Something is better than nothing and it does mean that when the computer receives the questionnaire it won't send you a reminder.
- ◆ Send it back unanswered and in a few months time when the next one arrives life may then allow you time to fill it in. Of course we want as much information as possible but if a few gaps means that the pressure is taken off you at certain times, then it's worth it.

*And it means you stay with us*

- ◆ Need some help filling in or got a problem answering something? Then give us a ring; we are here to help and only too happy to talk on the phone or visit you. Ring 0117 928 5096.

We cannot recruit more children; they had to be born in Avon between April 1991 and December 1992, so you are all 'like gold'. This is no idle comment, it is one of my favourite phrases when I speak to mums on the phone. **Without you there is no study.**

*Thank you each and every one.*

*Pam Holmes Parent/Study Liaison.*

We all hope that these newsletters make interesting reading and we really do try to keep you up to date with the latest findings. If your group, school, association would like to know more about us, the study and how it all works, just ring Pam on 0117 928 5096 she'd love to come and talk to you.

## Sleeping Through The Night

If you have a child who does not sleep through the night, their sleeping behaviour can seem like the most important thing in the world. No wonder, when difficulties which would seem trivial after a good night's sleep threaten to overwhelm you as your mind cries out for sleep. Feeding back information about your children's sleep patterns may at least reassure parents that they are not the only ones coping with these problems.

We wrote about sleeping at 6 months in the Summer '93 newsletter. At that stage only 16% of babies never woke at night. 50% woke occasionally, 9% most nights, 5% once every night and 17% woke between 2 and 8 times every night.

At 18 months we asked you to look back at the past year. It seems to have been normal between 6 and 18 months for the children to

wake regularly at night. Two thirds (66.4%) of them did and 28% of their mothers (or fathers) were worried about it.

Half of all the children were still waking at 18 months. For many parents it was not just the one break in the night's sleep either, and that is before we consider disturbances from other children! In answer to the question 'How often during the night does (s)he usually wake?' you reported that

50% *did not usually wake*  
 30% *usually woke once*  
 13% *usually woke twice*  
 7% *usually woke 3 or more times*

We did not ask directly what you did to try to get your toddler back to sleep, but one answer may have emerged in the response to the question shown below. Quite a few toddlers were taken into their parents' bed in the course of the night.

### *Does (s)he sleep on (his) own most nights or does (s)he share a bed or cot?*

	(i) <i>when you put (him) down</i>	(ii) <i>when (s)he wakes in the morning from (his) night's sleep</i>
<i>in (his) own bed/cot</i>	94.4%	80.0%
<i>in bed/cot with other children</i>	0.8%	0.7%
<i>in your bed with you</i>	3.6%	15.6%
<i>in bed with other adult</i>	0.1%	0.6%
<i>other place</i>	1.1%	3.1%



### at the Royal Society

On November 25<sup>th</sup> we held an international meeting at the Royal Society in London to talk about the progress of the study to leading people from Government Departments here and in the United States, politicians, industrialists and researchers as well as representatives from some of our European collaborator countries. There was enormous interest in our results so far and in the possibilities for the future, and we felt very proud to be part of this exciting study.

## Your Comments and Questions

"Most of this questionnaire makes me feel you are studying me and not my child!! I thought it was the child's own progress you were interested in, how can these questions help that cause?"

*I expect many of you feel like this sometimes, but there are excellent reasons for what we ask. I'm sure you would agree that the parent's situation and physical and mental well-being are part of the child's environment. As such they could influence the child's development and health - but we expect that not all children will react in the same way even in similar situations.*

*Another reason for asking about your lives is that we are also interested in what it's like to be a parent in the 90s. Are there problems that could be solved by changes in the health care system for example?*

"When we started this study we were told it was to cover the first 5 years of our child's life. Does this mean this is the last questionnaire? If we are being asked to continue longer - how long?"

*You may have realised from the last questionnaire that the plan is to see all the children at age 7, and to send questionnaires until then. What happens afterwards will depend very largely on you, the parents. There are obviously very good scientific reasons for continuing to follow this group of children about whom there is already so much invaluable data. But nothing can be done without your help. It's your study.*

"I don't think the importance of this research can be over-stressed. I'm sure parents everywhere appreciate and value your findings, advice and hard work. Thank you."

"I'd just like to say how great it feels to be part of a great team. I love doing every bit of the questionnaires. An excuse for a coffee.

I won't sign my comments, I know how busy you are, I don't need a reply. Thanks."

"I'd just like to say Thank you for including us in your survey. I have enjoyed very much filling them in. Keep up the good work. [Mother of 4 year old (monster)]."

"Nichola is very impressed with the fact that you have sent her her own questionnaire this time. She has always been interested in the Children of the Nineties and loves getting her birthday cards. When we were asked to send nail and hair clippings Nichola was over the moon. Six months later every time I cut her nails she still wanted a little bag to put them in so that we could send them to Jean Golding. At the moment she cannot wait for her teeth to start falling out and is all ready to send them off to you!" *Great!*

"You mention an all-day visit to the clinic at 7 years. What about we working mothers. I would very much like to bring my daughter but do not really wish to use up annual leave doing so. Have you thought about Saturday opening or early evening?"

*We are very aware of the problems posed for working mothers. The majority of our staff are, or were, in the same position. On the other hand we need to see around 30 children a day, 6 days a week, for almost 2 years to get through them all. We will be open on Saturdays, but there's only one in each week! We are seriously considering early evenings, but there are problems; the children may well be tired at that time, and the amount of time available in a child's evening is not enough for the thorough observations we need to carry out. We plan two sessions of about two and a half hours with a break for food and relaxing activities in the middle. Your comments would be welcome.*

## Living with a Disability

*Most children can be a bit of a challenge for their parents to cope with sometimes, but for some parents the demands are much greater. Two mothers, Lorraine and Michelle, have written to us about their experiences of bringing up two children one of whom has a disability, and as you will see, there's much joy and laughter as well as the tears and stress.*

### **Michelle writes:**

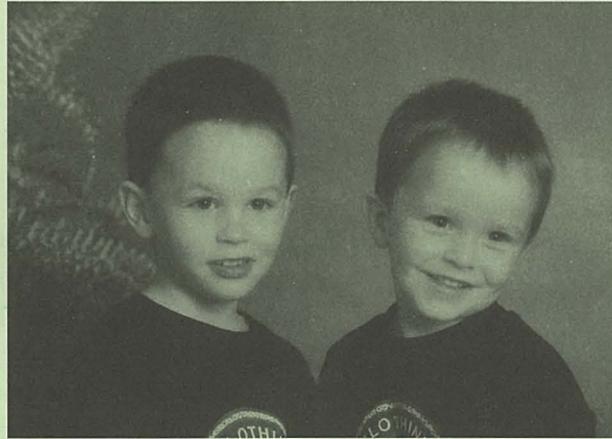
"I've been married to Andy for ten years and I'm a full time mum to Christopher (7) and Daniel (4). A normal family unit you might think! Daniel is a normal, bright, intelligent, cheeky four year old who has just started school. Christopher has hydrocephalus, severe learning difficulties, aphasia (lack of speech), poor attention span and is quite often incontinent. He can walk and run but cannot pedal a bicycle, he cannot wash or dress himself but is a loving, happy, adorable child that can melt even the sternest face with his smile. He needs constant care to keep him safe; he doesn't understand about the dangers of everyday life around him.

Christopher's difficulties make family life anything but normal. We have to be on our guard both in and out of the house when Chris is about; doors must be locked and windows and cupboards too. A trip to the supermarket, park, swimming pool, zoo, visiting relatives and friends can prove very stressful for all concerned.

We've explained as best we can to Daniel that his brother's 'body' doesn't work properly and that he's slower to learn things than he is,

but it is so very hard for him to understand why his older brother can't do things he can do. Why can't he pedal a bike? Why does he run away? Why does he wet himself? Why can't he dress himself? Why does he go to a special school? Why can't he talk and play with me? If only we had all the answers.

We do have a lot of laughs too, that's very important and we take one day at a time, we dare not think about Chris's future. Chris has a wonderful sense of humour, like the time we were woken up at 6am by bouncing and giggling noises:- Chris was bouncing across the landing in the dark on his space hopper! When he was four, I woke up to discover him in the kitchen with eggs, margarine and flour everywhere. It was 6.30am on a Sunday morning and Chris wanted to bake a cake! He had watched me the day before.



*Chris, left, and Daniel, Christmas 1995*

Holidays are difficult. Daniel wants to do all the things boys do: - climbing, swimming, cycling, football etc., but Chris can't do these easily. A trip to the seaside we thought was a good idea - wrong - Chris wanted to run away and try everyone else's picnic. We took it in turns to play with Daniel and chase after Chris. The second attempt was more successful, the sand was hot so Chris didn't venture far off the rug. Bliss. Daniel loves to go cycling with his dad at the weekend which gives him some special time not interrupted by Chris.

Once a month Chris goes to respite care for the weekend. We can all have a good break and we can be a 'normal' family for two days.

*Michelle's story continued*

We go cycling, swimming, to the pub or just relax at home. Daniel knows that Chris is different from his friends' brothers and sisters but loves him all the same; hopefully his friends will understand about Chris too!

We have gone through many emotions with Chris, worry, tears, anger, sadness, acceptance and most of all laughter. We have to laugh or

we cry. Chris loves food, music and Disney videos and we know that Chris is happy, loving and enjoys life, that is important to us. We just hope that Christopher's handicaps will not affect Daniel's 'normal' childhood too much and that he doesn't resent him for his disabilities. Time will tell.

We thought this poem was very apt!"

*If a man does not keep pace with his companions,  
perhaps it is because he hears a different drummer.  
Let him step to the music which he hears,  
however measured or far away.*

*Henry David Thoreau, from Walden*

### **Lorraine writes**

"Adam was born at Southmead Hospital on the 5<sup>th</sup> September 1992, twenty-three months to the day after his brother James. He was a small baby at 5lb 13oz and was poorly for a few days with low blood sugar and jaundice, but once we got home he was a very easy baby who breastfed well, which was just as well, as James was a very lively 2-year-old.

We first noticed that Adam did not seem to be developing as he should at around 18 months, although looking back now there were earlier signs. He was an unnaturally quiet and lethargic baby, sleeping at 18 months for sometimes 5 hours a day, then 12 hours at night - ideal you say, but quite worrying when he showed no interest in the world around him, even though he seemed happy most of the time. What worried me most was the fact that he did not understand what you said to him. We began various investigations at the Children's Hospital, - leading to a developmental assessment at the Children's Development Centre (CDC), in Weston.

At 3 he started a nursery placement at the (CDC) to try and discover the extent of his problems. They were quite severe, no language, lack of comprehension - general delay all round. We were worried where Adam would fit in at local nursery. This was something that had been so easy with James,

who if anything was at the other end of the scale picking things up so easily and fitting into two different nurseries with no problems at all.

Adam's assessment at the CDC Weston lasted until May 1996 when there was nothing else they could do for him. He needed help, but they needed the space to assess more children. We were referred to a fantastic charity organisation in Clevedon called Springboard Opportunity Group, a pre-school group for children with special needs. I do not know what we would have done without this supportive group of people because (if they did not exist) there is no other facility for Adam in North Somerset. He started attending a nursery with one-to-one support from a Springboard member of staff for one session of 1½ hours a week. Not really ideal, but we had no options and had to take what we were offered.

This was really a hard time, James had started school in amongst all this and trying to fulfil both of their needs was difficult. Our family all live in Hampshire and Tony (my husband) commuted to Reading every day, most days being out of the house for 12 hours at a time. Hardly a recipe for a stress-free life.

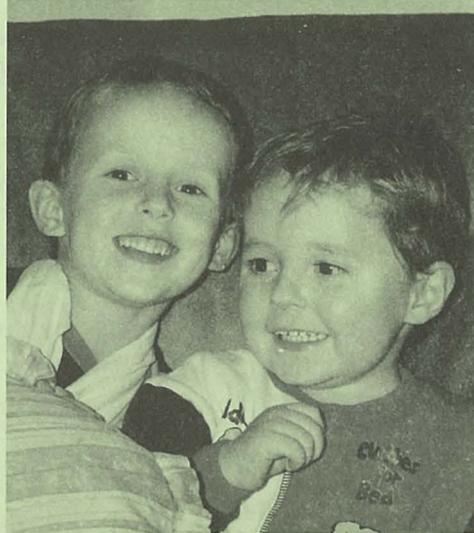
In June 1996 it was decided to start the statementing procedure to enable Adam to start school. We felt his needs were too great

*Lorraine's story continued*

to be met by our local school where James attends, and decided on Ravenswood School in Nailsea for children with moderate learning difficulties. We are currently waiting for a panel of educational professionals to decide where **they** think Adam should go to school and when he can start.

Adam himself has developed in some ways in leaps and bounds, he is still happy and very musical, enjoying music therapy weekly. His language has progressed fantastically thanks to a lot of work by everyone including his speech therapist whom he sees weekly. His understanding is better, but still not what it should be and behaviourally he has the developmental age of a 2-year-old and unfortunately he has no sense of danger or social awareness. His sleep pattern is now very erratic and unpredictable. He wakes a lot in the night and very early mornings. In the last two weeks, we have been told that Adam is autistic, a label which does explain a lot of his ritualistic and unusual behaviour. This basically means his mind cannot make sense of life or his surroundings. This label does help a lot in understanding Adam. He is very difficult to manage outside of his own surroundings, something you really take for granted with most children. We did.

The thing that really sticks in my mind most is how easy it was for James to cope with nursery, fitting in at school, making friends.



*James, left, and Adam*

Although this did take a while, we could talk to him, explain, and reason. With Adam we have had none of this, no real choices. There are very limited options for these children and society can be very discriminating. I have learned to take Adam to places even if people do stare or comment at this big 4-year-old child screeching or singing at the top of his voice. Adam is a very happy, musical child the majority of the time, with a loving disposition and personality. He loves to say "hello" to everyone he meets, and has a very winning smile. You have to teach yourself to be hard and think that people's opinions don't matter, when of course they really do. Having Adam has made me realise that you should accept people and not judge by

appearances.

I bring Adam to the Children in Focus Clinic. Again I have to work really hard with him to even manage getting him weighed and measured and it's hard when you compare him to the other children, but this is what this study is about - children - how they develop and unfortunately sometimes things don't work out as you think they will or should, but we are very proud of Adam.

At the end of the day Adam is our son first, a child with learning difficulties second and he should be treated by the outside world as a little boy, with equal opportunities made available to him as other children automatically receive."

### Bristol Council Listens

Bristol City Council has used some data from questionnaires in their 'sustainable city' document. It is feedback from those of you who live in Bristol about your neighbourhood which will influence the Council's policy making.

## Now it's Rebecca and James at No.1

**B**ack in the summer '95 edition we gave you the 10 most popular boys' and girls' names of the older brothers and sisters of the study children. Now that we have received the names of most of the study children along with samples of their hair and nails, we can give you their most popular names.

<i>Girls</i>	<i>Children of the 90s</i>	<i>Boys</i>
Rebecca	1 <sup>st</sup>	James
Sophie	2 <sup>nd</sup>	Thomas*
Charlotte	3 <sup>rd</sup>	Matthew
Jessica	4 <sup>th</sup>	Daniel
Amy	5 <sup>th</sup>	Samuel
Hannah	6 <sup>th</sup>	Michael
Emily	7 <sup>th</sup>	Alexander
Emma	8 <sup>th</sup>	Christopher
Laura	9 <sup>th</sup>	Joshua
Lauren	10 <sup>th</sup>	Benjamin

(\* Rises to equal first if you include the Toms)

Below are the older brothers and sisters

<i>Girls</i>	<i>Older children</i>	<i>Boys</i>
Emma	1 <sup>st</sup>	Daniel
Laura	2 <sup>nd</sup>	James
Rebecca	3 <sup>rd</sup>	Matthew
Hannah	4 <sup>th</sup>	Thomas*
Sarah	5 <sup>th</sup>	Christopher
Charlotte	6 <sup>th</sup>	Luke
Katie	7 <sup>th</sup>	Ben
Jessica	8 <sup>th</sup>	Michael
Amy	9 <sup>th</sup>	Sam
Kelly	10 <sup>th</sup>	David

(\* Rises to second place if you include the Toms)

## Teeth

By now all the study children should have received a bag to send their milk teeth to us. If you haven't received this please let us know.

For some children it may be years before a tooth falls out - please store the bag carefully, ready to send us the next tooth that drops out. (If the bag gets lost, phone us on 0117 928 5007.) Some teeth have already fallen out and been sent to us. These teeth contain a valuable history of development before and after birth, and scientists are thrilled at what they may be able to discover.

Each time we receive a tooth we will send your child a coloured badge like this:



All of us at Children of the 90s were saddened to hear of the recent death of Mrs Biss, at the age of 96. You would be forgiven for wondering what on earth a lady of that age was doing helping such a study as ours. But in the early days she helped us, as a volunteer, to label sample pots and fill in envelopes in their thousands. Though disabled, Mrs Biss worked for us week in, week out from home. We all remember her with great affection.

## RESULTS

### **Inequality in health and health service use**

Dr. Baker looked at the questionnaires that mothers completed when the children were 8 months old. She related mothers' social circumstances to how often they reported having 16 common health problems and whether they consulted a doctor about them.

She found that women with relatively poorer or disadvantaged circumstances were more likely than more advantaged mothers to suffer from, and see the doctor about, stress related conditions such as depression, anxiety and headache/migraine. Those with relatively advantaged circumstances were more likely to suffer from cough/cold, backache, and piles. These last two conditions were also more common in older mothers.

*Baker D, Taylor H, and the ALSPAC Study Team. Inequality in health and health service use. Journal of Epidemiology and Community Health 1997;51(1):79-84*

### **Alcohol in early pregnancy**

Dr. Passaro and her colleagues looked at how much alcohol mothers drank in early pregnancy and tried to see if this affected the weight of the baby. The data were from 18 weeks of pregnancy. Lower birthweight is seen as showing a harmful effect on the baby.

They found that women who, in early pregnancy, drank no more than 1-2 alcoholic drinks a day had babies with the highest birthweight whereas those who drank more than this had significantly lighter babies. This was after taking all other relevant factors into account. The researchers stress, however, that alcohol may affect other things besides birthweight and should, they thought, be avoided in pregnancy.

*Passaro KT, Little RE, Savitz DA, Noss J, and the ALSPAC Study Team. The effect of maternal drinking before conception and in early pregnancy on infant birth weight. Epidemiology 1996; 7: 377-83.*

### **Twin pregnancy**

Dr. Thorpe and her colleagues looked at the health and well-being of 147 women expecting twins compared with 11,061 expecting a single baby. They were significantly more likely to report ill-health in early and mid-pregnancy. The trend continued in late pregnancy.

In early pregnancy women expecting twins reported significantly more vomiting and infections, at mid-pregnancy more nausea, diarrhoea and sugar in urine. In later pregnancy, however, only sugar in urine remained more common for women expecting twins. They were more likely to receive scans in early and late pregnancy and 3 times more likely to be admitted to hospital in late pregnancy.

For the group of women as a whole, poor physical health was correlated with depression, but this was not true of those expecting twins. It is suggested that the 'special' status that goes with having a twin pregnancy somehow compensates for the physical problems that can go with it. It may also be that such women receive more support and are more likely to adapt what they do to adjust for the pregnancy.

*Thorpe K, Greenwood R, Goodenough T., and the ALSPAC Study Team. Does twin pregnancy have a greater impact on physical and emotional well-being than a singleton pregnancy? Birth 1995; 22(3):148-52.*

If you would like copies of any of these scientific papers please send us a large s.a.e. and say which one you would like.