Intended for parents of children with Down's Syndrome, the booklet describes causes and probable developmental patterns of the Down's child. It is stressed that parents need professional counseling to aid in adjustment to and rearing of a Down's infant. Discussed are incidence (1 in 700 births), and the accident of cell development which leads to the condition. Typical behavior and developmental characteristics as well as child rearing suggestions are given for the following age levels: infancy, 2 - 4 years, 4 - 8 years, 8 - 12 years, and over 12 years. In opposing the tendency to institutionalize Down's children early in life, the author notes a survey which showed that three fourths of the families who keep the child at home make a good adjustment. Guidelines for selecting an institution and reasons for later placement (such as behavior problems) are provided as is the suggestion that residential hostels are more suitable than large institutions for adult retardates. Also provided is a listing of 18 suggestions for further reading. (DB)
Your Down’s Syndrome Child...

...you can help him develop from infancy to adulthood

by DAVID PITT, M.D.
This booklet was published by the National Association for Retarded Citizens as part of an ongoing public information program made possible by a grant from the CIVITAN CLUBS OF NORTH AMERICA, including their junior and collegiate affiliates.

ON THE COVER are the National Association for Retarded Citizen's 1974 poster children — identical twins Mark and Mike Hembd.
Here's the author:

DAVID PITT, M.D., B.S., F.R.A.C.P.,
Consultant Pediatrician, Children's Cottages Training Center
Kew, Victoria, Australia
in about one in every 700 births
Introduction

This article has been prepared as an aid to parents. There is need for such aid since supportive services for these parents may be patchy and sometimes nonexistent.

Many parents have had wise initial advice and continuing support from an interested person such as a pediatrician. Others have had a diagnosis presented to them shortly after the birth and, after the first shock of learning that they have a handicapped child, find themselves left all on their own.

These parents have many questions to ask about their child's future, many of which can only be answered as the child's development is studied.

If there is no professional follow-up, parents may be left bewildered and resentful. The difficult question of home or institutional care may be presented to them in a clumsy or unbalanced way, and they are frequently subjected to pressures from well-meaning but uninformed relatives and friends to part with their child. This article is intended to assist, but not to replace, the personal counsel which is the right of every parent. It is intended to assist by providing supportive reading, and so help to fill gaps that may exist in services to families.
there are differences from the average developmental rate
What is Down’s Syndrome?

Dr. Langdon Down first described this syndrome about 100 years ago, and it came to bear his name – Down’s syndrome. Because of a vague resemblance in the face of such a child to the Asian races, he was described as a "mongol," and hence the old terms "mongolism" and "mongoloid." However, it is incorrect to associate the condition with Asians, who are indeed offended by the term. It is considered demeaning and developmentally inappropriate to refer to a child as a "mongoloid."

A Down’s syndrome baby is "born different," it is often said. He is different both physically and mentally from a normal baby. The physical differences consist of some reduction in body and head size, and some physical characteristics which can usually be recognized at birth. The eyes are a little different, particularly in their upwards and outwards slope, the ears may be small, the tongue may be big, the hands and feet may have distinctive shapes. These characteristics, especially the small head, often become more obvious as the child grows older.

A child with Down’s syndrome, aged five years, may have the mental capacity and abilities of a child of perhaps two years. And there are similar differences from the average developmental rate all through life.

The cause of Down’s syndrome is not clearly understood. It is extremely rare for it to be hereditary and to occur more than once in a family. Usually it is a single event, occurring most often at the end of a family of children, when the mother is approaching the end of her child-bearing days. It occurs in about one in every 700 births.
The cause is not clearly understood.
Accident of cell development

Parents who have studied biology at school will remember what a chromosome is. It is a microscopic rod-like structure which carries the hereditary units called genes. The tiny cells of the human body each carry 46 chromosomes, which can be studied under a microscope. Each chromosome is made of hundreds of genes. The 46 chromosomes, which in varying sizes exist in pairs, are present throughout life, even from conception, when the fertilized egg contains its 46 chromosomes. Half of these are derived each from the parents' sex cells, the ovum (maternal) and sperm (paternal), which each contain 23 chromosomes. The 23 chromosomes of the ovum are derived from the splitting into two of an earlier cell, carrying 46 chromosomes, that comes from the mother's ovary.

If this splitting is uneven, for reasons ill-understood, then the ovum may contain 24 instead of 23 chromosomes. When fertilized by a sperm with 23 chromosomes, a child is formed with \( 24 + 23 = 47 \) chromosomes. If the extra chromosome is a particular one (number 21), then this child will have Down's syndrome. Somehow the extra gene material in the extra chromosome disturbs the orderly development of the body and brain, which is controlled by genes. This is no fault of the mother, as there is no evidence that any act or omission on her part is related to what is purely an accident of cell development.

This accident of cell development happens in about 95 per cent of children with Down's syndrome. In the remaining five per cent there are other disorders of chromosomes, also resulting in extra chromosome material that causes Down's syndrome.
"Sitting without support..."
The Down's Syndrome Baby

At first the baby may look like any average baby, and the special features may not be noticed until seen by an alert nurse or doctor. He may have a low birth weight (one-fifth are premature), and sometimes may not suck as strongly as the average baby; a few have to be fed with a tube, especially the smaller ones. A few also are troubled with heart defects, which may have some effect on their physical health. For these reasons, a Down's syndrome baby may sometimes have to stay in the hospital a little longer than usual, until feeding and sucking is well established. The baby can then go home with its mother, and be cared for and loved like any other baby.

Feeding

Some babies with Down's syndrome feed well at the breast, provided sucking is vigorous. Otherwise, bottle feeding will be necessary. The baby should be as upright as possible during feeding to prevent any tendency to inhale the milk. For the same reasons the baby should be laid down on his right side after feeding and not on the back. The nurse at the public health department or "well-baby clinic" will help with feeding difficulties, and if these are troublesome will suggest a suitable doctor.

About the age of six months is the time to introduce semi-solid food — usually mashed natural or prepared vegetables, or cereal — on a spoon. If the child seems unable to cope with swallowing it, force should not be used. The attempt should be deferred a couple of weeks for another trial; when he is ready to swallow, he will do so, and a baby-mixed diet can be built up from this point. A gradual introduction of semi-solid food helps the baby learn to accept the different food. Bottle and spoon feeding will be necessary for a much longer time than with the average child, who can usually abandon the bottle by 12 months and use a spoon between 18 and 24 months.
It is important when the appetite is well established to avoid over-feeding— a natural reaction on some mothers’ part—as obesity can make a baby or child sluggish and unable to make the best of his abilities. An adequate vitamin intake is just as important as in any baby.

Development

Because of his retardation, it will be found that the baby stages of development are much slower. Thus, an average baby will hold up his head well at about three months, be able to sit without support at about seven months, be able to crawl at about nine months, and be able to walk at about 14 months. Although there is a great variation from baby to baby in reaching these “milestones,” a baby with Down’s syndrome will usually take longer to reach them.

In spite of these delays, it is important to stimulate learning in the Down’s syndrome baby rather than merely feeding and caring for him in a passive way. For example, if he does not lift his head or turn his eyes toward objects by the fourth month, he should be picked up with his head held firmly, so that he sees objects about him. For a few minutes each day, a light or bright color should be moved before his eyes to attract his attention to follow its movement. If at the same age he is making no attempt to grasp objects or toys, his hands should be curled firmly around them, enclosing things of various shapes such as a square block, round ball, rattle, etc.

If over the age of six months he does not move his legs or arms much, this should be done for him each day, e.g., at bath time or during a short sun-bathing session, so as to teach him the pleasures of movement.

Mother-child relationship

Experiences and stimuli to which the growing baby is exposed are essential for the greatest development of his mind. These come naturally from the attitudes and actions of a mother, and are just as necessary for the handicapped child as for the average child. There are many research studies which have shown that children
deprived (for various reasons) of a mother's care and stimulation are found on psychological testing to be duller than those who have had the full opportunities of a good mother-child relationship. This rich relationship brings many stimuli to the infant—strokings and cuddling, feeding, the sound of her voice, a rattle, a ball, a doll, and all the other things that most mothers naturally produce to give full early experience of the world to the baby.

Sitting without support is usually achieved by about 13 months of age, but may be delayed in some cases to 30 months. This can be actively encouraged by propping the baby up with pillows from about the age of 10 months, or by the use of little baby chairs.

Exercises should be given at changing times—raising the feet to encourage leg movements; moving all four limbs to encourage active resistance and, therefore, movement; pulling the baby (after four months) into a sitting position, to exercise the back and neck muscles, and so on.

Teaching the meaning of speech should be attempted from about the time he learns to sit without support. Simple words should be repeated directly to him, which have a direct relation to obvious things, such as himself, "Mamma," "Daddy," "bath," etc. Any child, whether average or mentally retarded, learns to speak only from a flood of conversation around him. This needs, of course, to be related to common objects about him, so that gradually a vocabulary of simple words is built up. Thus we say, "kitty, kitty," pointing to it, letting him hear the sound and see how we use our lips.
Baby's health

There may be physical problems of health in the Down's syndrome baby. Many are subject to colds and bronchitis, which may call for medical help. Antibiotics such as penicillin may be prescribed for such an acute illness, and may also be used in a low dose as a preventative measure. Coughing may be troublesome, and may sometimes be relieved at night by a sedative cough mixture. In general, cough mixtures are otherwise fairly useless, and the best relief is obtained by removing the cause, which is mucus irritating the lung tubes. By upending the baby over the knee with the head down ("postural drainage") and patting the back firmly, this mucus is encouraged to flow out of the lungs. This is best done before meals, and at night if sleep is disturbed. Cod liver oil and other sources of extra vitamins are traditional helps in colder climates, but are unnecessary in warm climates.

Nasal discharge may also be troublesome even at this age. Nasal discharge calls for the frequent use of tissues — and sometimes nasal drops — if there is much infection. The nose should be cleared first, and then the baby held on his back on the lap, with the head wedged down between the mother's knees, so that the baby's nose is almost upside down. One hand can control the baby's two hands, while the other administers the drops. In difficult cases, and in older children, repeated mild suction inside the nostrils may help to clear the nose, but this means obtaining a suitable suction apparatus and taking antiseptic precautions. However, the family doctor should always be consulted and asked to demonstrate the treatment for the parent of a child who has severe problems.

Skin, nose and teeth

The skin of the young baby with Down's syndrome is usually good, but towards the end of babyhood it starts to roughen and becomes less pliable, and is more prone to cracks and infections such as boils. The roughening may be helped with the use of lotions and
creams—especially on the lips, which are apt to dry and crack. Prevention of infections is achieved by the use of antiseptic soap and by the proper care of the nose, which in infected cases can act as a nest, spreading germs both outwards to the skin and inwards to the lungs. From the end of the first year of life, the teeth should be cleaned daily by the mother, either with an ordinary or electric toothbrush.

Immunization against diphtheria, tetanus, whooping cough, poliomyelitis, and measles should be arranged through the well-baby clinic or doctor, just as with any baby.

Heart problems, from congenital defects, are common in Down’s syndrome babies, and if present will call for regular medical supervision.

**Mother’s health**

The mother’s own health might be mentioned here. She is a busy person and for everyone’s sake, including her own, must keep fit. This means a good diet, fresh air, regular exercise and, if possible, a holiday occasionally away from the baby.

Her mental health is just as important. After recovering from the initial disappointment of having a handicapped baby, it is vital that she face the world confidently, and on no account must she hide herself or her baby from ordinary human contact. This may lead to initial difficulties with well-meaning people who may show annoying pity or criticism, but this can be overcome usually by cheerful firmness and tact. It helps the mother’s morale, too, to join a parents’ group, even at this early age, where she can discuss her problems freely with other mothers, and learn something of the baby’s future. These groups can be contacted through the local mental health/mental retardation center, through the state association for retarded citizens, or the nearest training center or school for mentally retarded children. A visit to the latter can be very rewarding.
activities to capture his interest
Down’s syndrome from two years

A child with Down’s syndrome may be able to stand with support by the age of two years (again, this can be helped with training). When he can do so well, he should be encouraged to take his first steps by holding his hands and pulling him forward gently. If he collapses, he is not ready to walk, and the attempt should be postponed for a few weeks. When he is able thus to take a step or so, he is ready to be put into a little walker. By propping himself on the top part with his hands, he gradually learns to push himself forward with his feet. Eventually he is ready for separation from the device and independent walking, which takes place on an average of 27 months, but may be delayed in some cases to four years.

Self-feeding is generally achieved by the fourth year (sometimes earlier), and may be encouraged in the same way as training the average one to two year-old child – by holding both hands and spoon from behind the high chair during plate feeding, by encouraging the use and eventual holding of a cup, etc.

Toileting

Bladder training in Down’s syndrome children is usually achieved during the third or fourth years of life, or sometimes later. It cannot be achieved before the child can walk, though this is sometimes enthusiastically attempted. After walking, he may be gradually introduced to the pot or lavatory when it is thought his bladder should be full, and involuntary passing of urine on these occasions leads eventually to voluntary control.

Just after this stage, bowel control may be achieved -- at an average age of 40 months, though in some cases it may be delayed to about five years. As a bowel motion most often occurs after a meal, it is usual to place the child on the toilet for a short period after a meal, until eventually voluntary control follows. It is useless and harmful to prolong the time of sitting on the toilet, or to use it too early, before voluntary
control of urine is achieved. Some months after toilet scheduling becomes successful, the child will be able to indicate his needs by gesture, grunts or even speech.

Night control of the bladder — an accomplishment which is variable in all children — is often very delayed, and mothers should not be overly concerned about bed wetting, which is common.

Speech
An average child uses single words at about one year of age, phrases (two words) at about two years, and short sentences (three-four words) at about three years. This is delayed in the Down's syndrome child, particularly if the child has had to be placed in an institution, where opportunities for speech stimulation are so much less than in the home. Some speech is generally present by the age of four years. If speech delay seems excessive, compared with the child's progress in other ways, a doctor should arrange for a test to check the possibility of a hearing defect.

In teaching speech, it is important to be patient and not to expect the child to repeat words before their meaning is clear. This means that taught language must be planned and simple, with the use of key words over and over again to give the basis of speech. Mentally retarded children are often called "slow learners," and one must therefore prolong the teaching process accordingly, and not give up too soon. The child should be talked with frequently, and common objects and parts of the body named. These can be made into verbal games.

The size of the tongue may cause some speech difficulty, especially if there is a "tongue-thrust" and it protrudes excessively. This should be corrected if possible by tongue exercises, with gentle but frequent reminders to "close your lips."
Personality

The child's individual personality will have been developing throughout his babyhood. Like all children, he usually shows acceptable characteristics which are also common in Down's syndrome children. These are cheerfulness, enjoyment, humor and fondness for imitation. He may be mischievous. Most children are pliable, though some are stubborn and may need firm handling. He may be shy with visitors, though some are over-affectionate towards strangers. There are differences between child and child, and resemblances to parents, both physically and in personality. Many are fond of music and games. Some develop bad habits, such as tongue thrust, rocking, or finger-sucking. These are usually the result of boredom; correction consists of relieving the boredom by gentle distraction with games and introduction of other activities to capture his interest.

Preschool contacts

At about this age the parents should be in contact with the nearest day training center or special school—the name varies from state to state. These centers or schools provide appropriate education and training for children with various degrees of mental retardation. They may have a waiting list on which the child's name should be enrolled and the parents will also have the opportunity of meeting the teachers who can give much useful advice. Other parents will also be met, and many centers have a parent group where the problems of their preschool children can be discussed. There will also be the chance of watching activities at the school, and seeing other children with a similar handicap, which deepens the mother's understanding of her child's future.
should be taught to clean their teeth
Down's Syndrome from Four Years

The personality will now be more apparent and varies from child to child. Most of these children are active, full of curiosity and possess a considerable power of mimicking. This is true also of their social graces, which often outstrip their actual intelligence. This, of course, is a good thing and helps to make them more able to live in the community.

Exercises

Muscular development needs to be stimulated by exercises, by marching to music, and by the use of trampolines, on which many Down's syndrome children become very expert. Likewise, swimming is an enjoyable and helpful pastime that can also be taught to these children, even from an early age.
Training and education

Training in this age group should continue just as with an average younger child. Use of the toilet and self-feeding, if not already achieved, need to be stimulated; speech also will still need to be helped. Color discrimination may be taught by presenting brightly colored objects; ribbons, balls and brightly colored building blocks are excellent for this purpose. As many of these children have poor vision, it is wise to have an optometrist check the eyes at this age.

Much of this training by parents is a responsibility which they have to assume in order that the handicapped child may develop as much as possible. Fortunately, in most advanced communities, public facilities for training ("training centers" or "special schools") are available, as was mentioned earlier, so that this task is taken over by trained teachers. The child benefits from more intensive training and simple education, and the parents have the advantage of being able to share their responsibilities of both care and training. They should, therefore, neglect no opportunity of making the most use of these facilities, both for their child's and their own sakes. Parents are often surprised when the teacher shows some knack in handling the child in some respect which has eluded them. They should not be upset about this, but remember the teacher's special experience and training in this field.
Self-care

The child should be taught to clean his teeth during this period. An electric toothbrush is efficient for the parent to use prior to this stage. Cleansing of the body is also learned at this time. Dressing in part or in whole should be encouraged, and the temptation to hurry things by doing these things for him must be resisted.

Safety

In modern urban society, safety is a most important subject for training in all children, and should not be overlooked in the handicapped child. It is, of course, a special feature in programs in centers and schools, but should also be taught in the home. Caution with fire and hot objects should be taught, so that the child learns to avoid them and other obvious dangers.

At the same time a careful scrutiny of the home should be made to eliminate hazards for the grasping little hands — accessible drugs, faulty electrical equipment, open flames, pots of boiling water, etc.

Parent relationships

There should be by this age (four to eight years) good relationships and interaction between mother and child. The father is equally important, and he should be playing a significant part in home games and general stimulation of the handicapped child.
The Down's syndrome child of eight to twelve years...
Down's Syndrome from Eight Years

Except for the few who are more severely handicapped, most children with Down's syndrome who live at home are now attending a public school for mentally retarded children. Although a great deal has been done by both parents to bring out the best in the handicapped child, the job still continues out of school hours, and the parents' duty of teaching remains. Not only do they have to teach the handicapped child, but also they should influence others who are in daily contact with him. From an early age the brothers and sisters need to be helped to understand and accept their slow brother or sister. It is wonderful to see many families in which love and understanding flourish, so that the handicapped child is neither over-protected on the one hand, nor neglected on the other. Relatives also need to be informed of many elementary truths, e.g., that the child is not insane, that he will not become dangerous or sexually aggressive, etc. They will need to be taught tactfully the need for kindness and stimulation, if they do not already realize this.

The Down's syndrome child of eight to twelve years has of course grown, but is probably shorter than normal children of the same age. In other respects, e.g., his personality, he is very likely to be much the same as he was earlier, but of course has more accomplishments, usually those of a three to four-year-old child. However, social accomplishments may be better. He will probably be toilet-trained, be able to help with dressing, have simple but useful language, and be able to care for himself in most respects except for free movement in streets and traffic. This is a complex accomplishment that often comes a little later, and forms part of training programs.
“In school, the child will now be in the middle range.”
Down's Syndrome from 12 Years

The child is now advancing towards adolescence. Puberty may be somewhat delayed. Contrary to the expectations and fears of many parents, sexual problems seldom exist.

In the school, the Down's syndrome child will now be in the middle range, preparing soon for workshop activities, and it is remarkable how expert he later becomes in both repetitive and creative manual tasks. In some places you will see young adolescents or adults doing skilled work comparable to that of average workers. Many such children learn to express themselves quite well, and in one instance a book, "The World of Nigel Hunt," has been published by a youth with Down's syndrome.

In the home he will probably have a definite role by now - the cheerful helper. Simple tasks about the home, suitable for a mental age of about five years upwards, such as washing dishes and helping in the garden, are usually enjoyed. He will probably be able to be trusted in the street, go on simple errands and even handle money. He will have useful speech.
"Simple tasks about the home are usually enjoyed."
Home Care or Institution

In former years it was a common custom to place infants with Down's syndrome in an institution shortly after birth. Often the making of the diagnosis was followed swiftly by the committal. The child was often not seen by the mother, but was transferred to an institution. The unfortunate custom of early placement is still occasionally known.

The reasons given for early institutionalization include:

- **Disadvantage to other children in the family.** It is said to be unfair to the other children to keep a handicapped child at home, that they will get less of the parents' attention, and that they will be exposed to ridicule by neighbors and friends. These things do happen sometimes, especially with other varieties of mental handicap that are severely affected or disturbed. They are unusual with Down's syndrome. In surveys of families that had kept their child at home, it has been found that in about three-quarters there was good family adjustment.

- **In the other quarter there were problems and stresses, and perhaps placement would have been the best solution for these.** Of course, shortly after birth, there is no way of looking into the future and foretelling how such things will turn out, and many parents decide that, as home placement is obviously best for the child himself, they will try to keep their handicapped child and teach the rest of the family to love and care for him.
Another reason sometimes given is that since placement will be inevitable some time in the future, it is best to "get it over now," to "make a clean break," so that later pangs of separation are avoided for both child and parents. Parents are even sometimes advised never to see the child again. This point of view overlooks the grieving that inevitably strikes a mother who puts aside her baby, and also deprives the child of the early years of mother love and stimulation, which might be said to be a right of the child, even though in later years placement away from home may be wise.

"These children are happiest living with children of like ability." Again, this point of view overlooks the great value of family life, and the lessened stimulation often received by young children in residential institutions. Some of the happiest Down's syndrome children I have seen are those found in the special day centers or schools, where they have a jolly and interesting period with other mentally retarded children before they go home to their families.

Nevertheless, there are many families who have considered all these factors and have decided to place their child in a residential institution. However, they cannot do so for quite a time nowadays, due to the long waiting list for admission to most institutions.

If there is a choice of institutions, the parents should certainly look carefully at them before deciding where to apply. They should inquire about facilities for stimulation, training, occupational therapy, and medical and nursing care. A good guide to the quality of the institution is to look at the children already there, and to observe whether they are sitting around sullen and bored, or whether, as they should be, they are both busy and happy. The parents should also discover if the residential facility is accredited.
After admission it is important for the parents to keep visiting their child, and to arrange outings and holidays. Again, opportunities exist in most of these residential facilities for parents' groups and activities in which parents should join.

**Later Placement:**

Not all children with Down's syndrome turn out to be the happy placid people I have described. A few children are found later either to be so grossly handicapped as to be unable to look after themselves, or to have behavior abnormalities such as restlessness and aggression. These children put too much strain on family life, to which they have little or nothing to contribute. Placement may be wise in these rare cases.

Residential placement of older children may be considered for other reasons. Parents' advanced age, ill health or fatigue are obvious reasons; and provided family contacts are maintained by regular visits and holidays at home, the stress to the child caused by the change in circumstances need not be severe.

The view is gaining ground that small residential hostels, in preference to large institutions, provide a more suitable home for older mentally retarded people who are employed in "sheltered workshops." Such hostels are gradually becoming available in many places in the United States.
it is remarkable how expert he becomes
Conclusion

The birth into a family of a child with Down's syndrome raises special problems, but need not be the great tragedy that it is often described. With proper support in the earlier years, and the later help of the day centers or special schools, the rearing of a handicapped child with Down's syndrome can be a rewarding experience. Tolerance and understanding are both requirements of the fruits of this rearing, and these gifts can flow from the parents to their other children. In many instances, with everything in their favor, parents can care for the child for years. In other cases, good reasons may impel parents to put their child into a residential center for the handicapped. In all cases, parents will be wiser and more mature for having faced the problem honestly and squarely, and for having done the best for all parties concerned in this problem of the child with Down's syndrome.

Acknowledgements

My thanks for criticisms and suggestions are due to Miss A. Wills, supervisor of the Oakleigh Retarded Children's Center, Victoria; to Mrs. Mavis Cragg, B.Sc., Ph.D.; and to Sister Nacha of the Children's Cottages Training Center, Kew. My thanks are due also to the Mental Health Authority, Victoria, for permission to publish this article.
Further Reading

National Association for Mental Health,
39 Queen Anne Street, London, W.1.


Following is a list of publications more accessible, perhaps, to readers who live in the United States. It should be pointed out that, although the items listed are highly recommended for additional reading, the list by no means includes every book on the subject.


David, by Nancy and Bruce Roberts. Published by John Knox Press. Box 1176, Richmond, Virginia 23209. Price $4.50.


PERIODICALS

The Exceptional Parent. Order from the Exceptional Parent, P. O. Box 101, Back Bay Annex, Boston, Massachusetts 02117. Six issues per year. $10 per year.

Sharing Our Caring. Written especially for parents of Down's syndrome children in order that they might help themselves, and, thus, help their children. Order from Caring, P. O. Box 196, Milton, Washington 98354. Five issues per year. $3 per year contribution.