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ABSTRACT

Information is provided for parents of handicapped children, aged 0-2 years, on the uniqueness of each infant's learning processes and the valuable role that parents and others can play in helping their infants with special needs to make the most of their abilities. The digest examines parents' concerns during the infant's hospital stay and early days at home, emphasizing the stresses on not only the parents but other family members. It notes the availability of early intervention programs, and describes methods of identifying infants who need early intervention services. Principles of infant development are discussed, along with the sequence of development of motor skills, language or communication, cognition, and socialization. Throughout, the digest stresses the uniqueness of each child's skills and personality and the parents' roles in stimulating their infant's development. The digest concludes with a bibliography and list of organizations that can provide information and assistance. (JDD)

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Early Intervention for Children Birth  
Through 2 Years

News Digest, Number 10, 1988  
National Information Center for Children  
and Youth with Handicaps

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NUMBER 10 1988

# NEWS DIGEST

National Information Center for Children and Youth with Handicaps

## EARLY INTERVENTION FOR CHILDREN BIRTH THROUGH 2 YEARS

The National Information Center for Children and Youth with Handicaps (NICHCY) regularly receives requests from parents and others for information on raising infants with special needs and on programs, resources,

and support groups that can help. This issue of *News Digest* is written to provide parents with information on (1) how each infant learns in his or her unique way, and (2) the valuable role that parents and others can play in helping their

infants with special needs. Most of all, this issue of *News Digest* is intended to help parents deal confidently with the challenges of helping their child make the most of his or her abilities.

**I**nfants are active learners from birth. Having a handicap or serious illness doesn't change this fact; however, these infants may need extra help in developing the skills needed to learn and grow. This help may come from structured early intervention programs as well as from normal, everyday interactions with parents and other family members. Parents need to become aware of the importance of their role in facilitating, guiding, and supporting their baby's development. With time and understanding, parents can become their baby's best ally in interpreting needs. Also, with time and understanding, they will be able to develop the coping skills they'll need to face the day-to-day realities of the handicap or illness.

The majority of new parents start out with little preparation or special training in meeting the unique, ongoing challenges and demands of a newborn. Even experienced parents must readjust their lives whenever another child is added to the family. Yet, parents of infants who have handicaps or serious illness, or who are at risk of developing handicaps as the result of prematurity or other birth complications, must deal not only with the normal challenges of parenthood, but with additional stresses and concerns for which they are typically not prepared. Regardless of the seriousness of the handicap or illness, each change in their baby's condition presents a new set of questions, concerns, and challenges that parents must confront.

### In the Hospital

Many infants are born with handicaps that may appear serious but do not necessarily pose an immediate threat to their health. Parents of these infants often experience a range of emotions during the hospital stay that may or may not be offset by a caring and understanding hospital staff and by the support and encouragement from family and friends. The sense of lightheartedness that often accompanies the birth of a child can be displaced by the thoughts and concerns about the unexpected and unknown, turning this into a time of stress and uncertainty for parents.

When a baby is born with complex medical problems or is at risk for developing serious handicaps through prematurity, illness, disease, malformations, arrested development, or other complications, the hospital experience can be particularly unsettling for parents. The fast-paced, high-tech atmosphere of the neonatal intensive care unit (NICU) can be frightening and may contribute to the stress and confusion parents already feel with the child's birth. Often, parents are faced with making life-or-death decisions about situations unfamiliar to them at a time when they are most vulnerable. In addition, they may be exhausted from traveling back and forth to the hospital several times daily and disappointed at not being able to take their baby home.

### At Home

Even when it has been determined that an infant is well enough to leave the hospital, parents' fears do not immediately dissipate, in fact, they are very often intensified. While all parents wor-

ry about their newborn, most parents of vulnerable infants find it more difficult to put aside their fears. The stress and emotions of the first days and weeks of the baby's life will take time to fade, and anxiety about the future is very real.

When parents bring their baby home, they often find that they have exchanged one anxiety-provoking situation for another. In some cases, they are bringing home an infant who has been cared for by a large staff of well-trained professionals in a carefully controlled and highly specialized environment. If the infant had been connected to intravenous (IV) tubes and monitoring equipment from the first days of life, he may be leaving the hospital still requiring special equipment, complicated feeding procedures, and frequent, precisely administered medications. Suddenly the parents alone are responsible for that same care at home. And although they may have received thorough, but accelerated, "on-the-job" training from the NICU staff at the hospital, parents still may not feel confident in providing that same care at home to their new, and often fragile, baby. Even in the safety of their home, parents may be afraid to leave their baby unwatched even for a moment, and may be easily upset by any unusual noises or movements their baby makes. Exhaustion from sleepless nights, responsibility for continuous monitoring of the baby's vital signs, and intricate, round-the-clock feeding and medication schedules can cause even the most conscientious and self-assured parent to become stressed and distracted. These circumstances may cause parents to remain anxious long after the baby looks -- and is -- less fragile.

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*... the emotional and physical demands that accompany the birth of a child with special needs should never be underestimated.*

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## Other Concerns

In addition, the birth of an infant with an illness, handicap, or condition that can lead to later delays can put undue stress on family finances and family life. Most new parents have not had time to cope with the stresses and emotions of the early days of their baby's life or accept the fact of the handicap or illness, before they must also cope with present realities.

Parents may have to negotiate with insurance companies over hospital bills; arrange for and coordinate home care, nursing services, and special equipment; and schedule follow-up visits with medical professionals. Consequently, the needs of other children in the household, although important, may be inadvertently overlooked or neglected in the hectic pace of caring for the new baby. Parents may be unable to set aside the necessary time to talk with their other children about their new sibling's problems and needs.

Parents' own needs may be neglected, as well. Finding adequate childcare and getting social and moral support from others may be particularly difficult. Friends, neighbors, and family members -- especially grandparents -- may want to help, but may feel afraid, confused, or overwhelmed themselves. They may not know how they can help and may feel inadequate in offering any help at all, for fear of harming the baby, especially one that is fragile. As a result, parents may miss out on sorely needed respite and privacy at a time when they need it most. Single parents may feel these stresses even more intensely and may need help in finding and developing support systems within the family and the community.

All of these concerns and pressures can cause many parents of infants with handicaps or serious illness to feel isolated and singularly responsible for raising and caring for their infant. As parents struggle to come to terms with the problems they face, they need information, support, and encouragement to

do the best job they can. They especially need to know that other parents of children with special needs have had similar problems and feelings and that help and support are available.

Professionals, family members, and friends also must recognize that parents do not always find involvement with their infant's development and progress to be a satisfying or rewarding experience. Some parents may always have difficulty coping with a child with handicaps.

There are many ways that parents can obtain help and emotional support. They can join therapy or parent support groups made up of parents of children with handicaps. In these groups, participants can offer support and encouragement to each other and exchange information about helpful resources. Parents can also seek help through individual and group counseling sessions offered by counselors, social workers, psychiatrists, and psychologists in private practice or in public agencies. Other parents of children with handicaps, as well as family members and close friends, can offer much-needed understanding and support. In addition, the physicians and nurses at the hospital or clinic, as well as the family's pastor, priest, or rabbi, may be good sources of advice and help in obtaining resources. However, it is important to remember that the emotional and physical demands that accompany the birth of a child with special needs should never be underestimated. Life as these parents have known it has changed!

## The Future

Once parents have had time to consider the future, they may find some of the recent research about infants as learners reassuring. In the last 5 to 10 years, the areas of infant development, infant education, early intervention, and infant mental health have become ever-expanding fields of study and research. One reason for this increased attention to infants is that medical science and

current technology have made it possible for an increasing number of low birthweight and other at-risk babies to survive.

Another reason for expansion in this area is that since the 1960's there has been an increased awareness of the value of early intervention for young children in general and particularly for infants and toddlers who have handicaps or who are at risk for developing handicaps. Research suggests that early intervention with infants, in which problems are identified and treated as early as possible, can make a significant difference later in their physical, cognitive, and social abilities, and can minimize the effects of present or potential handicaps (Weiner & Koppelman, 1987).

The impact of studies and research on the effectiveness of providing special education to very young children has resulted in a federal law, passed in 1986, known as Public Law 99-457. This law requires that early intervention and special education services be provided to children (ages birth through 5 years) who have handicaps or who are at risk for developing handicaps. Under the provisions of the law, these services must be provided no later than school year 1990-91. (For more information on Public Law 99-457 and accessing services for your infant with special needs, write to NICHCY and ask for a free copy of "A Parents' Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Handicaps.")

## Early Intervention Programs and Parent Involvement

Public Law 99-457 should increase parents' access to early intervention programs. Such programs can make a difference for infants born prematurely, or with handicaps or illness -- and their families. Through these programs, parents can understand more about their baby's abilities, make decisions about the goals they have for their baby, and discover ways to stimulate their baby's growth and development. In many cases, parents can get support in adjusting to and meeting the needs of an infant with handicaps or delays. But probably the most important function of such programs is to help parents develop a close and satisfying relationship with their

child. When parents find ways to enjoy their baby and are able to give the needed support, they very likely will increase the prospect that their child will have a happier and more productive life within the family and the community.

Traditionally, the approach to delivering services to very young children has focused on identifying strengths and weaknesses, then remediating deficits and "teaching" the child the needed skills. In recent years, however, the focus in many early intervention programs offers a more positive approach for children, their families, and the professionals who work with them. This approach, often referred to as prevention-intervention, recognizes that not all problems or deficits can be "fixed" through many of the medical or educational therapies available, and that parents and professionals cannot change the long-term problems that occur at birth, such as brain damage or severe hearing loss. Parents and professionals can, however, minimize or prevent impairments from causing secondary handicaps, such as emotional problems, or problems with thinking or communicating. They can work with the child's strengths and help their child develop alternative or compensatory learning strategies. (Campbell, 1986).

While many programs focus on parents being given advice and educational and therapeutic tasks to do at home, others are beginning to develop systems that recognize parents and professionals as equal partners. In such programs, professionals serve as consultants to families, helping them determine the goals and activities they want for their child. The changes in the approaches taken and attitudes adopted by professionals working with parents reflect a focus on family needs, with an emphasis on enhancing the child's growth, development, and sense of well-being, rather than a singular focus on correcting a problem. Parents need to be regarded as full partners in this effort, and valued as prime contributors in decisions made about their child's program and progress.

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## *Parents need to be regarded . . . as prime contributors in decisions made about their child's program and progress.*

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### **How Infants are Identified as Needing Early Intervention Services**

Some babies are identified at birth as having genetic/congenital conditions such as Down syndrome or spina bifida that cause, or are likely to cause, delays in development. Other babies are identified as being at risk for developing handicaps as the result of prematurity or other birth complications. In both cases, infants are generally monitored by physicians and/or other health care professionals for early signs of developmental problems, such as a delay in one or more of the areas of development (cognition, motor skills, communication, or socialization). In some cases, parents (or other family members) identify their baby as not developing in expected ways. Alerting someone who can help is an important and necessary step for anyone to take if they have concerns about how their baby is developing.

The period in which parents await results from medical (or other) tests that will provide additional information on how their baby is developing can be a stressful one. Balancing the possibility of "good" news against the threat of "bad" news creates uncertainty and anxiety that can last long after parents' suspicions are confirmed or denied. Even though parents need to have information about their child's condition, they may not always be ready or able to "hear" the information. They may need to have it repeated many times and may need to talk about it at length. Professionals' awareness of and sensitivity to parents' vulnerability during this time is vital to creating a climate in which discussion about the baby's condition is welcomed and encouraged.

Often, babies will appear to be at risk for developing a handicap when, in fact, they are only taking a little longer than others to develop certain skills.

Babies with serious handicaps can make remarkable progress when they are provided appropriate opportunities to learn within a caring and nurturing environment.

When parents first suspect that there may be a problem, it is important to have a physician check for physical problems. The infant may have a health, vision, or hearing problem that is interfering with appropriate development. When physical concerns have either been ruled out or identified and addressed, the infant's developmental level can be better assessed.

An important step in determining whether an infant needs early intervention is the assessment -- the process of gathering information about an infant's development to make decisions about the kind of help the infant might need. Parents may first want to discuss their concerns with their child's pediatrician, or with someone at a nearby children's hospital or the pediatric department of their local hospital or health clinic who is a qualified specialist in infant development.

In addition, many states have established programs to identify children ages birth through 2 years who may have developmental delays. Someone in your local school district or in your state's Department of Education can give you information about whom to contact to arrange for an assessment. Typically, the contact person may be located within the education department, the health department, or the local Child Find office.

In an assessment, a team of professionals, which includes an infant specialist, observes and evaluates the infant to determine his or her eligibility for early intervention services. If the child is found eligible for services, the family may be assigned a case manager who coordinates the services and consults with the family about their needs and concerns for their baby. The case manager can also offer families the support and information they need about how their baby is developing.

## Test results alone should not be considered the final predictors of a child's later functioning.

Bailey and Wolery (1984) propose certain guidelines for giving an assessment:

- o It should be administered in a relaxed, comfortable manner, with parents present whenever appropriate; and
- o It should be conducted in as many sessions as are needed for an accurate assessment.

They also identify three methods that are recommended for obtaining this information:

- o Naturalistic observations -- in which children are observed in a variety of settings that allow for typical behaviors to occur;
- o Interviews with parents -- which are conducted either formally, using questionnaires and other assessment procedures, or informally, with parents supplying anecdotal information;
- o Testing -- which involves giving an infant a variety of screening tests and assessment scales to help gain more information about his or her present level of development.

Regardless of how a baby is assessed, it is important to remember that tests often do not accurately predict the long-range outlook for a child. Each test is only a "snapshot" of an infant's development at a particular point in time, and often, several different tests are needed to get a more complete picture of how a baby is functioning. The interaction of a number of factors, including the baby's temperament, the supportiveness of his or her environment, and the child's overall progress all help to determine how the child develops over time.

Physicians, nurses, psychologists, child development specialists, and others who work with infants use a number of different scales or screening tests to answer questions about an infant's development. Wodrich (1984) and Bailey & Wolery (1984) review some of the

more commonly used scales. These include:

**The Brazelton Neonatal Behavioral Assessment Scale** - This scale provides measures of the behaviors of newborns (ages birth to 4 weeks). It also provides estimates of an infant's neurological functioning and assesses the infant's capacity to respond to and interact with "events in the environment" (such as light, sound, and touch). It is typically, though not exclusively, given to at-risk babies or to those who show some delays in development. This scale provides estimates of developmental progress and indicates signs of delay.

**The Gesell Developmental Schedules** - This measures the developmental status of infants (between the ages of 1 to 36 months) in terms of fine and gross motor behavior; language behavior; adaptive behavior, including eye-hand coordination and imitation; and personal-social behavior, including reactions to persons, initiative and independence, and play response.

**The Bayley Scales of Infant Development** - This well-known and widely used infant scale provides a diagnostic measure of an infant's mental abilities, including memory, learning, and problem-solving behavior; rates motor skills, such as body control, large muscle coordination, and control of the hands and fingers; and assesses behaviors such as social orientation, fearfulness, and cooperation. The Bayley is a norm-referenced test or scale that indicates a child's developmental level in relation to other children, specifically to a group of other children in the same age group. As a diagnostic tool, the purpose of the Bayley is to verify the nature and extent of a child's developmental delay. It is a fairly lengthy test and must be administered by a well-trained examiner. (Bailey & Wolery, 1984).

**The Denver Developmental Screening Test** - This test is a screening instrument designed to determine

whether a baby is at risk for developmental delays and whether he or she should be referred for further evaluation. (Bailey & Wolery, 1984). Like the Bayley, it is a norm-referenced test, indicating how a child compares with a group of other children of the same age group. It is used to screen or detect problems in children from birth to approximately 6 years in four areas of development: personal/social, fine motor/adaptive, language, and gross motor. It is important to remember that the Denver is a screening test and not an in-depth assessment test (Wodrich, 1984). Its primary advantage is that it is relatively short, easy to use, economical, and accurate (Bailey & Wolery, 1984).

While the above-mentioned screening and assessment tests are very useful in detecting lags in development, it is important to be aware of the limitations of such tests. In general, tests or scales used with infants 18 months or younger are less able to predict later IQ (intelligence quotient) than tests given to children older than 18 months. Infants with low scores on tests may be more at risk for developmental delays in later childhood than infants who score higher, but making a developmental diagnosis is more limited in infancy than at later stages.

Parents should keep in mind that in all assessment situations, it is important for the process to be carried out in a nondiscriminatory manner. The administration of tests and the interpretation of the results to gain information about a child must be done carefully and according to guidelines specified by such professional organizations as the American Psychological Association. By becoming more informed about psychological testing, parents can make clearer decisions about whether or not test results and the test interpreter's comments and observations are acceptable or unacceptable. Above all, test results need to be worded in such a way that they are useful to families seeking information and assistance (Wodrich, 1984).

Test results alone should not be considered the final predictors of a child's later functioning. Parents' observations and knowledge of their child's strengths, weaknesses, and needs also should be considered when a child is evaluated. Because of the importance of the family environment for the development of young children, evaluations can

include observations of the child at home. Some families might find this process helpful; others might consider it intrusive, feeling as though they were being evaluated as parents. Each family needs to decide whether home observations would meet their specific needs, and members of the early intervention team should respect that decision.

## How Infants Develop

Over the past 20 years, developmental specialists have changed their views of infants. It once was believed that an infant's capacity to learn emerged slowly after birth. Infants were viewed largely as being passive recipients of care. Some specialists believed that development took place primarily as a result of the unfolding of the child's inborn capacities; others believed that development was influenced primarily by the experiences the child encountered in the environment. Now it is widely believed that infants develop through a continuing interaction between their inborn abilities and the stimulation they receive from their environment (Anastasiow, 1986).

The following principles summarize contemporary thinking about infant development, according to Lewis (1984), Hanson (1984), and Anastasiow (1986). While these principles are based on studies of infants without handicaps, we have included them to provide a basis for an understanding of normal development.

### 1. An infant's capacity to learn is present from birth.

Research data from the last 20 years on early childhood development reveal that infants learn, respond, and interact from the moment they are born. Their capabilities and their sensory and cognitive skills are greater and more complex than researchers had thought possible (Hanson, 1984).

Even very young infants can process information and respond to it based on their experiences. For example, research and studies by Robert Fantz in the 1960s demonstrated that newborns could see and process information and showed signs of visual preferences. When newborns were given a choice between simple and complex visual patterns, they preferred the more complex (Lewis, 1984).

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### 2. Infants learn through social contact.

Infants begin their social contact by engaging in soothing bodily contact and eye contact with their parents, and later by smiling and making sounds. Infants like to look at faces and can understand facial expressions and tone of voice. A social smile and cooing are part of an infant's way of communicating and have an important role in social interaction between the parent and child. A large part of early learning takes place through play and other interactions between the parent and child (Anastasiow, 1986).

### 3. Infants are active learners.

Infants like to have an influence on the people and objects in their environment. Several researchers (Watson, 1966; Siqueland and DeLucia, 1969; in Lewis, 1984), have demonstrated this principle by giving a group of infants control over what they see while other infants observe the same thing without having that control.

In the Watson study, the infants who had control were able to move a mobile which was attached to their arms by a string. In the Siqueland and DeLucia study, infants could change the brightness of a projected picture by sucking a pacifier. In these and similar studies, the infants whose actions made a difference in what they saw were interested for longer periods of time and smiled more than those who could not affect what they saw (Lewis, 1984). Similarly, infants like to produce an effect on the people around them. When they make faces, they like someone to make faces in return; when they make sociable sounds, they like responses from those around them.

### 4. Infants affect their parents, just as parents affect infants.

We think of parents as having the primary influence in the parent-infant interaction. More careful observation of play and other social interaction has

taught specialists that just as the parent's attention, affection, requests, physical interactions, and warmth trigger a response by the infant, so also, do the child's responses affect the parent. For example, when a baby smiles, the parents smile in return and often talk to the baby. The baby, in response, may coo or gurgle and thrash around, which, in turn, causes the parents to continue the interaction. What is important is that each partner in the parent-child interaction influences the other and sets up a response to the reaction for the other.

When interactions between infant and parent are strained and seemingly unrewarding, parents' feelings of self-esteem may be threatened, and a cycle of rejection may result. In *Handicapped Infants and Children - A Handbook for Parents and Professionals*, (1983), Carol Tingey-Michaelis emphasizes that even though parents may feel like playing and talking less with their non-responsive infant, it is very important that they play and talk even more than they would if the infant were responsive. Although an infant may have some difficulty interacting with others, he or she may very much want to play and respond, but may not know how or be able to "signal" others to do this. The important point is to "listen to" and watch your infant to find out the unique signals or cues he or she uses to indicate a willingness or readiness to play and respond.

There are various ways parents can interact with an infant who is slow to respond that are mutually pleasurable and rewarding. Siblings, grandparents, and other adults who are comfortable with the baby can initiate and participate in these activities, as well, and should be encouraged to do so. Some of these activities include simple, spontaneous interactions, such as stroking or gently touching the baby; talking or singing in a quiet, soothing voice; or holding and rocking or swaying the baby. These activities can occur during day-to-day interactions, when your baby is being fed, dressed, or bathed.

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## *A child with a handicap is first of all a child; the handicap is secondary.*

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Remember that an infant who is slow to respond may need to interact more often and continue the activity longer than other infants. It is also important to remember that the activities suggested here may not be appropriate or advisable for infants who are considered high risk or sick. Parents should always consult a pediatrician or infant specialist about activities that are appropriate for their baby.

Whenever possible, (and with a physician's approval), keep your baby where the action is in your household, rather than secluded in a separate room. Take your baby on as many outings as possible, and with other people, for added stimulation. Try to maintain contact with others to expose yourself and your baby to common, everyday experiences. For example, if others are taking their infants to the park, take your infant out as well, even if doing so seems discouraging at first. Although your baby may not be able to participate in the same way the other infants do, try to make his or her everyday experiences as normal as possible. Parents need to respond to a baby with special needs the same way they would to any baby, and should encourage others to do the same. While it may seem that your child is not progressing in certain areas of development (for example, walking or talking), it is important to remember that there is a wide range of abilities that all individuals possess. Some of those abilities may include (but not be limited to) good listening skills, good short- or long-term memory, and socialization skills. Many inborn abilities may not be seen in the first few years of life, but may unfold as time goes on.

As a parent, you can help your child mature and grow by focusing on your child's strengths and worth as a human being and, more importantly, by giving your child what every child needs: acceptance and a sense of belonging to a family and being valued and loved. As much as possible, try to focus on your baby's positive qualities, and concentrate on the potential your child has for

experiencing joy, love, and the security of the closeness of his family and those around him. It is also important to keep in mind that you are a valuable and important asset to your child, and that your child's sense of identity originates with you. Your attitude toward your child and yourself is vital to your ability to put the situation in perspective.

It is important that parents confront and manage any negative feelings they may have about themselves and try to rid themselves of any guilt they might feel over their baby's problems. Parents who are able to let themselves experience their infant as a separate being rather than a negative extension of themselves, and who can recognize the unique qualities that make their infant an individual, have begun to take the first steps toward growth and survival as a family.

The needs of an infant with handicaps are the same as every child's needs, but there may be more of them. The infant with special needs may require help and attention more often and in different ways than do other infants. Meeting these demands is often difficult for parents to handle alone, and they may need more support and encouragement than those around them can give. Parent support groups can be an excellent source of needed assistance, practical advice, and understanding. Through such groups, parents can share their experiences and feelings with other parents who can empathize, rather than sympathize. Quite often, parents maintain close personal contact with each other through phone conversations. Other support may be in the form of informational meetings, informal get-togethers, or structured discussion groups. (For more information on parent groups, contact NICHCY and ask for our "Parent Pack.")

Even if your baby isn't developing normally in every aspect, you will want to strive to make his or her everyday experiences as normal as possible. A child with a handicap is first of all a child; the handicap is secondary.

## **Infants as Individuals**

Today, we know that every infant is a unique being with an equally unique temperament. One infant may be placid and easygoing from birth; another may be constantly restless. Each grows and learns at his own pace and according to his own style. The growth and development of infants born with handicaps or chronic or life-threatening illness may be as erratic as their first days or weeks after birth. As these infants grow, they may be "on and off" the chart of developmental milestones: they may seem to follow normal patterns of development in some areas but not in others. The ways in which skills and personalities unfold and develop make each child a unique individual.

Regardless of how fast or slow growth and development are, all infants possess a set of skills and abilities which change with development. In addition, all infants progress through similar stages of development. The growth may be slower and the needs at each stage may be more pronounced, but there is an overall sequence to the stages. Some infants may take longer than others to reach a goal, but what is important to remember is that it is not a matter of how much time it takes to reach a goal, but that there is progress towards reaching that goal. By understanding the steps or sequence of normal development, parents are better prepared to help guide their infant with handicaps or delays from one stage to the next.

The following section includes general information about the predictable sequences of normal infant development in the areas of motor skills, language or communication, cognition, and socialization. Also included are suggestions on how parents can stimulate development in each of these four areas. Much of this information is based on the *Parent Helper* series from the Maryland State Department of Education and is consistent with many of Hanson's (and others') points, with additional suggestions from interviews with parents.

Generally speaking, infants develop in a predictable sequence in each of the following areas:

**Motor Skills** - This area includes gross and fine motor development. Gross motor activities involve the use of large muscles for sitting, crawling, and



walking. Fine motor activities involve the use of small muscles, such as those in the hands and fingers used in the pincer grasp for picking up small objects. Initially, gross motor development occurs in a head-to-foot direction, so that facial, oral, and upper limb movements develop before many movements involving the leg muscles. At the same time, as motor control continues, muscle groups that are close to the trunk of the body develop before those that are further away. For example, an infant will learn how to use the arm and hand together before being able to pick up a small object with the fingers.

Gross motor skills generally follow a sequential pattern, with each new skill providing a basis for later skills. While infants are mastering one type of activity, they are experimenting with the next kind of activity in the developmental sequence. In general, when babies begin to experiment with a new activity, their movements are quite awkward; over time, the movements will become better coordinated. With infants who have handicaps, motor skills development is often varied. Parents and others working with the infant need to keep this in mind.

Variation in the patterns of motor development is common; some variation is normal, some is abnormal. The rate, pattern, and quality of motor development varies from child to child. With infants having abnormal variation, it is often difficult to tell if the problems are temporary or long-lasting. In cases where abnormal variation is due to poor muscle tone or delays in motor abilities, an intervention program might be recommended, even without a specific diagnosis. Parents need to be aware that intervention therapies may be short-term and that many problems may not affect the overall developmental outcome of their child. Many children who are born prematurely, with handicaps, or with serious illnesses that put them at risk for developing handicaps may not have any problems later on. However, other infants, such as those with Down syndrome or cerebral palsy, often have problems in motor development that are more easily identifiable and which may remain with them. Such problems often can be greatly modified or lessened with early intervention. Today, infants who have motor development problems may be referred for intervention therapy once a diagnosis is made

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## *The rate, pattern, and quality of motor development varies from child to child.*

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(Hanson, 1984). This can occur as soon as an infant is discharged from a neonatal intensive care unit.

If you are concerned about your infant's motor development, ask your pediatrician, a pediatric nurse, your baby's case manager (if you are enrolled in an early intervention program), or another parent for information (books, pamphlets, or charts) on the steps in normal infant and toddler motor development. If you have concerns about how your infant's motor skills are developing, express your concerns to a professional, such as your baby's pediatrician or your baby's case manager (if applicable). They can refer you to a pediatric developmental specialist, a physical therapist, or an occupational therapist. (Occupational and physical therapist organizations are listed under "Organizations" at the end of this *News Digest*.) Another good source for information and referrals are parent support groups. Often, these groups have lists of names of professionals, and will give parents the names of several professionals from which they can choose.

You can help your baby develop gross motor skills by providing experiences that stimulate the movement of eyes, head, body, arms, and legs. For example, dressing your baby in brightly colored mittens and booties with bells attached can help your baby become more aware of his or her hands and feet. Remember that your child needs to touch and handle objects in order to learn. It should be noted, however, that some babies cannot tolerate stimuli and are negatively affected by bright colors and even by being touched.

You can stimulate movement by giving your child simple, safe objects such as empty boxes or plastic containers to stack and build with and by providing push/pull toys. In addition to having safe toys available for your child, make sure that your home is "baby-proofed" so that your child can move about without getting hurt. If your baby cannot move around, find a safe location for

him or her in the main room, around other members of the family, if possible.

### **Language or Communication -**

This area involves the development of receptive language -- the ability to receive information and process and understand its meaning -- and expressive language -- the ability to transmit information, through the use of various forms of language, including making gestures and signs, babbling, head shaking, and speech. Facial expressions, body movements, gestures, and changes in tone and volume of voice are all examples of early forms of normal communication. Research studies into mother-infant interactions have shown that a continuous, two-way process in which each partner modifies the other's interactive behavior can develop early in an infant's life. In this process, the infant's behavior (such as opening its eyes or making gurgling sounds) is reinforced by the mother's responses, such as making face-to-face contact, touching, or vocalizations. The evidence of how this reinforcement affects different aspects of an infant's development, including language and communication, is significant for infants born at risk or with special needs.

Studies of infants with handicaps have revealed that many of their interactive behaviors, such as frequent and loud crying, difficulty in being comforted, and infrequent eye contact, did little to encourage or reinforce the caretaker's behaviors. From these and similar studies, it is thought that an infant's earliest interactions with its environment can significantly, although not totally, affect future language and communication development (Hanson, 1984).

You can help your baby develop the ability to communicate by talking to her while you are performing daily activities. For example, while dressing your baby, you can talk or sing about what you are doing, using simple action and descriptive words as you go through each step. By reading to your baby while she sits on your lap, you can help in the development of attending, listen-

## Infants learn about their world primarily through the experiences they have with those who take care of them, beginning at birth.

ing, and memory skills. If you are otherwise occupied, you can also use the radio and the television to stimulate your baby's communication skills. Remember, however, that these devices provide one-way communication only and are not interactive in nature. Encouraging your baby to use her voice to make new sounds; increasing your baby's awareness of voice, lip, tongue, and jaw movement; and prompting your baby to imitate your gestures all add to the development of communication skills.

**Cognition** - This includes an infant's processing of information in the environment and constructing knowledge based on his or her experiences and perceptions. In order for infants to function and adapt in their environment, they need to be able to receive information from their surroundings, understand what it means, and act on it. Seeing, hearing, touching, smelling, and tasting are the starting points for the infant's expanding understanding of the world. Memory is also a part of the process of cognition. As an infant's capacity to remember grows, he or she is able to make decisions based on experience. Infants learn about their world primarily through the experiences they have with those who take care of them, beginning at birth. According to the late Swiss psychologist and leading infant development theorist, Jean Piaget, an infant must be given certain "environmental experiences" if basic cognitive skills are to develop. Infants with handicaps need to be given alternative ways to develop their cognitive abilities. For example, most infants use reaching behavior to learn about their world. An infant who is blind, however, does not attain eye-hand coordination, and needs to be taught "ear-hand" coordination -- that is, locating an object by sound and reaching for it -- to make possible future explorations of his or her world (Garwood and Fewell, 1983).

You can help your child develop abilities in knowing, understanding, and remembering by making your home a stimulating learning environment. You

can do this by providing your child with different sensations as part of his or her everyday routine. For instance, you can attach a homemade mobile with two or three safe, sturdy objects to your baby's crib to stimulate awareness of differences in shape, color, and texture. You can renew your baby's interest by changing the objects in the mobile as often as you like. Similarly, you can give your baby lessons in listening by speaking and singing in different tones. If you are too busy to do this, you can sing into a tape recorder and play it back whenever your baby is ready for a listening activity. You can use a traditional game of peek-a-boo to develop your infant's memory (usually successful with babies at least 3 to 4 months old, or older). After playing the game many times, your infant learns to look forward to special words or actions, repeated in sequence, that act as cues for what will come next.

In addition, infants can learn a great deal from toys that are attractive, versatile, durable, and easy to pick up and hold. If your baby's ability to grasp and hold is delayed or impaired, try toys that hang or roll. In choosing toys, become your own expert. Make a list of your baby's strengths and weaknesses and choose those toys which meet your child's requirements. Other parents of children with special needs, such as those in parent support groups, can be excellent sources of information about what toys work with children having certain types of handicaps. Physical and occupational therapists can also provide advice on techniques and materials that will encourage use of hands through manipulation of toys and objects. Many local libraries have toy-lending services or can refer you to libraries or other facilities that do. (Additional information on toys and ideas for play can be found under "Developmental Toys and Play Therapy" at the end of this *News Digest*.)

**Socialization** - This area involves the development of a child's self-awareness and ability to respond to others. An infant's self-awareness and interest in others begins with early experiences in

seeing, hearing, touching, moving, and tasting. The first social interaction an infant experiences is usually with the mother. As these interactions continue, they develop into mother-child games, such as "this little piggy went to market" or "peek-a-boo."

The social behaviors of infants who have handicaps may not follow the same patterns. The give-and-take interactions between the parent and infant may be disrupted due to a number of factors. The infant with a physical, sensory, or cognitive disability may not be able to send clear social messages to the parent. The inability of an infant with a handicap to smile or gaze in ways that encourage social responses from parents and others may negatively affect their overall patterns of social interactions. In such cases, parents may need help in finding alternative ways to interact with their infant. One way parents can receive help is to participate with their infant in an early intervention or infant stimulation program, where they can learn ways to encourage social responses in their infant.

Other factors that may play a part in the altered patterns of social interaction between mother and infant are the infant's temperament, appearance, and habits. Parents may find it more difficult to react positively to an infant who is unloving, who rarely sleeps, or who elicits negative feelings from family members and others. Both handicapped infants and their parents may need specific support in learning how to develop reciprocal social skills that promote greater social interaction.

Early intervention groups and parent support groups can help parents learn how to interact with their infant. Many parents in these groups have had difficulty relating positively toward their own special needs infant and can offer encouragement and support for other parents.

You can help your infant develop self-awareness and an ability to respond to other people by getting into the habit of taking your baby with you as you move through your daily routines. Infants who frequently are left alone get bored and lonely just the way older people sometimes do. Encourage other family members to become involved with the baby's activities. This will enrich the baby's life, expose him to others in his life at an early stage, and aid in the development of his social skills.

## Parents' Roles in Stimulating their Infant's Development

For any child, the parent is the first and often the most important teacher, and a major influence on how the child develops. Long before child development specialists identified the important factors in infant learning, parents were playing with their children, talking to them, and providing a variety of stimulating experiences. Although your child may be receiving help from specialists, these specialists cannot take your place because they do not have the relationship that you have with your child, and they will never know your baby as well as you do.

Parents can play a major role in encouraging and shaping the development of their child with special needs. The reciprocal teaching and learning can begin during the infant's first weeks of life. The process used by parents in stimulating their infant's early learning is described below. This information has been taken from material written by Marci Hanson (1987), from pamphlets published by the Maryland State Department of Education (1980-84), and from interviews with mothers who have lived the experiences. Helping an infant learn involves certain basic steps. Hanson suggests that parents begin by becoming aware of how their baby responds to various situations in daily life. In addition, Hanson points to six strategies that have proven effective in helping babies learn:

### 1. Be responsive to your baby.

It is important to learn how your child signals his or her needs. All infants, including those with disabilities, develop "signalling systems." For example, parents should think about what their infant does to signal feelings of hunger, sleepiness, or the need for a diaper change. Are the clues subtle or very obvious? Once it has been determined what some of the signals are, parents will be able to recognize when and how their infant is communicating his or her needs. Many parents can tell what a baby wants by the subtle tone of the cry they hear.

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*There is no prescribed way or time to teach your infant; it should be natural and unaffected.*

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### 2. Teach your baby through social experiences.

Most infants enjoy and are motivated by learning activities that are made into games and other kinds of social activities. Play activities and social experiences are learning experiences. They should be planned according to the baby's tolerance level for stimulation and should occur at a time when both parents are relaxed. A baby's attention span may vary according to activity as well as mood. Some infants can spend no more than a few minutes on an activity; others can remain involved for half an hour at a time. There is no prescribed way or time to teach your infant; it should be natural and unaffected. However, parents must learn about their child's unique way of absorbing information.

Parents need to learn what their baby's activity limits are. The limit is the point at which an activity becomes a strain to the parent or the child. If parents need to spend 15 minutes on an activity, it does not have to be 15 consecutive minutes in a row; it may be three 5-minute sessions. If the infant is extremely active and does not sit down and attend to a task well, parents can think about activities that their child can do standing up or moving around. They need to choose activities and settings that are relaxing to both of them. Such activities may offer the child the greatest opportunities for learning. One mother reported that when her baby became tense or overactive, she placed him in a tub of warm water, where he played happily.

### 3. Take turns when interacting with your baby.

Imitation is one of the basic ways we all learn. After demonstrating to your infant how to do something, give him time to absorb the lesson. Wait for him to try the activity before demonstrating it a second time. Remember, it's not how long he does something that is important, but rather that he responds. Give

him time to show you how he is doing with an activity. Most important, be flexible and try to relax and enjoy the time together.

### 4. Be consistent with your baby.

Try to be as consistent as possible in your responses to your child's signals. For example, if you smile and clap when your baby pats his or her hands together, respond the same way each time your baby does that. Consistent responses make your child's environment more predictable and help your child learn.

### 5. Give your baby varied experiences.

As part of a natural routine, you can offer your child a variety of experiences in different locations and situations. For example, take your child on walks or outings and point out things that increase awareness of and familiarity with the environment. Your home can provide your child with a variety of sensory experiences, such as feeling different textured materials, smelling and tasting different foods, and seeing and hearing different shapes and sounds. The children's television show "Sesame Street" was designed around the idea of a child's surroundings as a natural learning place. Such places as the kitchen, the stairway, or the backyard can be as exciting to an infant as a shopping mall is to some adults. Stacking pans or empty food cartons or playing with water can be as stimulating (and often, less frustrating) to an infant as playing with the most sophisticated toy on the market.

Depending on your baby's handicap or unique style of learning, determining what is interesting and stimulating may take a lot of creativity on your part. For example, if you can't get to a play ground or to the city or town easily, a grocery store may be the best "museum" for your baby.

Parents should be discriminating in the types of toys they introduce to their infant: most have been designed with no thought of their use by children with

handicaps. Infants who are not able to pick up or manipulate objects will not benefit from the newest or latest toy being advertised as "educational." Discover what works with your baby and put away the other toys that frustrate or confuse.

Also be careful not to overstimulate your baby or introduce new experiences when she is tired or ill. Be aware of the signs or signals your infant gives when overstimulated, frustrated, or just tired of the activity. Pick a time of day to introduce new places or experiences when it is best and easiest for both you and your baby. This might be when you are driving in the car, making meals in the kitchen, or changing diapers in your baby's room. The timing of introducing learning experiences should be part of the natural rhythm of your baby's day, and the experiences should be fun and relaxing for both of you. You needn't feel compelled to teach at every opportunity.

**6. Maintain a positive attitude about teaching your child.**

Sometimes this won't be easy. You may feel guilty that you don't always enjoy teaching your child. All parents feel stressed, but parents of infants with

handicaps feel additional pressures. While keeping a positive attitude will have rewards not only for your baby, but for you, this may be difficult, depending on the nature and severity of your child's handicap. You, as well as the other members of your family, need to be aware of your child's strengths as well as weaknesses. Try to maintain a sense of humor and your perspective on what you are trying to accomplish with your baby. Others, especially parents of children with handicaps, often are able to help you with this. Remember that playing with your child is not a job; it is a part of the life you have with your child. The most important things you can give are the feelings of love, enjoyment, and a sense of belonging to the world. In doing these things, you will naturally be helping your child develop self-esteem.

Of course, parents do not and cannot always maintain a positive attitude. If you are having a bad day with your baby, change what you are doing and do something else. Take a break whenever possible; it is important that you maintain your sense of equilibrium. Like all parents of young children, you need to take time for yourself to renew your strength and spirit.

## A Final Word ....

Babies born with handicaps often may need more help and require more planning from their parents and others to get the skills they need to be able to progress. Parents of special needs infants also may need extra help and support. With it, they can accomplish a lot. Even though a child's growth and development may be delayed in certain areas, the most important goals for children with special needs are the same as they are for children without special needs: to develop feelings of self-worth and self-trust, to become as independent as possible, to develop trust in others, and to develop to the fullest his or her abilities.

One of the most important goals to strive for is to help build your child's self-esteem and to plan for and anticipate future successes for your child. Even if you cannot cure the problems or speed up development, you are capable of raising a child who has a sense of accomplishment and feelings of self-worth. As one parent cautioned: "Don't sell your child(ren)'s capabilities short. Encourage them every step of the way and help them to believe in themselves." (Thompson, 1986).

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*Raising Kids*. A newsletter published monthly that focuses on the many aspects of normal development in young children, and often includes articles on disabilities and health problems. (Available from Raising Kids, P.O. Box 273, Braintree, MA 02184.)

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## For Grandparents:

*Especially grandparents: A newsletter for and about grandparents of children with special needs*. (Write to ESPECIALLY GRANDPARENTS, 2230 Eighth Ave., Seattle, WA 98121.)

# ORGANIZATIONS

## Association for the Care of Children's Health [ACCH].

An association of professionals and parents promoting health care for children and their families. Publishes a quarterly newsletter. (Contact: ACCH, 3615 Wisconsin Ave., N.W., Washington, DC 20016. Phone (202) 244-1801.)

## The National Center for Education in Maternal and Child Health/ National Maternal and Child Health Clearinghouse [NCEMCH].

Has information for organizations, agencies, and individuals who have an interest in maternal and child health. Produces publications on topics related to maternal and child health. Provides information on request. (Contact: NCEMCH, 38th & R Streets, NW, Washington, DC 20057. Phone: (202) 625-8400.)

National Early Childhood Technical Assistance System [NEC\*TAS]. A project funded by the U.S. Department

of Education to provide technical assistance to states in providing services for children with special needs, birth through 8 years, and their families. Also provides limited technical assistance and information to professionals and parents. (Contact NEC\*TAS, CB# 8040, 500 NCBN Plaza, The University of North Carolina at Chapel Hill, Chapel Hill, NC 27599. Phone (919) 962-2001.)

## Therapy Organizations:

American Physical Therapy Association - Section on Pediatrics, 1111 North Fairfax St., Alexandria, VA 22314.

The American Occupational Therapy Association, Inc., 1383 Piccard Drive, P.O. Box 1725, Rockville, MD 20850.

Neuro-Developmental Treatment Association, P.O. Box 70, Oak Park, IL 60303.

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