

## **TRANSITION/SEPARATION ISSUES FOR THE PERSON WITH SPINA BIFIDA**

This article was excerpted by Dr. D. B. Shurtleff, Medical Advisor to the Spina Bifida Association of Washington State, from --- several previously published works.

--- Parents of children with any disability should recognize that the transition from childhood to adulthood requires an infant or child to progress through stages of development, and to learn age appropriate skills of independence, self care and social interactions to achieve autonomy. Families teach some of these skills and children learn some without being formally taught. Anyone caring for a child, including those with a disability, should consider reviewing and understanding each developmental "touchpoint." (T. Berry Brazelton [1992]).

Erickson (1950) and Piaget (1929) described the need for appropriate early infancy and childhood learning within a social context in order to develop an intact, functional personality later in life. To become a competent adult, they state a child must understand society's emphasis on attainable goals. These observations --- are not just theoretical. No literature known to us addresses these concepts in children born with neural tube defects. A series of articles (toilet training and sexuality covered in other postings on this WEB site) will discuss the skills that infants and children should master for them to develop into competent teenagers and adults. In each subsection we will suggest, in my opinion, how rearing a child with impairment can be modified, facilitating acquisition of these requisite skills at approximately the same age as children without disabilities.

### **Initial Contact and Counseling**

----- We believe it is important ----- for parents of a fetus, infant or child with a disability to acquire as accurate information as possible about their affected child. Prognosis varies with the type of Spina Bifida and the extent of nervous, musculoskeletal, genitourinary, and gastrointestinal systems involvement as described in the article on this WEB site as the *What is Spina Bifida an Editorial Definition*

The type of Spina Bifida, the degree of impairment and possible malformations of other organ systems can be determined by prenatal testing or intrauterine, newborn or post natal examination. Children can be assessed at birth or later---and more specific information can be ----- acquired by the parents and, if old enough, the patient. The prognosis may change, becoming more specific and accurate as the child with the disability ---- develops. This evolution allows the current health professional to explain the differences in the predictions by prior providers due to the more accurate current assessment as well as any improvement in management that has developed in the interim.

Parents should be particularly interested in their child's potential to grow up into a socially functional adult. ---- Parents should recognize that brought up ----- properly, the majority of children born with any one of the varieties of Spina Bifida can become socially well-adjusted adults.

### **Infancy and Toddlerhood**

#### **Transition/Separation for Infants and Toddlers without Disabilities**

T. Berry Brazelton (1992) describes the emotional and behavioral development of children without disabilities in his book, "Touchpoints: the Emotional and Behavioral Development of

Children". Readers are encouraged to review this text, adapting Dr. Brazelton's recommendations to their child or patients with disabilities.

Transition and the development of autonomy begin as an infant with the ability to move away from her or his mother. The infant creeps or crawls out of sight of mother but returns quickly for assurance that mom is still there. If the primary caretaker tries to leave the child, vocalizations are utilized to resist and prevent it. This developmental stage represents the first adversarial relationship between the child and parents or care givers. The duration of these child-initiated periods of exploration gradually grow longer, particularly when the child begins to walk. The distances also become longer, gradually progressing from rooms in the house to play yard, from the yard to day care, church school, preschool, school and the homes and gardens of peers. Separating from a parent and substituting other care providers also occurs naturally for longer periods of time and distances. These child initiated separations help build the child's concept of autonomy.

### **Transition/Separation for the Infant or Toddler with Spina Bifida**

Lower extremity paralysis impairs mobility and interferes with the developmental process of separation/transition. Less well recognized, however, is the poor general tone and decreased motor abilities in the body and upper extremities of children with myelomeningocele and its effect on these same processes, regardless of their level of paralysis. Professionals and parents of small children with spina bifida should consider introducing their affected child to multiple methods of alternative mobility, such as wheeled toys for two reasons.

First, children with higher level myelomeningocele generally do not maintain biped ambulation beyond mid or late childhood. With a large proportion of children with myelomeningocele becoming wheelchair dependent, it would seem at least partially appropriate to consider teaching methods of wheeled mobility early in life and to avoid the concept "of retreating to a wheelchair". This "retreat" must be a depressing event for children brought up to believe ambulation is an important goal to achieve and maintain.

Secondly, with these mobility devices, children can be as mobile as they desire and can explore their environment. They can participate in floor level activities and, later in childhood, can actively participate in wheelchair activities inaccessible to children solely dependent on crutch and braces, e.g.; basketball, bowling, archery, racing, etc. Other options for early mobility include hand-propelled devices into which the infant or young child can crawl. Some are made with handles and wheels on pivots that allow the child to move forward, backward and pivot. There are many devices available locally or via the internet.

Infants and toddlers should be allowed to be on the floor and encouraged to move about by rolling, scooting, combat crawling and propelling themselves on a wheeled device. Children as young as 18 months can learn to manipulate a motorized wheelchair. Using multiple methods of mobility will facilitate the typical stages of physical separation of infants and toddlers from their primary caretakers. We recommend that these devices be close to the floor, allowing the infant or early toddler to crawl or scoot onto and off them.

---- I have learned that cumbersome devices designed to aid walking may actually impair the small child's mobility. --- I recommend braces that might encumber mobility be used only during walking exercises and during nap or bedtime to maintain joints free of contracture. When out of their braces, they should be dressed in pants and footwear made of material that will slide

easily over rugs and rough surfaces in order to make mobility convenient and to protect their skin from friction burns.

From the very first, it is necessary to encourage self-accomplishment by the infant and young child. A study of our patient population revealed that a maternal belief in independence was a common psychosocial contributor to independence in self-care skills, achievement in school and high self esteem. During this early developmental period, play activity with same age peers should be encouraged at the floor level. Adults should also consider engaging the infant in interactive floor level play. The child's toys can be kept in a place where they can be reached from the floor or a wheeled device. We recommend that caretakers actively encourage the child with a disability to explore their environment; allow the infant or young toddler to fetch their own toys or desired articles and to put them away. Caretakers should discourage others from automatically responding to the child's request to have toys or other desired objects brought to them. Carefully encourage the child's drive for self-achievement while minimizing the child's frustration. Allowing the child to use only verbal commands to demand action by others on their behalf may lead to learned helplessness and a poorly adjusted child.

### **Initial Ambulation for the Infant or Toddler with Spina Bifida**

The natural development of upright posture in the infant without a disability occurs at 8 to 18 months of age, starting with a crouched knee position. When their balance fails they drop softly onto their buttocks. We have learned from our children and adults with spina bifida that in braces, they double their height in relationship to sitting. As they attempt to stand with rigidly constrained ankles, knees and sometime hips, they will fall to the ground much as a felled tree. No wonder they are terrified!

Thirty-seven years ago we published advice derived from an incomplete study, recommending upright posture and simulation of "normal" ambulation (Shurtleff, 1966). Our colleagues in our multiple disciplinary clinics also reported on a standing frame, the Verlo, that could be used for standing and ambulation much as the Parapodium of today (Taylor and Pemberton, 1972). This intervention proved to be of no benefit and, indeed, caused skin break down and fractures for the patients and frustration for their caregivers. I ----- suggest to our skeptical physical therapists that they build a pair of stilts that will double their height above the ground (their usual perception of their body in space). With these stilts strapped to their legs, they should prop themselves against a wall and take off walking with or without appropriate supportive devices such as a parallel bar, walker or crutches. It can be done - circus clowns do it all the time without assistive arm support! But can the average person or child? This difficulty is amplified by the considerable impairment of motor coordination and, to a lesser extent, visual perception exhibited by most ---- children born with myelomeningocele.

Whether these suggestions and modifications to promote a child's mobility will enable them to develop appropriate autonomy is currently unknown. There are nine reported benefits of an upright standing or walking program: improved urinary tract, bowel, and cardiopulmonary function, decreased osteoporosis and lower extremity fractures, decreased lower extremity joint contractures, obesity, skin break down, degenerative joint disease, and improved hand-eye-motor coordination function. None have been proven. A study by Liptak et al (1992) suggested that age and disability matched pairs in a parapodium program were more obese, watched more television and were less mobile over rough surfaces than children with myelomeningocele brought up to utilize multiple methods of alternative mobility. In another study, patients with spina bifida enrolled in a program of early upright ambulation were found to have better independent skills of daily living compared to those involved in a program that emphasized the

use of multiple methods of alternative mobility devices (Mazur et al, 1989). The patients in the biped ambulatory program used an A frame and had daily physiotherapy throughout their enrollment in residential schools; the patients in the multiple methods of alternative mobility program did not. Few of the patients in the multiple methods of alternative mobility group used standing or biped ambulatory devices and if at all, only for a brief time.

Since long term ambulation is not a realistic goal for most high level lesion patient, its effect on development is the remaining indication for expensive and time consuming ambulation programs in childhood. Whether a child's intensive drive toward upright ambulation and autonomy is best served by intensive biped ambulatory training or being able to explore their environment with the least restrictive bracing and multiple methods of alternative mobility or a combination of these two approaches has yet to be determined by accepted evidence-based criteria.

### **Preschool and Early School Years for the Child without a Disability**

The toddler progresses to the next stage of development having learned trust and mistrust from mother or primary caretakers. Shame, part of Erikson's first stage of development of man is replaced by autonomy. Autonomy, Erikson's second stage of development, is practiced through interaction with parents, caretakers and family members. The young child may first identify with one parent and then the other, excluding the opposite parent during each time period. Close contacts experience the young child's frustration, anger, hostility and aggression. Limit setting by these adults also helps the child to learn self-control. Brazelton states that a sense of discipline is a parent's second most important gift to a child next to love. He also notes that setting limits in a consistent, effective manner is one of the most difficult tasks for parents. Limit setting is essential. It enables the child to learn self-control before interacting with peers. The young child benefits from social interaction with peers in five major ways (Brazelton, 1992; Erikson, 1950). During these interactions, they learn: 1.) The need for self toileting as they tease one another about wearing diapers, 2.) The difference between boys and girls, 3.) The limits on exposing their perineum, 4.) The limits on their anger and aggression toward others and 5.) To accomplish joint tasks or develop industry as opposed to inferiority. The young child begins to accomplish these developmental tasks by separating from family through attendance at church school, play school, day care and, by age 3 years, preschool. Initially, these activities are closely supervised and attended by parents or their caregiver. The time away from parents and caregiver gradually lengthens, becoming more frequent and less supervised. The child's absences from their parents and caregiver provide opportunities to learn about themselves. They become more mobile and "liberated," learning to use their wheeled vehicles - first the tricycle and then the bicycle.

### **Transition/Separation for the Preschool and Early School Years for the Child with Spina Bifida**

Too often, the young child with spina bifida is separated from their parents by hospitalization, an emotionally and physically traumatic experience for any child. At this age, children attribute the creation of all objects and order in their lives to be under the control of their parents (Piaget, 1929). Hospitalizations, therefore, require explanation and support from the parents. ----- Preparation for the hospital admission should include clear reasons and objectives and a full explanation of the sequence of events. The parent ----- should be with the child during admission, bloodletting and other painful procedures, preoperatively and during recovery from anesthesia.

Separation for social reasons such as daycare, parents' absences, preschool, etc should be associated with clear limits, the exact time of return and assurances that the parent will return,

helping the child overcome any anxiety about abandonment. Absences by a child from their parents to be with same age peers and to develop autonomy should be encouraged. Parents of children with spina bifida tend to avoid, rather than encourage, such separations because of the child's limited mobility, incontinence and previous traumatic hospital separations. What children with spina bifida learn during separations from their parents are the same five noted above for children without a disability.

Erikson describes child play as an opportunity to learn self-control with other children, to develop new mastery skills over fantasy and the give and take with peers through experimenting and experience. Parents should-----involve their children with spina bifida in social activities with family friends and in group activities such as music, arts and crafts, gardening, caring for pets or farm animals, church school, preschool, swimming, rowing, sailing, bowling, childhood social groups such as Boy and Girl Scouts, Camp Fire Girls, Indian Guides, Brownies, Cub Scouts, etc, and, of course, fishing. The main objective of these activities is to place the child in frequent situations to interact and play with other children both similarly disabled and able-bodied in order to learn autonomy.

### **Ambulation for the Preschool and Early School Years for the Child with Spina Bifida**

The mobility needs discussed above for infants and toddlers become more important for the preschool and early school age child. Opportunities for floor level play, unencumbered by heavy bracing should be considered to provide opportunities to explore and learn autonomy. Caretakers should consider restricting brace and crutch-assisted ambulation to exercise periods, teaching the child without producing frustration and intolerance or interfering with the child's opportunity to explore and be with age peers. We believe that the availability of mobility devices for the more severely motor impaired and wheelchairs should be provided to brace and crutch-assisted walkers in order to learn how to compete in wheelchair activities and experience extended trips. As noted above, a number of authors describe many biped ambulatory children with spina bifida prefer wheelchair use as adults, at least part time. Many of the activities suggested for increasing a child's social interactions such as basketball, bowling, archery, fishing, etc, noted above can be performed more easily with the assistance of a wheelchair. They cannot be performed when the children's arms are holding crutches. At this age parents and caretakers should encourage multiple methods of alternative mobility and participation in, rather than observation of, other children's games and activities.

### **Late Childhood and Preadolescence for the Child with out Disability**

This period of growth and development includes the second phase of conflict between the child and authority figures. Children this age are entering into the last of the four stages of the development of man described by Erikson. 1.) Learning limits on self identity, compared to role diffusion, including physical genital maturity; the child must learn to distinguish between self centered existence and participation in the world of peers, 2.) Learning intimacy, compared to isolation centering on close personal relationships; the child must learn the difference between close and friendly relationships and intimate relationships with a personal partner, 3.) Learning generativity, compared to stagnation; deciding if they will become productive, contributing members of society or withdraw into themselves, 4.) Establishing ego integrity, compared to despair; being able to keep one's self-identity while interrelating to others and society rather than collapsing into a self-centered and isolated state. In summary, Erikson describes teenage as a normal phase of crisis with increased conflict characterized by fluctuations in ego strength and a high growth potential. The preadolescent and adolescent are learning independence and are often in as much turmoil over these changes as their parents (Brazelton, 1992). Offer (1969)

describes adolescence as a transitional period presenting adolescents with special burdens, challenges and opportunities. The children develop a personality independent from their families, increase their self confidence, establish a sense of comfort and strength in their own abilities, and make important decisions for their future, free of their families influence. Elkind (1976) describes adolescents as being in a state of extreme egocentricity: everyone is watching them. Friedrich and Shaffer (1986) emphasize that adolescents are learning responsibility, independence and heterosexual relationships. Davis (2001) emphasizes that psychologists and psychiatrists describe adolescence as stages of development not specifically related to age. These systems do not take into account the fact that some children begin their “adolescent transition” in late childhood, before the teenage years. Others do not begin until later in their teen or young adult years. A study of independence skills in preteen age children and teenagers using the Vineland Adaptive Behavior Scales (Sparrow et al, 1984) presents concrete data on age and acquisition of skills for independent living. The study by Davis et al (2001) demonstrates several independent activities are acquired by children in the myelomeningocele group prior to 12 years of age. The most notable of these skills are personal toileting, hygiene for teeth, hair and nails; personal choices when shopping; being on time for activities outside the home; knowing their own telephone number; using a telephone directory; understanding time as measured by a clock; monitoring their spending and remembering special dates such as birthdays. Data for more intimate situations such as first date of sexual intercourse, on the other hand, are not well known.

### **Late Childhood and Preadolescence for the Child with Spina Bifida**

Rutter (1980) has demonstrated that severely deprived children can overcome early childhood deprivation if provided the opportunity in later childhood. This stage of childhood development is the last opportunity to prepare the child for transition in adolescence. Davis et al, (2002) have described patients with myelomeningocele being 2 to 5 years behind same age peers in acquiring daily living skills. Children with myelomeningocele younger than 12 years of age had accomplished 11 of 31 skills for independent living. In her study, the acquisition of independence skills correlated best with cognition and was not related to level of lesion or gender. The greatest discrepancies between children without disability described by Sparrow et al and the delays for children with myelomeningocele involved stool and urine hygiene (Davis et al, 2002). The average age for attainment by 75% of the former was 4 years of age compared to 14 years for the latter. Participation in organized extracurricular activities declined to only 30-40% among older teenagers. Of teenagers 18 years of age, 21% did their own laundry, 37% fixed their own meals, 49% cleaned dishes after a meal and only 39% managed their own money. Hopefully, teaching the developmental stages and using some of the suggestions previously reviewed in the articles on this WEB site will properly prepare children with myelomeningocele for the period of transition.’

### **Transition/Separation for the Late Childhood and Preadolescent Child with Spina Bifida**

During this stage of development, the children’s increase in body size and their acquisition of autonomy skills often leads those brought up in a biped ambulatory program to “retreat” into a wheelchair, despite the early childhood goal of many programs to acquire and maintain biped ambulation as reviewed above. They often gain sufficient weight to become obese, preventing efficient ambulation. Do those children, brought up to equate walking with success, become depressed when they fail to continue walking and withdraw into themselves and overeat? Have these expectations placed them in a position where they are bound to fail? Like the Ogala Sioux described by Erikson, they may have been presented with an unattainable goal, suppressing their initiative and becoming apathetic and depressed. A sense of despair and hopelessness will only

compound underlying developmental problems. If the marginal crutch and brace walker is also taught successful and enjoyable wheelchair use as a younger child, this assumption of wheelchair mobility may limit the conflict between their self concept and their physique (Anderson and Clarke, 1982; Friedrich and Shaffer, 1986; Piaget, 1929). Wheelchair use should be seen as a normal method of achieving mobility, not a “retreat”. We suggest that during this period of development, children also become oriented to independent mobility within the community using public transportation. They should also be assessed for hand control automobile driving.