

33. NORMAL DEVELOPMENT AND DISABILITY IN CHILDREN

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33.2 Introduction

33.2.1 In order to understand disability in children and where the consequent needs differ significantly from those of a non disabled child it is necessary to have an understanding of the normal development process. The sequence of development is normally the same for all children, eg they sit before they can walk etc, but the rate of development varies. For example, up to 10% do not crawl before they walk but "bottom-shuffle", creep, roll, or just stand and walk. This may occur in those children who have an inherited pattern of low muscle tone and there is usually a history of affected relatives. Most children walk (even if its only a few steps) by the age of 2 years. The median age (ie the most commonly encountered age in years) of walking in shufflers, creepers and rollers is several months later than for crawlers and a few are still not walking by the age of 2, but eventually they function normally, with walking established by the age of 3 years in the majority of these children. Those who just stand and walk also have low tone and a similar family history but walk a month or two earlier than the crawler.

33.2.2 Development may be divided into four broad categories:

- (i) Vision and manipulation
- (ii) Hearing and speech
- (iii) Gross motor skills
- (iv) Social behaviour

The table at the end of this chapter gives some examples of the normal development by chronological age of healthy children during the first six years of life in each of these main developmental areas.

33.2.3 Disability or disease in a child has a great impact on parents and the immediate family. Chronic illness or disability in the infant or young child may produce considerable additional care needs - usually provided by the parents themselves. Increasing numbers of children receive high dependency care provided at home over long periods.

33.2.4 The attention which is given, particularly to infants and very young children

with disabilities, may **differ in kind** from that given to healthy children of the same age; but this may not mean that the amount of attention given is in excess of that usually required by a healthy child of the same age. Many healthy children waken at night for a variety of reasons and require attention. Likewise young children who are not disabled require care in relation to bodily functions such as eating, washing, dressing, undressing, and using the toilet. Some children, however, may not be receiving the attention they need as a result of their disabilities. The particular circumstances and needs in each case must be individually assessed and considered.

33.2.5 Assessment of care needs is also influenced by the fact that children develop both physically and mentally. This may result in decreased care needs; on the other hand, some care needs may increase. Physical development of the upper limbs in a child with defective lower limbs may enable him to move independently with mechanical aids where these are used. Increasing maturity may lead some children with chronic illness or disabilities (eg. the child with diabetes mellitus, or with cystic fibrosis, or arthritis, etc) to assume responsibility for the care of his condition and so require less supervision. Training received may also have its effect, notably with blind and deaf children. On the other hand, physical development may increase the burden of disablement: a child with learning disability may require more rather than less supervision as he gets older and becomes more mobile. Adolescents with disabilities will also have to cope with care and/or mobility needs against a background of changing patterns in body functions, social attitudes, and sometimes non-conforming and "rebellious" behaviour commonly encountered at this time.

33.3 The Care Needs of Infants

33.3.1 The Non Disabled Infant

An infant for the purposes of this text is taken to be a child aged less than one year old. Healthy infants require a great deal of attention in connection with their bodily functions. They must be fed, winded, changed and bathed frequently. In addition, if emotional development is to proceed normally, an infant must be handled, cuddled, talked to and played with regularly. Furthermore, during the times when the infant is sleeping periodic checks are made to ensure that all is well.

33.3.2 The Infant with Disabilities

Because of the amount of care and supervision/watching over required by a

healthy infant, that required by an infant with disabilities may not usually be much greater than that needed by a healthy child. The kind of attention given may differ: for example, instead of being handled in an ordinary manner, the infant with disabilities may need more specific stimulation or formal passive movements of the limbs in the form of physiotherapy, but the amount of care or supervision/watching-over may not be greater than that given to a healthy infant.

33.3.3 Disabilities Posing Very Substantial Needs

Infants with certain disabilities will require considerable amounts of stimulation, care or supervision, in addition to the normal care routine. These disabilities include:

- (i)** Infants with frequent loss of consciousness usually associated with severe fits secondary to birth asphyxia or rare forms of congenital metabolic disease.
- (ii)** Infants with severe impairment of vision and/or hearing. (Unless there is reason to suspect that a baby may be born with hearing impairment, and has been checked with special techniques, it is unlikely that hearing loss will be picked up until the child is several months old).
- (iii)** Infants with severe multiple disabilities.
- (iv)** Other categories of infants with disabilities may well require extra care: infants with renal failure [Chapter 24], with cystic fibrosis [Chapter 44], with asthma [Chapter 45], with cerebral palsy [Chapter 40], and those survivors of extremely pre-term birth.
- (v)** Infants with severe feeding problems which are due to physical reasons, such as oro-facial malformations (eg. cleft palate), or cerebral palsy.
- (vi)** Some infants with developmental delay/learning disabilities who require prolonged periods to take adequate amounts of each feed. Some children with Down syndrome may fall into this category.

33.3.4 Care Involving Technical Procedures

The care of some infants with disabilities involves the use of technical procedures such that the attention or supervision/watching-over required from birth may be greatly in excess of that required by a healthy infant.

These include:

- (i) Infants requiring regular mechanical suction because they have a tracheostomy or other upper airway problem.
- (ii) Infants being fed by tube into the stomach or a vein.
- (iii) Infants who need oxygen regularly in order to survive. These include infants with bronchopulmonary dysplasia (impairment of normal lung development and impaired lung function) as a result of very premature birth.
- (iv) Infants with one of the following surgical procedures whereby a segment of the stomach or bowel is opened up onto the abdominal wall for feeding or for the elimination of waste: gastrostomy (the stomach has an opening onto the abdominal wall to assist in feeding by tube); ileostomy; jejunostomy; colostomy (all these are connections between a particular part of the bowel and the abdominal wall. They are usually constructed to form an exit from the intestine when part of it is blocked or has been destroyed by disease).
- (v) Infants with a nephrostomy (a connection between the urinary tract and the abdominal wall, constructed to form an exit for the passage of urine).

33.4 The Older Infant/Young Child

33.4.1 The Non-Disabled Infant

As the healthy infant gets older the emphasis shifts from attention to supervision. Feeds become less frequent; winding is no longer necessary; the child begins to feed himself. However, from the age of about six months the development of investigative skills in tandem with increasing mobility puts the healthy child at risk of danger; the level of supervision required to avoid danger is considerable.

33.4.2 The Infant With Disabilities

At this stage (often between 9 and 15 months), the gap between the care needs of a healthy child and a child with disabilities may have widened to the extent that the needs of the child with disability are significantly in excess. These may include continued attention to bodily functions no

longer required by the healthy child, and more attention than needed by the healthy child for the development of new skills such as crawling, standing, and walking. The age at which the need for attention of the child with disability becomes greater than that of the healthy child cannot be defined precisely and judgement will depend on the evidence available in the individual case.

33.4.3 Disabilities Posing Substantial Needs

There will be some children with disability with needs persisting or first manifesting at a level in excess of the norm at this age, for example:

- (i)** children with brittle bones [osteogenesis imperfecta - see Chapter 46], haemophilia [Chapter 47] and other severe bleeding disorders, in whom bumps and falls are associated with the risk of fractures or haemorrhage.
- (ii)** mobile children with hearing and/or visual problems who cannot respond to a warning shout or see a potential danger, which a healthy child would avoid.
- (iii)** children with cerebral palsy whose mobility is impeded and whose risk of postural deformity is reduced by frequent changes in position by parents.
- (iv)** children with a severe learning disability who eat undesirable substances (pica) or exhibit self-mutilation behaviour. A child with severe learning disabilities may also require substantially more stimulation to maximise potential.
- (v)** children in whom developmental delay may first become evident because of a need to continue a level of attention appropriate for a much younger baby.

33.5 The Older Child and Adolescent

33.5.1 The variety and level of care needs and mobility requirements in the older child and adolescent with disabilities are dependent not only on chronological age but also on a number of other complex and interrelated factors which arise not only from the disabilities themselves but from consideration of the circumstances operating in the individual

child/adolescent. Information on the care needs and mobility requirements likely to arise in the older child and adolescent are dealt with in the context of the remaining chapters of this section devoted to disabilities in children.

33.6 Night Needs in Infants and Young Children

33.6.1 Healthy children **under the age of two years** normally require a considerable amount of attention, both in frequency and duration, during the night hours, for feeding, changing, or "settling" - the latter especially during teething. Specific, regular attention at night in excess of the norm may be required by some children with disabilities whose medical condition calls for parental intervention in the form of turning, nebulizer or oxygen therapy, suction, intubation, care during fits, etc. The majority of such disabled children have already been described under paragraphs 33.3.3 and 33.3.4.

33.6.2 If precautions are taken at night (such as the child being safely placed in a cot with sides, and bumpers if required and used) there may be few conditions requiring watching-over in the absence of attention needs which are substantially in excess of those needed by a child of comparable age.

33.6.3 However, the need for watching over in excess of normal will depend on the evidence available in an individual case. Notably, children with severe learning difficulties may have an abnormal tendency to develop a persistent habit of night wakening. In such cases attention from parents may be required more than once a night, and may last one hour or more.

33.7 "Difficult" Children

Some healthy children are described by their parents as 'difficult' because they require more attention or supervision than other children of their age. However the increased needs here may not necessarily arise from severe physical or mental disability. It is however important to determine that children with disruptive behaviour at home have been assessed properly to ensure there is not a physical, intellectual or other reason for their behavioural problems. [See also Chapter 36].

33.8 Duration of Need

33.8.1 It is not possible to give generalisations on the duration of needs. This will depend entirely on the particular disability or disabilities for which the child has care and/or mobility needs.

33.9 Further Evidence

Most Child Development Centres provide parents with a report on the child's assessment which may be a useful source of additional information, should this be required. A report from the GP or hospital may also help in determining the level of disability and the likely duration of care needs. By the age of six the child may have been in some form of education for a year and assessment of potential will have been made. At that time, a school report may help in determining the level of any

continuing care needs and their likely duration.