Emotional Problems of Childhood and Adolescence

Emotional Disturbances of Handicapped Pre-School Children and their Families - Attitudes to the Child

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The late Donald Winnicott provocatively stated¹ that "there is no such thing as a baby." He meant that it was impossible to think of a baby in isolation without considering his environment: his caretaker, his mother, "or at least a pram with someone's eyes and ears glued to it." It is also impossible to think of a pre-school child without thinking of his family. The philosophy which considered the child in isolation, allowed the 2-year-old blind or severely deaf child to be taken away from his family and placed in an institution or special school for early training, has now undergone a welcome change. Through an "at-risk" register and regular screening, the handicapped infant and child should be identified at the earliest possible time and treated within the community.² The family, and particularly the mother, is often used as the first therapist, with the support of the professional giving the appropriate information and teaching the necessary skills. Comprehensive assessment and co-operative support is essential from the team of general practitioner, community physician, health-clinic doctor, paediatrician, health visitor, district nurse, and social worker. All these should be the aims in the development of a comprehensive Health Service.

When a mother or her medical adviser senses that something is wrong with the child, intervention should not have to wait until a final diagnosis is made. Deficits in locomotion, perception, or expression should be attacked and the individual child's needs met for nurture, stimulation, and an early opportunity to fulfil his potential.

Aspects of Normal Early Development

Before discussing abnormalities of development the relevant aspects of normal development should be considered. Motor, sensory, perceptual, cognitive, language, social, and emotional development all go hand in hand and cannot be isolated from one another. Each is intertwined and relies on the other for progressive steps towards maturation. Impairment or dysfunction in any area can affect overall development and result in permanent handicap or deficit.

The journey towards maturation starts with a newborn infant with no speech, comprehension, and only a limited repertoire of generalized responses to communicate his primitive states of comfort and discomfort. He exists in "expanses of limitless substance"³ as an extension of existence in the womb, with no idea of himself or his mother as separate beings. From this state he eventually has to become a 5-year-old, emotionally ready to learn—with a clear idea of himself as an independent person, a sexual identification with the

appropriate parent, and an appreciation of the adult roles of his father and mother. He needs the ability to relate to other children, to be able to control and postpone urgent needs, and to use initiative to find gratification in play and activities which are socially acceptable and controlled. To solve the problems posed by such demands he must have sufficient language, understanding, and comprehension of the world and the objects it contains, together with sufficient trust in them and a flexible imagination. By 5 years he should have learnt many of the skills necessary for an eventual adult independent existence.

THE PARENT'S ROLE

How does this remarkable change take place normally and how are these lines of development⁴ towards emotional maturity affected when there is a degree of impairment present—whether of sight, hearing, comprehension, speech, motor dysfunction, limited ability, or severe subnormality? As stated already, the family comes first. Indeed, to be complete the infancy and childhood of the mother and father would have to be considered, the circumstances of their growth and development and the relationship with their own parents.

Nevertheless, starting with the pregnancy the intense psychological changes of a "developmental" crisis occur while the woman becomes a mother, and the man a father. Up until this time, despite her wishes to be a mother, the woman may have seen herself only as a daughter, a wife, or a woman with a career. She has to face giving up her independence, her status, her work colleagues and has to make herself ready for what Winnicott¹ described as the normal pathological state of "primary maternal preoccupation," while father has to give up his exclusive relationship and be prepared to share. During the crisis both parents keep in front of them the positive side of parenthood, and through the new person the hopes of enrichment and of fulfilment of secret aims not reached personally. Yet to reach their goal they have to cope with the feelings of anger and depression at the loss of their former state—and even the paradoxical feeling of rage with the forthcoming baby who caused the change. This is not expressed usually, but sometimes experienced as fears that the child will be born deformed or handicapped.

Problems during Pregnancy

The first question always asked after the birth is whether the baby is a boy or girl, and if "it is all right." Problems arising during pregnancy may affect the quality of the initial maternal state. Excessive excitement or anxiety arising from conflicts during pregnancy may result in more intense puerperal depressive symptoms. Satisfactory resolution of the "crisis" may also be affected by threatened miscarriages, previous stillbirths, marital difficulties, unresolved problems in relationship to

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own parents—or the loss of a parent—moves of house, losses of security through husband's changing job, moving away from familiar neighbourhoods. Such factors can intrude into the relationship of mother and newborn baby and affect her ability to become "the ordinary devoted mother" or "good enough" mother,¹ who can "provide contact, movement and quiet according to needs and make the transition between quiet and excited states." She has to see the child as part of herself and satisfy his needs as if they were her own, gratifying needs immediately and "providing a setting for the infant's constitution to make itself evident and unfold."

The work of Winnicott¹ and Brody⁶ emphasizes the way that a mother's own feelings, personality, and affective state can change her mothering ability and lead to problems in the newborn and infant and pre-school child. To this has to be added the impact on her of the infant or child where a diagnosis of an impairment and the possibility of handicap has been raised.

THE INFANT'S ROLE

Normally the early responses of the infant help to "release" the right response from the mother.⁷ She is taught by his ability to suck and root, to grasp, to turn his head when his cheek is stroked, by eye to eye contact, and a social smile. Quick, incoördinate movements of body limbs and head, flushing, pallor and crying will teach her to recognize the message of hunger, fatigue, pain, cold, startle, boredom, or loneliness. The right response on her part will lessen such distress and an affectionate bond of attachment grows. Through the initial preoccupation and perfect adaptation between infant and mother, the infant gains sufficient sense of security to begin to explore his new surroundings and those in it with his eyes, hands, and mouth. To bridge the gap between mother and himself he starts to use his thumb, or incorporates a soft toy, a blanket, or even a piece of fluff as a "transitional object."⁸ He can use them to feel safe and recreate the early "good" state or can abuse them to vent his frustration, and yet find comfort later on.

Such transitional phenomena start from a meeting between infant and mother and their mutual attachment. They help the infant move away from his own and his mother's body to play and explore the external world of object, sound, and sight enriching his inner world and stimulating him to gain control of the external world.⁸ This competence is aided by the development of speech, locomotion, memory, fantasy, and symbolization, which contributes to the feeling of comfort, security, and emotional self-reliance. Pathways can be found for the safe expression of the frustrations inherent in growth so that the conflicts and difficulties of the second and third years will not become excessive.

MOTHER-INFANT INTERACTION

Between four and six months the mother is usually recognized as being separate from a stranger, as a firm attachment develops between them.⁷ This attachment has to lessen gradually so that a forward movement can occur towards independence, linked with identification with the adult role of the parent and the appropriate sex role.

The initial phase of development implies a close and intense interaction between parents and child. The mother at first provides a perfect adaptation to the infant's needs. With the father's support, the mother is helped later to "fail" in meeting these needs and to tolerate the child's resulting frustration and rage. The child faces the state of loss by using his new-found skills and his drive for competence to cope with the new demands on him. He moves forward to independence instead of holding back, to walk instead of holding on, to demand with speech instead of having ex-

pectations omnipotently met, to gain bladder and bowel control and sufficient self-care to prevent hurt instead of having to rely on others. Throughout he is sustained by the internal memory and the external evidence of parents and transitional objects to know that he has been cared for well enough in the past, and that the parents who have become frustrating are also those who did look after him perfectly.

Problem behaviour can arise during this process in several ways. The mother may be unable to meet the early needs because of her own difficulties, or may be insufficiently supported by father to provide the necessary degree of frustration later. The infant's temperament, his activity level, regularity, mood, or adaptability may affect the quality of the interaction.⁹ Either case may result in a wide variety of early management problems, including "battering," failure to thrive, feeding problems, crying, clinging, separation difficulties, withdrawal, tantrums, hyperactivity, impulsiveness, sleeping disorders, and socialization problems—failures to gain control of bladder, bowel, and speech.

Birth of the Handicapped Child

INITIAL IMPACT ON THE PARENT

How are the normal processes affected when there is evidence at birth or in the first days of some possible impairment—spina bifida, hydrocephalus, deformity of a limb, Down's syndrome (mongolism), cleft-palate, syndactyly, a severe birth injury or phenylketonuria diagnosed after the first blood test?

The initial responses are those of an intense crisis, instead of the feeling of relief that the baby is apparently normal. Numbness, grief, disgust, waves of helplessness, rage, disbelief are felt; the expected perfect child is lost, and the feared damaged, deformed child is born. Parents may wish at first to "get rid" of the child, followed by feelings of guilt, self-blame, shame, and intense anxiety.

Such feelings disrupt the necessary state of maternal preoccupation and the way that she perceives the initial cues from her baby and responds to them. Unless intervention is successful—and the situation is handled with considerable skill—disappointment, rejection, and long-term failures in holding, adaptation, and attachment may occur. Information, discussion, and support of both parents by the paediatrician and his team will need to be repeated on numerous occasions, so that gradually the process of mourning the loss of the "normal" child can be achieved and the acceptance of the "impaired" child accomplished. The continuing role of the nursing staff, health visitor, social worker, and general practitioner may be arduous and lengthy in the exacting task of bringing mother and her baby together under these circumstances.

Increased Problems

Periods of rejection or despair may be more pronounced if prolonged admissions become necessary for operations or investigations. To prevent this mothers should be admitted with their infants for a time, particularly a first child. Problems increase if the infant is apparently sickly, in real danger of dying, feeds reluctantly, is unresponsive, or is seen as monstrous or deformed. Fears and anxieties for the present and the future will need to be ventilated; guilt must be recognized and relieved, reassurances given that a fall, drugs, or the normal rejecting feeling during pregnancy have not magically contributed to the deformity. The need to find some cause for the damage has to be recognized, since the unknown and feeling a victim of fate or chance are more painful than a cause, no matter how inappropriate. Spouses, families, doctors may all be blamed with intense rage, amplified by the normal depressive reactions of the postpartum period.

INITIAL ACCEPTANCE OF THE HANDICAPPED CHILD

The importance of the initial acceptance of the handicapped child is reflected in the repeated finding^{10 11} that satisfactory emotional development of the handicapped child depends more on the way in which the parents and family relate to the child, than the extent of the handicap itself. Long-term rejection or anxious over-protection masking ambivalent hostility shown to a child over the years markedly affects his degree of self-regard, and self-confidence. Successful intervention at the beginning may have a profound influence on the child and family life for years to come.

Acceptance of the handicapped child by the parent is a slow process. "Working through" the loss of the normal child often takes time. Feelings often have to be borne by both parents in their loss, and shared with their doctor—who may find himself leaned on at one time, rejected another. Requests for other opinions may be made to deny reality, demands for surgical intervention made to "rescue" the child. Eventually the bonds attached to the original expected perfect child can be broken, and re-directed to the child who exists, and can be accepted with hope alive for what can be reasonably achieved through medical or educational intervention. The mutual adaptation between infant and mother should begin to take place while the initial crisis is being negotiated, the operations performed, the diets started, and the probable outcome and expectations clarified concerning the genetic aspects of the problem. It is usually possible for the infant who is expected to be dependent to provide sufficient gratification for a satisfactory mothering response to be evoked, but the demands on medical and nursing staff in promoting this may be considerable.

It should also be noted that at the present time childless couples are facing the possibility of adopting or fostering a handicapped child, and the care of such a child may fill a need. Parents who are aware that there is a high risk of handicap—for example, when rubella occurs in pregnancy or where there is a high genetic risk—may choose to have a child and face the consequences.

Emotional Support

During these early anxiety-fraught months it is of considerable importance for both mother and father to have ongoing emotional as well as medical support. So often the maternal grandmother or relations cannot help at first as they have to cope with their own personal crisis at having a handicapped child born in their family. In these circumstances the nurse, paediatrician, and staff in hospital—and the health visitor, general practitioner, and social worker in the community—may find themselves acting as surrogate mothers, as they are seen to have had the experience of helping others in these situations. They act as a grandparent who has already brought up her family safely and can be trusted by the mother to contain her feelings of uncertainty, unsureness, and insecurity at each point of the child's maturation, so as to provide the right first mothering relationship.

LATER PARENTAL ADJUSTMENT

A similar process occurs if a diagnosis of handicap is made through later symptoms or the regular observations of the infant in the health clinic. The impact may be less if a relationship has already been established. Nevertheless, problems may persist from infancy through a failure to resolve the early crisis adequately. There may be an abnormal mourning and grief reaction, particularly if the handicapped child is felt to represent a threat to the parent's personal system of values. Long-lasting feelings of shame and stigma can occur in relation to the extended family, or the neighbourhood in an upwardly mobile family. If there are long periods of separation

such feelings can grow stronger. There may be attempts to hide, deny, or minimize obvious problems. The child's impairment may appear to be accepted, yet the parent may present to the general practitioner inexplicable deepening depressive symptoms with suicidal impulses, agoraphobic symptoms, marital tensions, obsessional house-proudness, chronic irritability, or psychosomatic symptoms.

Cause of Symptoms

Personality factors and habitual methods of coping with stress may account for these symptoms, but they may represent pathological ways of dealing with a conviction of responsibility. Guilt, frustration, and rage may be directed at the self instead of towards the child. Psychiatric intervention may be necessary, with an attempt to understand the individual's unique way of coping with the strain, and channel the feelings in a more healthy direction. Crises can still arise for the parent who may have made a good adjustment.

While "helplessness" is expected in infancy, anxiety may be less; but there may be fresh disappointment when it is realized at each stage that head control, sitting, and standing are delayed; speech does not develop; socialization, bladder, and bowel control are not attained. Acute painful feelings may recur at these times. They may also be experienced when taking children to hospitals, visiting various specialists, waiting for consultations, being unable to ask or get questions answered, or obtain practical devices, feeling that there is insufficient co-ordination and that there may be confusion between different departments, medical and social, or different workers. There may be distress when it is felt that conflicting advice is given, and that covert disagreement exists between departments—so that no one can be trusted to take complete charge. There may be insufficient information available, insufficient time from professionals, insufficient case-work help from skilled social workers. Numerous admissions to hospital may worsen an already precarious balance.

At each stage there may be a fresh feeling of loss: the precarious balance is once more shattered, rage, depression, rejecting feelings, fear of battering, strain, somatic aches and pains, may be the result. Problems such as financial difficulties, poor housing, marital strain, pressure from siblings can compound such problems. Social life can be severely restricted and the handicapped child then has to cope with the additional handicap of a withdrawn, preoccupied, depressed, angry, and hopeless parent, as well as the effect of the handicap itself. Requests for admission to hospital or residential care may be made at these times and, while this may be inevitable in some cases, it should be avoided and preventive action taken whenever possible.

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