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# NURSING MENTALLY DEFECTIVE BABIES: WHOSE RESPONSIBILITY IS IT?


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The problem is conveniently presented by reference to two letters of application for accommodation addressed to the physician superintendent of a State institution for mental defectives.

## CASE 1

The first is from the medical superintendent of a large general hospital, on behalf of a baby, JA, and read: 'The above-named child is suffering from cerebral atrophy and requires tube feeding, which involves skilled nursing. Owing to this latter factor we are unable to send the child home. It would be appreciated if you would consider this case as most urgent. We realize that you have a long waiting-list, but if it is at all possible to make an exception in this case it would be helping us exceedingly'. In the opinion of the hospital paediatrician, therefore, an institution for mental defectives obviously has to care for JA. It can't be left to the mother, and the hospital can't keep her.

The institution psychologist saw JA in the hospital. Although 9 months old, she is still a 3-months-old baby for all practical purposes. She is retarded, her intellectual level being about 3-4 months, which would give her an IQ of 33-45 and place her in the imbecile group. The paediatrician's diagnosis of cerebral atrophy was based on an encephalogram. She has the physical appearance of a normal baby, somewhat under-weight, and there are no obvious physical stigmata of mental defect. She is being tube-fed but, as the sister explains, this is due to the exigencies of hospital routine. It would take too long to feed her by bottle or spoon. The reason for sending her to hospital was to obtain advice because her food intake was inadequate.

The nursing of JA consists mainly in keeping her dry, comfortable, bathed and fed. If she were transferred to the institution for mental defectives, she would at once be trained to bottle or spoon feeding, and much of the actual routine nursing would be done by a high-grade feeble-minded patient or a junior nurse, no very special or highly skilled nursing being involved. With a little guidance from the district health-visitor or the local clinic, the mother should have been able to care equally well for her at home. It was accordingly suggested to the hospital authorities that the mother visit the institution for mental defectives in order to observe how imbecile infants are fed, what they are given, how much their food intake is, how long the feeding takes, and what degree of patience is needed, and that she then take the baby home to nurse her under the guidance and general supervision of the district nurse.

This arrangement would allow the parents, especially the mother, also to share in the care and maintenance of their offspring. Eventually, when the child reaches the optimum age for admission to an institution, the State will undertake the responsibility, probably for the rest of her years, but it should not bear the entire burden. This may seem hard on the mother, but the facts are that if it had been a normal baby, she would have had to nurse it and keep it under close supervision until school-going age. Instead of this, JA will presumably have a prolonged babyhood and infancy. The nursing and care involved will differ in kind, but little in complexity and volume.

A strong probability, if not a certainty, is that the mother is craving for her baby and is being emotionally starved by the present separation. The plea that she will become too attached to JA and neglect the rest of her family, or that JA will disgrace her siblings, can be dismissed as unimportant and frequently exaggerated. The child would be happiest and develop most favourably at home, where she would be loved, picked up, carried about and stimulated in various ways to handle all sorts of objects, to sit up, stand, walk, play, talk and comprehend speech. It is every baby's birthright to develop to its maximum capacity all its latent powers and abilities, however meagre these may be, and for this purpose she will find the proper emotional warmth and more *Lebensraum* at home than in a hospital setting.

An important consideration, frequently under-rated in dealing with a mentally defective baby, is that the child's innate intellectual capacity may not be so low as it appears at the present stage. JA's intelligence seems low, but by no means extremely so; 414, or 48% of the total patients in the institution to which the hospital authorities sought admission on her behalf, had IQs below 35, her approximate level. At the age of 9 months an IQ assessment is not reliable and its predictive value is low.

Moreover, we are aware that she had trouble with her nutrition at an age when nutritional factors can have considerable weight in mental growth. We don't know what weight to assign to this factor in the aetiology of her amentia, but it may quite possibly be unusually big. We cannot be certain at this stage that her mental growth will not be so favourable as to allow her eventually to attend a special class for backward pupils in one of the schools for normal children.

It is in her best interests to correct her nutrition and accelerate her physical development, when we may hope her intellectual level will improve. We cannot be sure, but it is a possibility. Much is at stake and we are not allowed to make mistakes. There is no need for over-hasty action, and the child can be given a fair chance before she is certified as a mental defective and dispatched to an institution, perhaps irrevocably.

Our question who must be responsible for JA's nursing has to be treated on its own merits, but it is worth noting that as she grows older she will be easier to manage, more interesting, and more satisfying and acceptable to her parents, and it is just possible that they will rather keep her at home for a considerable time than send her to an institution, even if she is very retarded.

A fitting answer to the question seems then that, under the general supervision of, and perhaps with more concrete assistance from, public-health and social-welfare agencies, the mother will be the best person to nurse this particular baby, and it remains a parental privilege and responsibility to do so. Little can be found in favour of an institution as an alternative.

## CASE 2

The second letter is from the mother of MW, a 3-months-old baby, who is in a private nursing home where it is difficult to

keep her any longer because the fees are out of proportion to the husband's salary. MW is tube-fed, and the mother states that it is impossible for her to feed the baby. In writing to the institution, she did not act on her own initiative, but on the recommendation of the family doctor and the paediatrician who, when the baby was 4 weeks old, diagnosed 'multiple congenital abnormalities and retarded cerebral development'. The mother states that there is a deformity of the hands, feet and jaws, the heart is reduced in size and the baby can't swallow. If this was not a case of mongolism or cretinism, the fact that it was possible to diagnose amentia when the baby was only 4 weeks old (in contrast, JA, our first case was 9 months) suggested that the defect was profound.

The institution psychologist saw MW in the nursing home, where she had been sent on the recommendation of the family doctor the day after her birth, and also interviewed the parents. (They explained that the family doctor thought the attention in the nursing home would be better than in the local general hospital where no fees would be charged). There is no doubt that the baby is mentally defective. Auditory and visual reflexes are absent, and the mother's inventory of physical stigmata was not exaggerated. She has a nice face, the matron says they like her, and she is quiet and easily nursed and doesn't cause much work. Asked whether it would entail much to train the mother to nurse the baby at home, the matron unhesitatingly said this could easily be arranged. This possibility had not been presented to the parents and it hadn't occurred to them.

Unfortunately however, owing to the prior arousal of a negative emotional set to the baby, the father rejected this suggestion as outrageous and unreasonable—the mother couldn't do it, there are already two children in the family, they have no servant, it will be too much for the mother, and they will continue to make sacrifices and keep the baby in the nursing home. In the end they promised to consider the matter, and it is possible that they will change their attitude to MW.

It is almost certain that for the rest of her life this child's mental condition will remain static, her chances of reaching a mental age beyond a few weeks seem poor, she isn't expected to live long, and there is little that can be done about her. She has to be kept clean, fed and bathed. This is a domestic and nursing matter which, in the opinion of the matron, could easily be undertaken at home. It was explained to the mother that she would in any case have had to care for the baby if it had been normal, and even a fraction of the money now spent on nursing fees could pay for a servant to help; the staff at the nursing home like her baby, and she will very soon also be attached to it.

There is no dire necessity for this baby to be cared for by the medical and nursing body of an institution.

## CONCLUSION

A convenient way of dealing with a mentally defective baby is to recommend institutionalization. In contrast, to initiate a plan of treatment which involves supervision and guidance of the mother by health visitor and social worker seems less direct and simple. In both our cases—and we venture to think that the same may be said of nearly all mentally defective babies who come to an institution—it was the paediatrician or family doctor who advised the parents to have the baby certified, and the parents followed the advice. Quite probably both doctor and parents honestly believed this to be the best course. The doctor believed that he was acting in the light of the best modern medical practice, and the parents believed that in consenting to part with their baby they were doing their supreme duty by it.

Our conclusion is that the mother is nearly always the best nurse, and the best place is at home. In some cases institutionalization will never prove necessary; in others it is best postponed until the child is older. Social workers and health visitors can supervise and give the necessary guidance.

When amentia is diagnosed soon after birth, except of course mongolism and cretinism, then the defect is profound, the prognosis is always unfavourable, and the expected span of life is small. An exception can be made in those very rare cases when the child is a monstrosity, but as a general rule it is not asking too much of parents that they care for their baby in the same way as they would have done had it been normal. If the home is unsuitable, the next best place, namely a foster home, would be indicated.

When amentia is diagnosed later in the baby's life, as in case 1, then it is seldom so profound, the reliability of the diagnosis is low, and we have to reckon with the possibility that mental growth will be accelerated. The child may even perhaps remain permanently at home and eventually take its place, even if it is a lowly one, in the normal social order. In most of such cases the mother will be the best nurse, the child will be happiest at home, and the most favourable conditions for its optimum mental growth would thus be created.

Whether the parents will reject or accept their child emotionally, will depend largely on the mental set induced in them by suggestions emanating from the family doctor or paediatrician. In most cases, suitable guidance should go a long way towards helping the parents to view their child's disability objectively, to accept it as it is, and to build up a healthy, positive attitude to it.

Mentally defective babies are invariably sincerely loved and considered as pretty by their nurses, and we believe that the mother will learn to feel the same way about her handicapped baby. We deeply sympathize with her; but, however severe the blow to her self-esteem and maternal sentiments, however keen the disappointment and frustration, hospitalization or institutionalization is not indicated merely on the grounds that the baby has low intelligence.

It is felt that we need not enlarge upon the moral and socio-economic aspects of our question, important as they may be. With the passage of time we have regrettably lost sight of the fact that, in their historical setting, institutions for mental defectives were founded as adjunctive to mental hospitals and reformatories. They were not originally intended for babies.

## SUMMARY

Using 2 illustrative cases, we try to show that the best nurse for a mentally defective baby is its mother. It is her responsibility. The child will find the optimum conditions for emotional and mental growth at home. This would also give the child a fair chance to show its final intellectual level and be placed in a special class for backward pupils when it reaches school-going age. If it is necessary, social and welfare agencies can supervise the home.

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