

# The British Journal of MENTAL SUBNORMALITY

Editor: H. C. GUNZBURG

Vol. XXVII, Part 2

DECEMBER 1981

No. 53

## EDITORIAL

The decision, made by the doctor, who was recently accused of the attempted murder of a Down Syndrome baby and found not guilty, must have drawn wide attention by highlighting the desperate dilemma of parents and doctors in such situations. Prosecution and defence were unanimous in stating that the doctor, a consultant paediatrician, was a conscientious, kind, humane man, who had acted from the best possible motives. He and the parents had agreed that the D.S. baby, rejected by the parents, was better off dead than being in an institution or with foster-parents.<sup>1)</sup> He had, therefore, ordered nursing care only and prescribed a drug to relieve distress allowing the baby to die after 69 hours of life, though it had, according to the prosecution, an 80% chance of survival. An eminent child health specialist pointed out that doctors think it reasonable to accept the parent's decision "that allowing babies to die ... is in the baby's interest at times."

The arguments brought forward demonstrate the grey area where deliberate decisions have to be made, which, as far as the doctor is concerned are said to be based on informed medical opinion. The doctor has to help his patients, among whom, one might argue, is also the baby and not only the parents, and he has to advise and support the parents in an agonizing situation. Parents, at that time, are apparently forced to make an irreversible decision, and they rely strongly on detached, objective professional counseling. Whether with all good intentions the information generally given at that time, is as complete, reliable and lucid as is needed, could be doubtful, judging by parents' reports, one of which happened to be published in these pages not so long ago.<sup>2)</sup>

One can not help feeling frightened that doctor and parents — whose insight into the situation depends nearly entirely on the information given to them by the doctor, who may have profound medical knowledge, but whose view of the future is essentially no more than speculation, should feel themselves entitled to make private decisions of life and death, when there is no immediate, urgent necessity. This omnipotence, exercised, it is said, on the baby's behalf, rests on extremely shaky foundations. Firstly: parents' rejection — but this may not continue as is borne out by much evidence as also found in the article mentioned. Secondly: Down's Syndrome — considering the wide range of ability found among the D.S. population, ranging from profound to very mild mental handicap, is it seriously suggested that a mildly handicapped baby, rejected by the parents, should be allowed to die if early enough diagnosed? Or does this happen only to D.S. babies because the diagnosis is relatively easier? Thirdly: Institutionalisation — one feels this is really the decisive factor which led to the baby's death. After all no problem would have occurred if the parents had accepted the D.S. baby or if it had been adopted. And what about institutionalisation? Quite apart from the fact that modern management of mental handicap has insisted and is largely succeeding in preventing children being brought up in institutions<sup>3)</sup>, and that, therefore, institutional life for a D.S. baby is by no means inevitable, there is also no certainty that in sixteen year's time the D.S. young adult will be sent to an institution/hospital which, by that time, may well only be used for those m.h. people who genuinely require special medical attention which can only be given there. Nor is there any certainty that these institutions will still look like those depicted in the various horror reports and horror films which have shocked the public in

<sup>1)</sup> The Times, 4.11.81

<sup>2)</sup> Lucas & Lucas (1980), Down's Syndrome: Telling the Parents, Brit J Mental Subnormality, XXVI, No. 50, pp 21—31

<sup>3)</sup> Mr P Jenkin, Secretary of State for Social Services, announced on 10 December 1980 "In 1969, there were 7,100 children under 15 in m.h. hospitals, in 1977, there were 3,900."

recent years. The authorities, the institutions and staff are nowadays very busy with bringing their house in order and in sixteen years from now on they will have changed the scene to such an extent that institutionalisation will have become an acceptable alternative among various courses of action in the interests of a handicapped person.

In view of this, can it really be justified to let a baby die in his own interest, because one is afraid that the inhuman situation of which we are all aware, will still prevail in the future. Quite frankly are parents and doctors not immensely conceited in making pronouncements about the quality of life which the handicapped will experience? Sure, the life even in "good" institutions does not correspond to our notions of normality, but how are we to judge whether those D.S. people and their intellectual peers are not happier, more content, more appreciative, more settled and more secure than we, who have, most likely, a completely different scale of values, of expectations, of goals? Making the pronouncement that a m.h. baby will not be able to live a happy and contented life because he will not have, neither now nor in the future, those things in life which the decisionmakers consider to be vital for themselves and their children, is presumptuous thinking which does not allow for the existence of other modes of living.

Of course, we professionals, working in the field of mental handicap, are not at all blameless and have to shoulder quite some responsibility for those honest, though misguided desperate decisions by doctors and parents. We have failed to make them and others aware that the bleak, dreadful institutional life is beginning to be a thing of the past, that expectations about the m.h. person's abilities *have risen considerable and that the results of directed and intensified efforts support our realistic optimism.* It must be possible to destroy the inheritance of outdated information! What a testimonial, what a judgement of our efforts if a baby is left to die rather than handed over to institutional care.

Of course, this puts us under an obligation to reach a widely acceptable standard of care — and this does not depend solely on the amount of money made available. In the past, the doctor's impressions of institutional care were supported by much dreadful evidence, for the present they are no longer valid to the same extent, for the future let us make sure that they are quite wrong.

The improvement of our care provisions to acceptable, humane standards will be, for many people, a weighty consideration but it must never become a prime criterion for decision making. We are here reminded of a doctor in a very impoverished, but spotlessly clean Yugoslav hospital for the mentally handicapped. We were permitted to visit his ward for the profoundly mentally handicapped only after having donned white gowns and surgical masks to reduce the danger of infecting his patients. There we saw one of those shattering collections of grossly deformed and repulsive looking children, whose pictures illustrate the pages of medical textbooks. They induced in us obvious, but unspoken questions, which are unavoidable when faced with such tragedies. Sensing our reactions, the doctor lifted with great care one of those mishapen, hideous looking bundles of humanity to make him more comfortable and said quietly: "He also has a right to live."