

POINT OF VIEW
MENTALLY HANDICAPPED PARENTS –
SOME ISSUES TO CONSIDER IN RELATION TO PREGNANCY

Changing patterns of care, in the field of Mental Handicap, towards de-institutionalisation and community care, are providing more opportunities for a normal life style for mentally handicapped people. Amongst these is an increased opportunity for mentally handicapped adults to have children, either by choice, or by accident. The purpose of this article is to:

- I. discuss the literature and research on the subject.
- II. discuss the special issues that may arise whilst counselling and supporting a mentally handicapped mother during pregnancy and immediately afterwards.
- III. consider some issues for the future of such parents in relation to service provision.

The right of mentally handicapped people to express their sexuality is becoming increasingly recognised and hence the right to get married and have children. Decreased segregation will inevitably lead to increased opportunities for them to meet a partner, fall in love, to live together and to get married. Unfortunately, we still find instances where the sexuality of the individual is denied by the parents or carers. These people will grow into adults without adequate understanding of their sexual feelings; their peers are often equally ignorant or misinformed and teachers or supervisors may be embarrassed to talk to them about sex, so that they do not know who to approach regarding their feelings. This denial of sexuality and subsequent ignorance, however, does not prevent sexual intercourse and may therefore lead to unwanted pregnancies. On the other hand, adequate information will hopefully lead to pregnancies only when wanted and planned by the individual with the support of those involved in the care and proper counselling prior to and after the birth of the child.

I. LITERATURE REVIEW

Most of the studies on the subject focus on three areas:

1. the risk of handicap in the offspring.
2. fertility and family size of mentally handicapped parents.
3. assessing parental competence.

Most of the studies have been done on married mentally handicapped couples and families, often with a history of some form of institutionalised care. Some of these (e.g. the Mattinson Study) took population samples who were initially hospitalised and diagnosed as mentally handicapped "prior to the 1959 Mental Health Act". Therefore this diagnosis of "mental handicap" does not necessarily equate with the present criteria for diagnosing intellectual impairment.

1. Risk of Handicap in Offspring

The findings from these studies vary enormously. Hall (1974) reviewed 31 studies dating from 1913 - 1965. The percentage of mentally handicapped children produced ranged from 2.5 to 9.3. Definition of handicap and the criteria used in the studies were important factors affecting the results, e.g. retardation in one versus two parents. IQ level of parents, cause of mental handicap, prenatal factors and socio-economic status will all influence the results.

Reed & Reed (1965) at the Institute of Human Genetics looked at the records of 7,728 children. In 89 cases where **both** parents had an IQ under 70, 40% of the children were classified as educationally retarded. (IQ at 74). When only **one** parent had an IQ below 70, 15% of children were retarded with 54% of children having an IQ above 90. Of 7,035 children with **neither** parent retarded, 1% had an IQ less than 70. They calculated that for a mentally handicapped person with an IQ under 70, the expectation for one of their children also to score consistently with an IQ under 70 was 17.1%.

The tendency generally is for a regression of the IQ towards the mean (at both ends of the scales).

2. Fertility and Family Size

Fertility has two aspects:

- (i) the biological capacity to reproduce
- (ii) effective reproduction (i.e. number of children actually produced.)

(i) Biological Capacity

Most mentally handicapped people apart from a few exceptions, e.g. Klinefelter's/Turner's Syndromes, are fertile at the biological level.

(ii) Effective Reproduction

The more severe the physical damage, the less is the likelihood of a functioning reproductive system (Wolfensberger 1972). Also the social status of particularly the severely mentally handicapped person makes them less likely to have children. However, this is not necessarily so in those with milder mental handicap, particularly with the current changes in care.

The Mattinson Study (1975) on married mentally handicapped couples reported an average of 1.5 children compared with 2.1 in the general population. A longitudinal study by Higgins et al (1962) showed that there was no correlation between IQ and family size. Of the lowest IQ group, only a small number reproduce.

Two studies done on married mentally handicapped couples have the following data regarding their ability to cope with children.

P. J. Mattinson Study – Published in 1975

This study was done on 80 ex patients who were married, i.e. 40 couples – both partners having been diagnosed as mentally handicapped between 1914-1963. They had an average IQ of 61.23 (38 - 93) (Stanford Binet) and had spent 3 - 14 years in hospital (average 13.6 years). Of the 40 couples traced, 4 had separated leaving 36 couples. 17 of the couples had children, 40 in all (average of 1.5 per couple).

Of 40 children, 6 were in care and 34 at home, 3 other children were being brought up in the families. Of the **school age children** (13), school attendance was reasonable but 4 out of 13 were unsuitably dressed (e.g. clothes too large). No truancy was reported but 6 children were considered maladjusted at school, 2 had severe mental retardation and 1 epilepsy. None had, so far, a record of offences or court appearances.

Of the **pre-school children** (23) none appeared malnourished, consistently ill, unfairly treated, cold or unhealthily dirty. The care was often erratic and inconsistent. Only 3 families out of 13 coped with minimal support. 5 families needed regular support and advice whilst in the other 5 families intensive care was required.

Craft and Craft Study – Published in 1979

45 couples referred via hospital or other services in which at least one partner had an IQ of 70 or under were taken into this study. 41 couples had intact marriages. 14 out of 45 couples produced 30 children. 4 children out of 2 families were in care, 2 mentally handicapped children lived in hostels and 2 children from 1 family were on an "at risk" register. In several families an unemployed father had taken up much of the child care responsibility. In all but two families with children under 12 years a social worker or health visitor actively supported the family.

3. Assessing Parental Competence

Health professionals are often asked to advise about the suitability of an individual as a parent (mentally handicapped or otherwise). Assessing parental competence is a complex process as it involves not only measurable **objective** values but also **subjective** values, which in turn are dependent on the society in which we live. It is difficult not only to decide what is parental incompetence, but also what qualities are necessary to make an adequate mother. Most studies consider a child neglected, only when evidence is overt and conclusive. Children who are not overtly neglected may, however, be deprived due to distortion of relationships, limited cognitive growth, etc. Various factors need to be taken into account in such an assessment including:

- (i) The ability of finding and keeping appropriate accommodation — including paying rents.
- (ii) Income, money management — amount of spending, savings, paying debts, etc.
- (iii) Employment/unemployment — the consequences of each on child care. Unemployment of the father may mean that he is at home to support the mother in child rearing and may in some cases be a positive factor.
- (iv) Furnishing a home — adequacy of this.
- (v) Laundry/cooking/hygiene in house, etc.
- (vi) Feeding, clothing and general care of children.
- (vii) Management of spatial, temporal and numerical relations, e.g. managing time, travelling, keeping appointments, etc.
- (viii) Health — personal and of children, physical problems, actual or functional; psychiatric problems; ability to medicate themselves and their children. First Aid and capacity to respond in an emergency.
- (ix) Education of the parents — ability to read and write. Do they send the children to school? Do they dress them appropriately, etc.
- (x) The effect of the mental handicap on the individual or others. There is often an expectancy to fail and poor self esteem.
- (xi) The presence or absence of support systems, e.g. extended families, benefactors, etc.
- (xii) The ability to ask for support when necessary.
- (xiii) Keeping within the law and disciplining the children.

Measuring the material aspects of parenting is much easier than emotional aspects.

One must also distinguish those parents with stable personalities and a low IQ from those parents with apparent or real mental retardation, temperamental instability, squalid living and the presence of numerous children. It is the latter group which tend to be the problem families. We know that certain factors within the environment are important in the development particularly of mild mental handicap, maternal deprivation being one of them. Many mildly mentally handicapped children even today have chequered lives. They may have been subject to non accidental injury, neglected by their families, or have had repeated separations due to a number of reasons including hospitalisations for concomitant physical problems. Some are put into care, and if not fostered or adopted, may have been moved later from home to home. They are then met as "difficult adolescents" who never quite fit in anywhere because of their failure to have established secure relationships earlier on in life. All these factors will affect the development of the personality of an individual and their ultimate capacity to make adequate parents.

II. COUNSELLING

The following mainly addresses pregnancy in a mildly mentally handicapped mother.

1. How did the pregnancy come about?

The pregnancy may have been planned and preceded by adequate advice about contraception, the issues surrounding motherhood, etc. However, in a number of cases the pregnant mother has been inadequately prepared because of the lack of understanding regarding sexual intercourse and its consequences. In some instances the woman may have been exploited or even raped because of her ignorance and this needs to be dealt with initially by discussion with someone she can trust, e.g. her key-worker(s) and then taking the necessary, possibly, legal action. Over-protection by the relatives and anger towards the man who made their child pregnant may be added problems.

"Miss Y. is a nineteen year old single woman who is mildly mentally handicapped. Her family have always been over-protective towards her and felt that sexual education was inappropriate for someone of her mental capacity. About two years ago Miss Y. had sexual intercourse a number of times with a family friend. She had no idea that this could lead to pregnancy. Some months later she was admitted to a medical ward with abdominal pain with a suspected urinary tract infection. On investigation, she was found to be twenty-two weeks pregnant. Here was an unwanted pregnancy which may have been prevented had the family been more realistic and accepted the fact that their daughter was 19 years old not 9 years (her mental age)."

In this case much time was spent helping the family come to terms with the fact that Miss Y. was really pregnant, that their over-protective attitude did not serve her well and that they would need to be supportive to her. We also had to help them in dealing with the 'family friend' who had caused the pregnancy.

2. Diagnosis of Pregnancy and what is to be done about it

Mentally handicapped people, particularly when inadequately advised, may not be aware they are pregnant and diagnosis may come late in the pregnancy. This is particularly important if time is to be given regarding the possibilities of abortion and any counselling required prior to this. Once the woman is told she is pregnant she needs to be given time to accept this before any further decisions are made. Decisions regarding the future need to include her opinions and not be made only by the family and professionals without consideration of her needs.

"Miss J. is a single young mildly handicapped woman who some years ago set up home with her boyfriend Mr. L. In spite of repeated advice to the contrary by relatives Miss J. decided that she would have a baby and duly became pregnant. The feeling by the family was that the pregnancy should be terminated but Miss J. and Mr. L. both insisted that they wanted the child, and eventually this decision was accepted."

What, I wonder, would have happened had the pressure on this couple to have the termination been so great that they had consented to it? One sees many clients who after enforced terminations still have fantasies about their lost babies and who have never been given the right to make a decision about what they want for themselves, nor have many of them had any counselling prior to the termination being performed.

3. The Pregnancy

Who is going to counsel the woman? It is often assumed that the client does not understand what is happening to her or any procedures being undergone, so little or no attempt at any explanation may be made, particularly by those services not directly concerned with the m.h. client group.

Education about pregnancy is necessary and needs to be simple, giving consideration to the limitations of the client, e.g. problems with the management of time, lack of understanding about change of shape, etc. Instructions may need to be repeated several times with the aid of simple diagrams. The usual ante-natal classes are often unsuitable for this client group and may need to be substituted by individual instruction by midwives or others and given not only to the client but also to their partners, relatives and carers. Ante-natal care in hospital can be very confusing, especially if the woman sees a different doctor or mid-wife on each visit. Adequate liaison between all those involved with the client is particularly important.

The client's deficiencies should be assessed or brought into focus at this stage so as to plan the support required once the baby is born. It is also of importance to know who is going to be concerned with supporting the mother if one is to match the service to the needs requiring attention.

I have spent time beneficially instructing hostel care staff and staff running a drop-in centre, about pregnancy and the signs and symptoms of labour when I recognised that as none of these had any nursing training they were unaware of what "breaking of the waters" meant. I have asked a client's unmarried sister to attend ante-natal classes with her to learn how to change a nappy and make up a bottle. I have also spent precious time liaising with midwives, obstetricians and others working within hospital systems and discussing the limitations of our clients; e.g. how confusing it can be for a client if she is told that her baby will be born in four month's time when she has little concept of what four months means.

4. Labour and Confinement

How is this to be managed? The patient may refuse consent to any manipulation or operation because of fear and ignorance, or may panic because she is not fully aware of what is happening. Previous instruction about what happens may go some way to alleviate her fears. In the post natal period the ward staff may need support to understand that the patient is like any other, only slower and needs longer to learn basic tasks like making up a bottle, feeding, etc., - again one might need to stress the numerical and temporal problems if present. The expectancy to fail could be a real handicap at this point.

The attitude of the other mothers on the Ward is also important. "Mrs. S. was a mildly mentally handicapped mother with epilepsy who had her third baby by caesarian section. Most of the other mothers on the ward were intelligent women from a 'middle class' background who largely ignored her and when she did speak they did not listen. The nurses on the post-natal ward were very busy and had little spare time for her. The turnover of new mothers was very fast as most of those who did not have a caesarian section were only patients for two days and then left. In a corner of the day room one could see Mrs. S. talking to herself all alone." Daily visits by her key worker from the Community Mental Handicap Team concerned went some way to ease her isolation.

5. Will she cope once the baby is born?

This needs to be considered well before the baby is born if adequate support is to be given once a mother is discharged from hospital. Family support is very important if this is available. If not one must consider a mother and child support placement, where, if possible there is some night supervision, particularly in the early days. If it has been decided at this stage that the child should be adopted the mother-to-be needs to be prepared for this.

"A client decided that she could not cope with a baby single-handed and she agreed that the child should be adopted. She received counselling, with this in mind, whilst she was pregnant and eventually when the child was a few days old she was able to hand him over to foster parents, whom she met, knowing that he would be well taken care of." Early consideration of this had given the client enough time to come to terms with the adoption and to a happy ending for both mother and child.

6. Being a Mother

Support at home is very important for every mother, mentally handicapped or otherwise. Special problems may arise if there is no father or extended family, and a stay in a mother and baby home may be necessary. Involvement of the extended families or other support systems is often very useful but can also cause problems such as conflicts over child rearing practices. Jealousies may arise between the mother and other carers who in their keenness "take over" the parenting role leaving the mother as a mere onlooker as happened to Miss C and her baby when they were both placed with foster parents. There may also be "fears of handicap" in the child which may cause anxieties for those offering the support, particularly if these are the child's grandparents. These may re-live the time of their own fears prior to their child being diagnosed as mentally handicapped and may need special support.

Assessments of parental competence may need to be done at this stage especially if there is a strong suspicion that the mother is probably unable to cope.

7. Contraception, Sexual Education and Family Planning

Advice about these is particularly important especially for those who are inadequately informed, both if further unwanted pregnancies are to be avoided or for planning future pregnancies at appropriate time spans.

8. At Risk Registers

Questions often arise about putting the baby of the mentally handicapped mother on an "at risk" register. Every case should be judged on its merits and it should not be assumed that the baby is necessarily going to be neglected or hurt.

Health visitors and other support systems have a particularly important role to help these mothers and good liaison with them is important.

III. ISSUES TO CONSIDER WHEN DEVELOPING SERVICES

- (i) With increased community care are we going to meet more mentally handicapped people who will become parents by choice or by accident? Are the present support systems equipped to cope with them and who needs to be involved?
- (ii) Previous Care – are mentally handicapped women having adequate experiences in their upbringing to enable them to make an appropriate choice about parenthood? Is the present counselling providing them with a realistic outlook?
- (iii) What role do the Community Mental Handicap Teams and other related services have in supporting and counselling these parents, particularly the keyworker involved?
- (iv) How will living with a mentally handicapped mother/parent affect the children in the long-term?
- (v) What role do these Community Mental Handicap Teams and related services have in educating other medical services and the public?

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