Parents of Mentally Retarded Adolescents
Evaluate the Past and Face the Future of
Their Child

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Introduction

Most parents expecting a child anticipate that the child will be a normal or even more a perfect one. The discovery either after birth or at a later age that the child is retarded may bring about a crisis in the family from which many parents may be unable to recover. The crisis has been called ‘tragic’ and has been compared to death and to a state of bereavement (2). It has also been suggested that most parents ‘suffer chronic sorrow throughout their lives regardless of whether the child is kept home’ or removed (6). Furthermore, mourning has been considered necessary before the parents could effectively cope with the new condition in their lives (7). Studies have shown that parents of retarded children may experience continuous stress (3) or marital disharmony and marital breakdown more often than families with normal children (4). In the present area of wide expansion of community services for the handicapped, many retarded children are raised by their parents, no one of whom, according to Clarke and Clarke (1) ‘should be expected to rear that child without the fullest support’. Wolfensberger and Menolascino (8) proposed that the management needs of a family with a retarded child arise from three major sources. First, the ‘novelty shock’ which results from the shattering of the parental expectations of having a normal child, second, the ‘value conflicts’ which the parents experience in relation to their attitude about defect, and third, the ‘reality stress’ which results from the situational demands of raising or caring for a retarded person. The same authors argued that the ‘reality stress’ on the family could be alleviated by the provision of concrete relief measures and education rather than counselling centered on the parental psychopathology.

The present inquiry was concerned with some aspects of the ‘reality stress’ which many parents with a retarded child experienced while coping with the pragmatics of raising their defective child in a community which at that time offered little in terms of concrete services.

In particular, we inquired on how many, among the children who had been
assessed and diagnosed as being retarded, received special education and/or training
during the years which followed initial assessment and counselling. We also
inquired about the concern of the parents regarding the future of their child and
what, if any, were their own actions to safeguard the child’s future.

Material and Methods

The parents of 202 adolescents were contacted by mail and asked to answer a chain of
open-ended questions pertinent to the support they received from services or others and
their own concern about the child’s future. All children had been assessed at the Mental
Health Center of Athens from 1958 to 1975 and were of age 13 to 21 at the time of the inquiry.
The parents of 69 adolescents answered the questionnaire. Details of the study have
been reported elsewhere (5).

Results

Out of a total of 69, the parents of 19 adolescents reported that their child
attended or was still attending a special school and 7 more reported that they
had received support from the services. The parents of 14 adolescents reported
that they received some support or good advice from close relatives and friends,
and 26 said they did not receive support or assistance from anyone. In other
words, in terms of concrete services, only 27% of the children had received special
education or training.

Since there are only limited prospects of employment or sheltered employment
for the retarded in this country, which would have enabled several among
them to become self-sufficient, and since there is no universal welfare coverage
of the retarded, it was not surprising to find that several parents were preoccupied
with problems related to the future of their child. The parents of 19 adolescents
reported they had already secured for their child either a pension, mostly
by the State Insurance Foundation or real estate, 7 were in the process of achieving
similar financial security, 11 were striving ‘to do something’, 12 had either
arranged the training of the child in a trade or were hoping the state would provide
training. The parents of 20 adolescents, or 30% of the total, reported they
could do nothing themselves because they were poor; the answers of several
among them were quite apologetic in tone. What became quite obvious was the
fact that several families who had satisfactory income had embarked on a solitary
effort to secure the future of their child from the financial point of view.
Several parents appeared well informed about what services might be of help
to their child and wished and hoped that community services, mostly governmental,
would extend their support to the child. Financial support, special institutions, training in trades and medical care were prominent among their suggestions. 20 parents reported they did not expect any help from anyone; among them there were only 5 who had reported earlier they were unable to do anything themselves because of poverty. It was of interest that although several parents indicated clearly their expectations from the state services, which at the time were not very promising, no one mentioned that forming a pressure group or mobilizing an existing organized group of parents might be of help. One might argue at this point that the parental solitary coping with the problems of their child is one more aspect of the well-known inability of Greeks to act collectively. Several parents appeared increasingly concerned about the future of their child. The parental concern appeared heightened with increasing age of the adolescent and of the parents, this being apparently the result of the increased awareness that not much community support was forthcoming. 70% of the parents who had a child in the age-group 19-21 expressed worry about the future while only 39% of the age-group 13-15 expressed similar concern. Among all parents, 52% were worried about what might happen to their child after their own death.

Discussion

Having a retarded child need not be a disaster which will hamper the life of the family for most of the years of its existence. The parents may eventually be able to overcome the ‘novelty shock’ or even the ‘value conflict’ with either considerable or limited support but may be unable to cope with the ‘reality stress’ which arises from the every day problems and difficulties of raising a defective person and from the frustrating effort to provide education, training and security for the child extended into the future. The need of the family for real support, and the need of the retarded for special education or training in order to develop and use the abilities he has for his own benefit are fundamental and self-evident preventive measures. What this inquiry has shown, we believe, is the distant echo of the family suffering when the preventive measures are inadequate.

Summary

This report deals with answers to a questionnaire given by 69 parents of retarded adolescents living in a community which, at the time of the study, offered little in terms of concrete services to mentally retarded persons. The inquiry concerned basically the parents’ evaluation of the support they received from services or other sources and their concern about the child’s future.
References


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