

22.

Working with Parents — A Community Doctor's Approach

Dr. Sarah Portelli

Member of the Action Research Project

Traditionally, in Malta, the handicapped child has been treated medically by the hospital doctor in the hospital and by the general practitioner. In the absence of highly developed community medical services, follow - up of handicapped children is usually either hospital-based or non-existent. Too often the pattern for the handicapped child is of non - attendance at the Children's Outpatient Department for follow-up appointments. The lack of any Social Workers or Health Visitors in Karen Grech Hospital means that there is no - one to follow - up any child who does not attend for a hospital appointment. We need to find out why they did not attend and whether perhaps the reason is that the family are not coping with some psychological or social problem.

In conjunction with this we must remember that the average family doctor will have only one or two handicapped children in his practice and is therefore not necessarily familiar with their special needs.

We need to ask ourselves whether or not hospital should be the main supportive medical service for handicapped children and their families in the future, or whether perhaps this could be better done in the community.

Many years ago Dr. Mary Sheridan gave an important lecture to the National Childrens Home in Britain on THE HANDICAPPED CHILD AND HIS HOME. In this lecture, which is very relevant to our situation today, she emphasises the fact that the domestic and social implications for the family of the long term care of their handicapped child are of major proportions and demand extensive supportive services if families are to succeed in their task.

She says that there are seven basic provisions which must be made by the community on behalf of the handicapped child. They are:

1. Early Identification
2. Comprehensive Assessment of Handicaps AND ASSETS
3. Prompt Medical and Surgical Treatment
4. Parent Guidance
5. Suitable Educational and Vocational Training
6. Follow - up and Periodic Reassessment
7. Final Placement in the Community or in Special Care

The Action/Research Project, as we have seen, does address itself to some of these provisions, particularly numbers 2, 4, 5, and it lays the basis for 6.

The role of the Community Doctor in this project is:

1. To conduct a joint interview, together with the Psychologist, with the parents and the child in the school.
2. To conduct medical examinations on individual children in the school.
3. To liaise with other medical colleagues.
4. To take part in the follow - up interview with parents after the Case Conference.

1. Joint Interviews

This interview allows us to get to know the parents and the child and to take a detailed medical and psychological history. A number of questions are included on parental attitudes and expectations towards their child, as well as those concerned with the full genetic, family, obstetric and child's medical history.

2. Medical Examinations

These are conducted in the presence of either the Project Nurse or the School Nurse, both of whom are now very familiar figures to all the children. In this situation children are relaxed and accept a medical examination readily - in fact most of them look forward to meeting all the various professionals, and to getting some extra attention.

3. Liaison with Colleagues

I meet Professor Cuschieri, Dr.Vassallo Agius and Dr.Farrugia Sant Angelo at least once a fortnight at the Case Conferences. Professor Cuschieri is a research co-ordinator and has particular interest in any children with a genetic component to their handicap. Dr.Vassallo Agius is the senior Consultant Paediatrician and chairs all the Case Conferences at the school. Dr.Farrugia Sant Angelo is the Clinical Research Assistant and examines the children, with particular interest in certain features relative to genetic research, and through her, we are all able to have access at the Case

Conference to important information about previous hospital admissions and investigations.

The child's General Practitioner, the School Medical Officer and the School Nurse are always invited to attend Case Conferences. The General Practitioner is sent an individual letter for each child, and the School Medical Service receive all the correspondence which is sent to Team Members.

4. Follow-up Interview.

This part of my work involves giving information to parents on the medical findings and recommendations made jointly at the Case Conference. There may be unexpected medical findings and the recommendations may include further medical investigation at hospital. This needs to be explained fully to parents, and any questions must be answered. Time for discussion is an essential part of this interview.

On this Action Research Project as you can see a great deal of time has been devoted to contact with parents because the essential part that parents have to play in the assessment of their child is fully recognised. Two hours at home with the Social Worker, two hours at school with the Doctor and Psychologist, together with some time spent on informal discussion with the Headmaster, Class Teacher and the Speech Therapist, and then the follow-up interview, usually mean at least five hours of professional time spent in contact with parents. Some parents might think that this is too much!

In conclusion, I would like to say that we have already established at Wardija Special School that by a process of participation of all involved parties i.e. child, parents, school, University, Department of Health, Department of Education, Department of Welfare and Voluntary Agencies, Community-Based Programmes for the Handicapped can be developed in Malta by the use of Multi-Disciplinary Approach, and we look forward to further developments of this kind in the future.