I would like to start by quoting the Head of Psychology at the University of California, an international authority on autism, Dr. Lovaas, who during the research that led to his excellent programme admitted:

"The first serious mistake we made was to treat the children within an institutional (hospital or clinic) environment ... We had hospitalized the children in the first place because we still held the old view we had been taught, that children like those with whom we worked were ill. It seemed to follow then, that since they were ill, they needed treatment, ideally in a hospital.

Given our background, it was an easy mistake to make. We decided then to change the place of treatment from the institution to the children's natural environment; that is we began to treat him in his home and school.

We were successful and this brought us to question the necessity or desirability of using a hospital as a teaching and learning environment. Our goal was to help these children to live and function in the real world and not in an artificial setting, such as an institution."

(Teaching Developmentally Disabled Children)

The Eden Foundation was set up by a group of parents determined to achieve a better future for their children than the present situation of institutionalisation or hospitalization offers.

The Eden Foundation's programme is essentially an educational one and is based on the strong belief that people with disability are educable provided they follow a system which is intended to bring out the abilities hidden behind the disabilities.

This system, in turn, is based on Eden's view that people with disability rather than ill or diseased, are simply "different", and that what was needed was an environment in which the child could learn. So the place of intervention became the child's own home and we chose to teach the children, whenever possible, in the same way normal parents teach their normal children. We supplanted treatment by teaching and de-emphasised diagnostic testing.

Allow me briefly to explain how our systems function.

In the Early Intervention Programme for children up to the age of 5, we have about 100 clients. After assessment by the various professionals involved, a case conference is held which determines each child's individual programme. This is the starting gun that sees the child receiving a lesson at home together with speech, physio and occupational therapy sessions on a weekly basis.

Naturally there is constant meeting of these professionals on an informal basis, but teachers meet regularly every other Tuesday while Departmental Heads meet every forthnight. Review meetings are now being conducted at 3-monthly intervals while Enhancement Courses aimed at creating a Transdisciplinary model are on-going and take place twice monthly. Eden indeed teems with creative activity and I assure you that you would be most welcome to visit and see for yourselves.

That of course, is only one programme. We have gone into the homes and institutions to take out adults lying idle, living on the state disability pension of almost Lm1000 a year, and put them to work. Adults between the age of 18 and 30, who had never gone anywhere on their own in their life, were taught to travel by public transport to our Centre in Valletta. After 3 months of life and social skills aimed at making them function as people, where they learn to shop, count their change, make a telephone call, reach a destination, etc, they embark on another period of 3 months of on-the-job training where the abilities that had been identified are now translated into job-holding skills. Job coaches, specially recruited for the purpose, accompany the trainees during this period and help them to integrate with their work companions.

There are 10 of these people now working independently, doing normal work and earning a normal salary. 10 people whose parents had long given up on them after the long years of failure. Who, when their disability was first diagnosed would have bet that one day they would be working?

There are 14 others doing on-site training while 90 await their turn. The first intake of trainees have now been working independently for over 3 months.

Eden achieved this with people whose schooling did not amount to much, and during a period when we were still finding
our feet. For the young children benefiting from our services and who by the time they have left school will have absorbed so much from our programmes, the future should be far brighter.

The systems we are using have been advocated before by far-seeing people in our society as far back as 1989 to my knowledge. At Eden we have simply had the courage to put them into practice. Very conscious of the fallout that would arise, we decided that the time had come to admit that the medical model was not adequate enough on its own. As doctors, our knowledge of disabilities and how to deal with them is scanty and it is indeed time for medical students to be taught how to identify disabilities and how to treat them.

I speak nothing but the truth when I tell you that there have been instances of parents being put off by some doctor from enrolling their child with Eden because professionally he could see no reason for it, only to have these same parents begging to be allowed to join the programme a few months later when the disability had become more evident.

Precious months had been lost to children who are not in a position to readily make up for lost time.

I have just mentioned parents. From the very beginning at Eden we had to face a familiar problem: where to draw the line separating the parent from the professional. Again I believe you will agree with me when I say that in Malta the professional brooks no interference. We feel that medical problems being so complex, only highly educated persons can be allowed to view the way we work.

In turn of course, this has burdened us with a tremendous responsibility. In English colonial times, in the East they used to speak of “the white man’s burden”, meaning that the Europeans, having persuaded the natives to view them as superior beings, could never afford to own to a mistake or weakness.

We too have fallen into this trap. This is a mistake. At Eden we reason differently. We parted from the obvious position that there simply are not enough professionals available to meet the educational, therapeutic and psychological needs.

Secondly, if parents didn’t know exactly what their child’s treatment programme consisted of, what we were doing, why we were doing it, and what the final goals were, then they wouldn’t be able to help their child maintain the gains made in therapy, and the child would regress. The parents and teachers are the child’s primary therapists while the specialists act as consultants.

If a child’s behaviour is influenced by the environment in which he lives and learns, and since a child’s environment is composed of several different settings (such as school, home and neighbourhood) then it follows that the child’s total environment should be arranged to become therapeutic and educational if the child is to make maximal gains in treatment.

And this is where a great concern of mine comes in. In a system where, quite rightly, the parents’ role is essential, we have to be careful not to overburden the parents. And they are tremendously overburdened. There are their endless hospital appointments in hospital with their often discouraging results. There is their membership of any organisation that offers a quick fix to their problem. Torn as they are between conflicting loyalties, they are in danger of collapsing, and if the parents collapse, their child and his future – despite everybody’s good intentions – will collapse.

I appeal here to those of you present who have the power to provoke change, to join Eden round the table and find ways and means of collaboration to spare the family that reduplication of services, that hostile jealousy they at times encounter in quarters that should know better, that mad chase from one place to another; all so unnecessary and certainly in no way acting for the good of the child we all claim to be concerned with.

Believe me when I say that Eden does not want to intrude on anybody’s turf. Our joys are simple ones. We celebrate when the child whose parents assured us he would never talk, is now talking and more, understanding concepts. The child who up to three years had not walked and, according to the medical diagnosis was not really expected to walk, is now slowly, painfully making a few steps, enough to fill his parents with that dose of hope that will enable them to carry on.

It is time for us to accept that, as doctors, we cannot work alone. In the modern world there are many other professionals in possession of skills that could do mankind – and especially disabled mankind – a lot of good. To some extent this is a principle we all accept and practice. People who suffer a stroke are sent for physiotherapy; people who suffer accidents are given occupational therapy. But we do not seem to apply this principle right across the spectrum. In the case of developmental disabilities this could be a case of tacitly accepting that the input required is so great that the medical profession on its own cannot possibly deliver it.

And it is right that it should be so. Most of the money spent on medical treatment and medical rehabilitation will be of little value if we forget that it is our duty to bring the disabled person back to a social life and to give him the
Possibility of living such a life. What is the use of stretching rehabilitation services to meet ever increasing demands if in so doing the real needs are not met?

That is why Eden’s slogan is “Towards an Independent Life”. We believe in the integration of the individual, for all psychological and sociological investigations show the impossibility of improving the individual resources of a person if he lacks stimulating contacts with other human beings.

That is why the social and psychological situation of the disabled will be a better one if those who meet him do not fix their interest on his disabilities but on his abilities. There is a need for Rehabilitation and Disability Medicine in which very few medical people are interested. There is need of Prevention Child Care Programmes. At Eden, we have noticed how often our children seem to fall sick with consequent loss in lessons and therapy not to mention the parents’ distress. Indeed, since the Eden Foundation is affiliated to the Institute For Child Development of the University of Malta, I am looking forward to the day when this joint venture between the two parties will initiate research that we at Eden – unhindered as we are by bureaucratic considerations – can immediately put to the test.

And while we are far from claiming that we have all the answers, or even half the answers or only a few, we do have the facility of being able to initiate action within the constraints in which we operate. That is the main reason behind the results already achieved in the space of 15 months since we commenced operations.

You cannot give holistic education using specialists, however gifted, however dedicated and committed, if they come from several departments all of which tend to operate within castle walls higher than the Valletta bastions and who consider the protection of their turf to come before any other consideration.

You have heard me give you the details of how we operate. In all honesty, and I say this quite humbly, despite our shortcomings, despite all we have yet to learn, what government department is in a position to deliver the same? Can any other department ever be able to function in this unique, highly focused way?

At Eden my staff know only when the day will start, never when it finishes. Ring up and find out for yourself. At Eden we have members of staff who forfeit, of their own free will, expenses due to them for services rendered. At Eden, when the need arises we go in even during the weekends. At Eden, despite the enormous pressure of work, we have staff who refuse lucrative offers from other educational organisations because they know that nowhere else will they find the same atmosphere, the same commitment, the same family set-up based on the slogan “working together as a family for the good of the family.”

The Eden Foundation is not the Garden of Eden and we do have our disagreements but it is nothing like what prevails in the normal places of work. This is the primary resource that every other state department lacks and can never hope to possess. And all this activity is carried out after a day’s work elsewhere, for most of our staff work part-time.

And it is with my heart full of this goodwill that animates our work that I most earnestly request you not to let this conference end up as yet another bit of printed paper, a showcase of good intentions that nobody buys. Let us, all together, be partners in a noble quest for the good of disabled persons and before we leave this hall fix a date when, gathered around a table, we can pool resources, apportion limited expertise and set up a functioning model aimed at providing persons with disability with the opportunity they need in order to show that their contribution to their country and their society can be as valid, in human terms, as that of the best among us.

Thank you
Josie Muscat
President – The Eden Foundation

Winter C.P.D. Meeting

Wednesday, 5th October 1994
Pitfalls of the Chest X-Rays – Dr. M. Crockford
How I Manage ... – Dr. J.K. Soler

Thursday, 6th October 1994
Well Woman Clinics – Dr. A.P. Scerri
A Lesson I’ve Learned – Dr. P. Sciortino

Friday, 7th October 1994
Promoting Health in the Family
A Forum Presented with the Help of the Promotion Department
Miss S. Bugaj – Health Promotion Manager
Miss S. Scicluna Calleja – Psychology Lecturer
Mr. A. Zammit – Physiotherapist
Dr. G. Farrugia – Family Doctor & Local Council Mayor
Reception
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