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Introduction

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Over the last 20 to 30 years there has been a radical change in the way in which we approach people with mental handicaps and associated physical, emotional or social disabilities. This is reflected in the use of new terms such as "learning disabilities". The new approach is designed to recognise the learning potential of such people, to acknowledge that they, as citizens, have equal rights, and to encourage acceptance of the fact that they are, indeed, individuals. As a result, the various types of institutional care, in particular, that reflected the once prevalent social policies and attitudes towards such people have undergone a marked change. New models of care have emerged that go far beyond simply making asylums more suitable places for human beings to live in. These new models of care rely on the philosophy of normalisation and the process of deinstitutionalisation and rehabilitation; they are community based, and they provide improved survival and quality of life, as well as opportunities for the individuals to develop their potential by means of education and vocational training, which in many cases will make possible their social integration.

In Greece, developments of this kind have been delayed by the accepted social policy, which has led to the confinement of patients in asylum-type institutions without recognition of their individuality or their capacity for education, vocational rehabilitation or social integration. To make matters worse, the staff of such asylums are inadequate in number and untrained in the provision of specialised care. In addition, the attitude prevalent in Greek society has caused people with learning disabilities to be concealed and isolated within the family or in institutions. These people are considered to constitute a social stigma and disgrace for their families. The lack of appropriate support services for the families has contributed decisively to the rupturing of their family bonds and to causing their own isolation from society. As a result, pressure in the direction of reforming social policy towards meeting the needs of these people has been inadequate. Another factor is the lack of a systematic study of the magnitude of the problem in Greece, which is an essential prerequisite for designing an effective nationwide system for providing care.

It is our impression that these same factors responsible for delaying the reform of the care system for people with learning disabilities were also responsible for delaying the reform of public mental health care in Greece until the early 1980s. However, publicity about the conditions prevailing in Greek mental health institutions in general, and in the Leros asylums in particular, led to a public outcry that eventually initiated the process of reform. Greek accession to the European Community allowed funds to be secured through Regulation 815/84 to put the reform into effect.

Leros is a small island at the south-eastern part of the Aegean Sea, near the Turkish coast; it is 12 hours away from Athens (Piraeus) by boat. The island has been a host of two asylums since the late 1950s: these are the Leros state mental hospital for psychiatric patients, which today houses some 900 patients, and the lesser-known PIKPA asylum for children, adolescents and young adults with moderate or severe learning disabilities and associated conditions.

The Leros PIKPA asylum is a typical example of the extreme of custodial-type care for people with severe learning disabilities and multiple handicaps. It also illustrates how a small isolated community can accept and maintain an asylum structure that is disgraceful by all human standards, developing a social pathology as it does so. The residents of the PIKPA asylum were effectively sequestered from their families and society at large, and were condemned to live in inhumane conditions. The 165 patients at the PIKPA institution in 1991, aged between 8 and 46 years, were housed in a dilapidated two-storey building inappropriate for occupancy by human beings. The care they received was very poor. They lived in a depersonalised environment in which the predominant processes were those of desocialisation, excessive dependence, and inhibition. Most of the residents had been in the asylum since early childhood and had no contact with their families or the community. It was obvious that these residents had been exposed to institutionalisation of the severest kind. The appalling living conditions in conjunction with the almost complete lack of medical care for the residents – a population whose special needs for medical care are certainly above average – caused the mortality rate among the residents to be excessively high. Most of the staff caring for the residents possessed no more than primary school education, and had no formal training or professional

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specialisation in the field. There was no role differentiation among staff members.

It was against this background that the Leros PIKPA pilot intervention project started in February 1991. It was originally planned to last 18 months, but after a number of extensions it ended in December 1994. The intervention was carried out by a multidisciplinary team of mental health professionals. The team, led by Professor John Tsiantis, established a dual base in Athens and Leros and had the assistance of a number of experts from other European countries who were invited for study visits.

The main aims of the project were to evaluate the situation and needs and, on the basis of this evaluation, to help reform the asylum in such a way as to improve the quality of life of the residents, making the conditions more suitable for human beings, and to do as much as possible to rehabilitate the residents and integrate them into the community. The long-term goal is the closing of the asylum.

The intervention has attempted the following:

(a) to change the practices of the asylum staff by teaching them new models and appropriate ways of resident management and care
(b) to make the staff aware of the potential and individuality of each resident
(c) to develop demonstration projects designed to provide care and education for residents, helping them to improve their living and social skills and behaviour
(d) to create or re-establish bonds – as far as possible – between the residents, their families and the local community
(e) to improve the building, the hygiene conditions and the overall quality of living, while providing the necessary medical and nursing care
(f) to enlighten the community of Leros on issues relating to the needs and rights of the residents and their families.

The four papers in this supplement describe the highlights, the process, the dynamics and the results of the implementation of the pilot intervention project at Leros PIKPA. The first paper describes the philosophy and the method of intervention, along with its qualitative and quantitative results. The material presented covers the initial period through to February 1994. The second paper discusses the psychological and social dynamics involved in our attempt to bring about change at the PIKPA asylum; it focuses on the processes underlying the strong resistance with which intervention was met at all levels of its implementation (e.g. residents' families, staff, local community, welfare services). The third paper examines in depth the effects of our intervention on the attitudes of the asylum's care staff towards people with learning disabilities and associated problems. The last paper is a study of the population dynamics of the PIKPA asylum over the initial 30 years of its operation, with particular emphasis on the comparative survival of specific subpopulations of residents.

The change that has taken place during the pilot project has been slow and painful. There has been fierce resistance to change on various levels, expressing itself in many forms, such as complex bureaucratic procedures at the administrative level, or as active opposition on the part of the islanders to any attempt at deinstitutionalisation. Cognitive and emotional factors have strengthened the staff's resistance. Their reaction has, in part, resulted from the economic dependence of the island on the asylum. Moreover, in expressing their predominant attitudes towards the residents, staff members displayed a trend to view these individuals as a single, undifferentiated group with the same characteristics (stereotyping), seeing their confinement and isolation (segregation) as essential. In addition, founded and unfounded fears of losing their jobs interfered with their performance and provided the grounds on which they could rationalise and maintain a physical and emotional distance from the residents. With the intervention that was developed, it was expected that a gradual change in staff attitudes towards the residents and people with learning disabilities in general would occur in due course. In fact, a year after the intervention began it was noted that the staff's notions of segregation had, indeed, become more complex, in the sense that they seemed to acknowledge the need for alternatives to custodial care, as well as the need to differentiate residents.

Our impression is that this experience could prove useful in the reform of similar asylums that provide care for people with learning disabilities and multiple handicaps in other parts of Greece or in other countries. It is essential to emphasise that the reform of such asylums needs to form part of the framework of a more general reform in the public mental health care system, which should be accompanied by a change in the prevailing social concepts and attitudes towards mental disorder, learning disability and associated problems.

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