## An Ordinary Life Mr.A. Mifsud Departmental Nursing Manager

fundamental question that has been addressed by parents, service providers and planners when designing services for people with learning difficulties is :

"What are we aiming to achieve?"

Most of us take our homes for granted. A home means something different to each of us, it enhance our lives in many different ways. There is no doubt that most of us would fight, to preserve a nice supportive place we have to control, to protect our identities and our right to have the kind of home we want.

In 1975 the General Assembly of United Nations adopted the Declaration of rights of Disabled Persons, this includes :-

- 1. Disabled persons have the inherent right of respect for their dignity, they have the same fundamental rights as their citizens of the same age.
- 2. They have the same civil and political rights as other human being.
- 3. They are entitled to the measure designed to enable them to become as self-reliant as possible.

The move from the more traditional model of hospital – based care to ordinary life provision requires changes in attitudes not only by the general public but also by those involved in the care process. Such changes cannot be assumed to occur naturally, but require specific programs of preparation , coaching and support.

So that such services are tailored to the individual preferences, strengths and needs of the users, within the context of the least restrictive environment, the following objectives should be met :-

- a. new skills be acquired so that they enhance the ability to cope with normal social envi ronment.
- b. to engage in a wide range of ordinary activities to practice and consolidate skills that have been acquired.
- c. to engage in a full range of home making activities and household duties.

- d. join in as many community base activities as possible.
- e. use local facilities whenever possible.
- f. be involved in all decisions affecting their lives.
- g. modify disruptive behaviors that limit or deny access to ordinary activities.

The services should be offered in such a manner that are appropriate to the person's age and that they respect his dignity. To achieve this, individuals require opportunities for informed choice and autonomy over their own lives, which may involve taking defined risks.

One natural consequence of increased opportunities for ordinary living and for encouraging people with learning difficulty to make their own decisions, is that they will be exposed to the hazards of daily living.

Staff will also be placed in the potentially difficult situation of being involved in making decisions that will actively introduce an element of risk into the person's life. It is important that the staff feel confident that, providing they act in a professional and competent manner, their employer will support them, should incidents occur.

It is therefore crucial that risk – taking guidelines are prepared and agreed at the highest level of management, otherwise life planning is likely to be severely restricted in its scope.

These should include :-

- a. degree of risk prevention is better than cure, therefore predicting possible harm is the first step towards preventing it.
- b. monitoring it is wise to use past experience, but if this is not available, rather than not doing anything at all, one should test out the situation with careful monitoring.
- c. priority of objectives one must not weigh the degree of risk involved with the importance of the objective. The word caution is never to be forgotten.
- decision-making shared decision-making can never be emphasized enough. Once a decision is taken, everybody involved has the responsibility to implement it faithfully, until it is again reviewed.

It is towards these aims that the Learning Disabilities Training Unit ( L.D.T.U.) at Mount Carmel Hospital was opened more than a year ago, in May 1996. A lot of work and dedication has been put in this project during and before this period. especially by Occupational Therapist of the the Psychoaeducational Department. Infact the whole O.T. department helped and encouraged us in this venture. But I'm afraid we are lacking the support one expects from other agencies and government departments.

If we really want a better life for persons with a learning difficulty residing in MCH , all of us must support such initiatives. If these people are not given a chance to live an ordinary life in the community, we will be just wasting time and money.

It is the community (all of us) who years ago put these people in MCH, now it is the duty of the community to help in every way possible so that, with dignity not charity, they are helped to find their way back where they rightly belong.