

Feasibility Study: Services for persons with Disability  
National Commission Persons with disability

January 2000

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## Executive Summary

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Following a request from the National Commission People with Disability, the Management Efficiency Unit delivered a report in June 1999 regarding residential service for people with disability.

It was evident from that report that people with disability and their carers have no choice of support services, no formal assistance with forward planning and no adequate guardianship function after the carers' demise.

The report recommended various solutions to this problem. Following discussions with the client, it was agreed that the management Efficiency Unit would develop a feasibility study on a number of these recommendations.

In this report we are proposing the setting up of a Supported Living Fund and an Agency to manage such a fund. The Agency, while still being held accountable to Government, should have sufficient autonomy to provide people with disability and their families with a supported living package in the most efficient and effective way. The Agency should be administrated by a Board, which should also set the policies and directions of the Agency in consultation with the Minister for Social Policy.

Traditionally, Government has had a monopoly position in assessing users' needs, in financing the services and also, in the actual provision of these services. However, today there is a growing number of professionally trained people within the rank and file of people with disability who can formulate their own needs and translate them into design criteria and the management of such schemes. Therefore we are suggesting that people with disability should sit on the Board of the Agency.

The report suggests that the eligibility criteria for services to be provided by the Agency should not be based on medical categories but on functional impairment. The criteria should be based on both the needs of the disabled person and the respite level required by the family.

In addition we are also suggesting the setting up of a Guardianship and Administration mechanism to protect the civil rights of persons with a mental impairment. A draft Act for this purpose has been annexed to this report. It is further recommended that this should be achieved through a separate Act and not through prescriptive changes to the current Civil Code. In this regard we were greatly assisted by the legal firm Ganado and Associates. This legal firm has offered it's further assistance, if required.

One of the aims of the report as set out in the Project Brief was to study the possible merging of the Housing Authority's Scheme One with the handyman Service as provided by the Department for the Care of the Elderly. However, during the course of the report, talks had already started between these two Departments for the possible transfer of the Handyman Scheme from the Department for Care of the Elderly to the Authority. Therefore this proposal was not dwelt upon in depth in this report.

## **01. Purpose**

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In December 1998, the Management Efficiency Unit (MEU) delivered a report entitled 'Residential Services for Persons with Disability', to its client the National Commission Persons with Disability. In that report, MEU made several recommendations, the principles of which have been accepted by the Commission. In order to assess these recommendations in their proper context, MEU was requested to develop a detailed Feasibility Study.

The scope of this project is to set out in a clear, quantitative and qualitative manner, the financial, legal and managerial implications of implementing four of the key recommendations made in the Unit's previous report.

### **1.1 Terms of Reference**

As set in the Project Brief, the terms of reference established for this project are to provide the Commission with a recommended Implementation Plan for the following four proposals;

- Facilitating various inputs towards the establishment of a Guardianship Board;
- The design of a Group Homes consultancy function;
- The possible merging of Housing Authority's Scheme One with the Handyman service; and;
- Designing the organisation eligibility criteria services and cost of a Supported Living pilot project.

During the course of the reports, talks had already started between the Housing Authority and the Department for the Care of the Elderly for the possible transfer of the Handyman Scheme from the latter to the Authority. In view of such discussions, this issue is not dwelt upon in depth in this report, as it was felt unnecessary to hold consultations with these two parties in this regard.

### **1.2 Methodology**

In undertaking this assignment, the project team reviewed the legislation and considered what amendments are required. On this subject, the legal firm of *Ganado and Associates* assisted the team and Chapter Eight draw the news mainly on their submissions and submitted at **Appendix 01**. The team also considered the organisational set-up and staffing implications, conducted research for appropriate benchmarks of service delivery, considered the

impact on the target beneficiaries and in consultation with related players, outlined the project milestones for each recommendation in chronological sequence.

### **1.3 Acknowledgement**

In preparing this document we would like to acknowledge the help and co-operation we received from the legal firm of *Ganado and Associates* and Mr. Alfred Bezzina, Manager, National Commission Persons with Disability

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## 02. Background

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In June 1998 the Management Efficiency Unit was requested by the Permanent Secretaries of the then the Ministry for Social Welfare on behalf of the National Commission Persons with Disabilities to submit a report regarding residential services for persons with disabilities. The scope of the report was to examine international policy and practice concerning residential and support services for persons with disability, to examine the local situation, and to formulate recommendations. The recommendations were based upon a series of focus groups held in various localities; a number of case studies; and a very wide spectrum of interviews with professionals and service providers.

The main issues that emerged from these interviews and focus groups were that, at present, persons with disability and their carers have no choice of support service, no formal assistance with forward planning and no adequate guardianship function after the carers` demise. The need to address these three requirements appears to be fundamental if carers` preoccupation with the future of people with disability is to be adequately addressed.

The report examined three scenarios;

- The institutional paradigm;
- The development paradigm; and
- The support living paradigm.

The supported living framework is not only the most cost-effective scenario but it is also recommended by United Nations and European Union documentation. It widens individual choice, is closer to the way most people choose to live, and has been found time and again to be more cost-effective than services tied to homes. Costs tend to be less due to:

- fewer overheads than those incurred by residential care:
- the mobilisation of cheaper sources of labour, including family and friends and:
- the more flexible use of resources, training support workers to do tasks that might otherwise be carried out by specialists.

The report also recommended the establishment of Guardianship Board. This board would bypass the lengthy and undignified system prevailing in Maltese Courts. Apart from being more humane, the establishment of such a board would offer an individualised and rapid response service.

The recommendations in the report, which was submitted in December 1998, were endorsed by the Commission and, in a public conference held in July 1999, the Minister for Social Policy also endorsed the recommendations submitted in the report.



### **03 Proposed Supported Living Scheme for Persons with Disability**

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At present, Government is providing living support services to members of the public such as the Home Help (HH) Scheme by the Department for the Care of the Elderly. Although the application for the scheme states that it is intended to provide a service both to elderly people and to people with disability, the former are by far the major client group. In fact in 1998, of the 2678 people who made use of this service, 2567, or 95%, were over 60 years old. This Department is providing other schemes, for example, Handy Man Service and the Tele Care, which could be of benefit to people with disability, but similar to the HH are provided mainly to the elderly.

However, any scheme set up to assist people with disability should not be incorporated into the one for the elderly. The main reason is that the needs of an elderly person are often very different from those of a person with disability. Most elderly persons require basic domestic help and companionship while the assistance required by a disabled person is more of a personal nature such as assistance in washing and bathing, assistance in traveling to work and so on. Thus, HH staff may not be suitable for providing the assistance required by a person with disability. Over and above service differences, the issue of ownership of the HH scheme by the Department of the Elderly may serve to restrict access by disabled users. For these reasons, we are suggesting that the Government should set up a Supported Living scheme to assist people with disability.

### **04. Setting up an Supported Living Fund**

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Government may wish to consider establishing a Supported Living Fund to which people with disability or their carers could directly apply for assistance. For the rest of this report, any person applying for assistance, whether he or she is the person with disability or is the carer applying on behalf of the person with disability, shall be referred to as the client. The objective of the fund will be to aggregate money from different sources and to provide financial support for services that assist people with disability. One such source is the Social Security Non-Contributory Fund. The Supported Living Fund should continue for an indefinite period and may only be dissolved by a resolution of Parliament.

If one takes the Home Help Scheme as a benchmark for budgeting purposes, the scheme provided each person in 1998 an average between three and four hours of service per week for a total of 8161 hours weekly. 346 Casual Social Assistants (CSA) who are paid Lm1.58 per hour provide this service. Government also provides 84 cents subsidy to the CSA's weekly Social Security contribution. This means that the Government spent circa Lm 680, 000 to provide this service.

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## **05. Assistance to be provided**

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Government has to decide whether the Supported Living Fund is to be used either to;

- provide it's clients with financial assistance so they can purchase the services they require; or to
- deliver the service it's clients require.

If the first option is chosen, the management of the Supported Living Fund would carry out an assessment of the client's needs and on the basis of this assessment, would provide the client with the financial assistance necessary to purchase the services required.

Research evidence in the UK shows that direct payment have consistently been a cost effective mechanism for enabling disabled people to access high quality support. More important, the same research also indicated very clearly that people receiving direct or indirect payments have higher overall levels of satisfaction with their support arrangements than did those receiving service directly. This was particularly noticeable in relation to reliability and flexibility and the degree of confidence people had in their support arrangements being able to meet their needs.

The direct engagement of the Personal Assistant by the client approach also has the advantage of requiring less administrative effort since the management of the Fund would have only a passive role. It will not recruit any Personal Assistants, even on a definite contract, it will not provide any training and so on.

However, there may be cases were the clients are either insufficiently articulate or lack the necessary experience to clarify their needs and, and, as a consequence, they may be unable to seek the services they require, even if financially assisted. Therefore, with such an approach, there is the possibility that a number of clients, who are probably the most vulnerable and most in need of assistance, will remain without the service they require.

A middle way between these two options can be chosen and this is to provide all the flexibility to the clients of choosing, the service of their choice while providing all the assistance required to those clients who are unable or unwilling to seek such assistance.

### **5.1 Services to be provided**

If the supported living fund is to be utilised as a service provider, such as a service can be encompass a range of needs including personal hygiene, dressing, domestic chores, driving and, in a variety of situations, at home, work, play and in school. Breaking up these needs into several distinct programs for certain activities and certain situations can entail several funding

sources and separate service delivery systems each with its own eligibility requirements, administrative routines, and staff. As the number of different agencies involved increases, so does the time and energy spent by the client seeking assistance from different sources. Therefore, it is suggested that the Fund should strive to provide these needs as one package on a one-stop-shop basis.

Due to budget constraints it will be necessary to prioritise what type of assistance it is to provide. However, it is suggested that the service provided should not be reduced to a convenient domestic service that provides a minimum support to people with disability and leaves those mostly in need without any real change in their quality of life. But it should not keep back from providing basic services if the client requires them. Faulty plumbing will happen irrespective of whether there is a disabled person living in the house or not. However, a disabled person living on his or her own can find difficulties in carrying out tasks where other able-bodied people will not.

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- (1) The most detailed study carried out in the UK, for example, showed that support packages based on direct payments were, on average, 30 to 40 per cent cheaper than equivalent directly provided services. (Direct Payments Campaign in the UK – Presentation for the ENIL Seminar Stockholm, June 9-11, 1996)

It is suggested that people with disability living on their own should be provided with a package of assistance to enable them to participate in the community similar to non-disabled people and to exercise choice and control over the decisions affecting their own lives. Such a package will also provide parents with more peace of mind on how their children will cope when they cannot provide them with the assistance without any fear that their children will be institutionalised.

The following list is not exhaustive. There are other services that can be provided including professional services. As pointed out above, the extent of service provided will always depend on the budget Government makes available.

### **5.1.1 Personal Assistance**

Personal assistance can include

- Washing and bathing in bed or in bathroom;
- Grooming; attention to hair, nails, feet, skin, eyes, etc;
- Dealing with continence management;
- Assisting in maintaining a bowel and bladder routine;
- Assistance dressing and undressing;
- Serving and cutting of food as required;
- Assistance in and out of car;
- Upkeep and maintenance of equipment; i.e. wheelchairs, hoists and other technical aids; and
- Escorting to work, social meetings and events.

### **5.1.2 Domestic Help**

If a disabled person lives alone, he / she should qualify for a number of hours of domestic help per week. If two disabled persons live together, the number of hours can be increased but not necessarily doubled.

For reasons already explained above, it is recommended that such scheme will be kept separate from the one being provided at present by the Department for the Care of the Elderly.

### **5.1.3 Emergency Call Systems**

Another development intended to decrease the need for institutions consists of installing devices in the user's home through which assistance can be summoned. People with disability often express their fear of an unforeseen emergency, which would leave them helpless and unable to call for assistance. This insecurity is a reason why many older persons who do not have actual functional disabilities move to institutions.

There are various devices and solutions that can be grouped into so-called active and passive systems. One active system, for example, is the Tele Care service being provided at present by the Department for the Care of the

Elderly. An example of passive systems might be one where periodic phone calls are made to the clients to check whether they are well.

#### **5.1.4 Handyman Service**

It is suggested that Government should also make available a similar service to the Handyman Service, at present being provided to the Elderly. Discussions between the Housing Authority and the Department for Care of The Elderly are currently underway for the possible transfer of this scheme from the latter to the former. Therefore, this proposal was not dwelt upon in depth in this report. However, we would like to make the following observations:

1. Similar to the personal and domestic service, this scheme should be based on a means test.
2. Again it is suggested that this scheme should not be incorporated in the service being provided by the Department for the Elderly.

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3. Although setting up a separate scheme would entail a certain amount of duplication of work, for reasons pointed out above including the advantages of a one- stop. It is more desirable if a scheme for people with disability is set up.
4. It is recommended that service for such a scheme should be contracted out whereby private contractors will bind themselves to provide a number of services within a response time at a fixed rate. There can be different rates depending on the response time. Thus, there could be one rate if service is provided within a time limit and a higher rate if service is required in a shorter time.

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## **06. Personal Assistants**

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If Government decides that the Supported Living Fund is to be the service provider and will deliver the personal and domestic assistance outlined above, the client will need to employ a Personal Assistant.

The fund can assist the client in engaging such assistant. Language reveals and influences attitudes.

Terms such as “attendant” and “care” should be avoided, as they carry institutional connotations and project the image of passivity and dependence. “Personal Assistant” (PA) is suggested here, because this expression is believed to contribute to an image of consumers as self-directed, independent people who are capable of managing their own lives.

### **6.1 Right of Client to engage Personal Assistants**

Having to depend on strangers can be humiliating, as the personal assistance constitutes a close social relationship and consists of very personal and intimate activities. Therefore it is suggested that once a level of services has been approved, the client should have the widest possible flexibility in determining how such services are to be delivered, and who will deliver them as long as the financial assistance provided to that client remains the same <sup>(2)</sup>.

It should be recognised that there may be cases where the clients may be unable to seek a PA even if financially assisted. In such cases, if the clients are not provided with assistance, there is the possibility that they will remain without the services they require. The Fund must work to ensure that assistance is available to people who are less than fully articulate and have little experience with engaging employees. In such a situation, a client should be assisted in engaging a PA.

To this end, we suggest that the management of the Fund should issue a call for ‘expressions of interest’ from people who are willing to provide services as Personal Assistants and a database for those willing to provide such services should be kept. If a client is unable or unwilling to seek a PA, he or she can decide either to have a PA chosen for them by the Fund or to have a list of potential PA’s forwarded to them by the Fund and they will interview and choose the person they want.

### **6.2 Contractual Relationship between Client and Personal Assistant**

The provision of personal assistance should not rely on volunteers. People with disabilities do not have the same possibilities of demanding competent, punctual, and courteous work from volunteers as they do from paid Assistants. On the other hand, we suggest that PA’s should not be employed on indefinite contract, as it is often very hard to terminate the service of incompetent employees when they are employed on an indefinite contract.

The client group for these services is often very vulnerable and safeguarding the client's interest and the use of public funds should take priority above other considerations.

We suggest that the relationship between the person with disability and the PA should be a Contract for the Supply of Services similar to that of the Casual Social Assistants engaged by the Department for the Care for the Elderly. Such contract, which is of a definite duration, will define details such as duration of contract, number of hours to be provided, what services are expected, payment terms etc. The PA will have the status of self-employed and they will pay Social Security Contributions and will be entitled to sick leave benefits accordingly.

The client should have the facility to engage different persons in order to be flexible enough to allow for the PA's need for free time, vacations, sick leave, and other emergencies. Having more than one PA will also help to decrease dependence on the person providing these important services.

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(2) About fourteen per cent of all assistants in Sweden are relatives employed to work for spouses, parents or children who have disabilities. (Source: Independent Living and Attendant Care in Sweden author: Adolf D. Ratzka, Ph.D.)

### **Option 1**

If the client decides to take full responsibility for the contractual arrangements, the payment process can be as follows:

- The PA will forward an invoice for services rendered to the family;
- The client will pay as agreed in the Contract for the Supply of Service;
- The PA forwards fiscal receipt to the person with disability or that person's family;
- At the end of each month, the family will forward the fiscal receipts submitted by the PA to the Agency; and
- The Agency will reimburse the family within the limits of the service approved.

### **Option 2**

Alternatively, reimbursement by the Agency can be made up-front as follows:

- The Agency forwards to the family the amount approved before service is provided;
- The PA will forward an invoice for services rendered to the family;
- From the amount forwarded to the family, the family pays the PA as agreed in the Contract for the Supply of Service;
- The PA forwards the fiscal receipt; and
- At the end of each month, the family will forward the fiscal receipts submitted by the PA to the Agency for verification.

The fact that the client is required to forward the PA's fiscal receipt will serve a safeguard against any risk that the money is put to different use. The second option involves extra administrative work for the administrators of the Fund but it can be more beneficial to clients with low income. The paper work that is required on behalf of the client for both processes is very minimal.

### **Option 3**

The client can decide to leave the contractual arrangements in the hands of the administrators of the Fund. In this case the PA will be paid directly through the Fund.

### **6.3 Training of Personal Assistants**

Except for the Handyman Service where one requires skilled tradesmen to provide such service, individuals who are not highly specialised can provide the services outlined in Section 05. Also, more importance should be given to the clients expertise in managing people than to the worker professionalism. Clients who want to improve the quality of the service and consequently the quality of their lives have to be encouraged to take more initiative and work with their PA's as a team where they instruct and direct. Therefore, a PA needs not to be a highly qualified person.

However, there is still scope in providing training to PA's. For example, if the PA is already trained in assisting a client with certain services such as bathing or basic physiotherapy exercises, the PA can provide such services to the client much more quickly than one who would need to be taught everything by the client. Also, personal assistance requires a motivation that not every person possesses. A person may be willing to provide personal assistance to a person with disability but hands-on practice may reveal that such tasks could be too daunting for him / her. Also, there is the possibility that some people may see such work as a possibility of earning easy money.

For the above reasons, all prospective PA's should be provided with a course of a few weeks duration regarding essential skills on how to carry out their functions. It is recommended that a person should require a license to work as a PA. Such license should be issued by the Fund and subject to certain conditions.

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These conditions can include successful completion of the PA course, satisfaction of service delivery by the client and so on. The Fund should continue to monitor the service provided by the PA. If the PA does not adhere to any of the conditions regulating the license, the Fund can retrieve the license, either temporarily or permanently, depending on the severity of the case.

### **6.4 Personal Assistants' Remuneration**

There are individuals who are prepared to carry out domestic work but who are not inclined to provide personal assistance. On the other hand, there are people who will be prepared to provide only personal assistance while others will be prepared to provide both personal and domestic assistance.

For the above reasons it is suggested that to be in a better position to provide the above services, the Fund should provide two services:

- Domestic assistance; and
- Personal assistance.

As pointed out above, the service provided should not be reduced to an easily delivered and convenient domestic service. It is much more desirable for the Fund to provide personal assistance only than to let the service be reduced to solely a domestic one.

It is recommended that remuneration should reflect these different services. In the case of domestic service, compensation could be similar to the rate payable to the casual Social Assistants for the Home Help Scheme provided to the elderly. However, personal assistance is of a different, more intimate nature and warrants higher compensation.

Thus, payment terms per hour can be as follows;

Domestic Assistance	Lm 1.75
Personal Assistance	Lm 2.50

If a client is entitled, for example, to 10 hours of personal assistance and to four hours of domestic help and a personal assistant is ready to provide both services, he or she will be paid 10 hours at Lm 2.50 and four at Lm 1.75.

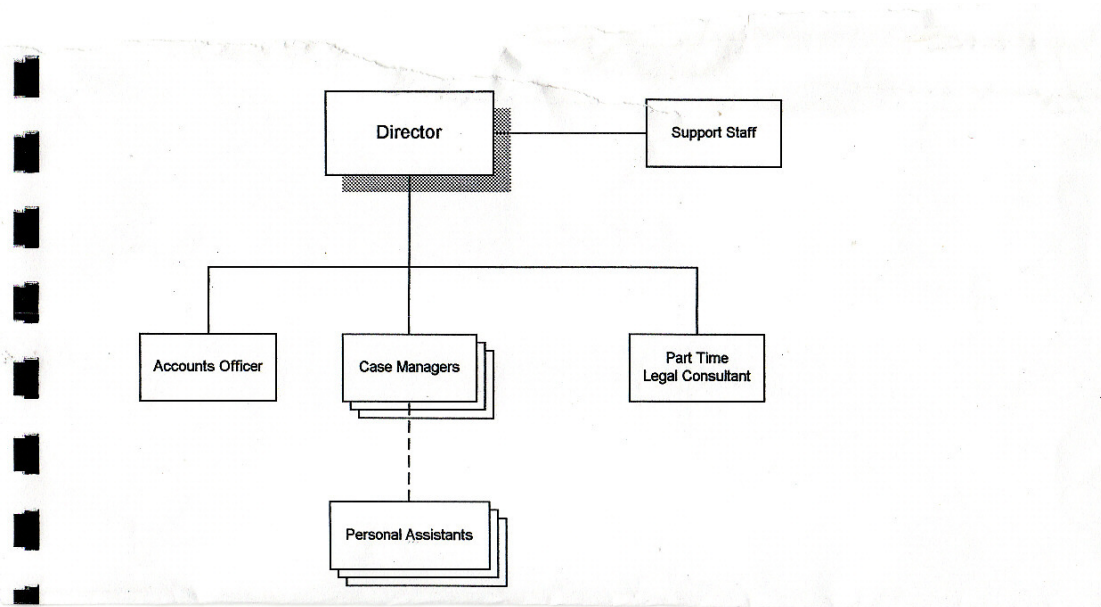
## 07. Organisation / Human Resources

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For the Supported Living Fund to be able to deliver the above services, an administrative set-up needs to be established. The human resources required for such a set-up will include a Director, an Accounting Officer, Case Managers, a Legal Consultant and support staff. The number of both the Case Managers and the support staff will depend on the extent of the services provided and the demand for these services. However, for the first period of it's operations it is not envisaged that there will be required more than a Director, one Accounting Officer, two Case Managers, one Accounts Clerk and one support staff person.

### 7.1 Proposed Organisation Structure

The structure below outlines the proposed organisation structure for the administrative set-up for the Supported Living Fund.



### Director

A Director should be appointed to manage these schemes and his / her duties will include:

- Managing the service in accordance with established policies and directions;
- Drawing up a strategic marketing plan;
- Ascertaining that the optimum level of service is delivered in the most cost-effective manner;

- Liaising with the client to ensure client satisfaction in the implementation of the service provided, including follow-up and resolution of any complaint;
- Managing human resources issues including matters related to the staff attendance, grievances discipline; and
- Providing advice and assistance to the Board.

One of the main purposes of the strategic plan should be to ensure that the services provided are not overwhelmed by demand. Therefore, the Director must make sure that the Fund targets the right market for its services. The market would be defined by the factors such as the extent of services provided, the financial budget of the Fund and so on.

## **7.2 Legal and Accounting Officers**

The Accounting Officer will be responsible for the Fund's financial aim. He or she will provide advice on financial management matters for the Director to achieve better and more effective results and economy in the Fund's operations. Other responsibilities will include preparing and regularly updating the Fund's budget, ensuring that effective systems exist for safeguarding public money and property and for the collection and bringing to account all receipts arising from the Fund's operations.

The management of the fund is expected to be active in curbing abuse with regard to the services it provides. To this end, it is suggested that a lawyer be engaged so that effective legal action against such abuses can be taken in court. It is not envisaged that such service will require a full time position.

## **7.3 Case Managers**

Case Managers must be able to assess clients' needs according to a set criteria (via section 8.2 Eligibility Criteria), recommend the appropriate level of assistance, and, monitor the service provided.

They must also be able to provide the client with information, procedural guidance and support. To the end, Case Managers should preferably be qualified Social Workers with a number of years of experience.

The Case Managers should provide their clients with consultancy service to enable them obtain the maximum benefit from the assistance provided by the Supported Living Fund. For example, a client can decide to carry out interviews to choose a Personal Assistant. However, interviews can be a daunting experience. In such cases the Case Managers can assist the client to prepare for the interview. The Case Manager can be present during the interview to assist with questions and can provide a second opinion if the client is unsure about whom to employ.

Another area where counselling can be provided is in the client / PA relationship. Such a relationship is a very complex one. In most cases, it is a one-to-one relationship and, on occasion, it can become very intense and personal. So one needs to consider the vulnerability of both parties. In order to guard against any upsets which might occur, 'professional' boundaries need to be established. If both parties know exactly what their responsibilities are, there is less likely to be a problem. Clear guidelines will help to eliminate such problems. The case manager can assist the client in drawing such guidelines.

The case manager must be prepared to assist clients in legal and management problems. For example, a number of parents will need to know what are the legal requirements for establishing and running a group home.

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To this end, we recommend that the case managers should set standards of best practice, advice on the service development, and, make available to their clients, procedural booklets that would, for example, explain how to set up such a group home.

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## **08. Management Issues**

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### **8.1 Principles of Quality**

The following are principles of Quality that should assist the management of the Supported Living Fund in providing a quality service to the clients:

- People need to have information about the availability of programmes and the requirements for entry. They also need to know where and how they can obtain access to the services. These schemes should be publicised and efforts should be made to ensure that they are presented in a manner that is understood by the public;
- The response to requests for delivery of service needs to be done in a timely manner. For many people, there are few other options available, and each day of delay can have significant repercussions;
- Once enrolled in a programme, another requirement is that they receive fair and equal treatment in regard to the services being delivered;
- The people eligible for supported living services are usually people with chronic disabling conditions that are likely to have a lifetime impact. The scheme should be continued as long as the need for those services exists. Arbitrary time limits that might result in a disruption of services should be avoided;
- If there is a client's share of costs for any services, it should be a reasonable cost. The majority of people with disabilities live on severely limited income. Sometimes any co-payment can have severe negative repercussions on such a budget. If there are co-payments required for services, they should be on a sliding scale in consideration of income availability and the cumulative impact of all such fees on the individual;
- In most cases, the person most likely to understand the needs of a person with a disability is that person. If a level of service is approved, the individual should be able to determine how the services will be delivered, and who will deliver them;
- Categorical definitions of disability or age should be replaced or supplemented by functional need as a prime factor used for qualification for personal assistance. Any future restructuring in existing schemes should be accomplished in a manner, which results in improved service delivery; and
- Policy development processes should include continual feedback from clients and providers of services to determine program effectiveness. Review processes should include an evaluation of the administrative aspect of the Fund, as well as a thorough evaluation of the quality and quantity of services being delivered for the amount invested in the program.

### **8.2 Eligibility Criteria**

Any person with disability should be eligible for personal assistance. When the disabled person is under 18 years of age, the responsibility for applying to

the Fund will belong to the parents or the head of household. When the person is over 18 years of age, unless prevented by disability, it should be the responsibility of that person to apply.

The amount of assistance to be provided should depend on the needs of the person with disability and his / her family <sup>(3)</sup>. To this end, as pointed out above, a Case Manager should assess each application.

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(3) If one was to take the Sweden as a model, the average number of hours per person of personal assistance provided is 3.3 per week with wide variations, from two hours every other week up to several hours a day. Yet more than 30 to 40 hours a week are rare. (Source: Independent Living and Attendant care in Sweden author: Adolf D. Ratzka, PhD.).

In certain cases, there will be the need for medical expertise to appraise correctly the level of disability of a client. For example, a Case Manager can find it difficult to assess the severity of a disability due to a back injury. However, as a role, it is suggested that eligibility should not be based on medical categories but on functional impairment. It should be based on both:

- The needs of the disabled person: and
- The respite level required by the family

The level of respite will depend on factors such as whether the disabled person attends school, work, training centres and so on whether that person has to spend most or all of his / her time at home. Also, the type of disability and the pressure this puts on the other members of the family must be reflected in the estimation of respite needs.

### **8.3 Help Desk**

It is suggested that a customer care desk should be set up. All reports from the clients including reports of lack service, requests for information, etc, could be referred to this desk. It would be the responsibility of this desk to follow up these reports including informing the person making the reports of the action being taken.

Whether there is a need to a full-time customer care person depends on the volume of reports received.

### **8.4 Right of Appeal**

There should also be an appeals mechanism for clients who are not satisfied with the level of assistance recommended by the Case Manager. If the person applying for personal assistance does not agree with the assessment of the Case Manager, he or she should have the right to appeal for a second assessment. A different person with the necessary expertise should be appointed from outside the organisation managing the Supported Living Fund to carry out such assessment. On the basis of these two reports, a final decision should be made.

### **8.5 People with Disability over 60 Years of Age**

According to the National Commission Persons with Disability database, circa 40% of people with disability are over 60 years old It is suggested that if a person with disability within the age group requires assistance similar to the schemes provided by the Department for the Care of the Elderly, he or she should be encouraged to apply for assistance under that Department's schemes.

### **8.6 Informing the Public**

People need to have information about the availability of the services and the requirements for entry. They also need to know where and how they can

obtain access to the services. The Fund's management should publicise these services, and ensure that they are presented in a manner that is understood by the public.

Additionally, an effort should be made to extend the outreach through support groups and other agencies, as well as at conferences through a toll -free telephone number, information officers, via the Internet, and so on. However, a degree of prudence is required in the scheme's initial stages, in order that a potentially overwhelming demand does not hinder the programme's establishment and consolidation.

### **8.7 Client Feedback**

Processes should be developed that would include continual feedback from clients and providers of services to determine program effectiveness. Review processes should include an evaluation of the administrative aspect of the Fund, as well as a thorough evaluation of the quality and quantity of services being delivered for the amount invested in the program.

When the person with disability receiving the service is capable of providing feedback on the service provided, regular feedback should be pursued directly from that person. In cases where the person

with disability is unable to choose a PA and the PA is chosen by the carer, there is the possibility that such an approach will be abused. When there is doubt about the ability of the person to provide reliable feedback, regular physical visits should be carried out to make sure of the adequacy of the service being provided.

## 8.8 Means Testing

Due to public finance constraints, eligibility for the fund's services should be means-tested on a sliding scale in consideration of income availability. Many local agencies complain that abuses with regards to declaration of income are rampant. Therefore, if the service provided is to be means-tested, a system of controls to minimise abuse needs to be developed. The management of the Fund should have the executive power to actively prevent the abuse of its schemes, including instigating legal action. Application Forms should request client authorisation to make enquiries to the Department of Social Security with regards to the family's income.

The means test can be calculated in a manner similar to that for other benefits provided by the Department of Social Security. By this method, the subsidy on personal assistance is calculated according to the percentage difference between a fixed maximum and minimum ceiling i.e. social wage, and the family's income.

Thus, assuming a ceiling of Lm 10, 000 and a threshold of Lm2, 700 and a family income of Lm 3,000, the subsidy will be calculated as follows;

Step	Calculation
Step One	10,000 less 2,700 = 7,300
Step Two	3,000 less 2,700 = 300
Step Three	Assuming 7,300 as 100, calculate 300 as a % of 7,300 = 4.1

Thus a family with an annual income of Lm 3,000 will have to pay 4.1 of the cost of personal assistance provided by the Agency. The difference i.e. 95.9% will be a subsidy provided by the Agency.

If the family income totals Lm9, 500, the subsidy will be as follows;

Step	Calculation
Step One	10,000 less 2,700 = 7,300
Step Two	9,500 less 2,700 = 6,800
Step Three	Assuming 7,300 as 100, calculate 6,800 as a % of 7,300 = 93.2

Thus, a family with an annual income of Lm 9.500 will have to pay 93.2% of the cost of personal assistance provided by the Fund. The Fund will provide a subsidy of 6.8%.

Clients who earn Lm 2700, or less will enjoy a 100% subsidy while those who earn Lm 10,000 or more will not benefit from any subsidy.

In those cases where there is more than one person with disability living in the same family, it is suggested that the ceiling will be set at a higher level. Thus, if there are two persons with disability living in the same household, the ceiling can be raised to Lm12500 while in cases of three persons or more, the ceiling will-be Lm15, 000. We are not suggesting that, in such cases, the ceiling should be doubled as, in most cases, the assistance required would be duplicated, as for example, domestic help.

Thus a family with an annual income of Lm 9,500 and two persons with disability, the subsidy will be calculated as follows:

Step	Calculation
Step 1	12,500 less 2,700 = 9,800
Step 2	9,500 less 2,700 =6,800
Step 3	Assuming 9,500 as 100, calculate 6,800 as % of 9,800 = 69

Thus, a family with an annual income of Lm 9,500 and two persons with disability will have to pay 69% of the cost of personal assistants provided by the Fund: the subsidy will total 31%

### **8.8.1 People with disability beginning full-time Employment**

When Persons with disability consider joining the workforce, they should not have to risk the loss of supported living assistance due to their increased income. We suggest that in such cases an exception should be made and people with disability should be offered work incentives by providing them with partial benefits during a transition period of 1 year while they are beginning full-time employment.

To this end we suggest that for a person with disability starting a full-time employment, for the first year, only half of the total earned income should be considered for means test purposes.

## **09 Service Delivery**

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Government can decide to manage the Supported Living Fund either through:

- A Government Department, or
- An Agency with a legal personality separate from that of a Government Department.

### **9.1 Within a Government Department**

The first option is more in line with common practice within the public sector. By tradition Government has had a monopoly position in assessing users' needs, in financing the services, and also, in the actual provision of these services. This option will give the Department full control on what and how the service is to be provided.

If a Government Department is to manage the Supported living Fund, the client, i.e. persons with disability and their carers will have no direct say in the policy-making decisions. The Department can consult with the clients' associations and their representatives but it will be Department who will have the final say in the management of the Supported Living Fund. However, the Department may not have the necessary expertise in the disability field. This can seriously limits the effectiveness of the service provided.

If the first option is chosen, it will be the Department of Social Security to deliver these services. In such a scenario, certain posts as defined in Section 06 – Human Resources, including the post of Director, can be filled with public Officers in the general service. The Accounting Section of the Department can serve as the financial arm of these services. This has the advantage also of providing an accounting and audit mechanism already in place. The Department's personnel can also carry out the function of support staff. However certain posts, mainly those for Case Managers, will have to be filled from outside the public sector.

### **9.2 Within an Agency**

There are a number of valid reasons why an Agency, operating outside the public sector, and not a Government Department should manage the Supported Living Fund. For example, Government Departments are more exposed to pressure from external interest groups. This could seriously curb the trust of the clients in the impartiality of the service provided.

A Government's Department hiring process is highly bureaucratic and, thus, it is difficult to respond quickly to staffing needs. We foresee the establishment of an Agency that would have the right to enter into agreements and contracts and have more ability than a Government Department in hiring and retaining professional people required in providing a specialised service.

#### **9.2.1 Management Board**

If Government opts to set up such an Agency, a management Board to administer the Fund has to be established. We propose that the Board should be composed of five members. It will be the responsibility of the Board to administer the Supported living Fund in accordance with the policies and direction established by Government.

As appointed out above, traditionally, it was up to the Government to assess users' needs and to finance and deliver these services. However, today there are a growing number of professionally trained people within the rank and file of people with disability who can formulate their needs and translate them in design criteria and the management of such schemes.

Therefore, we are recommending that the Commission will nominate a number of persons with disability to sit on the Board from which Government can choose two to ensure relevant and appropriate standards of service.

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In addition to these two, Government should appoint the remaining three members of whom one will be the Chairperson. One of these two members could be the Director of Social Security or his representative to ensure that the schemes cohere with the financing of the social programmes. The other member could be the Chief Government Medical Officer or his representative to link with the Ministry of Health's Community Care policy. The Minister of Social Policy should appoint the Chairperson for a period of one year, renewable, following consultation with the National Commission Persons with Disability.

The success of service provided will be directly related to the competence of the people appointed to manage it. Therefore, it is imperative that both Government and the Commission identify suitable people to sit on this Board. By reason of the active involvement required of them, the Board members should not be on a voluntary basis but should be entitled to payment. Payments to individual sitting on such boards are regulated by the Government.

### **9.2.2 Setting up of a Foundation**

If Government opts to manage the Supported Living Fund through an Agency, it can regulate such agency through a Government Department. The advantage of this option is that there is no need to establish new organisations for such purpose. However at present the Department of Social Security is not a regulator. It only provides financial assistance to its clients. If Government continues to adhere to the policy, it can regulate the Agency through a Foundation.

At present, although there is no comprehensive legal framework for their regulation, a number of foundations already exist. One such foundation is the

Foundation for Social Welfare Services (FSWS). It is presided over by the Permanent Secretary in the Ministry of Social Policy and an interdisciplinary Board of 8 members from various Departments of Government. The Statute of the FSWS allows for and regulates the provision of social welfare services. At present, it regulates services provided by Sedqa and the Social Welfare Disability Programme, including the auditing of the services provided by these agencies. Both these agencies are administered through a separate Board.

If Government decides to regulate the Supported Living Fund through the FSWS, this falls within the scope of this Foundation. Therefore, Government already has in place a Foundation that can regulate and audit the Fund. Also, the FSWS's interdisciplinary Board provides the Foundation with a pool of highly valid expertise. However, the Foundation Board members are on a voluntary basis, meeting every 4 to 6 weeks. As a consequence, their effectiveness on Board is limited.

If Government decides to set up a new Foundation, it has to appoint a new Board to manage it. In view of the limited number of persons with the necessary expertise in the disability field, it could be difficult to find suitable persons to sit in its Board. A new deed and statute also has to be drafted.

The experience gained from the operations of the FSWS can assist in drafting a more effective Deed and Statute for the new Foundation.

Instead of setting up a new Foundation, Government can opt to amend the Deed and Statute of the FSWS to make it more effective.

## **10. Guardianship Board**

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### **10.1 Background**

Subsequent to its report of June 1999, the Management Efficiency Unit was requested by the client, the National Commission for Persons with Disability, to further explore the concept of a Guardianship and Administration Board. Such Boards, that have become increasingly prevalent in a number of countries, tend to offer a more private and personalised service than do typical courts of Justice. The scope of these boards is to 'protect' persons whose mental faculties are severely impaired, by appointing a guardian to assist such persons to take decisions, or take decisions on their behalf.

The appointment of a guardian presumes the interdiction of the protected person, whereby a number of the protected person's civil rights are suspended. The advantage of a Board – at arm's length from the justice system yet still answerable to it in cases of appeal – is that such interdictions are reviewable with greater speed and personalised attention than the mainstream courts usually allow for. Thus, interdictions may be partial and

temporary as the case may require, and the Board may be itself composed of the necessary social and medical expertise that allows for decisions more relevant to cases in particular.

As noted in the first report, the need for such a Board in Malta was raised by a number of parents and carers. To this end, further consultations were held with the client, with the Second Hall of the Law Courts and with a legal firm that volunteered its assistance. The client agrees in principle to the establishment of such a Board, and would welcome the broader social perspective that the Board would allow for. Preliminary consultations with Justice J.D. Camilleri of the Second Hall also indicated that the current provisions regarding interdiction in the civil code. Sections 520 to 527 inclusive, are out-to-date in respect of terminology resourcing and procedure.

As regards terminology, Section 520 (1) (Chapter 12 of the Laws of Malta), instructs that ‘A demand for the interdiction or incapacitation of persons who are habitual idiots, insane, frenzied or prodigal, is made by an application to the Civil Court Second Hall’ [Act 520(1)]. These provisions are also applicable, by way of Section 190, to any person “congenitally deaf-mute or blind”, where in such cases, no further proof is required that such persons are incapable of managing their affairs. The issue here is far greater than political correctness; such ‘categories’ of persons do not reflect the diagnostic advances in medical and social expertise and do little to assist the Courts in their assessment of the need for interdiction.

With respect to resourcing, this latter situation is currently requiring the Court to fulfill multiple roles in such assessments, or to rely upon the testimony of external medical expertise without the means to evaluate the reasonableness of such testimony. It seems reasonable to imagine that there may be occasions where legal and therapeutic imperatives clash, making decisions very difficult to Court concerned.

Concerning procedure, current legal provisions do not seem to allow for sufficient flexibility in the issuing and monitoring of curatorship orders as would seem warranted by possible changes in circumstances of protected persons. The significant workload in the Second Hall does not allow for as wide a collection of case-related information nor for as personalised a following of each case as seems to be necessary, thereby ensuring that the best interest of the protected person are upheld at all times. Neither does the workload allow for a periodic review of the progress made by the protected person and his or her curator, nor for tailored amendments to interdiction orders to reflect changing circumstances.

In a possible response to these issues, a particular legal firm with personal and professional experience of such a Board in another country has kindly volunteered a draft Act providing for the establishment of a Board, attached as **Appendix A**. There are one or two points in this draft that we believe require more clarification. For example, in our opinion, the difference between a guardian and administrator should be better defined. Also since the **Guardianship Board** is to deal with medical procedures, should the CGMO

sit on it? However, the draft provides a very valid basis for the setting up of such a Board. A summary of it's scope and functions is given here under.

## 10.2 Scope and Functions

As may be noted in Section 1 of the Act, the purpose of the Act is to “enable persons with a disability to have a guardian or administrator appointed when they need a guardian or administrator”. The Act provides for the establishment of a Guardianship and Administration Board, made up of a President appointed by the Minister responsible for Social Policy; an Executive Officer; and other members as may be necessary for the Board to meet its responsibilities.

Any person may apply to the Board for a plenary or limited guardianship to be issued over a person with a disability who is over 18. The Act empowers the Board to regulate its own procedure in the collection of information, within the bounds of natural justice. A hearing is then held, and the Board is required to notify the protected person him or herself and all other interested parties at least seven days before the hearing. After the hearing, and only if it considers such a measure to be in the person’s best interest, the Board may decide to appoint a plenary or limited guardian, unless the person’s needs could be met by other means less restrictive of his or her freedom of decision and action.

Plenary guardianship confers on the guardian all the powers and duties that he or she would have were he the actual parent of the protected person. This includes residential arrangements, occupation and health care, although the Board may restrict such conferred powers as it sees fit. In limited guardianship, the Board specifies exactly those powers which it confers upon the guardian, and may again, make the order subject to any conditions or restrictions as it considers necessary.

Guardians are bound to act in the best interests of the represented person, taking his or her wishes into account as far as is possible. Guardians are to encourage such persons to participate as much as possible in the life of the community; to become capable of caring for oneself and of taking one’s own decisions. They are also obliged to protect such persons from neglect, abuse and exploitation. Guardians are not liable at law for any reasonable decisions that they take. However, if in doubt, they may apply for the advice of the Board in any particular instance.

The Act allows for temporary order for up to 21 days, before which the Board must hold a new hearing to determine whether a permanent order should be issued.

Permanent orders are nevertheless, periodically reviewable.

The Act also empowers the Board to intervene in cases where an oath has been taken to indicate that a person with a disability is being somehow ill-treated. In such cases, a member of the Board, accompanied by a police officer, may visit the person concerned and prepare a report for the Board, which in turn may order the police to take the person to a place of safety until arrangements are made.

Lastly, the Act requires that approval for major medical procedures on protected persons be acquired from the Board by guardians, before such procedures are carried out. In addition to the guardian, consultation in such instances is also held with the person concerned. Attorney General and any other person that the Board wishes to consult

## 11. Recommendations

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It is recommended that:

### Legislation

- Legislation for the setting up a guardianship Board independent of the law courts should be approved and enacted.

### Operational

- The Ministry of Social Policy sets up a Supported Living Fund and provides the necessary funds;
- In consultation with Government, the Fund sets the direction and policies it intends to implement;
- The fund carries out the recruitment of human resources:
- The Director of the Fund will submit a strategic marketing plan to implement the policies of the Agency;
- Case managers will be trained in relevant skills and knowledge;
- Procedural booklets will be prepared for the information of the clients;
- A call for expression of interest will be issued for Personal Assistants on a Contract of Services basis;
- A training course for Personal Assistants will be set up;
- Fund will issue a license to individuals to work as Personal Assistants;
- A marketing campaign to promote Fund's services will be launched;
- The Fund will monitor customer satisfaction;
- The Fund will monitor against abuse;
- Introduce new policies or charges to existing policies;
- The government can opt to manage the Supported Living Fund through either:
  - a Government Department; or
  - an Agency with a legal personality separate from Government Department.
- If an Agency is set up:
  - a deed and statute for the Agency have to be drafted;

- it can be regulated either through a Government Department or through a Foundation; and
- appointments to the Board to manage the Agency are carried out by Government in consultation with the National Commission Persons with Disability.