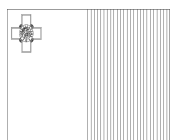




## Policy on Independent Supported Living for Disabled Persons in Malta

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2011

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### **Independent Supported Living: the right to choose**

“When I say independence, I mean the right to choose.” This is how one of the disabled participants in this study described the effect that independent supported living had upon individual quality of life.

The idea of disabled people benefiting from independent supported living in mainstream communities has been around for some decades now --- in principle if not quite in practice. The idea itself has stemmed directly from disabled people’s organisations and it ran directly counter to the economic/ political solution of ‘warehousing’, that is, the gathering together of large numbers of disabled people who have high support needs into big institutions usually segregated by gender and far removed from mainstream society.

Maltese Law, more specifically Act I of 2000 the Equal Opportunities (Persons with Disability) Act (EOA) has declared it unlawful to treat a disabled person ‘less favourably’ than one would anyone who does not have a disability. The prohibition applies generally to every aspect of one’s life. All-encompassing as this legislation is, it sometimes remains necessary for particular situations to be individually highlighted. This is exactly what the United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol of 2006 have set out to achieve. Several articles in the UNCRPD enshrine the right to independence and choice.

For example, Article 5 ensures equality before the law. Article 18 guarantees liberty of movement and the freedom to choose one’s residence on an equal basis with others and Article 19, especially, ``emphasises disabled people’s right:

- to choose their place of residence ... where and with whom they live on an equal basis with others and [that they should] not [be] obliged to live in a particular living arrangement;
- to have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- [to have access to]: ... community services and facilities for the general population [and ensure that they] are available on an equal basis to persons with disabilities and are responsive to their needs.

This Policy on Independent Supported Living for Disabled Persons in Malta, commissioned by the Kummissjoni Nazzjonali Persuni b'Diżabilità (KNPD) takes as its point of departure the principles enshrined in both the EOA and UNCRPD. Furthermore, it recognises the fact that disabled people vary enormously both in terms of individuality, in the nature and severity of their impairments, their functionality and their support needs. The policy states quite clearly that 'no one model that can be applied across the board' which is why nowhere in document will one find a 'one size fits all' approach.

In fact, the policy puts forward a number of recommendations all of which aim to take a holistic approach to the present situation. These include, but are not restricted to, the need for ongoing research, to the suggestion of private-public partnerships, the possible adoption of a universal policy to a disability pension entitlement, the need for *ad hoc* legislation focusing on the independent supported living, a reform of the disability pension framework, a transparent and open eligibility process. The policy also tries to identify and put forward for consideration models of good practice which have been recommended by disabled persons themselves.

The publication of this policy is very timely considering the fact that Maltese and Gozitan disabled people and their families have long been expressing their grave concern over what will happen when the family support networks many disabled people are gone. The spectre of institutionalisation and the loss of individuality and personal autonomy are very real to a large number of disabled people. The need for us all to take immediate, positive action has reached near-emergency proportions.

This policy will not, and does not pretend to be, a 'quick fix' answer, because of course there isn't one. However, it is the first comprehensive, factual attempt at properly identifying the problem and offering decision-makers a variety of possible options. We augur that disabled people, their families and advocates will use this document to help them lobby for change. Also, we augur that decision-makers will find it a useful tool to help them develop and implement strategies which will swiftly and effectively address the real needs of local disabled people living in today's realities.

Joseph M. Camilleri  
Chairman, Kummissjoni Nazzjonali Persuni b'Diżabilità

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## **Executive Summary**

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Although since 2000 the Government embarked on a systematic process to establish building blocks upon which an independent supported living policy framework can be built, this report concludes that to date there is an absence of a cohesive and universal policy for independent supported living for disabled persons towards which the primary stakeholders – that is the Government, Non Government Organisations, the parents and families, and, more importantly, the disabled persons themselves - are working towards to. There is also an absence of data relating to all aspects of the disability sector – data without which good policy design is difficult to attain.

Indeed, the absence of such a cohesive and universal independent living policy framework is, perhaps, best attested by parents of disabled persons who fear what the future holds for their children as they become frailer or pass away.

Through Aġenzija Sapport, the Government in the 2000s adopted an aggressive process to establish independent supported living placements for disabled persons. The focus of Aġenzija Sapport was, primarily to set up state run independent supported living home placements as well as in partnering with church foundations in this regard. There is now a need for a reform of the enabling framework to facilitate, support and simulate supported independent living for disabled persons.

There is also a need for reforms to the Social Security Act, the Income Tax Act, or to the handling of Capital Tax Gains of income generated by private trusts established by parents for their disabled children and other policy measures directed to encourage individual parents to finance through their savings the placement of their disabled children in an independent supported living environment.

Indeed, the Schedule V of the Social Security Act continues to penalise a disabled person who has means beyond the limited thresholds set – means which the disabled person could be receiving through a private trust.

In short, there was no policy-driven change directed to support families to invest in the well being of their disabled children by setting up independent supported living environments for them; and in doing so removing the quasi total dependence that the fulfilment of such an

aspiration is solely dependent on a placement, within the Government's small stock of independent supported living placements, becoming available.

The phrase *quasi total dependence* is carefully chosen. As this report shows an independent supported living environment with a basic level of care – 2 hours of individual personal assisted support – is estimated to cost annually €17,854 whilst one with an intensive level of care – 12 hours of individual personal assisted support – is estimated to cost annually €44,910. This report concludes that, even at the most basic level of care, private financing of an independent supported living placement for a disabled person, under current legislative conditions and constraints, is beyond the reach of most families.

Therefore, for a total financial budget of €4,097,000 between 2002 and 2006, the Agency invested in 44<sup>1</sup> independent supported living placements. This compares strongly with the investment in 16 independent supported living home placements since 2007, where the total financial budget for the Agency - excluding a constant expenditure base of €3,469,000 for Day Services – stood at €12,080,000.

Thus, the Agency between 2002 and 2006 opened a residential independent supported living placement for every €93,114 of the budget allocated to it when compared to an independent supported living placement for every €755,000 of the budget allocated to it excluding the Day Care financial estimates) since 2007.

The report presents the following recommendations with regards to the building of a robust and sustained cohesive and universal policy framework for independent supported living for disabled persons.

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<sup>1</sup> Includes residential placements at Dar Arka and Dar Pirotta



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### **Policy Recommendation 01**

The report finds the absence of data in the disability sector a serious lacuna and emphasises that there can be no good policy design in the absence of such data and thus recommends that the Kummissjoni Nazzjonali Persuni B'Dizabilità to agree with the National Statistics Office the introduction of a robust and structured statistical methodology.

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### **Policy Recommendation 02**

The report recommends that the Kummissjoni Nazzjonali Persuni B'Dizabilità submits, under the appropriate financing EU and local instruments for the financing of a comprehensive and statistically significant survey across a series of important policy issues relevant to universal disability policy design targeting, as a minimum, a statistical snapshot that will, amongst others, allow for a drawing up of a comprehensive picture of the capacity, depth, strengths and resources that can be mustered in order for stakeholders to participate actively and sustainably in supporting the implementation of an ISL policy framework.

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### **Policy Recommendation 03**

The report recommends that Government should in a concrete manner its commitment towards Article 19 of the United Nations Convention of the Rights of Persons with Disabilities, by ratifying this Convention at the earliest possible.

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### **Policy Recommendation 04**

The report favours a policy strategy for an Independent Supported Living policy framework that is separated and independent from aging and care for the elderly until at least, such time that appropriate State investment would have been directed towards securing a critical mass resulting in a sustainable environment for persons with disabilities which are not acquired through aging.

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### **Policy Recommendation 05**

The report recommends that an Independent Supported Living policy framework should be directed as a priority towards persons with an impairment that originates at birth as well as persons who acquire an

impairment that is not the result of aging.

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### **Policy Recommendation 06**

The report recommends that all mainstream and specialist policies are scrutinised on the basis of inclusivity, effectiveness, and informedness by the Office of the Prime Minister to ensure cohesion towards a holistic universal Independent Supported Living policy design.

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### **Policy Recommendation 07**

The report recommends the Kummissjoni Nazzjonali Persuni B'Dizabilità lobbies the responsible Minister to legislate for Independent Supported Living by means of introducing an ad hoc legislation; with the legislative provisions to include, amongst others (i) definition of entitled persons; (ii) articulation of rights with regards to Independent Supported Living; (iii) rules with regards to access to State and/or Local Government Independent Supported Living homes; (iv) policy co-ordination to facilitate Independent Supported Living; (v) individual income and delegated budgets; (vi) Independent Living Homes; (vii) Independent Living Fund; and (viii) Disabled Persons/s Private Trusts.

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### **Policy Recommendation 08**

The report recommends that the entitled support for a disabled person living in an Independent Supported Environment should embrace, amongst others: (i) personal assisted services; (ii) assistive technology support; (iii) property adaptation to meet impairment-related needs; and (iv) 24\*7 monitoring and emergency and uncommon support, where necessary.

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### **Policy Recommendation 09**

The report recommends that, within the parameters of the definition proposed in Recommendation 04.3, eligibility to Independent Supported Living services should be solely on the basis of a person's needs and regardless of his or her cause of medical diagnosis; and that a disabled person once qualified would continue to live in such an environment irrespective of aging or degeneration of their condition, subject, however, that living independently is feasible and / or does not actually become a threat to the well being of the said individual.

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### **Policy Recommendation 10**

Whilst the report is of the considered opinion that a person's eligibility for Independent Support services should not be subject to a means test of their income or capital to qualify for a disability pension, it recommends that an economic and social impact assessment is carried out to determine whether a universal policy to a disability pension entitlement is actually more cost effective to Government over the life cycle of a disabled person given that as this allows respective families to channel private investment and savings to secure an improved quality of life to the disabled child.

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### **Policy Recommendation 11**

The report supports a reform of the disability pension framework that reflects the degree of functionality lost and is decoupled from income earned subject that, however, the value of the disability pension income assigned to lost functionality is sufficiently adequate to allow a disabled person to live in an independent supported living environment.

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### **Policy Recommendation 12**

This report recognises that in a state of play where funding for the financing of an Independent Supported Living policy framework will never be sufficient to secure an equilibrium between the demand for and the supply of services leading to the rationing of a disabled patient's right to such services, it is imperative the process leading to eligibility is (i) transparent and open; (ii) based on a clear methodology that allows for a fair and true identification of risk and prioritisation; (iii) documented with appropriate audit trails; and (iv) subject to a fair review.

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### **Policy Recommendation 13**

The report recommends that when a disabled person cannot avail themselves of Independent Supported Living services, they are to be placed on a waiting list and that their ranking on the said waiting list will be based on a fair and open assessment methodology which includes risk and priority amongst its criterion.

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### **Policy Recommendation 14**

The report concludes that there is no one particular Independent

Supported Living housing model that can be applied across the board and, therefore, recommends a model that this is based on a mix of different types of accommodations designed on a universal best practice design but specifically tailored to account for the support needs of the persons who will be accommodated in such premises.

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### **Policy Recommendation 15**

This report recommends that the strategy that Agenzija Sapport adopts with regards to providing appropriate homes for Independent Supported Living should be very flexible and that, in the absence of excess building stock owned by the Housing Authority that could be made available for Independent Supported Living housing, the core of such a strategy should be directed to leverage the rental market.

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### **Policy Recommendation 16**

This report recommends that Agenzija Sapport in determining the appropriate balance, mix, size and number of residents of an Independent Supported Living home environment should take into account the optimisation of the right accommodation mix with regards to the cost of operations which will allow for a greater level of housing stock to be made available – thereby ensuring that a higher cohort of disabled persons are afforded the opportunity to live in an Independent Supported Living environment.

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### **Policy Recommendation 17**

This report recommends that Agenzija Sapport continues to supply Independent Supported Living housing to disabled persons who, without such support, would not be able to make the transition from a family home and/or institution to an Independent Supported Living environment.

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### **Policy Recommendation 18**

This report recommends that a disabled person once approved as a qualified applicant for Independent Support Living by the Independent Living Allocation Committee should have access to a personal budget should he or she so desire which shall provide for the following rights: (i) to choose a member of their family or a friend to act a Personal Service Assistant; (ii) to request assistance support in managing a payment; (iii)

to request Agenzija Sapport to make arrangements for support; (iv) to identify the person with whom they wish to live with; (v) to identify the location and building within which they wishes to inhabit.

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### **Policy Recommendation 19**

This report recommends rights of a disabled person under a personal budget mechanism are qualified as including, but not limited to, the accreditation of Personal Services Assistants, the certification of property that will be leased, the assessment of persons who will be living in the residency to ensure compatibility.

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### **Policy Recommendation 20**

This report recommends that Agenzija Sapport should provide appropriate assistance and support to disabled persons selecting a personal budget mechanism to an Independent Supported Living home environment to ensure that their choices and aspirations are met.

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### **Policy Recommendation 21**

This report recommends that the introduction of a policy of a personal budget to a disabled person for access to an Independent Supported Living home environment to complement the service provided by Agenzija Sapport should be launched in 2012 initially as a two year pilot that targets different levels of care and different disabilities who will opt for a personal budget mechanism over a different types of home mix; which pilot should be translated into an operational service once lessons learnt are assessed and incorporated.

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### **Policy Recommendation 22**

This report recommends that a ring-fenced Independent Supported Living Fund is created under independent governance, under annual external scrutiny by the National Audit Office, and access by Agenzija Sapport to income within the Fund should be on the basis of a business and financial plan.

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### **Policy Recommendation 23**

This report recommends that the main source of income to the Independent Supported Living Fund should be the Government as the

guarantor and custodian of social inclusion and that existing Independent Support Living financing is to be complemented by €13,146,920 between 2012-2021 as follows

- Two year investment in the pilot - €606,000.
- Operations of ISL homes / services previously under the pilot assessment framework - €2,678,916
- Launching of ISL Policy framework following pilot calibration and continued operations - €2,574,891
- Annual increase of the ISL community and continued operations - €7,287,113.

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### **Policy Recommendation 24**

This report recommends that the Social Security Act is amended so that a disabled person, irrespective of whether he or she is living in an Independent Supported Living home or otherwise, draws the full maximum disability pension entitlement irrespective of the value of the income earned or received.

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### **Policy Recommendation 25**

This report recommends that a disabled person living in an Independent Supported Living home provided by Aġenzija Sapport is to:

- pay 60% of their disability pension to the Independent Supported Living Fund to contribute to expenses related to food, water and electricity, transport, et al.
- pay 25% of income earned or received to the Independent Supported Living Fund to contribute to expenses related to food, water and electricity, transport, et al.

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### **Policy Recommendation 26**

This report recommends that a disabled person who opts for the personal budget mechanism as an access to an Independent Supported Living home will pay 45% of their disability pension to the Independent Supported Living Fund to contribute for expenses that Aġenzija Sapport

will incur with regards to specific services directed to support this mechanism.

### **Policy Recommendation 27**

This report recommends that it is evident that Government financing alone will not suffice to secure the right to Independent Supported Living to all disabled persons and to overcome any 'divides' in this regard the Government should encourage private financing, either as private benefactors or as corporate social responsibility measures to the Independent Supported Living Fund through the introduction of the following incentives:

- One-off tax deduction of up to a maximum of €100,000 income bestowed to the Independent Supported Living Fund by an individual during his or her lifetime.
- Exemption from the payment of succession taxation of up to maximum of €200,000 income bestowed to the Independent Supported Living Fund by an individual on his or her death.
- One off tax deduction of up to a maximum of €250,000 bestowed to the Independent Supported Living Fund by a corporation or legal entity.

### **Policy Recommendation 28**

This report concludes that the average annual cost of average annual cost of €29,476 (modelled on four different tiers of Independent Supported Living care) or for the matter the annual estimate cost of €14,632.8 as estimated by an NGO Foundation for a disabled person to be integrated in an Independent Supported Living home is an insurmountable figure for all but the very wealthy in Malta's society and the seeking of financing through the Good Causes Fund for such an assuredly good and worthy cause is complex and unwieldy an individual basis. It, therefore, recommends that the Good Cause Fund legislation is amended so that 10% of the annual revenue within the Fund is directed towards the Independent Supported Living Fund.

### **Policy Recommendation 29**

This report recommends that the competent authorities, in discussion

with KNPD and other interested parties, should introduce an appropriate framework that provides special favourable conditions with regards to the income generated by the Trust given that the purpose of such a Trust is clearly not to achieve tax avoidance or other indirect benefits but rather to secure an improved quality of life for a disabled person by rendering it possible for parents and families to be in a position to achieve this.



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## Glossary

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EOA	Equal Opportunities Act
ETC	Employment and Training Corporation
HBS	Household Budgetary Survey
IEP	Individual Educational Programme
ISL	Independent Supported Living
KNPD	Kummissjoni Nazzjonali Persuni B'Dizabilità
NGO	Non Government Organisations
NSO	National Statistics Office
SSA	Social Security Act

## **01. Introduction**

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### **01.1 Terms of Reference**

The Terms of Reference established in the Tender issued by the Kummissjoni Nazzjonali Persuni B'Dizabilità (KNPD) were the following:

- The extent to which current models of service provision provide supported living.
- Identification of different types of supported living services that can be provided for disabled people in Malta, including provision of services in disabled people's own homes, provision of services in residential settings shared by disabled people, provision of services in residential settings managed by governmental, non-governmental, Church or private organisations.
- Identification of the various types of personnel needed to provide supported living services, and their training needs.
- Consideration of the provision of interim services such as emergency homes and longer-term respite.
- Estimate of costs involved for the provision of each different type of supported living service being proposed and identification of possible sources of funding.

### **01.2 The Methodology Applied in the Preparation of the Report**

In preparing this report, the following methodology was applied:

01. A review of statistics and data relating to the policy issue under review.
02. A review of literature relating to the policy issue under review.
03. The holding of meetings to discuss the policy issues with appropriate stakeholders.

The Consultation process was launched on the 3<sup>rd</sup> December 2010, the International Day of Disabled People. Discussions then took place with support service providers, including state, non-

governmental and Church-run organisations, disabled persons and their family members. Appendix A presents a list of persons and entities consulted.

Another consultation session was held on April 2011 with representatives of disabled people's organisations as well as other other organisations working in the disability sector.

A Consultation Session with key government stakeholders and follow up meetings were held following the publication of the draft version of the policy report published by KNPD in August 2011.

The draft report was also made available on the KNPD website and feedback was invited through the website, articles in KNPD's magazine *Indaqs*, as well as a press release.

04. The carrying out of field visits to view existing different models of independent supported living present in the community.
05. The preparation and submission of the following two preliminary papers:
  - (i) Identifying Roles, Responsibilities and Skills required to staff a Supported Independent Living Unit.
  - (ii) Independent Supported Living in Europe: Select Case Studies.

### **01.3 Acknowledgements**

All persons that assisted through the provision of information, discussion of issues and the presentation of views in the preparation of this report are thanked.

## 02. Defining Independent Supported Living

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Over the past 15 years there have been significant changes in how people perceive disability and in the provision of adult social care – with the changes stemming from the growing permeation that it is society rather than the impairment itself that prevents persons from participating in everyday activities and in reducing their opportunities.<sup>2</sup>

There is a need, therefore, to define exactly what Independent Supported Living (ISL) means. Many definitions of ‘independent living’ exist within the research, policy and literature in the disability and ‘elderly’ sectors.

Article 19 of the UN Convention on the Rights of Persons with Disabilities<sup>3</sup>, titled ‘Living independently and being included in the community’ states that State parties to the Convention:

“...recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.”

To achieve this States are to ensure that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.<sup>4</sup>

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<sup>2</sup> Oliver M. Understanding Disability: From Theory to Practice, 2<sup>nd</sup> Edition, 1995

<sup>3</sup> Pg 1, Nason, E., Rabinovich, L., Ling, T., and Villalba van Dijk, L., Supporting Independent Living for Disabled People, RAND Europe, [http://www.rand.org/content/dam/rand/pubs/technical\\_reports/2006/RAND\\_TR388.pdf](http://www.rand.org/content/dam/rand/pubs/technical_reports/2006/RAND_TR388.pdf)

<sup>4</sup> <http://www.un.org/disabilities/default.asp?id=279>

Independent living under this definition means that disabled people are able to decide where and how they live, with access to a range of services (including personal assistance) to support their life in the community. Independent living does *not* mean that disabled people must do things for themselves, or live on their own. This is, indeed, not the case for anyone in society.

Independent living is about being free to make choices and to have control over one's own life. In terms of disability, independent living as defined by Article 19 is, therefore, about the principle of equal status: that is, that a disabled person has the same opportunities as the rest of society, and that this can be facilitated through additional support or technology.<sup>5</sup>

Achieving the equal right established in Article 19 requires a policy framework that is directed to bridge the disparity gap between an individual's ability to function and the constraints imposed by the surrounding environment which would otherwise limit a disabled person's ability to live in a community environment.

Thus, an ISL policy framework requires a universal policy design that ensures that all elements that constitute an incongruity or gap in all of the combinations of the different dynamics of what constitutes independent living are eliminated. Thus, if ISL is to mean the same equal opportunity for a disabled person as for a non-disabled person to live independently, then all the components have to be seen as part of a chain and addressed as such.

The report presents the following as core principles that should underpin an ISL policy framework:

(a) Disabled Persons have a Home of Their Own

This entails that disabled persons:

- (i) are able to live in a home that they own, lease or rent like other members of the community;
- (ii) choose where they may live and they decide what happens in their home;

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<sup>5</sup> Pg 3, Nason, E., Rabinovich, L., Ling, T., and Villalba van Dijk, L., Supporting Independent Living for Disabled People, RAND Europe, [http://www.rand.org/content/dam/rand/pubs/technical\\_reports/2006/RAND\\_TR388.pdf](http://www.rand.org/content/dam/rand/pubs/technical_reports/2006/RAND_TR388.pdf)

(iii) are secure in their own home and do not have to move if their needs, their services or their supported assistance requirements change overtime;

(iv) are safe in their home and neighbourhood.

(b) Disabled Persons have the Ability of Choice and Self-Direction

This entails that disabled persons are:

(i) able to make their own choices;

(ii) able plan for their future;

(iii) able to direct the services they receive;

(iv) supported on the basis of a personal plan to live independently.

(c) Disabled Persons have the Ability to Enrich their Social Network and Relationships

This entails that disabled persons are encouraged to fully participate in:

(i) community and social life in a way that this reflects their personal choices and preferences;

(ii) clubs, organisations, religious and other civic and or social groups.

An ISL policy framework directed to deliver on these principles will only, however, be successful if policy design in the following sectors is calibrated to support it:

(a) Education

Lack of education with regards to a disabled person is not necessarily an impediment to living independently. Nevertheless, the higher the level of education the higher is the possibility for a disabled person to live independently given that higher education is a gateway to employment and income – which in turn allow for a greater degree of independence. Additionally, ICT skills – which require a reasonable knowledge of English – is an increasingly important tool for disabled persons as a



gateway to employment, purchasing of goods including foodstuff, social networking, et al<sup>6</sup>.

#### (b) Employment and Income

Independent living requires a household budget that is constituted of both fixed and variable costs. Thus an 'adequate' level of independent living cannot be achieved unless there is a reasonable source of income – whether this is the result of paid earnings; private support; or disability pension income.

Employment, therefore, increases a person's financial independence and renders independent living more achievable.

#### (c) Accessible Transport

Independent living requires mobility – to travel to work; to make daily purchases; to socialise with friends; etc. A public transportation system that provides access to disabled people promotes the 'independence' of such persons to travel at will and reduces dependence on either a dedicated transport service which may have a fixed schedule or expensive hiring of taxis.

The introduction of the new buses as from 4<sup>th</sup> July 2011 equipped to allow disabled persons on wheel chairs to avail themselves of transport services has, as openly expressed by disabled persons themselves, resulted in a 'revolution' in their respective daily living.

Be that as it may, a public transportation system that provides access to disabled persons but wherein such access cannot be availed of because, for example, access to the bus stop is obstructed by street furniture is a clear example of the importance of universal planning with regards to independent living.

#### (d) Accessible Housing

Independent living requires access to housing – housing that is specifically designed to bridge the gap between the disability of the person or persons and the use and functionality of furniture and fittings. The purchase of a house and its subsequent disability-tailored furnishing

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<sup>6</sup> The provision of on-line networking and e-commerce should not remove the requirement of mobility given that the need for socialisation is very important due to the propensity of isolation of a disabled person

and fittings is an expensive investment – out of reach, potentially, to most Non Government Organisations (NGOs) let alone parents.

Whilst the reforms in the rent law may render the identification of property at reasonable rents more feasible, the cost of furnishing such a property with the proper fittings still constitutes a considerable expense.

(e) Accessibility to Community Health Care Support Services

The provision of community care support services – such as occupational therapists or nurses – are critical to an ISL framework as such health care service support provides community access to disabled persons with regards to nursing support facilitation or home adaptation counselling that cannot be provided by personal assistants and without which the incidence of institutionalisation would most likely increase.

(f) Supported Living

An ISL policy framework is designed to bridge the gaps between the limitations imposed by a person's impairment and an individually tailored support plan required to allow a person to live independently. Whether such support is through the provision of sheltered housing, personal support to assist the person with regards to activities of daily living, or intelligently designed homes with ambient assisted technologies, unless policy design is harmonised through joined up policy making there will always be obstacles and challenges to overcome to achieve a seamless and universal ISL.

The objective of an ISL policy framework should be that of mobilising all society, and primarily Government, as the custodian of the State, to secure that the right to ISL is truly available to all. This means that the equilibrium between the supply of universal ISL components across the policy chain is equal to demand for ISL at any point in time.

Experience shows, however, that such equilibrium may not be readily achievable despite best intentions, particularly in the early phases of policy mobilisation and implementation.

**Figure 01: Components of an Universal Independent Supported Living Policy**



The Equal Opportunities Act (EOA) provides a framework that protects a disabled person against discrimination and establishes governance in six areas. These are: Employment (Title 1); Education; (Title 2); and Access (Title 3); Provision of Goods, Facilities or Services (Title 4); Accommodation (Title 5) and Exemptions which covers amongst others Positive Discrimination (Article 15) and Insurance Coverage (Article 16) (Title 6).

Although the EOA implies that a person should have a right to ISL given that it provides for the core policy components discussed above it does not specifically legislate with regards to ISL. The EOA does not define what constitutes ISL, what measures and services should be made available for a person, who is assessed to require support, what are the duties of the responsible agency, etc.

Furthermore, it is pertinent to underline that Malta has yet to ratify the aforementioned the United Nations Convention on the Rights of Persons with Disabilities, including of course Article 19. The discussion on the appropriate governance for an ISL policy framework (whether this is achieved through the enactment of an ad hoc legislation on ISL that recognises ISL as a specific and important principle of the rights and status of disabled persons or whether some form of other legislative or non-legislative framework is selected) should be informed by this Article in order to ensure the full implementation of the UN Convention by the Government.

It is pertinent to underline that specific countries have or sought to introduce legislative instruments. The legislation of the United States of America (US), and Sweden is explored together with a Disabled Pension (Independent Living) Bill which did not make it beyond the first reading in the House of Commons in the United Kingdom (UK). These countries are selected for comparative assessment as they are recognised to be amongst three of the world's leading countries with regards to policy design and implementation in the disability sectors.

The US, for example, has legislated under Title VII of the Rehabilitation Act with regards to Independent Living Services and Centres for Independent Living<sup>7</sup>. The purpose of the act is stated as:

“...promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximise the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society, by-

- (1) providing financial assistance to States for providing, expanding, and improving the provision of independent living services;
- (2) providing financial assistance to develop and support State wide networks of centres for independent living; and

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<sup>7</sup> The Rehabilitation Act defines a Centre for Independent Living to mean “a consumer-controlled, community-based, cross-disability, non-residential private non-profit agency that (a) is designed and operated within a local community by individuals with disabilities; and (b) provides an array of independent living services.

- (3) providing financial assistance to States for improving working relationships among State independent living rehabilitation service programs, centres for independent living, State wide Independent Living Councils established under section 705, State vocational rehabilitation programs receiving assistance under title I, State programs of supported employment services receiving assistance under part B of title VI, client assistance programs receiving assistance under section 112, programs funded under other titles of this Act, programs funded under other Federal law, and programs funded through non-Federal sources.”<sup>8</sup>

In the UK a Disabled Persons (Independent Living), Bill was presented for a First reading at the House of Commons on 4<sup>th</sup> March 2008.<sup>9</sup> It is pertinent to underline that the Bill has since then not progressed beyond the 1<sup>st</sup> Reading. Be that as it may it is believed that a review of the Bill is still relevant as it portrays the legislators intentions. The Bill establishes a statutory obligation for the “appropriate authority [to] prepare and implement a national independent living strategy with a view to ensuring the effective and sustainable implementation” where:

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<sup>8</sup> Sec 701, Title VII, Independent Living Services and Centres for Independent Living, <http://www.access-board.gov/enforcement/rehab-act-text/title7.htm>

<sup>9</sup> <http://services.parliament.uk/bills/2007.2008/disabledpersonsindependentlivinghl.htm>

- “(2) The strategy shall include the following:
- (a) a national economic plan which:
    - (i) sets out the costs and benefits of implementation, and commits to the provision of such transitional or other funding as may be required, and
    - (ii) ensures that, as far as possible, consequential savings from any provision of this Act are utilised and re-invested in such a way as to support the effective implementation of other provisions of this Act;
  - (b) a national resource allocation framework to facilitate local implementation of individual budgets;
  - (c) a national workforce development plan that reviews the skills and numbers of skilled workers that are required to deliver effective, personalised support and associated support services to disabled persons and sets out measures to be taken to develop a suitably skilled and sufficient workforce;
  - (d) a national support services development plan that sets out the gaps in the current provision of practical assistance and support in relation to independent living and associate support services and measures to address these gaps; and
  - (e) any other measures which appear necessary to the achievement of independent living for disabled persons.”<sup>10</sup>

The Bill defines independent living very broadly:

“disabled persons enjoying the same choice, freedom, dignity, control and substantive opportunities as persons who are not disabled at home, at work and as members of the community in order to improve outcomes for disabled persons in relation to—

- (a) their individual autonomy;

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<sup>10</sup> Disabled Persons (Independent Living) Bill [HL], <http://www.publications.parliament.uk/pa/ld200506/ldbills/122/2006122.pdf>

- (b) their confidence and security;
- (c) respect for and full enjoyment of their rights to privacy and family life;
- (d) their participation in education, life-long learning, training and recreation;
- (e) the contribution made by them to society, including their participation in voluntary work and employment;
- (f) their social and economic well-being;
- (g) their participation in community and public life; and
- (h) their physical and mental health and emotional well-being.”<sup>11</sup>

Furthermore, the Bill in Part 14 places an obligation on the responsible authority to make arrangements with regards to the provision of resources for practical assistance and support and any associated services following an assessment of the disabled person.

Once again the Bill seeks a very broad scope with regards to the resources and arrangements that are to be provided:

- “(a) practical assistance and support for that person including, but not limited to:
  - (i) the provision of communication aids and equipment;
  - (ii) the provision of other forms of assistive equipment and technology for daily living;
  - (iii) the provision of one-to-one support for communication, access to information and mobility;
  - (iv) the provision of independent advocacy as required;
  - (v) the provision of practical assistance in the home (including assistance with personal care routines and help around the home);
  - (vi) daily living skills and social skills training;
  - (vii) assistance with shopping, food preparation and meals;
  - (viii) assistance to take advantage of educational facilities and opportunities;
  - (ix) assistance to participate in family life and in relation to persons who have parental responsibility for a child, and assistance and support in caring for and bringing up that child;
  - (x) assistance to develop and maintain social networks and relationships;

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<sup>11</sup> Ibid

- (xi) assistance to participate in job search, employment, training, work experience and volunteering;
- (xii) assistance to participate in inclusive play, recreational, sporting, religious or cultural activities;
- (xiii) facilities for, or assistance in, travelling to and from the home for the purpose of participating in any services or activities provided under arrangements made under this section or otherwise connected to independent living;
- (xiv) the provision of assistance with works for adaptation in the home and assistance in maintaining adaptations;
- (xv) the provision of suitable residential accommodation;
- (xvi) support related to housing provision;
- (xvii) the provision of holidays and short-term breaks;
- (xviii) the provision of, or assistance in obtaining, consumer communications apparatus and services such as a mobile or fixed line telephone, a computer, a digital television receiver, a digital radio receiver, a broadband service or digital television service and any assistive equipment required in connection with this;

(b) associated support services including, but not limited to:

- (i) the provision of mobility training, low vision training and equipment,
- (ii) the provision of talking therapies, community services for the alleviation of mental health problems, including crisis services,
- (iii) the provision of occupational therapy,
- (iv) the provision of physiotherapy,
- (v) the provision of speech and language therapy,
- (vi) the provision of orthotic, prosthetic and wheelchair services,
- (vii) continuing health care,
- (viii) the provision of specialist community palliative care services, or any other matter which would enable the disabled person to enjoy independent living, then it shall be the specific duty of those authorities to allocate the necessary resources to support the disabled person and otherwise to make necessary arrangements.<sup>12</sup>

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<sup>12</sup> Ibid



Another example of an Act directed to ISL is the Swedish Act concerning 'Support and Service for Persons with Certain Functional Impairments'. The Act establishes the provision of measures for special support and special service for those "who are:

- (i) mentally retarded, are autistic or have a condition resembling autism;
- (ii) who have a considerable and permanent, intellectual functional impairment after brain damage when an adult, the impairment being caused by external force or a physical illness;
- (iii) who have some other lasting physical or mental functional impairments which are manifestly not due to normal aging, if these impairments are major ones and cause considerable difficulties in daily life and, consequently, an extensive need for support and service.<sup>13</sup>

The Act defines the following as measures for special support and special service:

- “ 1. advice and other personal support that requires special knowledge about problems and conditions governing the life of a person with major and permanent functional impairments,
- 2. help from a personal assistant or financial support for reasonable costs for such help to the extent that the need for financial support is not covered by assistance benefit pursuant to the Assistance Benefit Act (1993:389),
- 3. escort service,
- 4. help from a personal contact,
- 5. relief service in the home,
- 6. short stay away from the home,
- 7. short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays,
- 8. arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home,

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<sup>13</sup> <http://www.independentliving.org/docs3/englss.html>

9. residential arrangements with special service for adults or some other specially adapted residential arrangements for adults,
10. daily activities for people of a working age who have no gainful employment nor are doing training.”<sup>14</sup>

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<sup>14</sup> Act concerning Support and Service for Persons with Certain Functional Impairments, Sweden,  
<http://www.independentliving.org/docs3/englss.html>

### 03. Issues with regards to the Design of an Independent Supported Living Policy Framework

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#### 03.1 Profile of Disabled Persons

The table below shows the official number of disabled persons in Malta as per the Census of 2005. The Census provides a far more comprehensive picture in this regard than the KNPD Register as the latter represents only those disabled persons who formally and voluntarily register with KNPD.

When the Census was taken, on 27<sup>th</sup> November 2005, the population stood at 404,962. Of these 23,848 were identified as disabled persons – or 5.89% of the population.

As can be seen in the Table below the population split between males and females disabled people is particularly equal.

**Table 01: Number of Persons with Disability by Gender as per Census 2005<sup>15</sup>**

Gender	Disabled		Non-Disabled		Total	
	No.	%	No.	%	No.	%
Males	11845	49.7	188974	49.6	200819	49.60
Females	12003	50.3	192140	50.4	204143	50.40
Total	23848	100	381114	100	404962	100

The Census leads to the following observations:

(a) Disabled and Non-disabled People<sup>16</sup>

In most, if not all, aspects of life, disabled people are more disadvantaged than non-disabled people. The main findings are:

- Disabled persons have a lower level of education, are less likely to continue studying and are 4 times more likely to be illiterate than non-disabled persons.

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<sup>15</sup> Pg 5, Census, Chapter 1, The Quarterly of Life of Disabled People in Malta: Some Answers from the Census 2005, KNPD, 2009; [www.knpd.org](http://www.knpd.org)

<sup>16</sup> Ibid

- Disabled persons are nearly 3 times less likely to be employed than non-disabled persons and if employed nearly twice more likely to be in elementary employment.
- Disabled persons are nearly 12 times more likely than non-disabled persons to be institutionalised, more likely to live in a dwelling that is not in a good state of repair and are less likely to have non-essential household goods.
- Disabled persons are less likely to have a computer and access to the Internet,
- Disabled persons are less likely to participate in sport.

(b) Disabled Men and Women<sup>17</sup>

Certain groups of disabled people are also at greater risk of disadvantage and discrimination. For example, when disabled men and women are compared with each other, it emerges that disabled women are more disadvantaged than disabled men in many areas.

The main findings are:

- The percentage of disabled women, compared to disabled men increases with age.
- Disabled men are more likely to be married; however there are nearly 4 times more widows than widowers.
- Disabled women are more likely to have finished their education at primary level than disabled men.
- There are more disabled women than disabled men with no qualifications.
- Disabled men are 3 times more likely than disabled women to be employed while disabled women are 34 more times than disabled men likely to take care of the household or the family.
- Disabled women are nearly twice more likely to live in an institution than disabled men. If they are not living in an institution, they are

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<sup>17</sup> Ibid

more likely to live in a dwelling that is not in a good state of repair when compared to disabled men.

- Disabled men are more likely than disabled women to have a computer and access to the Internet.

### (c) Disabled Persons by Type of Impairment<sup>18</sup>

There are many similarities between persons with different impairments. There are, however, also some noticeable differences. The main findings are:

- Nearly one third of disabled persons have a physical impairment.
- There is a decrease of persons with intellectual impairment or with a mental health condition in the older age groups.
- Persons with an intellectual impairment are more likely to be single.
- Persons with an intellectual impairment have a greater tendency to attend special schools. Of those who have attended mainstream schools, there is a tendency for them to have attended up to primary level only.
- Persons with an intellectual impairment are more likely to have no qualifications and are twice more likely to be illiterate when compared to persons with other impairments.
- Persons with a visual impairment are the ones with the lowest tendency to have attended a special school and the least to be illiterate when compared to persons with other impairments.
- Persons with an intellectual impairment and mental health condition are less likely to be employed. If they are employed they are more likely to be in elementary employment, especially people with an intellectual impairment.
- Persons with a visual impairment tend to be more employed than persons with other impairments.

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<sup>18</sup> Ibid

- People with more than one impairment are the most likely to live in an institution and the ones whose dwellings are in most of repairs.

Thus it can be seen that people with intellectual impairment are at most risk of being disadvantaged in all aspects of life. Persons with mental health issues are also more disadvantaged in the employment sector when compared to those with other impairments. In statistics related to dwellings, people with more than one impairment come out as the most disadvantaged.

When percentages of different groups are compared it is immediately evident that there are significant increases in the percentage of disabled persons in older age cohorts. For example the 14.54% of non disabled population is aged 40 – 49 compared to 11.60% of disabled persons. In contrast the next age group, 50 – 59, 14.51% are non disabled and 19.10% disabled people. As is discussed later in this Chapter, it is evident that there is a strong correlation between the incidence of disabilities and aging: that is, disabilities that are acquired during a person’s lifetime as against being present at birth.

**Table 02: Percentage of Disabled and Non-Disabled People by Age<sup>19</sup>**

Age Group	Disabled		Non-Disabled		Total	
	No.	%	No.	%	No.	%
0.9	710	3.0	41876	11.0	42586	10.5
10 – 19	1109	4.7	54525	14.3	56634	13.7
20 – 29	1171	4.9	57870	15.2	59041	14.6
30 – 39	1512	6.3	50741	13.3	52253	12.9
40 – 49	2767	11.6	55399	14.5	58166	14.4
50 – 59	4554	19.1	55294	14.5	59848	14.8
60 – 69	3871	16.2	35789	9.4	39660	9.8
70 – 79	4281	18.0	21501	5.6	25782	6.4
80 – 89	3276	13.7	7423	2.0	10699	2.6
90+	597	2.5	696	0.2	1293	0.3
<b>Total</b>	<b>23848</b>	<b>100</b>	<b>381114</b>	<b>100</b>	<b>404962</b>	<b>100</b>

The pattern of increased incidence of impairment comes out more clearly when one analyses the prevalence of an impairment within a

<sup>19</sup> Pg 4, ibid

person's life cycle. Table 04 below looks at the presence of a disability across four stages of a person's life cycle: childhood; teenage years; youth and old age.

As can be seen from the Table below in all of the impairment groups assessed, the actual percentage of persons born within a specific disability within each of the disability categories is significantly far lower than the cohort of disabled persons in the 'old' age categories.

A partial reason for the significant increase during this lifecycle period is due to the fact that persons with a disability are living longer, and hence longevity results in an increased population cohort.

The main reason, however, is that aging renders persons frailer; a fragility that increases exponentially the longer a person lives. It is also proven that certain mental disabilities such as dementia and Alzheimer's and physical conditions such as Parkinson's are strongly correlated with the 'old' age phase of a person's life cycle.

**Table 03: Percentage of Persons with a Particular Disability within a Specific Lifecycle Phase<sup>20</sup>**

	Age	Physical %	Cohort Total %	Intell-actual %	Cohort Total %	Psych-ological %	Cohort Total %	Hearing and Visual %
<b>Children</b>	0–4	0.74		2.6		2.39		1.46
	5–9	1.06	1.8	6.96	9.56	6.34	8.73	3.47
<b>Teenagers</b>	10–14	1.84		8.55		6.51		6.53
	15–19	1.85	3.69	8.90	17.45	6.43	12.94	6.43
<b>Youth</b>	20–24	2.23		8.51		5.35		6.62
	25–29	2.6	4.83	8.11	16.62	4.7	10.01	7.62
<b>Young-Old</b>	60–64	10.01	10.01	5.2	5.2	8.4	8.4	14.87
	65–	9.41		2.95		4.61		13.14

<sup>20</sup> Pg 39, Ibid

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	70-74	10.93	20.34	2.82	5.77	4.2	8.81	15.21
<b>Old-Old</b>	75-79	10.85		2.29		3.21		16.69
	80-84	10.66		3.04		3.95		18.02
	85	11.2	32.71	3.66	8.99	6.01	13.17	32.38

**The fact that the incidence of disabilities increases with age raises two issues with regards to the design of an ISL policy framework. First**, parents, in part due to the limited ISL framework and supporting facilities, are today the guardians and carers of their disabled children. As these parent age and become frail, potentially they themselves become vulnerable to a particular age-induced impairment, and uncertainty arises of who will assume responsibility for their disabled children when such a situation occurs.

In this regard, unless siblings or relatives – should there be any – assume responsibility for the disabled person a risk exists that such a disabled person will become a ward of the State. Given that the life expectancy of persons with disabilities is also increasing as a result of medical breakthroughs even in medical conditions which up to recently were known to have a short life expectancy, it is reasonable to assume that the majority of disabled persons will outlive their parents.

Although the Government and NGOs, jointly as well as separately, have invested considerable effort on a number of initiatives and supporting facilities, the views of this report are that these continue to be very limited in terms of outreach and capacity. Therefore, unless changes are affected, there is a greater likelihood that such persons will end up institutionalised when parental support is no longer available.

Indeed, the available data – limited as this is – supports this. The following are observations arising from the 2005 Census<sup>21</sup>:

- Disabled persons are nearly 12 times more likely than non-disabled persons to be institutionalised with 11.8% (2,808) of this group living in such a setting.

<sup>21</sup> Census, the Quarterly of the Life of Disabled People in Malta: Some Answers from the Census 2005, KNPD 2007, [www.knpd.org](http://www.knpd.org) Pg 2, Report on the Social Inclusion and Social Protection of Disabled People in European Countries, Academic Network of European Disability Experts, <http://www.disability-europe.net/content/aned/media/MT-12-ANED%202009%20Task%206%20Request-9B-Country%20update%20SPSI%20-%20report%20final.pdf>



- Disabled people are also more likely to live in a dwelling that is not in a good state of repair with just 46.9% (9,843) of disabled people having a dwelling in a good state of repair.
- Disabled women are nearly twice as likely as to live in an institution than disabled men. The rate of institutionalisation amongst disabled women is 15.2% (1,820) and that of disabled men is 8.3% (988).
- Disabled women are more likely to live in a dwelling that is not in a good state of repair when compared to disabled men. The rate for disabled women living in a good state of repair is 44.3% (4,502) and that of disabled men is 49.3% (5,341).
- People with more than one impairment are the most likely to live in an institution with this group representing 24.7% (930) of the disabled population living in institutions.
- People with more than one impairment also tend to live in dwellings with most need of repairs, with 62.8% (1,773) of people needing repairs ranging from minor to serious repairs.

It is pertinent to underline that such a situation is not unique to Malta. A survey of 1505 non-elderly adults in the US with disability found that<sup>22</sup>:

- 70% relied on family and friends for assistance with daily activities, and only 8% used home-health aides and personal assistants.
- 42% reported having failed to move in or out of a bed or a chair because no one was available to help.
- 16% of home-care users reported problems paying for home care in the previous 12 months.
- 45% of participants in the study worried that caring for them would become too much of a burden on the family.
- 23% feared having to go into a nursing home or other type of facility.

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<sup>22</sup> Pg 139, World Report on Disability, World Health Organisation and The World Bank, 2011, [http://whqlibdoc.who.int/publications/2011/9789240685215\\_eng.pdf](http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf)

The **second** issue as clearly shown by the data is that the vast majority of disabled persons are not persons who are born with a disability but who acquire an impairment later in life particularly in old age. A particular example is people who have dementia. Statistics in the United Kingdom show that dementia tends to become more prevalent with the 'old-old' elderly category: that is persons who are 75+ years and over:

**Table 04: Prevalence of Dementia in Elderly Patients**

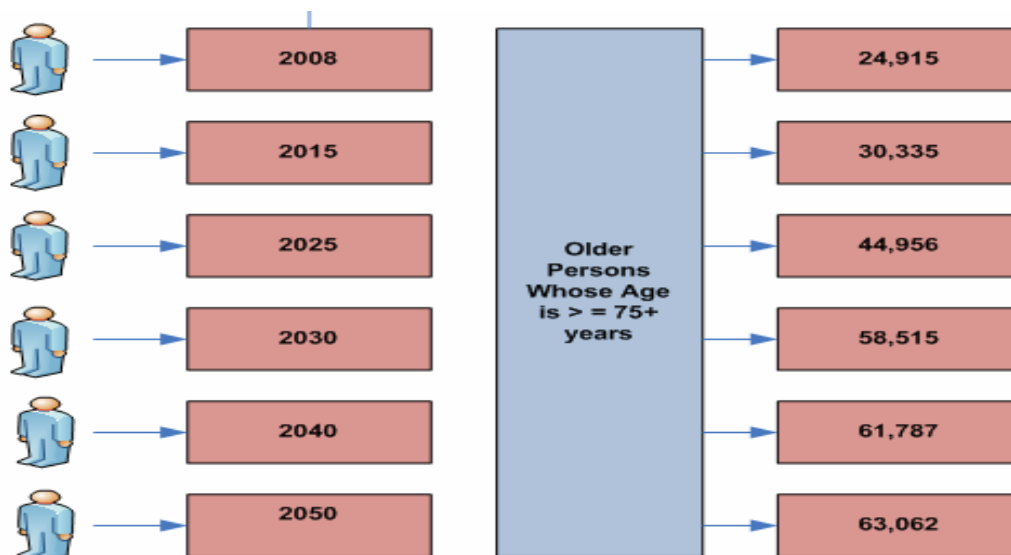
	Age in years	Female	Male	Total
From 1 in 100	65-69	1.0	1.5	1.3
	70-74	2.4	3.1	2.9
	75-80	6.5	5.1	5.9
	80-84	13.3	10.2	12.2
	85-89	22.3	16.7	20.3
	90-94	29.6	27.5	28.6
	95+	34.4	30.0	32.5

To 1 in 3

As people, therefore, live longer the prevalence of dementia will increase - given that the number of "old-old" will increase. The Figure below shows the projected population growth of the 75+ years of age and over population cohort of Malta over a 40 year period. As can be seen the population is expected to increase by 80% over 2008 by 2025 (that is, in 14 years time); by 135% over the said period by 2030 (that is, in 19 years time); and by 148% by 2040 (that is, in 29 years time).

**Figure 02: Projections of 75+ and Over Population in Malta: 2008-2050<sup>23</sup>**

<sup>23</sup> Projections by the Pension Working Group, 2009



A pertinent question with regards to the design of an ISL policy framework for disabled persons, therefore, is whether the ‘definition’ of disability in this regard is to be restricted solely to persons who are born with an inherent disability or whether it is to embrace persons who acquire a disability in childhood or while they are of working age, and those whose impairment is a direct consequence of aging.

It is pertinent to underline that a definition that applies a broader definition outlook that includes old age impairment as a disability demands a far more embracing and robust ISL infrastructure. Moreover, as the Table below shows, the number of persons who acquire an old age impairment will far outstrip that cohort of persons who are born with an impairment or those who acquire an impairment that is not due to normal aging. Additionally, as discussed above and given the projected behaviour of the 75+ and over age population cohort over the next 30 years impairment as a result of aging will increase significantly.

**Table 05: Number of Persons with a Particular Disability within a Specific Lifecycle Phase<sup>24</sup>**

	Age	Physical %	Cohort Total %	Intell-lectual %	Cohort Total %	Psych-ological %	Cohort Total %	Hearing and Visual %
<b>Children</b>	0–4	63		59		29		16
	5–9	90	132	158	217	77	106	37

<sup>24</sup> Pg 39, Ibid

<b>Teenagers</b>	10–14	156		194		79		70
	15–19	157	313	202	396	78	157	68
<b>Youth</b>	20–24	189		193		65		71
	25–29	220	409	184	377	57	122	81
<b>Young-Old</b>	60–64	848	848	118	118	102	102	161
<b>Old</b>	65–69	797		67		56		143
	70–74	926	1,723	64	131	51	107	164
<b>Old-Old</b>	75–79	919		52		39		181
	80–84	903		69		48		196
	>=85	904	2,726	83	204	73	160	348

There is no doubt that the consequences of a physical or intellectual impairment that a person is born with or acquired not as a result of aging and an impairment which is the result of aging are, to a degree, similar with regards to the support mechanisms and facilities required. Malta has been active over the past twenty years or so with regards to care for the elderly – primarily through direct or indirect investment by means of public private partnerships in the development of homes for the elderly in the village core.

On the other hand, the provision of community-based services directed to retain elderly persons with (or without) ageing related impairment has been more marked by its absence. Whilst attempts have been made to provide ‘personal support’ to frail elderly persons through direct government organisations or non-government organisations. Such institutions were and continue to be considerably under resourced and under funded to lead to significantly impact an increase in the number of frail and elderly persons to remain longer in their communities. It is to be noted that in the 2012 National budget the Government introduced a “community living” grant of €300 annually to those person who are 80 years of age and over and are living in the community to further incentivise them to remain integrated in their respective communities.

Thus the design of an ISL framework for disabled persons needs to determine whether its scope is to be limited to persons who are born with an impairment or acquire an impairment that is not related to aging only or to also include persons who acquire an impairment related to aging.

During the consultation process feedback showed preference to both options. Arguments were presented that an ISL policy framework for disabled persons that excludes persons who acquire an age related disability would be discriminatory and 'agist'.

This report, however, strongly expresses a concern that if a policy of ISL is to embrace persons who acquire age related disabilities than the real danger exists that persons who are born with a disability or acquire one in their childhood or adulthood that is not related to aging are likely to be marginalised particularly as the State would be overwhelmed in managing a 'tsunami' of long term care issues arising directly from Malta's aging population which, though are yet to be felt will occur rapidly and in an escalating manner over the next 13 years.

This report, thus, favours a policy strategy for an ISL policy framework, similar to that applied in Sweden, that is separate and independent from aging and the care for the elderly until, at least, such time that appropriate State investment would have been directed towards securing a critical mass resulting in a sustainable ISL environment for persons who are born with an acquired impairment that is not related to aging.

### **03.2 Economic Activity of Disabled Persons**

#### **03.2.1 Proposed National Policy on Disabled Persons and Employment**

As discussed earlier in this report, an essential caveat for the success of an ILS environment is the opportunity afforded to a disabled person to earn income, and therefore secure the financial 'independence' or, in the event that a disabled person cannot work an appropriate level of income substitution that would allow the person to live independently within society.

The KNPD in 2010 issued a document on disabled persons and employment. The salient recommendations set out are the following<sup>25</sup>:

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<sup>25</sup> Pg 6-7, National Policy on Disabled Persons and Employment, 2010, <http://www.knpd.org/>

- (a) Government ratifies the UN Convention and its Optional Protocol and strengthens the Equal Opportunities (Persons with Disability) Act, ensures that there are disabled people working at all levels in the public sector, and encourages the private sector to do the same, in order to promote equal opportunities for all.
- (b) The Ministry for Education provides disabled students with vocational guidance and training together with a comprehensive assessment of their abilities and needs, and should ensure that post-secondary and tertiary educational institutions offer support systems to disabled students.
- (c) The Ministry for Education and / or the Employment and Training Corporation (ETC) (depending on whether the disabled person is a full-time student) should carry out a comprehensive assessment of disabled students, disabled persons attending day centres and those who are seeking employment. The emphasis of this assessment should be on the vocational aspect and lead to vocational training and guidance as necessary.
- (d) The Supported Employment Section within ETC is strengthened so that it has the necessary resources for it to be able to provide the necessary assessment and training for disabled persons, identify job opportunities for them, and create schemes so that they can secure and retain employment, and advance in their chosen career.
- (e) ETC should provide the whole range of services necessary for persons with disability to be supported in employment according to their personal needs and abilities.
- (f) ETC should further develop existing schemes to support disabled people to enter the labour market. It should also introduce schemes to provide reasonable support for disabled people to work in an open environment.
- (g) Disabled persons should be given incentives to be able to start up and maintain self-employment.
- (h) Government should offer incentives for the setting up of commercial cooperatives where the majority of workers are disabled people.

- (i) Aġenzija Sapport, in collaboration with ETC and the private sector, should set up sheltered employment units to offer jobs to disabled persons who cannot work in open employment. These workers should be remunerated at a reasonable rate according to the work they carry out.
- (j) Aġenzija Sapport should be allocated all the resources that are necessary for it to provide day services for disabled people who cannot enter the labour market.
- (k) It should also be given extra funding specifically for the setting up and running of the sheltered employment units. These services should be provided in the hours when the person is active, including evenings and weekends.
- (l) Government should ensure that all clauses of the Disabled Persons (Employment) Act are enforced and that the structures that it refers to are set up at ETC. The quota of registered disabled persons which should be employed by any employer according to this Act should remain 2% for both the public and the private sectors. However the employer should, for valid reasons, be given the opportunity of either employing according to this quota or paying a sum of money which is equivalent to 20% of the minimum wage.
- (m) The disability pension should be raised to at least the minimum wage and all disabled persons who are unable to work because of their impairment, irrespective of the nature of that impairment, should be eligible for this pension.

### 03.2.2 Employment and Disabled Persons

The 2005 National Census confirms the low participation rate of disabled persons as well as the fact that such persons tend to occupy low paid work.<sup>26</sup> The Census identifies that 19.4% of disabled persons, compared to 1.1% of non-disabled persons, cannot work due to the disability or illness. Moreover, the number of disabled persons who are 'retired' approximate 39%. Disabled persons in employment constituted of 14.6% of the total cohort of disabled persons at the time the Census was carried out.

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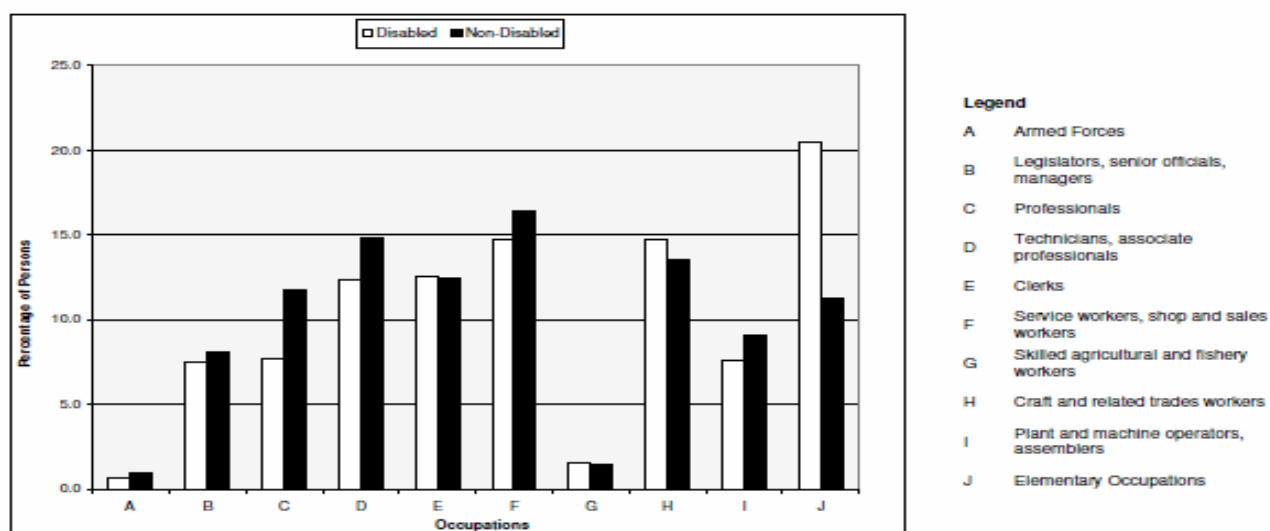
<sup>26</sup> Pg 16, Census Chapter 1, The Quality of Life of Disabled People in Malta: Some Answers from the Census 2005, KNPD 2009; [www.knpd.org](http://www.knpd.org)

In terms of actual persons employed, at the time of the 2005 Census there were 3,295 persons in productive employment – out of a total disabled population of 23,848.<sup>27</sup>

It is pertinent to note that the National Statistics Office (NSO) release titled ‘International Day of Persons with Disabilities (2009)’ identifies that persons between 16 and 64 years of age who are classified as ‘permanently disabled<sup>28</sup> or / and unfit for work’ to be 5,750 persons or 2.1% of the working population.<sup>29</sup>

The Table below shows findings of the 2005 Census with regards to the distribution of disabled persons in employment. As can be seen, disabled persons are under-represented in higher income employment.

**Table 06: Main Occupations of Disabled Persons<sup>30</sup>**



An analysis of the employment and gender of disabled persons shows that disabled men in employment outnumber women in almost every category. In the ‘employed’ category, 22.5% of the employees are disabled men whilst only 7.0% are disabled women. Indeed, the only category in which disabled women are far more highly represented is in the category of ‘taking care of the family and / or house’ – 1.0% of men compared to 34.6% of women.

<sup>27</sup> Pg 17, Ibid

<sup>28</sup> This cohort of disabled persons does not include persons who are in retirement – and hence presents a better representation of persons who have been born with an inherent disability or who experienced a disability experience during their work life

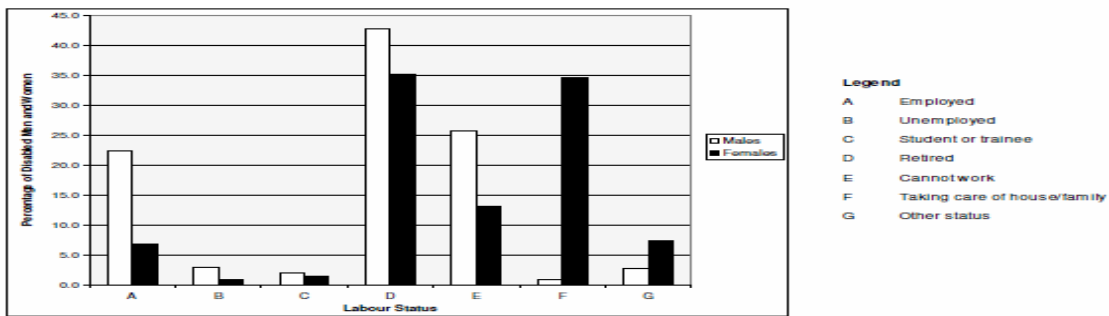
<sup>29</sup> Pg 5, International Day of Persons with Disabilities, 2009, News Release, 216/2009, 2<sup>nd</sup> December 2009

<sup>30</sup> Pg 19, Census, The Quality of Life of Disabled People in Malta: Some Answers from the Census 2005



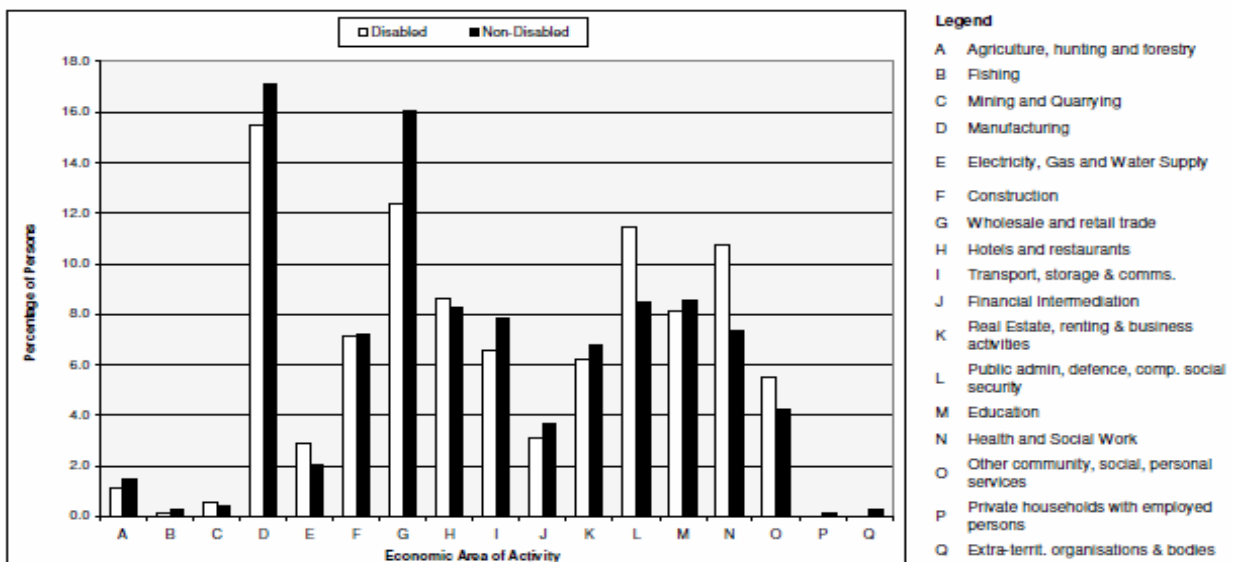
Not only does this suggest that gender plays a significant role in a disabled woman's labour status and choices but **within an ILS policy framework** the current gender inequality amongst disabled persons may render it far harder for a disabled woman to live independently as she will have less opportunity to access independent finance.

**Table 07: Employment of Disabled Persons by Gender<sup>31</sup>**



Furthermore, as can be seen from the Table below, the largest presence of disabled persons in employment is in manufacturing – which confirms the low income employment – followed by wholesale and retail trade,; government, and health and social work.

**Table 08: Employment Sectors and Disabled Persons<sup>32</sup>**



It is pertinent to underline, that in 2007 the number of disabled persons working with Government entities stood at 347 from a total employee

<sup>31</sup> Pg 53, Ibid  
<sup>32</sup> Pg 21, Ibid

base of 38,558 persons. The representation of disabled persons within Government as at 2007 thus stood at 1.2% - showing that Government itself was not adhering to the statutory obligation that mandates that, at a minimum, 2% of the employment population should consist of registered disabled persons.<sup>33</sup>

The work in employment schemes have had had mixed results. The Work Start scheme had a far less impact than expected as it attracted a small number of persons. The Bridging the Gap Scheme supported 16 persons – 13 of whom were disabled persons between 21 and 40 years of age; with the schemes evenly distributed across gender.<sup>34</sup>

There are a number of supported employment schemes in place. The ETC Support Employment Scheme supported 30 persons – of whom 25 persons were disabled persons between 21 and 40 years of age; with employment, however, heavily biased at 21 persons towards disabled men. The ETC Assisted Employment / Follow Up Support schemes supported 43 persons – again, with the majority of persons being 21 and 40 years of age; with the schemes being relatively evenly distributed across gender. The NGO Respite in its Individualised Transport Scheme supported 19 persons – where once again the majority of persons being 21 and 40 years of age; with the schemes being relatively evenly distributed across gender.<sup>35</sup>

The Table below shows the number of persons with disability who have registered under Part 1 of the Unemployment register. As can be seen, throughout this period, the number of disabled persons on the unemployment register remained relatively static between 1998 and 2003, increasing somewhat between 2004 and 2006.

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<sup>33</sup> Pg 27, National Policy on Disabled Persons and Employment, 2010, <http://www.knpd.org/>

<sup>34</sup> Pg 22-23, Ibid

<sup>35</sup> Pg, 23-26, Ibid

**Table 09: Number of Disabled Persons Registering under Part 1 of the Unemployment Register<sup>36</sup>**

Registered Unemployed	Dec 98		Dec 99		Dec 00		Dec 01		Dec 02		Dec 03	
	No	%	No	%	No	%	No	%	No	%	No	%
Males	262	85.1	264	85.4	255	85.6	269	84.1	253	82.7	250	82.5
Females	46	14.9	45	14.6	43	14.4	51	15.9	53	17.3	53	17.5
<b>Total</b>	<b>308</b>	<b>100.0</b>	<b>309</b>	<b>100.0</b>	<b>298</b>	<b>100.0</b>	<b>320</b>	<b>100.0</b>	<b>306</b>	<b>100.0</b>	<b>303</b>	<b>100.0</b>
Registered Unemployed	Dec 04		Dec 05		Dec 06		Dec 07		Dec 08		Sept 09	
	No	%	No	%	No	%	No	%	No	%	No	%
Males	253	78.6	264	75.0	279	79.9	210	76.6	241	80.6	336	83.4
Females	69	21.4	88	25.0	70	20.1	64	23.4	58	19.4	67	16.6
<b>Total</b>	<b>322</b>	<b>100.0</b>	<b>352</b>	<b>100.0</b>	<b>349</b>	<b>100.0</b>	<b>274</b>	<b>100.0</b>	<b>299</b>	<b>100.0</b>	<b>403</b>	<b>100.0</b>

The 2009 (latest) registered figure of 403 disabled persons is the highest number ever. The reason for this high number of unemployed can be various. It could be a result of redundancies triggered as a consequence of the economic recession or it could be the product of increased expectations of disabled youths graduating from the inclusive education policy effort who are actively seeking a job.

### 03.2.3 Income and Disabled Persons

The National Minimum Wage for full time employees in Malta is shown in the Table below.

**Table 10: National Minimum Wage<sup>37</sup>**

Age	Weekly Wage	Annual
<b>Age 18 and over</b>	€153.45	€7,979.4
<b>Age 17 years</b>	€146.67	€7,626.8
<b>Age under 17 years</b>	€143.83	€7,479.16

The average gross annual salary in Malta is €14,466.<sup>38</sup> The average national disposable income for persons aged 25 to 64 years is €11,387; whilst that of persons aged 16 to 24 years is €11,258. Persons in the cohort defined as 'permanent disabled or / and unfit for work' compare as shown in the Table below.

<sup>36</sup> Pg 6, International Day of Persons with Disabilities: 2009, National Statistics Officer, 2 December 2009, 216/2009, [http://www.nso.gov.mt/statdoc/document\\_file.aspx?id=2637](http://www.nso.gov.mt/statdoc/document_file.aspx?id=2637)

<sup>37</sup> [http://www.yesit matters.com/html/employment\\_faq.html#2011MinWage](http://www.yesit matters.com/html/employment_faq.html#2011MinWage)

<sup>38</sup> <http://www.timesofmalta.com/articles/view/20110106/local/average-salary-at-14-466.344004>

**Table 11: Average Disposable Income Comparison<sup>39</sup>**

<b>Age</b>	<b>Persons with Disability €</b>	<b>All Persons €</b>	<b>Difference</b>
<b>16-24</b>	10,226	11,258	(1,032)
<b>25-64</b>	8,497	11,387	(2,890)

The Household Budgetary Survey (HBS) does not specifically depict the income profile of a family that has a disabled child. The HBS, nevertheless, provides an income profile for a household with a dependent child / children.

Whilst the net saving ratio of a household with this characteristic is shown in the Table below, the application of such a household as a proxy for a potential household with a dependent disabled child is not seen to be an appropriate substitute.

**Table 12: Average Net Household Income and Expenditure<sup>40</sup>**

<b>Household Composition</b>	<b>Average Income €</b>	<b>Net Average Expenditure €</b>	<b>Difference €</b>
<b>2 adults, one dependent child</b>	21,801	21,991	(190)
<b>2 adults, two dependent children</b>	22,583	24,103	(1,520)

Whilst data from the 2008 HBS is taken from NSO with regards to specific characteristics of households with a disabled child, a survey carried out by KNPD and NSO in 2003 shows that 28.2% of disabled persons have to depend on paid support when faced with a problem.<sup>41</sup> This single indicator alone shows that the average expenditure of a family with a disabled person is likely to have a different spending profile than that of a household with one dependent as investment is required with regards to assistance, transportation, medication, and equipment.

<sup>39</sup> Pg 5, International Day of Persons with Disabilities, 2009, News Release, 216/2009, 2<sup>nd</sup> December 2009

<sup>40</sup> Household Budgetary Survey, 2008, National Statistics Office, 2010, [http://www.nso.gov.mt/statdoc/document\\_file.aspx?id=2833](http://www.nso.gov.mt/statdoc/document_file.aspx?id=2833)

<sup>41</sup> Pg 15, Research about the Major Concerns of People with Disability and their Families, National Council for Persons with a Disability and the National Statistics Office, <http://www.knpd.org/>

Reference, in this regard, is made to a similar analysis, however, based on the 2000 HBS presented in a study, by Dr Cordina, titled 'The Economic Dimensions of Independent Supported Living for People with Disability'.

The study states that the 2000 HBS featured 40 households having one person with a disability. The HBS shows that the average per capita income of persons living in households with a person with disability tends to be approximately 5% lower than that of other households.

The data for the year 2000 indicates that whereas the average income of households with a person with disability averaged €6,018 per person in the household, the comparable figure for other households stood at €6,354. This is indicative of the fact that persons with disability have a lower than average income, thereby constraining the per capita earnings of their household.<sup>42</sup>

Of particular note, 33% of the income sourced by a household with a member with a disability stems from social benefits compared to 16% in other households. The study further shows that the total expenditure of households with a disabled person is at €14,129 lower than that of other households which stands at €18,048. The report concludes that the resultant higher savings ratio of a family with a disabled child – 15% compared to 6% of another household – may be motivated by the fact that parents of a child with a disability may want to save more, so as to leave enough funds after their death as a support provision for their disabled child.<sup>43</sup>

Additionally, in the absence of new data on the local economic costs of households with a disabled person, reference was made to overseas studies. In the United Kingdom estimates range from 11% to 69% of income.<sup>44</sup> In Australia the estimated costs – depending on the degree of severity of the disability – are between 29% and 37% of income.<sup>45</sup> In Ireland the estimated cost varied from 20% to 37% of average weekly income, depending on the duration and severity of disability.<sup>46</sup>

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<sup>42</sup> Cordina, G., The Economic Dimensions of Independent Supported Living for People with Disability, <http://www.knpsd.org/>

<sup>43</sup> Ibid

<sup>44</sup> Zaidi A, Burchardt T. Comparing incomes when needs differ: equivalisation for the extra costs of disability in the UK. *Review of Income and Wealth*, 2005,51:89-114. doi:10.1111/j.1475-4991.2005.00146.x

<sup>45</sup> Saunders P. *The costs of disability and incidence of poverty*. Sydney, Social Policy Research Centre, University of New South Wales, 2006

<sup>46</sup> Cullinan J, Gannon B, Lyons S. Estimating the extra cost of living for people with disabilities. *Health Economics*, 2010,n/awww.interscience.wiley.com doi:10.1002/hec.1619 PMID:20535832

Disability thus results in “vulnerability and heightened concern for the future livelihood of individuals, constraining concerned households to save more and thereby enjoy a generally lower standard of living. For this reason, means testing based on the availability of financial assets often introduces an unfair bias in relation to persons with disability”.<sup>47</sup>

It is pertinent to underline, the median national equivalised income calculated from the Survey on Income and Living Conditions 2008 stood at €9,547, which is an increase of 5% on 2007.<sup>48</sup>

The at-risk-of-poverty threshold, which is equivalent to 60% of the median national equivalised income, was €5,728. The aforementioned survey calculated the corresponding at-risk-of-poverty rate at 15%. This means that 59,498 persons are estimated to be below the at-risk-of-poverty threshold.<sup>49</sup>

The survey does not determine the at-risk-of-poverty rates on the basis of economic or social conditions but rather on the basis of household and age-groups. In this regard, the analysis of the at-risk-of-poverty rates by age-groups indicate that the elderly and children made up the two population categories that were mostly at risk, with rates of 22% and 20% respectively. This high rate of at-risk-for-poverty for these two age groups is not surprising as both age groups are considered to be vulnerable groups.

The at-risk-of-poverty of children stems from the economic conditions of the household they belong to. Thus, for example, the rate of the at-risk-of-poverty increases considerably for children in households with a low work intensity or low disposable income. Children living in single parent households were the most likely to be at risk, with an at-risk-of-poverty rate of 59 per cent.<sup>50</sup>

On the other hand, with regards to pensions, the at-risk-of-poverty stems from the fact that elderly persons are likely to have a lower average disposable income than that of an employed person given that a pension, currently, can only be a maximum of 2/3 of €17,475 – which is €11,650. Moreover, the Strategic Review on the Adequacy, Sustainability and Social Solidarity of the Pensions Systems shows that the median pension is only 54.7 of the average wage – that is €7,913.<sup>51</sup>

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<sup>47</sup> Ibid

<sup>48</sup> Pg xxiii, Survey on Income and Living Conditions 2008, National Statistics Office, 2010

<sup>49</sup> Ibid

<sup>50</sup> Pg xxv, Ibid

<sup>51</sup> Pg 76, Strategic Review on the Adequacy, Sustainability and Social Solidarity of the Pensions Systems, 2010 Pensions Working Group, Final Report, December 2010

A disabled person, in fact, ‘mimics’ the economic activity of a person within both of these age groups. Disabled persons whose impairment is so severe that they are not in a position to work will depend on the economic circumstances of the household they are living in. On the other hand, persons with a disability even in employment is, as demonstrated in the report, are less likely to be amongst the middle and high earner incomes and hence their income is more likely to be at the lower end of the wage scales.

The key arising issue with regards to **the design of an ISL policy framework** is that for a person to live independently not only must they be in a position to secure a form of employment but as importantly the income level generated through that employment would provide the disabled person with the means to live an ‘adequate’ independent life.

The conclusion that arises is that a disabled person is unlikely to secure such a level of ‘adequate’ income. As shown, a severe impairment, coupled with existing socially-constructed barriers militate against the majority of disabled people acquiring high-income employment. Given the economic pressures that a family with a disabled child is likely to be under and the absence of incentive mechanisms in this regard it is most likely that most families will not be in position to provide the disabled child with private income or finance.

Indeed, the likelihood that an adult disabled person will be at-a-high-risk-of-poverty is greater than that of a non-disabled person.

The 2009 NSO release titled on ‘International Day of Persons with Disabilities’ shows that the number of disabled persons at the risk of poverty stands at 23% of the total population of the said cohort. This high figure is not surprising and reflects the high at-risk-of-poverty incidence found within the children and the elderly age cohorts.

**Table 13: At Risk-of-Poverty within Permanently Disabled and / or Unfit for Work Population Cohort<sup>52</sup>**

<b>At risk-of-poverty line</b>	<b>Number of persons</b>	<b>% total</b>
<b>Over</b>	4,440	77
<b>Under</b>	1,310	23

<sup>52</sup> Pg 5, International Day of Persons with Disabilities, 2009, News Release, 216/2009, 2<sup>nd</sup> December 2009

### 03.2.4 Disability Pension and Disabled Persons

A study carried out jointly by the KNPD and NSO identified that 15% of disabled persons had no financial income whilst 50%, have an income of less than €5,592 annually.

**Table 14: Net Monthly Income of a Disabled Person<sup>53</sup>**

Net Annual Income €	Total	Age		
		16-19	20-59	60+
0	14.6	6.3	13.7	16.1
=<5,592	50.8	87.5	58	30.7
5,592 – 8,360	20.9	6.3	13.4	29.8
8,388 – 11,156	8.2	0	8.8	8.1
11,184 – 13,952	1.7	0	2.3	1.6
13,980 – 16,748	0.6	0	0.8	0.4
16,776 – 19,544	0.2	0	0.4	0
>= 19,572	0.2	0	0.4	0
No Answer	2.9	0	2.3	3.2

The same study quoted above identified that 37.1% received a disability pension. In fact the number of beneficiaries as at 2008 stood at 2,250 – which increased from 2,094 in 2004; an increase of 7.5%.<sup>54</sup>

The framework governing disability pensions is the Social Security Act – Chapter 318 (SSA). Whilst it is the considered opinion of this report that those parts of the SSA that govern disability pensions require a fundamental review (for example removal of differentiation between a person entitled to a disability pension (Article 27(1)) and a visually impaired person (Article 27(2)); a definition of a ‘severely disabled person’ based on a condition which is neither conclusive nor complete, among others), the discussion, here, is limited to the parameters set by the SSA on the administration of the disability pension.

Article 27(1)(c)(ii) of the SSA establishes that in the event that the weekly income of a disabled person does not exceed the National Minimum Wage as applicable to an 18 year old person, they will be entitled to a Disability Pension.<sup>55</sup>

<sup>53</sup> Pg 5, Research about the Major Concerns of People with Disability and their Families, National Council for Persons with a Disability and the National Statistics Office, <http://www.knpd.org/>

<sup>54</sup> Pg 6, International Day of Persons with Disabilities, 2009, News Release, 216/2009, 2<sup>nd</sup> December 2009

<sup>55</sup> Chapter, 318, Social Security Act



Nevertheless, in the event that the weekly income of the disabled person does exceed the National Minimum Wage, the pension to which the disabled person will be entitled to, would be reduced so that the total income stemming from the means of the person and his or her pension entitlement does not exceed the National Minimum Wage.

It is important to underline that the full disability pension value as established by Schedule VI of the SSA is €90.47 weekly – that is €4,704 annually.<sup>56</sup> As can be seen from the Table below, the average value of the disability pension stood at €3,593 in 2004 – thereby enjoying an increase of €1,111 or 30.9%.

**Table 15: Total Disability Pensions: 2004-2008<sup>57</sup>**

Year	Number of beneficiaries	Government expenditure (€'000s)	Average expenditure per beneficiary (€)	% expenditure of non-contributory benefits	% expenditure of total social security benefits
2004	2,094	7,523	3,593	5.75	2.14
2005	2,134	7,838	3,673	5.80	2.07
2006	2,192	8,280	3,777	5.98	2.04
2007	2,235	8,644	3,868	6.12	2.01
2008	2,250	9,216	4,096	5.91	1.97

This means that, on the basis of 2003 figures, 50.8% of the persons who declared an income of €5,592 or less had either to forfeit in part or in full the disability pension received.

Additionally, as can be seen from the above table, the cost of the disability pension constitutes a small part of both non-contributory benefits and total expenditure in social security benefits: 5.91% and 1.97% respectively.

The current legislative requirements with regards to the disability pension give rise to a number of issues with regards to the **design of a legislative ISL policy framework**.

**First:** The value of the pension is so low that this report argues that it is not possible that a disabled person can live independently with this level of income. This is supported not only by the fact that the disability pension as at 2011 rates is €3,275.4 or 46.6% less than the National

<sup>56</sup> Part III of Schedule VI of the Social Security Act: Highest Rate of Disability Pension – Weekly rate €90.47

<sup>57</sup> Pg 6, International Day of Persons with Disabilities, 2009, News Release, 216/2009, 2<sup>nd</sup> December 2009

Minimum Wage but also by the findings of the 2004 Pensions Working Group in a study titled 'Determining Adequacy'.<sup>58</sup>

The 2004 Pensions Working Group had carried out the study to assign a value to what constitutes 'adequate' in order to guide the then Pensions Working Group to determine the appropriate 'adequate' replacement rate within a sustainable pensions system. In its definition of 'adequate' the Pensions Working Group applied the interpretation of the Watts Committee in the United States of America which had established that:

"Adequacy affords full opportunity to participate in contemporary society and the basic options it offers".<sup>59</sup>

The study was based on a methodology developed by the Family Budget Unit of the Social Policy Research Unit at the University of York together with Age Concern England and made use of the 2000 HBS data.

On 2000 HBS data<sup>60</sup>, the study found with regards to non-disabled persons who are 60 years of age and over:

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<sup>58</sup> Pensions Working Group, Determining Adequacy, Supplementary Paper to the Final Report of the Pensions Working Group, Supplementary Paper No 7, [https://secure2.gov.mt/socialpolicy/socprot/social\\_benefits/pensions\\_reform/suppl\\_papers\\_archive.aspx](https://secure2.gov.mt/socialpolicy/socprot/social_benefits/pensions_reform/suppl_papers_archive.aspx)

<sup>59</sup> Pg 1, Ibid

<sup>60</sup> The HBS date on which this study was based was small and, therefore, not representative. Thus in interpreting the results of this study this limitation should be noted.

**Table 16: Fixed Cost Budget for a Single Non-Disabled Male and Woman who is 60+<sup>61</sup>**

<b>Fixed costs</b>	<b>Single Man €</b>	<b>Single Woman €</b>
<b>Food Budget</b>	2511.74	2949.78
<b>Clothing</b>	435.71	253.97
<b>Personal Care</b>	556.87	549.88
<b>Household Goods</b>	74.56	258.63
<b>Household Services</b>	251.64	191.06
<b>Leisure</b>	368.14	286.59
	<b>4,198.66</b>	<b>4,489.91</b>

In determining the variable cost expenditure the study reviewed expenditure related to property (ownership or tenancy); transport (public or private); health; smoking, and alcohol. The study concluded that the minimum adequate level of a pension for a person to have dignity in retirement required to cover for fixed and variable budget expenditure is as shown in the Table below.

**Table 17: Average ‘Adequate’ Budget for Non-Disabled Male, Woman and Married Couple who is 60+<sup>62</sup>**

<b>Type</b>	<b>Single Man €</b>	<b>Single Woman €</b>	<b>Married Couple €</b>
<b>House Owner Average</b>	5,533.75	6,279.35	8,970.5
<b>Tenant Average</b>	5,356.67	5,571.03	8,234.22
<b>Final Average</b>	<b>5,445.21</b>	<b>5,922.86</b>	<b>8,602.36</b>

As can be seen from the above Table, an ‘Adequate’ budget for a 60+ non-disabled person was in 2004 on 2000 data established at €5,445.21 per annum. Assuming that the budget cost base for a disabled ‘male’ adult and a non-disabled elderly is the same – which is not necessarily

<sup>61</sup> Pg 7, Ibid  
<sup>62</sup> Pg 14, Ibid

so – this means that the Disability Pension at 2011 rates is below the final average adequacy level of a male person by €741.21 per annum or it stands at 89.39% of the final average adequacy level of a male person benchmark.

Assuming a rate of inflation of 2% between 2000 and 2011, the defined adequacy benchmark referenced above would in 2011 have a value of €6,770.43. This means that at 2011 levels the disability pension stands at 69.48% of an inflation adjusted adequacy benchmark.

**Second:** Despite the fact that the Disability Pension is so low that, in the considered opinion of this report, it cannot guarantee a level of adequacy that suffices to allow a disabled person to live independently with dignity, a criterion is in place that establishes that income earned by a disabled person who is in receipt of a disabled pension cannot exceed the National Minimum Wage. As shown earlier in this report, this means that the value of the disability pension received decreases in proportion of the income earned over and above the pension.

In effect, this legislative requirement renders it next to impossible for a disabled person to improve his or her income situation to render this sufficient to provide him or her with the appropriate level of adequacy. As this report documents, the majority of disabled persons – due to the condition or disability – are in low income employment.

Marginal as the increase stemming from a low income employment may be, the disabled person is penalised for showing initiative and for empowering him or herself to seek a more active engagement in the labour market or society as such income is immediately reduced from his or her disability pension.

Indeed, this report concludes that this particular provision seems to have had the counter effect of keeping disabled persons outside of active engagement in society as opposed to encouraging them to pick up a more active participation.

It is evident that the overwhelming majority of disabled persons will never be in position to potentially earn sufficient income to reach the inflation adjusted adequacy benchmark, let alone to generate and earn sufficient income to enjoy a comfortable lifestyle.

In this day and age, Government must rethink the philosophical underpinning behind the disability pension. This report argues that the

disability pension should complement any income earned and not be negatively pegged to income earned. Only through the re-orientation of the philosophical tenets of a disability pension as an income boost to compensate for income gaps as a direct correlation of the inherent disability and the arising impact on 'functionality', can a robust and sustained ISL policy framework be designed and introduced.

**Third:** The governance of the disability pension discussed creates what is termed a 'benefit trap' – that the disincentive relating to income earned and the disability pension, stifle motivation for the disabled person or his or her family to find employment.

This report argues that this criterion is anachronistic. It is pertinent to underline that it is Government's stated policy that it seeks to secure active labour participation – not only from non-disabled persons but from all cohorts and groups in society; including disabled persons. Indeed, in 2008 the Government removed a similar cap that was placed on persons who retire upon reaching the official retirement rate to encourage active aging – thereby allowing a person who is 61 years of age and over to draw a pension and earn uncapped income.

Moreover, in the aforementioned Strategic Review on the pensions system, the report, in Recommendation 22, proposes that the Government should consider the removal of Article 32(1)(a) which establishes that the earnings of a widow after the 21<sup>st</sup> birthday of her child are capped to the weekly average equivalent to the National Minimum Wage.

The provision of a disability pension is subject to a means test. Article 27 (3) of the SSA states that a person who becomes entitled to a pension shall have his weekly means calculated as established in the said Article as well as in Part V, titled 'Disability Pension and Pension for the Visually Impaired' of Second Schedule of the SSA. Part V of the Second Schedule of the SSA establishes that the means test for a single disabled person takes into account property that is not a house of residence where-in the first of €585 is ignored; and any income, privilege or cash settled in any trust which is enjoyed by the person, subject that any income paid out of a charitable fund as well as the first €470 by way of earnings derived by any person from the carrying out of hand knitting, lace making, crochet and embroidery activities at home, and the manufacture of which does not involve any mechanical processes are not taken into account.

This, too, raises a concern with regards to **an ISL policy framework**. This requirement of the SSA prevents a family or group of families from putting together a private trust that will guarantee independent income to the disabled person – a vehicle that is of importance with regards to guaranteeing a standard of living and care for the disabled person particularly following the death or inability of the parents to continue to provide personal care to their disabled child.

It is pertinent to underline that a recommendation to move towards a universal disability pension that assesses the recipient disabled person's means was identified as a concern by the Department of Social Security.

The argument presented by the Department of Social Security is that a universal policy is not sustainable and will not be maintained over the long term. On the other hand the current mechanism disincentivises parents of a disabled person to invest on his or her sufficient income to live a better life. It penalises self help – and in doing so it defacto shift or retain the burden with the State as no independent or private income will be made available.

In truth the true economic burden onto the State or the cost of the social transfer of either option is not known as no economic and social impact assessment has been carried out.

### **03.3 Education and Disabled Persons**

The first attempts at integrating disabled people into mainstream education started in earnest with the introduction of the Education Act 1988 (Spiteri et al. 2005). The Education Act (1988) represented an important step forward towards mainstreaming, disabled people were accepted on condition that "[the] handicapped child could manage successfully in an ordinary school [...]".<sup>63</sup>

Significant progress in inclusive education occurred following Malta's signing of the Salamanca statement (UNESCO 1994), which resulted in the adoption of an inclusive education policy (1995), which increased the number of disabled people in mainstream compulsory education.

Malta is now following an Inclusive Policy in Education, where students with Individual Educational Needs are included within the mainstream education system. Indeed, the Ministry of Education drew up the first

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<sup>63</sup> Pg 16, Spiteri, L., Borg, G., Callus, A. M., Cauchi, J., and Sciberras, M., Inclusive and Special Education Review, Ministry of Education, Youth and Employment, June 2005, [http://www.education.gov.mt/ministry/doc/pdf/inclusive\\_edu.pdf](http://www.education.gov.mt/ministry/doc/pdf/inclusive_edu.pdf)

National Inclusive Policy in 2000, which introduced the Individual Educational Programme (IEP) aimed at supporting disabled students within mainstream schools. This policy also proposed a strategy to achieve the goal of inclusion by providing disabled people with better quality education and learning support assistance to achieve this goal.

While this policy was a key catalyst in initiating a transformation in this sector, in 2004 a special review, titled, 'The Inclusive and Special Education Review', was tasked by the Ministry of Education to chart a way forward towards achieving a fully integrated mainstream education given that efforts till then were lagging and falling short of the targets that were sought.

The 2005 Census provides a snapshot of the presence of disabled persons in the education system only one year following the submission of the Inclusive Review. Other than the recently launched Education Statistics Report issued by NSO in 2010, which presents data for the 2005 / 2006 scholastic and academic year, there are no other recent statistics. Thus it is difficult to gauge in actual terms the extent of success as a result of the implementation of the recommendations presented in the Review<sup>64</sup>.

The 2005 Census further shows disparities between disabled and non-disabled persons. As can be seen from the Table below, 9.8% of disabled people have had no schooling compared to 1.9% within the non-disabled population. Similarly, 42.3% of disabled people were reported to have attained only up to a primary level of education, compared to 24.3% of non-disabled people. On the other hand, whilst 46.3% of the non-disabled population have been educated up to secondary level, only 42.3% of disabled people have reached this level.

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<sup>64</sup> It is fair to underline, however, that discussions with stakeholders shows that the quasi unanimous view is that tremendous progress has been made in this field

**Table 18: Disabled Persons by Gender and Level of Education Achieved<sup>65</sup>**

Educational level	Males		Females		Total	
	No.	%	No.	%	No.	%
No schooling	794	7.2	1421	12.4	2215	9.8
Special school	565	5.1	357	3.1	922	4.1
Pre-primary	115	1.0	268	2.3	383	1.7
Primary level	4089	36.9	5443	47.4	9532	42.3
Secondary level	4007	36.2	3040	26.5	7047	31.2
Post-secondary level	775	7.0	499	4.3	1274	5.6
Non-tertiary level	112	1.0	81	0.7	193	0.9
Tertiary level	621	5.6	371	3.2	992	4.4
<b>Total</b>	<b>11078</b>	<b>100</b>	<b>11480</b>	<b>100</b>	<b>22558</b>	<b>100</b>

As can be seen from the Table below, this pattern is replicated when one assesses the qualifications attained by disabled persons.

**Table 19: Disabled Persons and Level of Education Certification Achieved<sup>66</sup>**

Qualification attained	Disabled		Non-Disabled		Total	
	No.	%	No.	%	No.	%
No qualifications attained	17884	79.3	173185	55.3	191069	57.0
O level	1650	7.3	50091	16.0	51741	15.4
Intermediate level	118	0.5	2789	0.9	2907	0.9
A level	431	1.9	22433	7.2	22864	6.8
Certificate or diploma not issued	1483	6.6	33246	10.6	34729	10.4
University diploma	173	0.8	4821	1.5	4994	1.5
First degree	226	1.0	10509	3.4	10735	3.2
Professional qualification	256	1.1	4162	1.3	4418	1.3
Degree and professional qualification	110	0.5	3976	1.3	4086	1.2
Post-graduate diploma or certificate	79	0.4	2801	0.9	2880	0.9
Masters	98	0.4	4028	1.3	4126	1.2
Doctorate (PhD/DBA)	50	0.2	877	0.3	927	0.3
<b>Total</b>	<b>22558</b>	<b>100</b>	<b>312918</b>	<b>100</b>	<b>335476</b>	<b>100</b>

The data presented in the above Tables gives rise to concern with regards to **the development of an ISL policy framework**. As shown in the previous section, the majority of the jobs carried out by disabled persons are low employment ones. The level of education and the employment income earned are highly correlated.

Thus, albeit on the basis of 2005 Census data, the high percentage of disabled persons who have no schooling as well as the fact that nearly 60% of disabled students opt out following the primary level of education shows that disabled persons run a high risk of not only being confined to

<sup>65</sup> Pg 47, Census, The Quality of Life of Disabled People in Malta: Some Answers from the Census 2005

<sup>66</sup> Pg 13, Ibid



low employment jobs, but, more worryingly, of being completely marginalised from the employment sector.

The absence of data renders it difficult to see whether improvements are being reached following the implementation of the recommendations presented in the afore mentioned Review. A comparative indicator to determine progress between the Census and the NSO 2010 Education report is the number of disabled persons attending special schools. The 2005 Census identified 922 disabled persons attending such schools. By the time of the 2005/2006 the number of students attending special schools had fallen to 290. This indicates that within a very short period, 632 – or 68.54% - disabled students were mainstreamed within the State education system.<sup>67</sup>

If this is an indicator of improvements in other areas related to the education of disabled persons in a mainstream education environment, then the future vis-a-vis the education and skilling of disabled persons augurs well. It is pertinent to add that in discussions held in the drawing up of this report, persons representing KNPDP, NGOs and other stakeholders involved in the disability sector have all confirmed that major positive developments have been achieved in improving the education and skills level of persons with disabilities.

In the 2005/2006 scholastic year students were mainstreamed as follows:

**Table 20: Mainstreamed Disabled Students<sup>68</sup>**

<b>Level / Year</b>	<b>Government</b>	<b>Church</b>	<b>Independent</b>	<b>Total</b>
<b>Kindergarten</b>	199	18	52	369
<b>Primary</b>	1,628	738	153	2,519
<b>Secondary</b>	483	262	98	843

The categorisation of the above disabled students according to impairment is shown in the Table below.

<sup>67</sup> Pg 105, 2006 Education Statistics, National Statistics Office, 2010

<sup>68</sup> Pg 110-111, Ibid

**Table 21: Mainstreamed Disabled Students by Disability<sup>69</sup>**

Level / Year	Moderate Learning Difficulties	Severe Learning Difficulties	Mobility Problems	Hearing Impaired	Visually Impaired	Challenging Behaviour
<b>Kinder-Garten</b>	247	127	72	42	26	241
<b>Primary</b>	1,396	638	107	54	43	456
<b>Secondary</b>	888	104	28	24	24	131

The number of support provided through full-time or shared facilitation to these students is shown hereunder.

**Table 22: Provision of Full-time Facilitator and Shared Facilitator<sup>70</sup>**

Level / Year	Government		Church		Independent		Total
	F/T	Shared	F/T	Shared	F/T	Shared	
<b>Kinder-garten</b>	28	5	7	1		4	45
<b>Primary</b>	457	283	158	68	17	24	1,000
<b>Secondary</b>	158	61	104	42	5	5	375

A further concern that emerges from the 2005 Census is the relatively high level of illiteracy amongst disabled persons when compared to non-disabled persons: 24.5% and 7.2% respectively. The Census does not identify whether the rate of illiteracy is in one of the official languages only – that is a person who is literate in Maltese but illiterate in English is still designated as literate.

The issue of language is key as it constitutes one of the skills set important for higher earning jobs as well as the fact that within certain economic activities English is the working language – ICT, for example. Whilst the following is not backed by statistics, a concern garnered during the course of preparing this study is that the larger part of disabled persons are literate in Maltese only.

One other key concern that emerges from 2005 Census is that there are higher percentages of disabled women than men who have achieved a

<sup>69</sup> Pg 109, Ibid

<sup>70</sup> Pg 112-119, Ibid

low level education. Moreover, for the higher levels of education, percentages are higher for disabled men than women.<sup>71</sup> While most disabled men and women do not have any qualifications at all, there is a higher percentage of disabled women than men in this category (82.5% compared to 75.9%). Percentages of disabled men and women for all levels of education are similar with the exception of those whose certificate or diploma was not issued by the university – 9.0% of disabled men compared to 4.3% of disabled women.<sup>72</sup>

Of the disabled persons who were studying at the time of the 2005 Census only 2.1% (481 persons) were studying on a full time basis. 0.7% (150 persons) and 0.2% (46 persons) disabled persons were studying on a part-time and distance learning basis respectively. 97% (21,881 persons) were not studying.<sup>73</sup> From a gender perspective the number of male and women disabled persons studying was fairly evenly distributed – although there are slightly more males in full-time education than women (268 males as against 213 women).<sup>74</sup>

### **03.4 Provision of Independent Supported Living Services**

There is present today elements of an ISL operating framework. The current state of play with regards to ISL is serviced by the three players: Government, the Church, and NGOs.

The government agency providing ISL services is Aġenzija Sapport. The Agency has a number of functions. One function is the Social Work Service which acts as the first point of reference for disabled persons in need of a service. Services offered include:

- assisting disabled persons to address in an effective way any social issues they encounter.
- support disabled persons in their process of self advocacy and advocate with them when such assistance is requested.
- work with disabled persons to strengthen their informal networks.

The Table below presents an overview of the Social Work Service between 2007-2009.

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<sup>71</sup> Pg 46, Ibid

<sup>72</sup> Pg 47, Ibid

<sup>73</sup> Pg 14, Ibid

<sup>74</sup> Pg 50, Ibid

**Table 23: Social Work Service Overview: 2007-2009<sup>75</sup>**

<b>Status</b>	<b>Number of Clients</b>
<b>Number of persons requesting service</b>	950
<b>Number of persons who received service</b>	940
<b>Number of persons actively receiving service at the end of 2009</b>	213
<b>Number of persons presented to the Service Allocation Committee</b>	139
<b>Number of persons on waiting list for presentation to the Service Allocation Committee</b>	115
<b>Number of persons on waiting list for casework at the end of 2009</b>	10

Agenzija Sapport provides residential services for persons with disability directed to address an arising gap wherein:

“... in Malta, a number of persons with disability continue to live with their natural family, which arrangement serves both housing and support purposes. However, gradually, the complex reality of such living arrangements moved more to the forefront and a number of questions were being asked. Parents of persons with disability who had sole responsibility to support their son / daughter started to question what was going to become of their child once they are no longer present or when they will not be fit enough to continue providing such support. ... Above all, some persons with disability themselves, started to voice their wish not to continue being dependent on their family of origin for housing; several persons wished to move out and lead a more independent life.

If they are not provided with services to address their right to independent and community living, persons with disability have few alternatives. In fact, a number of persons with disability who required support in their day-to-day lives and whose immediate family was not in a position to provide this support ended up living in institutions such as the mental health hospital or in

<sup>75</sup> Pg 515, Report 2007-2009, Foundation for Social Welfare Services

residences for older persons – dwellings that were far from appropriate or adequate.”<sup>76</sup>

Aġenzja Sapport was therefore given the responsibility to “start addressing the needs of persons who, either by default or by choice, required alternative living arrangements ...”<sup>77</sup>

The Table below provides an overview of the residences managed by the Agency.

**Table 24: Residential Services Provided by Aġenzija Sapport<sup>78</sup>**

<b>Residency</b>	<b>Residents</b>	<b>Support</b>
<b>Fgura: Opened in November 2002 (Housing Authority)</b>	3 persons who previously lived with their family	Require intensive support – of whom 1 resident improved to intermediate plus in 2009
<b>Kirkop Apartment February 2003 (Housing Authority)</b>	4 persons. 2 previously with family and 1 from Mount Carmel Hospital, and 1 from Villa Chelsea	2 require intermediate support 2 require basic need support
<b>Villa Maria, Mtarfa July 2003</b>	8 persons of who 6 lived at Mount Carmel Hospital while another 2 resided with their families	2 require intensive level support 2 on intermediate level plus support 2 on intermediate level support 2 on basic level of support.
<b>Varjita Marsascala February 2003</b>	1, Can take 14 persons. As at end of 2009 there were 13 residents.  5 persons were from Mount Carmel Hospital 1 resided in a home for the elderly	3 required intensive level of support 1 required intermediate plus level of support 6 required an intermediate level of support 3 required a basic level

<sup>76</sup> Pg 527, ibid

<sup>77</sup> Ibid

<sup>78</sup> Pg 528-531, ibid

		7 lived with their families	of support.
<b>Varjita Marsascula December 2003</b>	<b>2,</b>	Can take 12 persons. As at end of 2009 there were 9 residents. Experienced movement due to deaths, et al.	1 required intensive level of support 4 required intermediate plus level of support 2 required an intermediate level of support 2 required a basic level of support.
		2 persons were from Mount Carmel Hospital 1 resided in a home for the elderly 3 from Villa Chelsea 1 from long respite at Dar il Kaptan 2 lived with their families	
<b>Dar Andrew (Housing Authority)</b>		Can take 7 persons. 1 person was from Mount Carmel Hospital 6 lived with their families	2 required intensive level of support 1 required intermediate plus level of support 2 required an intermediate level of support 1 required a basic level of support.

Additionally, the Agency is involved in the management and operations of Dar Pirotta and the Arka Foundation Respite Centre – collaborative initiatives between Government and the Church. With regards to Dar Pirotta, for example, Government provides working capital financing. Agenzija Sapport is involved in the assessment and selection of residents as well as, together with the Church, monitoring and assuring the quality of the service provided.<sup>79</sup>

<sup>79</sup> II-Qawsall, ID/07, [http://www.sapport.gov.mt/pdf/newsletter/qawsalla\\_issue10pdf](http://www.sapport.gov.mt/pdf/newsletter/qawsalla_issue10pdf)

**Table 25: Residential Services Provided by Aġenzija Sapport<sup>80</sup>**

<b>Residency</b>	<b>Residents</b>	<b>Support</b>
<b>Dar Arka, Ghajnsielem</b>	6 persons. 1 person were from Mount Carmel Hospital 1 from Gozo Hospital 4 lived with their families	2 required intensive level of support 2 required intermediate plus level of support 2 required an intermediate level of support.
<b>Dar Pirotta, B'kara</b>	7 persons. 1 from Dar Kaptan 1 from Jeanne Antide Home 5 lived with their families	2 required intensive level of support 2 required intermediate plus level of support 1 required an intermediate level of support 1 required a basic plus level of support 1 required a basic level of support.

As can be seen from the above Table, the property stock for residential services managed by the Agency includes a bungalow which the Agency built on land provided free to it by the Government Property Division, 3 apartments, and residential units leased from the Housing Authority.

The housing capacity managed by the Agency provides independent housing for 46 residents. The number of disabled persons who have been approved but are still awaiting assignment to an ISL residential home is 23 – which basically constitutes 50% of existing stock. Furthermore, an additional 69 persons are yet to be reviewed by the Admission Committee vis-a-vis their respective application for residential services.<sup>81</sup>

The Agency has a mixed complement of full-time and part-time personal assistants who provide services to persons with disabilities with regards to daily activities such as “bathing, toileting, dressing and undressing,

<sup>80</sup> Ibid

<sup>81</sup> Pg 535, Ibid

[and] feeding”<sup>82</sup>. The Agency also provides networking services directed to integrate the disabled person within the community and social activities.

The Agency complements such services with individualised holistic support services directed to ensure a personalised and individual support plan as well as by a 24\*7 support team geared to respond to needs as they may arise from the persons living in an ILS environment.

The Table below shows the community services provided by the Agency in 2009.

**Table 26: Community Service Overview - 2009<sup>83</sup>**

<b>Service</b>	<b>No of FTEs</b>	<b>Hours</b>
<b>Personal Assistance</b>	44	323 hrs / week
<b>Intervention</b>	43	199 hrs / week
<b>Combined</b>	18	121 hrs / week

Personal Assistance services averaged to 7.3 hours per week per disabled person and intervention to 4.62 hours per week per disabled person.

The other major actor with regards to ISL service provision is the Church through Id-Dar tal-Providenza and Dar Pirotta. Dar il-Providenza opened an ISL house in Siggiewi. The house accommodates five disabled persons: one person with a physical disability and four persons with an intellectual disability.

The residents are supported by a full-time carer and during weekends an additional carer is present who assists the persons with social activities. A 24\*7 care support facility is provided on a shift basis. All five persons have a form of employment. The person who is physically disabled holds a full-time job. Three of the intellectually disabled persons are employed in sheltered workshops at Dar il-Providenza whilst the fourth intellectually disabled person is employed at a sheltered workshop.

<sup>82</sup> Presentation, Agenzija Sapport, Foundation for Social Welfare Services, [http://www.appogg.gov.mt/pdf/downloads/presentations\\_leonardo\\_sapport.pdf](http://www.appogg.gov.mt/pdf/downloads/presentations_leonardo_sapport.pdf)  
<sup>83</sup> Pg 515, Report 2007-2009, Foundation for Social Welfare Services



With the exception of the physically disabled person, all the other persons receive a living monthly allowance of €1,000 – whilst the disability pension is deposited with the Dar tal-Providenza.

Dar il-Providenza has stated that the experience garnered is that mixed accommodation has not proven to be as successful as expected. Indeed, the Dar tal-Providenza is in fact actively looking at setting up a new ISL home in Qawra which will house physically disabled persons only. The reasons of why the mixed disability environment at Dar il-Providenza was not as successful as expected should be studied so that lessons are learnt as against discarding mixed ISL environment as model on the basis of this experience.

The third stakeholder in the ISL service provision are NGOs. As can be seen from the Table below, NGOs involved in the social and community sector constitute the largest group.

**Table 27: Enrolled Voluntary Organisations - 2009<sup>84</sup>**

Classification	No. of VOs	Percentage of Total VOs
Philanthropy	113	13.26 %
Education and Sports	150 (Sports 22)	17.60 %
Religion	39	4.57 %
Health	85	9.97 %
Social and Community	171	20.07 %
Culture, Arts and National Heritage	142 (Band Clubs 42)	16.64 %
Environment and Animal Welfare	73 (Animal Welfare 24)	8.56 %
Human Rights	80	9.38 %

The absence of data renders it difficult to assess the extent to which NGOs are supporting ISL and the resources available to them. Once again, the data available that is published is dated. As can be seen from the table below Government contributions in 2004 constitute 22.08% of the NGO's income stream – though it is not clear whether such financing is directed to church or lay NGOs, to which social welfare sector, and how this was distributed in terms of value. The largest income stream was donations – at 31.36%.

<sup>84</sup> Pg 14, Office of the Commissioner for Voluntary Organisations, Annual Report, 2009

**Table 28: Distribution of Income in Social Welfare NGOs<sup>85</sup>**

Type	Income			
	2001	2002	2003	2004
<b>Membership contributions</b>	960,275	1,225,177	1,231,652	1,019,720
<b>Government contributions</b>	4,726,076	4,996,720	4,942,471	5,216,052
<b>Grants for the EU Commission</b>			28,093	13,418
<b>Donations</b>	5,632,836	6,972,604	8,117,077	7,407,202
<b>Fundraising activities</b>	2,051,148	2,323,821	2,398,413	3,205,793
<b>Other services</b>	4,336,598	3,957,368	4,642,059	5,247,794
<b>Other</b>	3,186,597	3,525,835	1,943,483	1,508,633
<b>Total income</b>	<b>20,893,530</b>	<b>23,001,525</b>	<b>23,303,248</b>	<b>23,618,612</b>

Updated data sources were thrawled from Parliamentary Questions. The Table below demonstrates how the public financing was distributed in 2010 as well as the period covering 2000-2010.

**Table 29: Public Funding of NGOs in the Disability Sector: 2000-2010<sup>86</sup>**

NGO	2010 €	%	2000-2010 €	%
<b>Dar il-Kaptan</b>	209,614	17.31	2,138,843.46	16.3
<b>Down Syndrome Association</b>	700 (2008)		4194.05	0.03
<b>Eden Foundation (Inspire)</b>	689,630	58.74	7,974,712.14	62.56
<b>Equal Partners Foundation</b>	12,464	1.06	188,701.84	1.48
<b>Fondazzjoni Arka</b>	189,611.45	16.15	1,336,275.58	10.48
<b>Fondazzjoni Nazareth</b>	47,000	4	408,594.69	3.21
<b>Fondazzjoni St Jeanne Antide</b>	31,000 (2008)		31,000	0.24

<sup>85</sup> Pg 20, Study of Volunteering in the European Union, Country Report, Malta, 2009

<sup>86</sup> PQ 207799

<b>Fondazzjoni Wens</b>	25,020	2.13	585,152.96	4.59
<b>Health Services Group</b>	7,126		45,117	0.35
<b>Razett tal-Hbiberija (2007)</b>	13,976.24	0.61	97,504.33	0.76
	1,174065.45		12,747,597.14	100

As can be seen from the above Table, 89.34% of public funding distributed to NGOs between 2000 and 2001 was directed to 3 NGOs only – the Eden Foundation which at 62.56% received the greater part of the funds; and followed by Dar il-Kaptan with 16.3%, and Fondazzjoni Arka with 10.48%.

The Table below compares, over the 2000-2010 period the average public funds received by a NGO vis-a-vis the average number of beneficiaries over the said period.

**Table 30: Annual Average Funds Allocated per NGO Beneficiary<sup>87</sup>**

<b>NGO</b>	<b>Average Funds Received 2000-2010</b>	<b>Average Beneficiaries 2000-2010</b>	<b>Average Funds / Beneficiary</b>
<b>Dar il-Kaptan</b>	213,834.86	125.4	1705.22
<b>Down Syndrome Association</b>	N/A	N/A	
<b>Eden Foundation (Inspire)</b>	58,503.05 <sup>88</sup>	27.9	2096.88
<b>Equal Partners Foundation</b>	25,740.37	244.2	105.41
<b>Fondazzjoni Arka</b>	167,034.45	4.124	40,503.09
<b>Fondazzjoni Nazareth</b>	37,144.97	8.19	4,535.41
<b>Fondazzjoni St Jeanne Antide</b>	31,000	26	1,192.31
<b>Fondazzjoni Wens</b>	53,195.72	15	3,546.38
<b>Health Services Group</b>	9,023.40	233	38.73

<sup>87</sup> Ibid

<sup>88</sup> The PQ does not provided data with regards the number of beneficiaries that benefit from €6,746,148 assigned to the Eden Foundation

<b>Razett tal-Hbiberija</b>	11,938.04	30	397.93
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Of particular note are two matters. The first relates to the amount of funding relative to number of beneficiaries present at Fondazzjoni Arka. Beneficiaries at any one year during the period under review ranged from 1 disabled person to 6 disabled persons. The average annual cost at €40,503.09 per beneficiary is high – a figure which remains high even if the maximum number of 6 beneficiaries is taken: €27,839.08 per annum.

The second relates to the fact that with regards to €6,746,149 of funds allocated to the Eden Foundation / Inspire between 2000 and 2010 – which is 52.92% of all public funds allocated to NGOs in the disability sector – no account and disclosure was made of the number of beneficiaries who benefited as a direct resulting of this financing.

The absence of structured research and data with regards to service providers in the social welfare renders it difficult to draw up a composite picture of the capacity, depth, strengths and resources that they can muster in order to participate actively and sustainably in supporting the implementation of an ISL policy framework.

Rather, the impression garnered following the holding of discussion meetings with NGOs in the disability sector is that this sector is quite fragmented. Additionally, on certain issues, such as self-advocacy and the control that disabled people – including those who have an intellectual disability – should have over decisions affecting their own lives, there is a mismatch on the one hand between the varying positions of different organisations; and on the other between parents and the KNPD with regards to the level of parental involvement in the decisions made by their disabled children.

## **04. Options and Recommendations with regards to an Independent Supported Living Policy Framework**

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### **04.1 Policy Design and the Absence of Structured and Relevant Data**

It is not possible to design and formulate a good policy framework in the absence of quality data. The policy framework proposed in this report is limited by the fact that there is no comprehensive data with regards to the disability sector.

The most recent data available – other than basic data of disabled persons, type of disability, persons claiming disability pensions et al – is 2006 – stemming from the Education Statistics report issued by the National Statistics Office in 2010.

This report argues, emphatically, that KNPD must seek to address this serious shortcoming in the shortest time possible. It should seek to achieve this by agreeing with the NSO the introduction of a robust and structured statistical methodological framework for the ongoing collation of key data sets within the disability sector.

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#### **Policy Recommendation 01**

The report finds the absence of data in the disability sector a serious lacuna and emphasises that there can be no good policy design in the absence of such data and thus recommends that the Kummissjoni Nazzjonali Persuni B'Diżabilità to agree with the National Statistics Office the introduction of a robust and structured statistical methodology.

In tandem with the above, the report further recommends that the KNPD should draw up applications under the appropriate EU and local financing instruments for it to carry out a comprehensive and statistically significant surveys across a series of important policy issues relevant to universal disability policy design targeting, as a minimum, a statistical snapshot as at 2011.

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#### **Policy Recommendation 02**

The report recommends that the Kummissjoni Nazzjonali Persuni B'Diżabilità submits, under the appropriate financing EU and local

instruments at forthcoming call for applications, applications for the financing of a comprehensive and statistically significant survey across a series of important policy issues relevant to universal disability policy design targeting, as a minimum, a statistical snapshot as at 2011 that will, amongst others, allow for a drawing up of a comprehensive picture of the capacity, depth, strengths and resources that can be mustered in order for stakeholders to participate actively and sustainably in supporting the implementation of an ISL policy framework.

#### **04.2 Ratification of UN Convention Article 19 on the Rights of Persons with Disabilities**

Government's support to the principle and philosophical tenet of providing ISL for a disabled person should go beyond lip service. The Government's sincerity and commitment in this regard should be visibly demonstrated through the ratification of the UN Convention Article 19 on the Rights of Persons with Disabilities.

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#### **Policy Recommendation 03**

The report recommends that Government should in a concrete manner its commitment towards Article 19 of the United Nations Convention of the Rights of Persons with Disabilities by ratifying this Convention at the earliest possible,

#### **04.3 Defining Disabled Persons for an Independent Supported Living Policy**

As discussed in the previous chapter, the statistics put forward by KNPD with regards to disabled persons include persons who have some lasting physical or mental functional impairments which *is manifestly due* to normal aging.

This report suggests that disabilities that are manifestly the result of aging should not be governed by an ISL for disabled persons. Rather independent living with regards to aging should be tied with community care for the elderly policy design.

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#### **Policy Recommendation 04**

The report favours a strategy for an Independent Supported Living policy

framework that is separated and independent from aging and care for the elderly, until at least, such time that appropriate State investment would have been directed towards securing a critical mass resulting in a sustainable environment for persons with disabilities which are not acquired through aging.

It is pertinent to underline that this definition, similar to the Swedish model, therefore includes, for the purpose of an ISL policy framework, (i) persons who are born with a disability; and (ii) persons who acquire a disability that is not associated with aging.

As proposed the definition includes persons who experience a disability that is not a result of aging – including early origination of disabilities such as Parkinson’s and Alzheimer’s which are normally associated with aging.

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### **Policy Recommendation 05**

The report recommends that an Independent Supported Living policy framework should be directed as a priority towards persons with an impairment that originates as well as persons who acquire an impairment that is not the result of aging.

#### **04.4 Policy Integration and Coherence for Malta’s Independent Support Living Policy Framework**

Good ISL policy design transcends demands of different policy sectors - education, transport, accessibility, income to mention a few. Too often the dividing line between these and other different policy domains renders a comprehensive and holistic approach towards meeting disabled people’s needs difficult to attain.

To achieve policy integration and coherence across a number of other policy domains, a mechanism should be introduced to ensure that mainstream or specialist policy, stemming from another ministry, that may overlap or affect the universality of an ISL policy framework is scrutinised against three key policy design principles – thereby safeguarding cohesion towards a holistic universal ISL policy design.

The three principles against which such scrutiny is to be carried out are the following<sup>89</sup>:

- **Inclusivity:** Disabled people are to be enabled to contribute to the life of their local communities and to society generally. Disabled people's needs are therefore to be actively incorporated early on alongside other citizens.
- **Effectiveness:** Disabled people are to receive individualised responses to their additional requirements, to a high standard, when they need them, for as long as they need them; so that they are empowered as consumers and citizens.
- **Informed:** Disabled people should be supported to make informed choices, through peer advice and advocacy and to actively participate in consultations held by Government with regards to policy and strategy design.

The report recommends that the scrutiny process in this regard is carried out by the Policy Advisory Board recently set up within the Office of the Prime Minister.

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### **Policy Recommendation 06**

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The report recommends that all mainstream and specialist policies are scrutinised on the basis of inclusivity, effectiveness, and informedness by the Office of the Prime Minister to ensure cohesion towards a holistic universal Independent Supported Living policy design.

### **04.5 Establishing a Legislative Framework for Independent Support Living**

The report argues that KNPD should lobby the responsible Ministry to legislate for ISL by means of introducing an ad hoc legislation similar to the approach adopted by other jurisdictions overseas.

Entrenching the principle and regulatory framework for ISL in legislation would provide KNPD and the associated stakeholders with the appropriate leverage to:

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<sup>89</sup> Improving the Life Chances of Disabled People, Cabinet Office, Prime Minister's Strategy Unit, January 2005, [http://www.derby.gov.uk/NR/rdonlyres/1D796C7C-1092-417F-BAD5-FD2F603DEF0A/0/improving\\_the\\_life\\_chances\\_of\\_disabled\\_people.pdf](http://www.derby.gov.uk/NR/rdonlyres/1D796C7C-1092-417F-BAD5-FD2F603DEF0A/0/improving_the_life_chances_of_disabled_people.pdf)



- secure, on the one hand, a higher level of policy cohesion to universal ISL policy design particularly by establishing at law scrutiny mechanisms on policy principles discussed in 04.4 above; and
- on the other hand, establish a statutory platform that recognises ISL as a cornerstone of Government’s vision and strategy to improve the quality of life of disabled persons and in doing so positions ISL for mainstream financing.

The Table below compares the design of the legislative instruments on ISL drawn up in the US, UK (Bill) and Sweden.

**Table 31: Comparison of Provisions Independent Supported Living Legislation**

United States	United Kingdom	Sweden
Purpose	General Principles	Introductory Provisions
Definition	Relationship with Disability Discrimination Act 1995	Objectives and general orientation of the Act
Eligibility for Receipt of Services	Interpretation	Entitlement to Measures
State Plan	General Duties in relation to Independent Living National independent living strategy General duty of local authorities and NHS bodies Further duties of local authorities Further duties of NHS bodies Co-operation to promote independent living Independent living strategy	Measures for Special Support and Special Service

		Duty to identify and maintain register of disabled persons Duty to enhance capacity among local service providers	
State-wide Independent Council	Living	Right to Independent Living Right to information, advice and assistance Right to self-directed assessment of requirements Duty to make arrangements Individual and delegated budgets Discharge from hospital Authorised representative Disputes between carers and disabled persons Charging of disabled persons Co-operation between authorities to facilitate independent living plan Determination of living arrangements Amendment of the Children Act 1989 Co-operation between authorities to maintain support Amendment of the Mental Health Act 1983	Special Duties for a Municipality

Responsibilities of the Commissioner	Inspection and Complaints	Common provisions concerning the responsibility of country councils and municipalities
Independent Living Services	Inspection and Advocacy	
Allotments	Amendment of the Health and Social Care (Community Health and Standards) Act 2003	
Payment to States from Allotments	Care Establishments	Charges and related matters
Authorisation of Appropriations	Application of the Human Rights Act 1998 to certain persons and bodies regulated by the Care Standards Act 2000	
	Amendment of the Care Standards Act 2000	
Centres for Independent Living Programme	Housing and Planning	Committees
Authorisation	Allocation of housing accommodation by local authorities	
Grants for Centres in which Federal Funding exceeds State Funding	Disability housing service	
Centres Operated by State Agencies	Amendment of the Local Government Act 2003	
Standards and Assurances for Centres for Independent Living	Amendment of the Building Act 1984	
	Review of the Building Regulations 2000	
	Amendment of the Planning and Compulsory Purchase Act 2004	
Independent Living Services for Older Individuals who are Blind	General Regulations and orders	Supervision and related matters
	Minor	and

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consequential  
amendments and  
repeals  
Commencement and  
extent  
Short title

Appeals

Penalties

Confidentiality

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The report recommends that the legislative provisions that should be introduced should, amongst other matters, include the following:

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**Definition of persons entitled to measures under the Act**

**Articulation of the disabled persons rights' to Independent Supported Living**

**Policy co-ordination to facilitate Independent Supported living**

**Rules with regards to access to State and / or Local Government Independent Supported Living Homes**

**Individual income and delegated budgets**

**Responsibilities of competent authority including standards setting.**

**Independent Living Homes**

**Independent Living Fund**

**Disabled Person/s Private Trusts**

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All of the above are discussed in depth in this Chapter.

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**Policy Recommendation 07**

The report recommends the Kummissjoni Nazzjonali Persuni B'Dizabilità lobbies the responsible Minister to legislate for Independent Supported Living by means of introducing an ad hoc legislation; with the legislative provisions to include, amongst others (i) definition of entitled persons; (ii) articulation of rights with regards to Independent Supported Living; (iii) rules with regards to access to State and/or Local Government Independent Supported Living homes; (iv) policy co-ordination to facilitate Independent Supported Living; (v) individual income and delegated budgets; (vi) Independent Living Homes; (vii) Independent Living Fund; and (viii) Disabled Persons / s Private Trusts.

## 04.6 Entitled Support to Independent Living

For a person to live independently, he or she requires an environment wherein the gap between the disability and the said environment is bridged. The gap that needs to be bridged is unique to the individual and subject to the disability and the severity of the said disability. It so follows, therefore, that disabled persons would require a personalised plan.

In determining the personalised plan that will allow the disabled person through entitled support to live in an ISL environment, a holistic assessment that embraces the combination of use of assistive technology, adaptation of his or her living and working environment and barrier-free infrastructure planning, et al should be undertaken. The assessment should take into account matters such as<sup>90</sup>:

- the whole life situation enabling disabled people to fulfil their roles within their family, neighbourhood and society with all the resulting privileges and responsibilities including the culturally customary division of work within the family, care of household and property.
- the need of assistance at the work place, while attending educational institutions from kindergarten through university, during leisure time, outside the home, on travel and abroad.
- all, not only one or several, areas of activity in one's life.
- the need, if applicable, of experienced and specialised assistants.
- the need of third persons for supporting assistance users who, due to a cognitive or psychosocial impairment, need support in dealing with service providers and assistants.
- activities for the maintenance of one's health and well-being such as self-care or physical exercise. Assistants can perform tasks which normally non-disabled persons, after instruction by medical staff if deemed necessary, would carry out by themselves.

It is nevertheless to be underlined that the assessment on which a personalised plan is designed is built on what a disabled person needs to be able to live in a ISL environment.

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<sup>90</sup> Ratzka, A., Model National Personal Assistance Policy, (2004), GLADNET Collection, Paper 425, Cornell University ILR School, <http://digitalcommons.ilr.cornell.edu/gladnetcollect/425>

Thus, the entitlements to which a disabled person should be eligible to should encompass the complete gamut of assisted services required as well as securing the disabled person's safety in the home he or she is living in. These consist, though are not solely limited to, the following:

- (a) The provision of a personal assisted service / s to the disabled person to enable the carrying out of all living, social, networking and other activities. The World Institute on Disability defines Personal Assisted Service as "assistance, under maximum feasible user control, with tasks that maintain well-being, comfort, safety, personal appearance, and interactions within the community and society as a whole".<sup>91</sup>

In general, a Personal Assisted Service is used by a person with a disability to perform tasks that the person would perform for him or herself if he or she did not have a disability. It can include tasks that range from reading, communication, and performing manual tasks (e.g., turning pages) to bathing, eating, toileting, personal hygiene, and dressing.<sup>92</sup>

The Personal Assisted services and support, include planning, evaluation and assessment, and thus ensures adequate functioning of the person in his or her own home as well as for accessing entry into and / or participating in the community.

It is recommended that for the purposes of an ISL Policy framework, Personal Assisted services are to be considered to include assistance or training with a wide range of activities necessary to meet the daily living needs of the person in the home and community. These include:

- (i) Personal care such as hygiene, bathing, eating, dressing, grooming, bowel and bladder care, menstrual care, transferring, basic first aid, giving medications, relief to a family, emergency response in the form of human assistance and operating medical equipment.
- (ii) Household maintenance such as meal preparation, shopping and chores, assistance with money management and personal

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<sup>91</sup> Holt, J., Chambless, C., & Hammond, M. (2006). Employment personal assistance services (EPAS), *Journal of Vocational Rehabilitation*, 24, 165-175.

<sup>92</sup> Silverstein, R. (2003). The Applicability of the ADA to Personal Assistance Services in the Workplace. Policy Brief, Issue 10. Retrieved February 21, 2008, from [http://www.communityinclusion.org/article.php?article\\_id=21&staff\\_id=36&style=print](http://www.communityinclusion.org/article.php?article_id=21&staff_id=36&style=print)

finances, cleaning, laundry, household repairs and maintenance.

- (iii) Integrated employment support and services that encompass the following types of activities designed to assist a disabled to access and sustain employment in a regular work setting:
  - (1) Individualised assessment which may include community orientation and job exploration.
  - (2) Individualised job development and placement services that produce an appropriate job match for the individual and his / her employer.
  - (3) Ongoing support, training, and facilitation in obtaining and retaining a job, job skill acquisition, job retention, career development, and work-related activities.
  - (4) Intervention and training needed to benefit from community integrated employment services and other supports which would help to remove or diminish common barriers to participation in employment
- (iv) Mentorship activities such as planning, decision-making, assistance with his or her participation on private and public groups, advisory groups and commissions, person specific training costs associated with providing unique supported living services to an individual.
- (v) Community accessibility services to support the abilities and skills necessary to enable the individual to access the community and / or provide the basis for building skills which will assist the individual to access the community. These types of services include socialisation, adaptive skills, personnel to accompany and support the individual in all types of community settings, supplies, travel and providing necessary resources for participation in activities and functions in the community.
- (vi) Specialised habilitation services focus on enabling the individual to attain his or her maximum functional level, and are coordinated with any physical, occupational, or speech therapies listed in the Individualised Plan. These services will include such training as self-feeding, toileting, and self-care,

self-sufficiency and maintenance skills. These services are highly therapeutic in nature, highly individualised with sensory stimulation and integration as major components.

(vii) Pre-vocational services such as:

- (1) Teaching an individual such concepts as following directions, attending to a task, task completion, communication, decision-making, and problem-solving.
- (2) Training in the areas of safety, and mobility.
- (3) Training with regards to self-advocacy; that is that the disabled is provided with the tools and experience to take greater control over their lives.
- (4) Intervention and training needed to benefit from prevocational services which would allow common barriers to participation to be avoided.
- (5) Travel training services may include providing, arranging, transporting, or accompanying a person with developmental disabilities to pre-vocational services and supports identified in the Individualised Plan.

- (b) The provision of intelligent technology tools to secure the safety of certain disabled person living in an independent environment. Persons with a certain type of disability living in an ISL environment may be subject to risks: falling down and being unable to call for help, especially in case of loss of consciousness; leaving the gas cooker on; leaving the premises and getting lost or mired in a situation due to an obstacle.

One way of bridging this gap is through the use of assistive technology or adaptive technology. Assistive technologies promote greater independence to persons with certain disabilities by enabling such persons to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to or changed methods of interacting with the technology needed to accomplish such tasks.



Assistive technologies that may be applied with regards to persons with certain disabilities may include one or more of the following elements<sup>93</sup>:

- (i) Body Sensor Network (BSN): includes all devices that a person must wear (accelerometers, gyroscopes, spirometers, oxymeters, etc) or use to allow the services to work. Depending on the elderly profile and the services to be configured, the BSN may include continuous monitoring sensors and other health sensors.
- (ii) Wireless Sensor Network: includes the home infrastructure sensors (ambient, presence, pressure, home automation sensors, etc.), actuators and appliances capable of notifying their status. The Wireless Sensor Network station base will communicate with the BSN by using ad hoc networking capabilities. It includes local intelligent features to dispatch events and orders depending on the situation. These processing capabilities will be part of a home gateway which will connect the home ambient via station base with the Core Care Network.
- (iii) Core Care Network: serves as a bridge of communication between the home sensorial infrastructure and third parties and service providers (caregivers). Services may be enabled through the Core Care Network. It allows for the authorisation for the connection of external service providers, centralise system monitoring and guarantee the security of personal data.

The sensor design and real-time 'intelligence' of an Ambient Assistant Living system network may consist one or more of the following configurations<sup>94</sup>:

- (i) Event detection: This consists of sensor nodes that report the detection of an abnormal occurrence. The simplest events can be detected locally by a single sensor node in isolation – say, a temperature threshold is exceeded. More complicated types of events require the collaboration of nearby or even remote

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<sup>93</sup> pp. 1 –8, Martin, H., Bernardos, A., Bergesio, L. & Tarrío, P. (2009). Analysis of key aspects to manage wireless sensor networks in ambient assisted living environments, Applied Sciences in Biomedical and Communication Technologies, 2009. ISABEL 2009. 2nd International Symposium on

<sup>94</sup> Zapata, J., Fernandez, Luque, J. F., and Ruiz, R., Wireless Sensor Network for Ambient Assisted Living, <http://www.intechopen.com/articles/show/title/wireless-sensor-network-for-ambient-assisted-living>

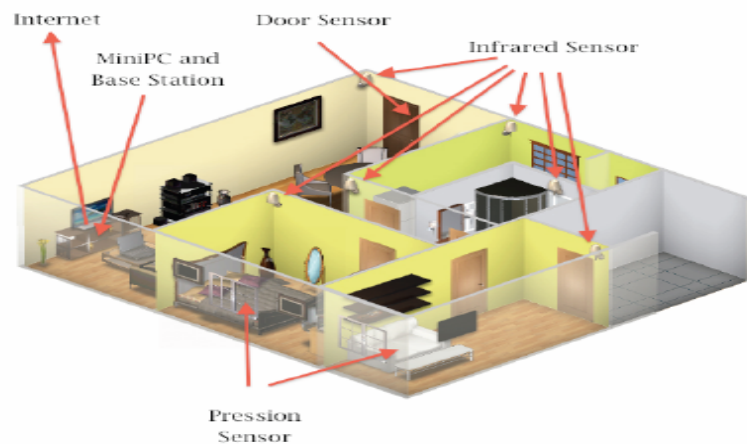
sensors, to decide whether a (composite) event has occurred – for example, a temperature gradient becomes too steep.

- (ii) Periodic measurements: This consists of sensors being tasked with periodically reporting of measured values. Often, these reports can be triggered by a detected event; the reporting period is application dependent.
  - (iii) Tracking: In this regard the source of an event can be mobile – for example, an intruder in surveillance scenarios.
- (c) The adaptation, if so appropriate, of a home to neutralise the disability gap of a disabled person living independently. The support that should be provided in this regard should include an assessment of the property and submit recommendations with regards to structural changes to adapt an existing property for independent living or provide design assistance in the event that a new property is purposely being built for such a purpose. Additionally it should also include financial assistance.

Such adaptative support should also be extended to the work place as well as to the elimination of barriers, in so far that it is possible, to allow accessibility to public transport.

- (d) The provision of a 24\*7 Command and Control Centre to monitor disabled persons during the night as well as to respond to emergencies and uncommon activities. Assistive technologies from different ISL homes could be linked to the 24\*7 Command and Control Centre. Thus, as shown in the Figure below, an ISL home can be equipped with sensors in locations such as the bedroom (pressure sensor); kitchen (gas sensor); hall (door sensor) – sending real-time monitoring data to the Command and Control Centre.

**Figure 03: Schematic View of the AAL Systems Network in a Home<sup>95</sup>**



The main challenge in a Command and Control Centre that is dependent on assistive-based monitoring technology is the balance between surveillance and privacy, i.e. safety versus ethics. A potential solution to privacy is that such technology is applied only if the disabled person or his or her guardian provides his or her consent.

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### **Policy Recommendation 08**

The report recommends that the entitled support for a disabled person living in an Independent Supported Environment should embrace, amongst others: (i) personal assisted services; (ii) assistive technology support; (iii) property adaptation to meet impairment-related needs; and (iv) 24\*7 monitoring and emergency and uncommon support, where necessary.

### **04.7 Eligibility to Independent Supported Living Services**

It is to be noted that a recent study on policies supporting independent living for disabled people in Europe demonstrates that seven countries (Finland, Netherlands, Austria, Bulgaria, Spain, Estonia, France) appear to apply an assessment medical methodology where access to ISL support including personal assistance is assessed in terms of the:

- nature of a person's impairment; and

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<sup>95</sup> ibid

- overall likely need for support in terms of hours per week, or per month.<sup>96</sup>

Trends in Europe seem to show that ISL support, primarily personal assistance, tends to be weighted towards people with physical / sensory impairments, as opposed to people with learning disabilities or mental health support needs. This is due to the nature of the formers' impairments which is more likely to meet assessment criteria which emphasise 'substantial physical care needs', as opposed to the social support needs more commonly highlighted by the latter two groups.<sup>97</sup>

Moreover, in some countries, eligibility is more a matter of where a person lives, since different geographical locations may have different services available, or there may only be one or two personal assistance 'schemes' in the whole country - thereby leading to significant inequality in access.<sup>98</sup>

On the other hand, countries such as United Kingdom, Denmark, Norway, Slovakia, Germany, Ireland and Sweden indicate that any disabled person (in some cases other non-disabled people like carers and older people) can apply for personal assistance services under their eligibility criteria.<sup>99</sup>

This report recommends that within the constraints of the definition proposed in recommendation 04.3 above, the ISL policy framework should base eligibility on the following principles:

- (i) Solely on the basis of the person's need of practical assistance vis-a-vis the bridging of the gap between the disability and independent living environment.
- (ii) Regardless of the cause or medical diagnosis of a person's disability care has to be taken to secure against differential treatment of people with certain types of disabilities, religious belief, ethnicity, sexual orientation, age or gender.

Furthermore, a person who would have qualified for Independent Supported Living services is to continue to live in such an

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<sup>96</sup> Pg 31, Townsley, R., with Ward, L., Abbott, D., Williams, V., The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report, Norah Fry Research Centre, University of Bristol, Academic Network of European Disability experts (ANED) – VT/2007/005, January 2010, <http://www.disability-europe.net/content/aned/media/ANED-Task%205%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf>

<sup>97</sup> Ibid

<sup>98</sup> Ibid

<sup>99</sup> Pg 31, Ibid

environment irrespective of aging or degeneration of his or her condition unless it becomes either not feasibly possible or actually a threat for well being on the person to continue to be supported in an ISL environment.

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### **Policy Recommendation 09**

The report recommends that, within the parameters of the definition proposed in Recommendation 04.3, eligibility to Independent Supported Living services should be solely on the basis of a person's needs and regardless of his or her cause of medical diagnosis; and that a disabled person once qualified would continue to live in such an environment irrespective of aging or degeneration of their condition, subject, however, that living independently is feasible and / or does not actually become a threat to the well being of the said individual.

Of equal importance is the recommendation that, in determining eligibility, a disabled person should not be subject to a means test of their income or capital or their parents or the household in the event that they are married.

KNPD, together with the Department of Social Security, should carry out an economic and social impact assessment to determine whether a universal system with regards to the provision of a disabled pension (or a variant there of) would in fact over the life cycle of a disabled person render it more cost effective to Government as it will 'reward' rather than 'punish' the family of the disabled person towards channelling private investment and savings to secure a better quality of living to their disabled son or daughter.

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### **Policy Recommendation 10**

Whilst the report is of the considered opinion that a person's eligibility for Independent Support services should not be subject to a means test of their income or capital to qualify for a disability pension, it recommends that an economic and social impact assessment is carried out to determine whether a universal policy to a disability pension entitlement is actually more cost effective to Government over the life cycle of a disabled person given that as this allows respective families to channel private investment and savings to secure an improved quality of life to the disabled child.

As previously discussed, the disability pension provision as governed by the SSA does not suffice to provide for an adequate standard of living. During the articulation of this report it was stated by KNPD and the Department of Social Security that work is underway to reform the disability pension.

It is understood that an inter-governmental committee is studying the possibility of reforming the disability framework from one that targets the condition of the disability to one that targets the degree of dysfunction arising from the said condition.

Thus for example, a person who has a physical or intellectual disability may carry out certain type of economic activity. A disability, therefore is not necessary an impediment to active participation in the labour market if the appropriate supporting structures are in place (skilling; re-skilling; etc)

The adoption of such a disability framework should, therefore, require that the current capping of the disability pension against income earned would be changed to a system where the pension provided to the individual reflects the degree of the incapacity whilst allowing the said persons to continue to participate in the labour market where income would no longer be capped against income earned.

It is further underlined that in the carrying out of such a reform the actual value of a disability pension that reflects the degree of functionality lost should be sufficiently adequate to allow a disabled person to live in an ISL ambient.

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### **Policy Recommendation 11**

The report supports a reform of the disability pension framework that reflects the degree of functionality lost and is decoupled from income earned subject that, however, the value of the disability pension income assigned to lost functionality is sufficiently adequate to allow a disabled person to live in an independent supported living environment.

A disabled person, however, should not be considered to be eligible for ISL support services if that person:

- (i) is not able to manage within a ISL environment without being a risk to him or herself or others.

(ii) poses no threat of physical violence, nuisance or anti social behaviour to other persons who will live with him or her in the ISL home environment or in society generally.

(iii) under 18 years of age.

Be that as it may, this report recognises that the funding that will be made available for the financing of an ISL policy framework will never be sufficient to secure an equilibrium between the demand for, and the supply of ISL services – which, as discussed in the next section can also be of a monetary nature.

In essence this will imply that at any point in time a disabled patient's right to ISL services will be rationed. Indeed, discussions with Aġenzija Sapport show that this is already the case today where as mentioned in the previous chapter there are approximately 60 disabled persons on a waiting list.

In a state of play where services are constrained and access is rationed it is imperative that the process leading to eligibility for ISL services is:

- transparent and open.
- based on a clear methodology that establishes measurable criteria that allow for a fair and true identification of risk and prioritisation.
- documented with appropriate audit trails.
- subject to a fair review.

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## **Policy Recommendation 12**

This report recognises that in a state of play where funding for the financing of an ISL policy framework will never be sufficient to secure an equilibrium between the demand for, and the supply of ISL services leading to the rationing of a disabled patient's right to ISL services it is imperative the process leading to eligibility is (i) transparent and open; (ii) based on a clear methodology that allows for a fair and true identification of risk and prioritisation; (iii) documented with appropriate audit trails; and (iv) subject to a fair review.

Disabled persons who would be eligible to ISL services but the exercise of such right is rationed due to capacity and cost effectiveness should, as is the case today, be placed on a waiting list which will continue to be managed by Aġenzija Sapport.

The report further recommends that, as with current policy today, the waiting list should not be managed on the basis of when a person applied for a service but rather on his or her level of risk and priority and how that ranks with other disabled persons on the waiting list.

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### **Policy Recommendation 13**

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The report recommends that when a disabled person cannot avail themselves of Independent Supported Living services, they are to be placed on a waiting list and that their ranking on the said waiting list will be based on a fair and open assessment methodology which includes risk and priority amongst its criterion.

## **04.8 Independent Supporting Living Framework**

### **04.8.1 Independent Supporting Living Housing Models**

The ISL model can be delivered in a range of settings and housing models which include but are not limited to the following:

(a) Individual flats and houses in ordinary streets.

A disabled person can live there as a tenant or owner or through shared ownership. The premises could be rented from government or a private landlord or even from parents or family. In this regard, Government, as has already been the case, could through the Housing Authority provide premises to Aġenzija Sapport.

Self-contained accommodation, undoubtedly, offers more independence. The degree of support required, however, may be higher particularly if a person is living on their own.

(b) Shared housing

Each disabled person in a share house will have a separate room and shared occupation of communal living, kitchen and bathroom space. A shared house is normally a small residential house and accommodates normally from two to six residents.



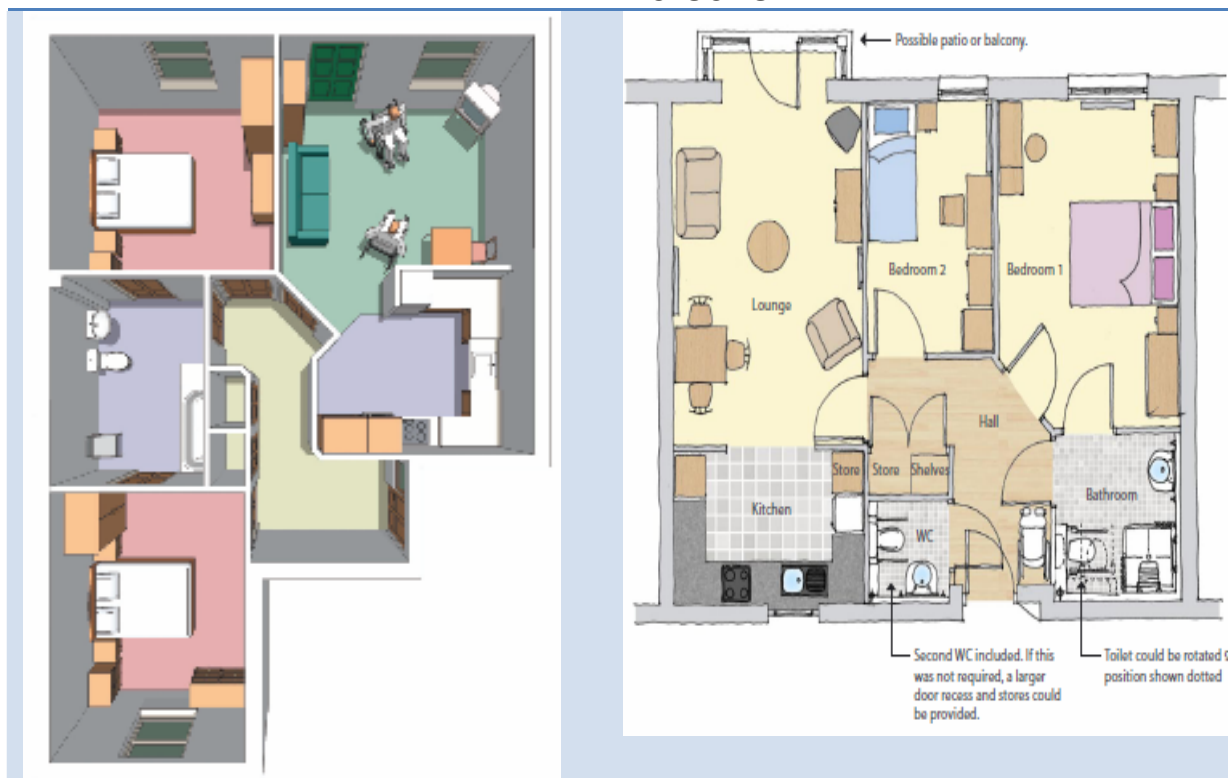
Small shared houses can work well where a group get on with each other. There can be problems if someone wants to move on and is unable to, or sometimes in filling vacancies as they arise. If two tenants want to stay together, but neither of them wants a third person to move in this could lead to affordability issues about rent and care costs.

It is argued that small shared houses therefore work best when friends choose positively to share together (rather than being matched because of their support needs).

**Figure 04: Typical Design of an ISL Flat for Two Persons**

**With a Physical Disability<sup>100</sup>**

**Care Services Improvement Partnership Best Practice Extracare Housing Flat for 2 Persons<sup>101</sup>**



**(c) Community Support Housing**

This model links up a number of separate flats or houses within a particular designated area. The most important feature is that the ISL provides for a networked environment where all disabled persons live “together” as a community, supporting each other.

Such networks are a suitable option for disabled persons with lower support needs, living in ordinary housing in a neighbourhood.

There are usually a handful of flats within walking distance. In some overseas jurisdictions such a model is designed on the basis where-in one flat is occupied by the Personal Support Assistants, who provide

<sup>100</sup> Pg 15, Nason, E., Rabinovich, L., Ling, T., and Villalba van Dijk, L., Supporting Independent Living for Disabled People, RAND Europe, [http://www.rand.org/content/dam/rand/pubs/technical\\_reports/2006/RAND\\_TR388.pdf](http://www.rand.org/content/dam/rand/pubs/technical_reports/2006/RAND_TR388.pdf)

<sup>101</sup> Pg 31, The Extra Care Housing Toolkit, Care Services Improvement Partnership

support, drawing on the skills of all the network members as well as linking them into the local neighbourhood networks.

(d) Cluster Flats

This model considers a small group of self-contained flats on the same site. Usually there would be between 6 and 10 flats. There may be communal living space and shared facilities like a laundry room.

There is a school of thought that such Cluster Flats are not truly an ISL environment but more of a residential living environment. This school of thought is countered by the argument that an on-site cluster gives people the best of both worlds, offering a protective environment that people can experience in residential care whilst strengthening independence, privacy and choice.

In most models based on Cluster Flats there will be a manager or support workers managing and supporting this housing site.

A review of foreign jurisdictions shows that there is no unique model for independent living. In Norway, policy orientation is towards larger forms of sheltered housing. In the Netherlands and Germany the living structures are directed towards disabled persons with physical/sensory impairments – which is the focus of their respective ISL strategy – and where such housing and support structures mitigate against those disabled persons with higher support needs.<sup>102</sup>

On the other hand, the Department of Health Care Policy and Financing in Colorado State in the US an eligible Supported Living Service setting is:

“... own home” which is defined as the following:

01. A living arrangement (e.g., home, apartment, or condominium) which the individual owns or rents or leases in his/her own name; or
02. The home where the individual lives with his/her family or legal guardian; and

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<sup>102</sup> Pg 15, Townsley, R., with Ward, L., Abbott, D., Williams, V., The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report, Norah Fry Research Centre, University of Bristol, Academic Network of European Disability experts (ANED) – VT/2007/005, January 2010, <http://www.disability-europe.net/content/aned/media/ANED-Task%205%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf>

03. No more than three (3) persons receiving Supported Living Services may reside in one household, unless they are all members of the same family.”<sup>103</sup>

The report titled ‘Deinstitutionalisation and Community Living – Outcome and Costs: Report of a European Study’ concludes that one of the identified six<sup>104</sup> main types of services provided are Group Homes were:

“Group homes: typically 5-6 people living together, though some examples may have up to 10 people resident. In some situations these are provided for people with mild or moderate disabilities but in others they are provided for people with more severe disabilities or complex needs (such as people with severe and profound intellectual disabilities whose behaviour also presents a major challenge, or people needing intensive nursing care). Staff support varies from visiting or drop-in support to 24-hour cover, depending on the needs of residents.”<sup>105</sup>

Irrespective of the form of housing design selected, the underlying principle of the ICL housing model should be similar to that applied with regards to extra care housing (which are also known as very sheltered housing or assisted living apartments – that is, housing designed or modified to enable a person or group of persons to live independently where-in varying amounts of care and support can be offered.

As the Figure below shows, the form and degree of care and support that will be provided depends on the level of care and support provided to the residents – which care and support reflects the degree of, physical, intellectual or other impairment of the persons accommodated within an ISL housing model.

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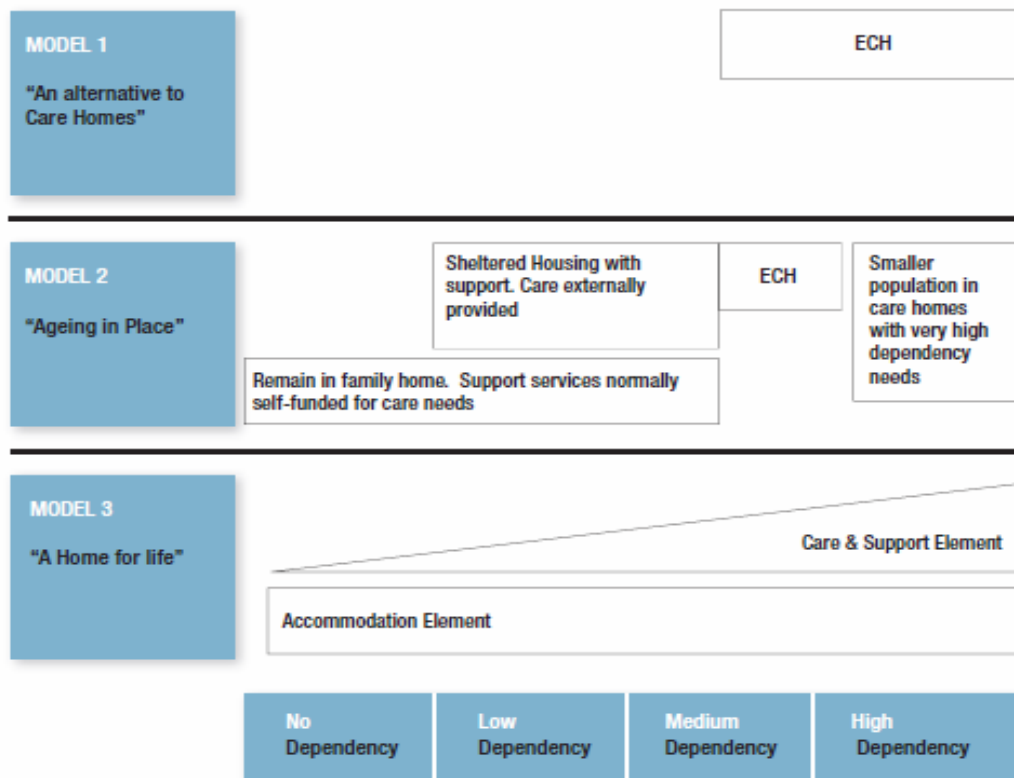
<sup>103</sup> 8.500.93(G), Supported Living Services Waiver, 8,500.90-8.500.102, Colorado Department of Health Care Policy and Financing

<sup>104</sup> The others are: **residential homes**: typically between 10 and 30 places, usually providing 24-hour staffing. In some countries these kinds of home may also provide nursing care but the ethos of the home is as a residential care setting providing a substitute home; **Campuses**: group homes clustered together on the same site and usually sharing staff and some facilities. Staff are available 24-hours a day; **Residential schools** for disabled children and colleges for young adults: these services are not distinguished by their size – they vary from establishments providing about 10 places to those providing for several hundred – but they are organised as schools or colleges providing education alongside residential care; **Social care homes or residential institutions**: large establishments serving more than 30 residents (sometimes many more residents than this). Sometimes these establishments serve people with one type of disability but some serve people with different disabilities (and sometimes people who are not disabled at all) within the same establishment; **Hospitals or nursing homes**: typically larger establishments, usually over 30 places, organised primarily around medical and nursing practices and providing 24-hour staffing.

<sup>105</sup> Pg 21, Mansell, J., Knapp, M., Beadle-Brown, J., Beecham, J., ‘Deinstitutionalisation and Community Living – Outcome and Costs: Report of a European Study, [http://www.kent.ac.uk/tizard/research/DECL\\_network/documents/DECLOC\\_Volume\\_2\\_Report\\_for\\_Web.pdf](http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf), 2007

As shown above, an ISL housing model based on the principle of extra housing care may take different formats and designs. Be that as it may, it does have a number of defining features.

**Figure 05: Extra Care Housing Model<sup>106</sup>**



These include:

- It is first and foremost a type of housing. It is a person's individual home. It is **not** a care home or hospital and this is reflected in the nature of its occupancy through ownership, lease or tenancy. Thus, a person in an ISL mode lives at home – not in a home.
- Having one's own front door.
- Flexible care delivery based on individual needs – which can increase or diminish according to circumstance – where accommodation is specially designed, built or adapted to facilitate the care and support needs that its owners/tenants may have.
- The opportunity to preserve or rebuild independent living skills.

<sup>106</sup> Pg 11, The Extra Care Housing Toolkit, Care Services Improvement Partnership

- The provision of accessible buildings with smart technology that make independent living possible for people with a range of abilities where access to care and support is available 24 hours per day either on site or by call.

As important a primary factor in the design of ISL housing is the location identified for such housing. Location enhances or inhibits a disabled person's access to education or job opportunities. A design of an accessible house that pays no attention to the pedestrian environment will, inevitably, limit the movement of a disabled person/s in relation to the nearest shop/centre for social (and religious) activity / park.

The Access for All Design Guidelines issued by the KNPD establishes the standards on which new buildings are to be designed, as and where appropriate existing building is structurally altered, in order to ensure that physical barriers in buildings do not exist as a matter of course.

Be that as it may, the guiding model of design should be a 'universal design'. Barrier free design provides a level of accessibility for people with disabilities but may also result in stigmatising or 'separate' solutions, for example, a ramp that leads to a different entry into a house or building. Universal design proposes solutions that help everyone, not just people with physical impairments.

The principles, as articulated by the Center for Universal Design are as follows<sup>107</sup>:

- Equitable use: design is useful and marketable to people with diverse abilities.
- Flexibility in use: design accommodates a wide range of individual preferences and abilities.
- Simple and intuitive: use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
- Perceptible information: design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

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<sup>107</sup> Pg 21, People with Physical Disabilities and [In]appropriate Housing in Calgary, Centre for Social Work Research and Development, February 2008

- Tolerance for error: design minimizes hazards and the adverse consequences of accidental or unintended actions.
- Low physical effort: design can be used efficiently and comfortably with a minimum of fatigue.
- Space and size for approach and use: appropriate size and space is provided for approach, reach, manipulation, and use regardless of the user's body size, posture, or mobility.

Additionally, the following are best practice principles that should be taken into account when designing or modifying premises for ISL housing<sup>108</sup>:

- Centrally located communal facilities should be designed with progressive privacy in mind. This is key to ensuring that residents are afforded the privacy and security that non-disabled persons have within their own homes. Thus:
  - Not only should a clear separation between areas just for residents, staff and visitors be evident but a distinction between shared spaces for residents and those for the wider community is also important.
  - Public spaces such as communal lounges and dining rooms along with ancillary spaces such as laundries and catering kitchens should all be located centrally and away from residents' flats.
  - Staff, visitors or day users of the building should not need to walk through the corridors of which flats are accessed in order to reach their destination.
  - Areas such as assisted baths and guest rooms are to be located away from the more public areas and closer to the individual dwellings.
- Restrictive internal locking systems in corridors, staircases and any communal spaces should be kept to an absolute minimum. This will ensure that residents can move around the building freely without the need to carry 'key fobs' or remember codes, since this

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<sup>108</sup> Pg 7-15, Factsheet No 6, Design Principles for Extra Care, Care Services Improvement Partnership, Housing Lin

can create an institutional environment and can outweigh the positive security aspect.

- All site and building accesses should be securely controlled. Entrance should be located close to the site edge. Entry points to the site should be kept to a minimum and if there is more than one, then this should lead directly to the main entrance door or service areas.
- The building should have a logical layout that can be clearly understood.
- Circulation areas should be adequately designed for the frail and the wheelchair user and avoid long, dull vistas. The general arrangement of circulation spaces should be clear and 'rational' to assist people suffering from memory loss. Breaking down the building into identifiable zones and the provision of visual clues (through pictures and graphics) and signage will greatly assist way-finding.
- Careful planning can reduce the length of corridors, thus reducing the travel distances and minimising an institutional atmosphere. Walking distances for all users of the building can be kept to a minimum by the sensible location of stairs and lifts. It is ideal for both a lift to all floors and stairs to be easily reached from the main entrance.
- In planning the layout, the acoustic separation of noisy rooms such as laundries, lift motor rooms, and other communal spaces from residents living, sitting and sleeping areas should be considered. If layout permits, try to ensure that the living rooms of two adjoining flats are next to each other, and bedrooms of adjoining flats are next to each other.
- Spaces should be arranged to take maximum advantage of what the site can offer: such as locating individual dwellings toward the quieter areas of the site, make a focal point of an existing tree or provide views of street life. Dwellings and principle communal spaces should be orientated to ensure sunlight for part of the day to create a good balance of natural and artificial light and use shaded areas of the site for service spaces.



- The site layout should be arranged to achieve usable external spaces; preferably a sheltered, reasonably private south facing garden, directly accessed from the principle communal spaces. If possible main circulation routes should be designed to overlook the garden, to assist orientation and to encourage a sense of community. Buildings should be located so that they create and define useful outside spaces that relate to the internal layout of the building. A warm south facing court yard will encourage residents to venture out and use outside spaces. Environmental considerations such as cross-ventilation, passive solar gain, avoiding double-banking etc will also contribute towards creating views and good visual access throughout.
  
- Flexibility should be a major consideration in order to avoid redundant buildings in the future or the need for residents to move on to other accommodation. Specialist Housing is always subject to changes in policy, legislation, funding and allocation arrangements. Expectations of subsequent generations will continue to rise in terms of what would be an acceptable home environment. A resident may arrive in the scheme as a wheelchair user or the onset of mobility difficulties may occur at any time during a resident's tenancy. As maximum flexibility is essential, the architecture and structural designs should allow for this. Communal areas on the ground floor should be arranged within the footprint of flats above for structural design. Adequate storage provision is often overlooked and should be included from the outset.

**Table 32: Care Services Improvement Partnership Best Practice Schedule of Accommodation<sup>109</sup>**

<b>Schedule</b>	<b>Space</b>
<b>Accommodation</b>	
<b>1 Bed 2-Person Flats</b>	Approx 54m <sup>2</sup>
<b>2 Bed 2-Person Flats</b>	Approx 68m <sup>2</sup>
<b>Main Communal Lounge</b>	1.5m <sup>2</sup> / flat
<b>Dining Area</b>	1.2m <sup>2</sup> / flat
<b>Kitchen</b>	10m <sup>2</sup>
<b>Small Lounge</b>	15m <sup>2</sup> minimum
<b>Care Staff Office</b>	18m <sup>2</sup>
<b>Staff Overnight room</b>	18m <sup>2</sup>

To a large extent the principles mentioned above are generic. Particularly disabilities may require different design and accommodation requirements. Understanding the different requirements may be critical in designing the person-disability mix to be assigned to a particular apartment.

Thus, for example, the following are important considerations that should be taken into account in the placement of person with visual impairment in a ISL housing<sup>110</sup>:

- The effects of visual impairments should be reduced by incorporating colour schemes that use contrasting tones to highlight features within the building and avoid 'visual clutter'. There should be a contrast between the floor, walls and ceiling so that those with visual impairment can have an increased awareness of spatial dimensions. There should also be a contrast between ironmongery, doors, door frames and walls to distinguish these clearly.

<sup>109</sup> Pg, 16-17, Ibid

<sup>110</sup>Pg 17, Ibid

- Shiny surfaces, especially shiny floor surfaces, should be avoided as this confuses those with visual impairment. Highly patterned floor and worktop surfaces should also be avoided as this makes objects set against them harder to distinguish, e.g. a set of keys which has fallen on the floor. Natural materials assist way finding, divide spaces, highlight level changes etc and help create a warm and less clinical environment.

Alternatively, finishes for large spaces with higher ceilings such as lounges and dining rooms should be specified with a high acoustic absorbency, in order to reduce echoes for the benefit of those with hearing impairments.<sup>111</sup>

It is pertinent to underline that over 50% of the persons who have been placed in ISL housing by Agenzija Sapport are formerly institutionalised patients at Mount Carmel Hospital. Research is clear that the type of supported housing that a chronically mentally ill person is placed in can be crucial to the person's integration in society. Thus, design is an important component with regards to persons with such a disability. Amongst the design needs required with regards to chronically mentally ill persons, research identifies the following<sup>112</sup>:

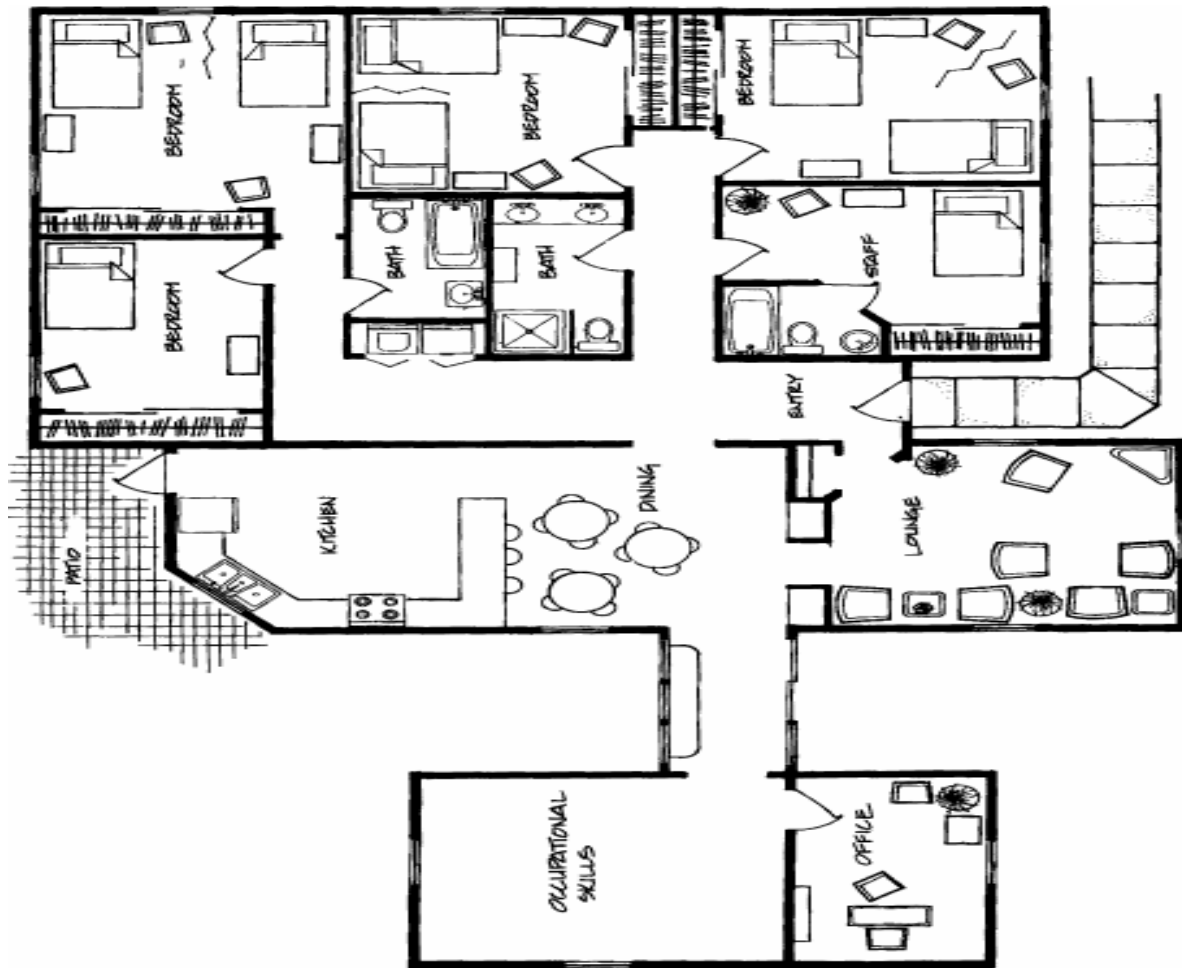
- spaces must not be overcrowded and there should be no more than one person per bedroom.
- persons must not be over-concentrated – that is forcing interaction when they do not wish to do so – and thus ability to secure privacy and a place of their own within the apartment is important.
- persons should be provided with a path of retreat so that if a person feels threatened he or she will have a place to withdraw and the ability to avoid confrontation. Two exits, therefore, are desirable.
- the physical surroundings must have a minimum of ambiguity and uncertainty, which may aggravate the perceptual illusions associated with mental illness.

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<sup>111</sup> Ibid

<sup>112</sup> Pg 33-35, Tremblay, R., K., Design Needs and Criteria for Chronically Mentally Ill Persons, Housing and Society, Volume 22, No 3

**Figure 06: Proposed Independent Supported Living 4 Bed Apartment Plan for Chronically Mentally Ill Persons<sup>113</sup>**



Similarly, patients with dementia in an ISL environment cannot be accommodated in any kind of property. Here too, a systematic approach is required to design the property environment to accommodate the unique needs of a patient suffering from dementia. Research identifies the following design features:

- small size.
- domestic and home-like.
- scope for ordinary activities.
- unobtrusive inclusion of safety features.

<sup>113</sup> Pg 35, Ibid

- rooms for different functions with furniture and fittings similar to the age and generation of the residents.
- a safe outside space.
- single rooms big enough for a reasonable amount of personal belongings.
- good signage and multiple cues where possible: sight, smell, sound.
- use of objects rather than colour for orientation.
- enhancement of visual access.
- control of stimuli, especially noise.<sup>114</sup>

#### 04.8.2 Options With Regards to the Provision of Independent Supporting Living Housing Stock

The above discussion shows, clearly, that there is no one size that fits all types of persons with disabilities with regards to the housing model to be applied for ISL. As shown in the discussion above accommodation without on-site support will suffice for a particular group; with others this may be a mandatory requirement; persons with certain different disabilities may not be compatible to live together as their behaviour can trigger mutually disruptive behaviours; that with certain persons a small group is more effective; and that with others a large group living in the same accommodation will result in mutually increased benefits such as social activity and networking.

The conclusion reached in this regard in this report is that the ISL housing model that is to be applied should be a mix of different types of accommodations designed on a universal best practice design but specifically tailored to account for the disabilities of the persons who will be accommodated in such premises.

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### **Policy Recommendation 14**

The report concludes that there is no one particular Independent Supported Living housing model that can be applied across the board

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<sup>114</sup> Pg 7, Fleming, R., Crookes, P., and Sum, S., A Review of the Empirical Literature on the Design of Physical Environments for People with Dementia: Translating Dementia Research into Practice, Version 1.1, University of Sterling, 2007

and, therefore, recommends a model that this is based on a mix of different types of accommodations designed on a universal best practice design but specifically tailored to account for the support needs of the persons who will be accommodated in such premises.

Given the principle of the right of entitlement of a disabled person for ISL housing proposed earlier as well as the recognition that the financing of an ISL policy framework, may, never be such that assures that supply will meet demand, it, therefore, becomes imperative that the approach to providing ISL modified accommodation is flexible to the widest extent possible.

The potential options that can be adopted in Malta with regards to the provision of the ISL housing stock is discussed hereunder.

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## Options

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**Build** This option is based on the premise that the Government will provide the land to Aġenzija Sapport at no cost. Aġenzija Sapport will be responsible for the design and build of the accommodation and its subsequent maintenance.

Construction rates within the regulatory framework of the Malta Environment and Planning Authority – therefore accounting for the Access for All Design Guidelines – range from €160/m<sup>2</sup> for shell construction to €650/m<sup>2</sup> for finished construction.<sup>115</sup> A semi-finished construction is estimated at €400/m<sup>2</sup>.

Moreover, these estimated costs whilst taking into account universal design principles, are not tailored to represent a specific disability.

The cost of building an ISL accommodation is shown in the Table hereunder.

**Table 33: Cost of Building a 2 Person 1 or 2 Bedroom Apartment**

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<b>2 Person 1 Bedroom Apartment</b>	<b>2 Person to Bedroom Apartment</b>
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<b>Footprint: 54m<sup>2</sup></b>		<b>Footprint: 68 m<sup>2</sup></b>	
<b>Shell: €8,640</b>		<b>Shell €19,880</b>	
<b>Semi Finished</b>	<b>Const</b>	<b>Semi Finished</b>	<b>Const</b>
<b>€21,600</b>		<b>€27,200</b>	
<b>Finished</b>	<b>€35,100</b>	<b>Finished</b>	<b>€44,200</b>

## Rent

The next table shows market rates for renting apartments in different localities.

**Table 34: Rental Rates of 2 Bedroom and 3 Bedroom Apartments<sup>116</sup>**

<b>Location</b>	<b>2 bedrooms in € Monthly</b>	<b>3 bedrooms € monthly</b>
<b>Attard</b>	450 – 500	550 - 750
<b>B'Bugia</b>	250 - 350	350 – 450
<b>B'Kara</b>	250 - 400	450 – 550
<b>Baħar iċ- Ċagħaq</b>	Over 400	Over 550
<b>Baħrija</b>		350
<b>Balzan</b>	Over 350	Over 500
<b>Bugibba</b>	250 – 375	375 – 500
<b>Fgura</b>	Over 250	Over 350
<b>Għargħur</b>	50 – 400	400 – 500
<b>Għaxaq</b>	Approx 250	Approx 400
<b>Iklin</b>	350 – 450	Over 450
<b>Lija</b>	Over 350	Over 450
<b>Luqa</b>	250 – 350	Over 350
<b>Mellieħa</b>	400 – 550	Over 550
<b>Mosta</b>	350 - 450	Over 400
<b>Naxxar</b>	Over 350	Over 400
<b>Paola</b>	280	350 - 400

<b>Rabat</b>	250 - 350	350 - 450
<b>Sliema</b>	500 - 700	Over 650
<b>St Paul's Bay</b>	280 – 380	350 - 450
<b>Swieqi</b>	450 – 600	Over 600
<b>Ta' Xbiex</b>	Over 350	Approx 500
<b>Tarxien</b>	Approx 250	300 - 400
<b>Valletta</b>	Over 550	
<b>Żabbar</b>	250 – 350	Over 350
<b>Żebbug</b>	250 – 450	Over 400
<b>Żejtun</b>		300 - 400
<b>Żurrieq</b>	Over 350	

**Private-Public Partnership**

Similar with the model applied by the Government with regards to residential care for the elderly, the Government would on the basis of a public call for applications issue a tender for a Public Private Partnership for the provision of ISL housing as per the design specifications set.

Under a Public Private Partnership model, the private sector is engaged to build the infrastructure and maintain it for a designated period: normally this is for a period that is not less than 20 years. The tender document may engage further responsibilities on the contractor such as the management of the facility, the provision of care services, the provision of hotel services, etc.

Once the contracted period expires, the contracting authority – which is assumed to be Aġenzija Sapport, will assume ownership for the housing infrastructure built under the Public Private Partnership Agreement.

The annual outlay in this regard is, however, considerable. The 2011 Estimates for the Ministry of Health, the Elderly, and Community Care show an annual cost of €2,999,180 and €3,145,000 for 2009 and 2010 for the Mellieha Home for the Elderly. This is estimated to be €3,145,000 in to 2011 and is complemented by an estimated cost of €4,000,000 for Government's homes for



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the elderly.<sup>117</sup>

Whilst the above includes cost of care which under the current Public Private Partnership Agreement is the Government's responsibility, a considerable part of this annual expenditure outlay relates to the financing of the partnership.

**Integrated  
Planning  
Criterion**

A potential option for the provision of ISL homes in an integrated environment could be that a condition that Government sets in the Development Briefs issued with regards long term lease of Government property or land for economic development which mandates a % of the said development and / or footprint is to be developed for such a purpose.

Government property and land are a resource of the public. Thus the combination of the use of government property for economic development with social development – in this case the integration of disabled persons in communities – will secure an immediate return from a public asset directed to further the improvement of an important group in society.

The introduction and application of such a criterion in the use of government land for economic development can only, however, be considered as supplementary to the core ISL policy framework.

This results from the fact that the issuance of Development Briefs for the re-use of government land and property is an ad hoc process which does not necessarily take place on a scheduled basis. Thus, such a scheme whilst useful in terms of complementing additional opportunities for ISL housing integration can never be the basis upon an ISL policy framework is designed.

The introduction of such a criterion and its application, should, therefore be cost neutral to Government; or rather the social cost of the use of the designated footprint of the government property to be offset by the economic return of the investment and the rate of return

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from annual rent paid by the tenant.

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This report recommends that Aġenzija Sapport should continue to provide residential services for persons with disabilities. Nevertheless, whilst retaining flexibility, Aġenzija Sapport should adopt the strategy that is most cost effective – both with regards to the capital outlay required as well as the annual recurrent costs.

This report does not recommend that Aġenzija Sapport adopts a policy that is directed towards building or buying residential stock for ISL homes. Past experience shows that, invariably, where such an approach has been adopted by Government entities, the capital outflow and investment required to build or to renovate a particular residential block will starve the said entity from funds to expand its services further.

Whilst a Public Private Partnership Agreement may be a way forward the adoption of this option will still result in a state of play where Aġenzija Sapport would have to pay a considerable annual outflow and following the expiry of the contract period will be saddled by the ownership of the said housing stock.

This report is of the considered opinion that the most appropriate way forward for Aġenzija Sapport, in the event that there is no excess building stock owned by the Housing Authority that could be made available for ISL housing, is to leverage the rental market. It is pertinent to underline that with the reforms to the rent laws in 2009 the Government has taken the appropriate steps to ensure a functioning market.

Moreover the housing market is in a period of lull – though prices are still seen to be over-valued. A structural adjustment, however, may take place in the short and medium term as the slow-down in the market may become protracted. Thus, behaviour of the market in the short and medium term may provide Aġenzija Sapport with the opportunity to strategically leverage it to establish favourable rates in this regard – particularly given that it is likely to opt for long term tenancies.

A potential way forward in this regard is the issuance of a tender by Aġenzija Sapport to set up a Register for ISL residential accommodation where-in a landlord and a particular tenancy is placed on the Register following the meeting of the appropriate specifications. It is suggested

that the Register is, through public tender, refreshed every other year – which will see rates changing according to market behaviour.

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### **Policy Recommendation 15**

This report recommends that the strategy that Aġenzija Sapport adopts with regards to providing appropriate homes for Independent Supported Living should be very flexible and that, in the absence of excess building stock owned by the Housing Authority that could be made available for Independent Supported Living housing, the core of such a strategy should be directed to leverage the rental market.

#### 04.8.3 Costs Related to Independent Supported Living

##### 04.8.3.1 Cost of Operations of Independent Supported Living Homes

The running of an ISL home includes costs other than rent or the costs of financing the building of an ISL premises. Costs related to independent living include food, water and electricity, telecommunication, and transportation costs.

This report recommends that Aġenzija Sapport together with KNPD should carry out a further study to understand the dynamics of the cost structures across different residences as well as over time.

Whilst this report has proposed that the ISL home strategy that Aġenzija Sapport is to adopt should be flexible and one that leverages the rent market; the adoption of the appropriate balance, mix and size, number of residents, and other factors of the ISL home environment should take into account the Total Cost of Ownership with regards to the operation of ISL homes.

The report is of the considered opinion that this is of critical importance given a state of play which may be constrained by the level of financing available. Thus, the optimisation of the right accommodation mix with regards to the cost of operations will allow for a greater level of ISL housing stock to be made available – thereby ensuring that a higher cohort of disabled persons are afforded the opportunity to live in an ISL environment.

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## Policy Recommendation 16

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This report recommends that Aġenzija Sapport in determining the appropriate balance, mix, size and number of residents of an Independent Supported Living home environment should take into account the optimisation of the right accommodation mix with regards to the cost of operations which will allow for a greater level of housing stock to be made available – thereby ensuring that a higher cohort of disabled persons are afforded the opportunity to live in an Independent Supported Living environment.

The other major cost relating to the financing of an ISL policy framework relates to the financing of direct human resources costs – the Personal Support Assistants, Team Leaders, 24\*7 coverage, among others.

### 04.8.3.2 Estimating Cost of Operations of Different Independent Supported Living Models

For the purpose of estimating different ISL models, costs for the provision of different levels of support are presented in the following Table. A daily wage of €59.3 (€7.41 / hour) with regards to the cost of labour for direct personal assistant support equates to an annual wage of €14,232 – slightly lower than the Average National wage which in 2011 stood at:€14,466.

The indirect labour cost of €16.24 is – at 22.26% of actual direct labour – is seen as high and efficiency improvement initiatives should bring this cost to no more than 15% of actual cost. This figure is retained to act as a buffer directed to absorb 2012 inflation rates.

The modelling is based on a scenario where-in ISL property will be rented from the open market at the lower end of current rates. This is based on the assumption that Aġenzija Sapport is in a position to exploit the current slow down in the rental and property market and in doing so it is in a position to obtain favourable rates.

**Table 35: Modelling Cost of Different Levels of ISL Care**

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<b>Intensive ISL Care 12 Hours</b>	<b>Semi- Intensive Care 6 hours</b>	<b>Intermediate Care 4 hours</b>	<b>Basic Care 2 hours</b>
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<b>Daily Rate</b>				
<b>Direct</b>	88.95	44.48	29.65	14.83
<b>Labour</b>	16.24	16.24	16.24	16.24
<b>Indirect</b>	10.31	10.31	10.31	10.31
<b>Labour</b>	7.54	7.54	7.54	7.54
<b>Direct</b>				
<b>Overheads</b>				
<b>Indirect</b>				
<b>Overheads</b>				
<b>Daily Cost</b>	123.04	78.57	63.74	48.9
<b>Total</b>	44,910	28,678	23,265	17,854

On the basis of four tiered level of care that would range from a maximum of 12 hours to 2 hours of personal assistance respectively the annual average cost would amount to €28,677 (or a daily rate of €78.56).

To the costs included in the models above, one would need to add the amortised cost related to Ambient Assisted Living technologies and specially designed furnishing and fittings as well – irrespective of whether the home is provided by Agencija Sapport or is rented directly from the market by the disabled person.

With regards to the structural adjustments to a home, the assumption taken is that the selected home – whether provided by the Agency or rented directly from the market by the disabled person – would be a property built following the introduction of the afore mentioned design guidelines. Thus, structural adjustments should, theoretically at least, be minimal.

The provision made in this regard for modelling purposes is that a one off cost for structural adjustments of €6,000 is budgeted for. This cost is assumed to be amortised over a 20 year period – which means that an additional annual cost of €300 is added to the above costs. The Table below demonstrates examples of costs of adaptations that may need to be carried out at a property to render it ready as an ISL home.

**Table 36: Examples of Cost of Home Adaptations (VAT Exclusive)<sup>118</sup>**

<b>Adaptation</b>	<b>Cost €</b>
<b>2 x Grab rails</b>	38.99
<b>Shower seat with legs and back support</b>	239.51
<b>Level access shower</b>	3,899
<b>Ramp</b>	612.7

Moreover, an ISL home would also have to be equipped with specialised equipment required to facilitate independent living – with the equipment required being specific to the disability or impairment of a person. The Table below presents a non-exhaustive example of such specialised equipment.

**Table 37: Examples of Cost of Specialised Disability Oriented Equipment (VAT Exclusive)<sup>119</sup>**

<b>Specialised Equipment</b>	<b>Cost €</b>
<b>Wheel Chair Use</b>	
<b>Bariatric Foam Cushion</b>	167.08
<b>Hand-reachers</b>	5.68
<b>Height Adjustable Commode</b>	167.08
<b>Leg lifter</b>	7.52
<b>Adjustable Height mobile commode chair</b>	211.66
<b>Adjustable height shower chair</b>	73.5
<b>Bath lift</b>	338.93
<b>Adjustable bed</b>	969.18
<b>Hearing Impaired</b>	
<b>Ringlash Phone Call Amplifier</b>	22.26
<b>Pillow Vibration Alarm clock</b>	10.02
<b>Visually Impaired</b>	
<b>Assist-a-tray</b>	133.66

<b>Bed cane</b>	66.82
<b>Adjustable bed rail</b>	94.67

The provision made in this regard for modelling purposes is that the cost of specialised disability oriented equipment would be €2,500 per person irrespective of the disability. On the assumption that this is amortised on 6 year basis, and there after refreshed, the annual cost per disabled person is €416.67

Additionally, furniture and fittings would need to be specifically designed for disabled persons. For example, kitchen fittings and appliances would require adaptable and adjustable kitchen tops, sinks and taps with disabled hand control, et al. Despite considerable research over the Internet it was not possible to obtain pricing.

Furthermore, the cost of Ambient Assisted Living technologies that may be installed in an ISL home should also be factored in.

**Table 38: Examples of Cost of Ambient Assisted Living Technologies (VAT Exclusive)<sup>120</sup>**

<b>Technology</b>	<b>Cost €</b>
<b>Bogus Caller Button</b>	55.71
<b>Carbon Monoxide Detector</b>	93.46
<b>Fall Detector</b>	93.46
<b>Movement Detector</b>	74.58
<b>Smoke Detector</b>	93.46
<b>Satellite Personal Tracker</b>	89.99
<b>Total</b>	500.66

Assuming that the technologies will be amortised over a period of 6 years, this would mean that an additional annual cost of €83.44 would need to be added

The Table below presents the annual cost of a person living in an ISL home environment taking into account capital as well as human resources and operating costs.

**Table 39: Scenario Modelling of Annual Total Costs with regards to a Rented Independent Supported Living Home**

	Intensive ISL Care 12 Hours	Semi Intensive Care 6 hours	Intermedia te Care 4 hours	Basic Care 2 hours
<b>Direct and Indirect Costs</b>	44,910	28,678	23,265	17,854
<b>Home Adaptations</b>	300	300	300	300
<b>Specialised Disability Oriented Equipment</b>	416.67	416.67	416.67	416.67
<b>Furniture and Fittings</b>	N/A	N/A	N/A	N/A
<b>AAL Technology</b>	83.44	83.44	83.44	83.44
<b>Total</b>	45,710	29,478	24,065	18,654
<b>Average Cost</b>	29,476			

As can be seen from the Table above, even under the most optimistic scenario, the total cost of a disabled person living in an ISL home is expensive – and the annual figure will be even more expensive if the amortised costs of furnishing and fittings is factored in.

The option to build as against rent property for ISL homes will be more expensive when compared to a market value rent of €3,600 annually given that apart from the:

- up front one-off costs required to build the property which will consume any budget put forward for ISL homes for at least three years
- exclusion of financial costs if construction is funded through a loan secured from financial institutions
- social value assigned to the land assuming that this will be made available by the Government



the amortised annual value calculated over a 20 year period on the basis of the semi-finished construction estimate discussed earlier would be €1,350 for a 1 bed room 2 person apartment and €1,700 for a 2 bed room 2 person apartment.

#### 04.8.4 Personal Budgeting and Independent Supported Living

To a large extent, the current ISL services are directly provided by Agenzija Sapport. It is Agenzija Sapport which identifies the location for the ISL residencies – invariably the location being the result of free or Housing Authority provided residences, matches the residents, selects the Personal Support Assistants, and so on.

The report acknowledges that this is a role that Agenzija Sapport should continue to be involved in by providing, as it does today, direct residential services to disabled persons who would without such support find it hard, if not impossible, to make the transition from a family home and/or institution to an ISL environment.

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#### **Policy Recommendation 17**

This report recommends that Agenzija Sapport continues to supply Independent Supported Living housing to disabled persons who, without such support, would not be able to make the transition from a family home and/or institution to an Independent Supported Living environment.

It is to be noted that Agenzija Sapport has a current arrangement with a family which it has assisted by:

- acquiring a property for them from the Housing Authority and sub-letting the rent to them.
- acquiring a one time grant from the Housing Authority for property restructuring needs.
- providing a number of daily designated hours of personal assistance support in accordance to their personal needs

The report, however, recommends that the limited ‘personal budgeting’ approach Agenzija Sapport should be extended and provided as an

alternative mechanism for access to an ISL home environment by disabled persons.

The advantages in this regard are various. It provides the disabled person with a choice with regards to the locality they may wish to live in. Thus a disabled person may wish to choose a location that is close to their workplace, or to their social network or their parents, and in doing so securing independence but still retaining sufficient proximity to his or her family for support.

It also allows the disabled person to choose the person or persons with whom he or she will share the ISL home. Independence of choice in this regard would secure that a person is not 'forced' to live with other tenants with whom he or she may not be comfortable with.

A disabled person who selects a personal budget as the vehicle to an ISL home environment should have the following rights:

- (i) to choose a member of his or her family or a friend to act a Personal Service Assistant.
- (ii) to request assistance support in managing a payment.
- (iii) to request Aġenzija Sapport to make arrangements for support.
- (iii) to identify the person with whom they wish to cohabit.
- (iv) to identify the location and building within which they wish to inhabit.

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### **Policy Recommendation 18**

This report recommends that a disabled person once approved as a qualified applicant for Independent Support Living by the Independent Living Allocation Committee should have access to a personal budget should he or she so desire which shall provide for the following rights: (i) to choose a member of their family or a friend to act a Personal Service Assistant; (ii) to request assistance support in managing a payment; (iii) to request Aġenzija Sapport to make arrangements for support; (iv) to identify the person with whom they wish to live with; (v) to identify the location and building within which they wishes to inhabit.

Be as it may, the rights that will be made available to a disabled person with regards to an ISL environment under a Personal Budget mechanism are qualified as, though not limited to, the following:

- A person can only be appointed as a Personal Services Assistant if the person is accredited by an institution recognised by Aġenzija Sapport.

The curriculum for accreditation will be set by Aġenzija Sapport. The accreditation modules that a Personal Services Assistant, together with the Position Description, could be considered to obtain are shown in Appendix B.

- A person can only be appointed as a Team Leader with authority to design a personal plan for the disabled person, if the said person is accredited by an institution recognised by Aġenzija Sapport.

The curriculum for accreditation will be set by Aġenzija Sapport. The accreditation modules that a Personal Services Assistant, together with the Position Description, could be considered to obtain are shown in Appendix B,

- The disabled person (where possible) and his or her family are to undertake a pre ISL orientation programme that will include the following subjects:

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### **Core Preparation for Independent Living Training**

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#### **Self-advocacy**

**Concepts such as following directions, attending to task, task completion, communication, decision-making, and problem-solving.**

#### **Safety and mobility.**

**Skills of how to overcome barriers to participation and the building of community / social relationships**

**Provision, arrangement, and management of transportation.**

**Training in relation to job interviews, job retention, career**

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**development.**

**Adaptations to living quarters including showers, toilets, control switches for the home, kitchen equipment**

**Group work and peer support activities for disabled people living together to guide and support one another**

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- An appropriate assessment will be carried out by Agenzija Sapport to certify that the persons who will cohabitate in an ISL home environment can do so.
- An assessment is carried out by Agenzija Sapport to certify that the premises identified as the ISL home meets the appropriate standards

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### **Policy Recommendation 19**

This report recommends rights of a disabled person under a personal budget mechanism are qualified as including, but not limited to, the accreditation of Personal Services Assistants, the certification of property that will be leased, the assessment of persons who will be living in the residency to ensure compatibility.

Moreover, Agenzija Sapport should provide support to disabled persons selecting a personal budget mechanism to an ISL home environment by, though not solely limited to:

- Maintaining a register of certified Personal Support Assistants and Team leaders for referral as appropriate.
- Securing fair market prices for rental values of property through the issuance of a public tender on an on-going basis.
- Maintaining a Register of certified property for ISL use for referral as appropriate.
- Providing advice with regards to the signing of a contract for a tenancy,
- Provide practical support and assistance as appropriate with regards to ensuring that choices and aspirations are met.

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## **Policy Recommendation 20**

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This report recommends that Aġenzija Sapport should provide appropriate assistance and support to disabled persons selecting a personal budget mechanism to an Independent Supported Living home environment to ensure that their choices and aspirations are met.

The report recognises that the potential implications of a personal budget mechanism to an ISL home environment can be profound. They imply major changes in organisational arrangements, processes, culture and professional roles particularly within Aġenzija Sapport, as the competent government agency in this sector; and in the expectations and responsibilities of both disabled persons as well as their families.

The existing conventional approaches that Aġenzija Sapport applies with regards to the provision of ISL services may not necessarily apply in a personal budget mechanism. As seen from the responsibilities proposed above with regards to Aġenzija Sapport, the Agency would need to garner new skills – skills which will range from supporting a disabled person who selects a personal budget mechanism to plan his or her arrangements; brokering expertise to enable personal budget holders to get their best deal from their budgets such as the negotiation of a rental value for a premises.

Moreover, the possibility that once a personal budget mechanism is introduced, Aġenzija Sapport may experience reduced demand for the ISL services it currently provides today as current clients of the agency may opt to switch to this mechanism.

Thus, whilst this report proposes the introduction of a personal budget mechanism on the basis of increased choice, enfranchisement, and greater opportunities for self definition of aspirations, as an alternative channel to disabled persons that complements the ISL service provided by Aġenzija, the report further recommends that such a policy is introduced in a phased manner.

The report, therefore, recommends that the initial policy direction in this regard should be the launch of a pilot that would invite a number of disabled persons to participate in an ISL home environment that would be supported by means of a private budget mechanism.

The pilot, which should be managed by Aġenzija Sapport, should target the possible number of disabled persons requiring different levels of care

and different disabilities who will opt for a personal budget mechanism over a different types of home mix. This will provide the Agency with a sufficient large base of disabled persons and a good mix of ISL homes to garner experience, learn lessons, refine procedures, et al. It is further proposed that the pilot should be conducted over a period of two years.<sup>121</sup> It is further proposed that the pilot project should be launched in 2012.

Aġenzija Sapport should apply an on-going evaluation process over the pilot period so that lessons learnt are iteratively applied during the life time of the pilot. A key premise for such an iterative approach is that Government should commit that upon the expiry of the pilot period the ISL services provided through the pilot would continue to be provided.

The budget proposed for the pilot is €600,000 over a two year period – which is based on the average cost for the four different ISL level of care modelled previous in this report.

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### **Policy Recommendation 21**

This report recommends that the introduction of a policy of a personal budget to a disabled person for access to an Independent Supported Living home environment to complement the service provided by Aġenzija Sapport should be launched in 2012 initially as a two year pilot that targets different levels of care and different disabilities who will opt for a personal budget mechanism over a different types of home mix; which pilot should be translated into an operational service once lessons learnt are assessed and incorporated.

### **04.9 Financing of an Independent Living Support Policy Framework**

This report proposes a number of recommendations that should be considered with regards to the establishing of a robust ISL policy framework. The extension of the provision of ISL services either directly by Aġenzija Sapport, as is the case today, as well as through a personal budget mechanism as proposed in this report will only occur if ISL is established as an important policy domain and financing in this regard is made available.

The financial vote allocated to Aġenzija Sapport increased from €583,000 in 2003 to €6,620,000 as estimated in the 2011 Government budget – an increase of 1,135%. The major increase in any one year in

the Agency's budget occurred in 2007 when the vote allocated stood at €4,823,000 to the €1,354,000 allocated for 2006 – an increase of 356.2%.

It is, however, pertinent to underline that this increase of €3,469,000 did not constitute an injection of increased financing in the budget of the Agency. Rather this increase in the financial vote reflected the organisational transfer of the Adult Training Centres, subsequently renamed as Day Services, from the Department for the Elderly and Community Care within the then Ministry for the Family and Social Solidarity.

It is to be noted, however that vote allocated in 2008 on 2007 – which incorporated the Day Services activity – increased by 22.7% or €1,099,000. By 2011, the vote allocated to Aġenzija Sapport increased to €6,620,000 – that is an increase of €1,797,000 or 37.26% on 2007.

Following an analysis of the funds voted by Government with regards to Aġenzija Sapport, it would be unfair to conclude or state that the Government has not identified support services to disabled persons, including the provision of ISL residential services and support, as a priority policy domain. Considerable funding has been assigned to Aġenzija Sapport – which financing, with the exception of 2009, enjoyed relatively high percentage increases from one year to the next even in circumstances where Malta faced economic difficulties and uncertainties.

**Table 40: Government Contributions to Aġenzija Sapport<sup>122</sup>**

<b>Vote</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>
	€m	€m	€m	€m	€m	€m	€m	€m	€m
<b>Recurrent 6774</b>		0.979	1,181	1,354	4,823	5,922	5,810	6,250 <sup>123</sup>	6,590 <sup>12</sup>
<b>Programmes 5439</b>									
<b>Supported Living Project</b>	0.583								
<b>Independent Community Living</b>									0.030

<b>Total</b>	0.583	0.979	1.181	1.354	4.823	5.922	5.810	6.250	6.620
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The question of whether such financing, however, suffices to build and maintain an environment that can support and sustain an ISL home environment for those persons of disabilities who are willing to make such a choice must be asked.

As can be seen from the Table below, the financing by Government over the past 10 years has resulted, together with other services provided by Agenzija Sapport such as Day Services, in 60 ISL home and residential places.

It is to be further noted that 44 of these ISL residential places become operational by 2003; with the remaining 16 places being introduced from 2007 onwards. It is pertinent to underline that as shown in the Table above the period since 2007 has seen the Agency's budget increase considerably.

**Table 41: Chronology of Independent Supported Living Opportunities Made Available: 2002-2010<sup>125</sup>**

Home	Date	Number of Residents
1	2002	3
2	2003	4
3	2003	13
4	2003	8
5	2003	9
6	2003	7
7	2007	7
8	2008	7
		2
<b>Total Number of Residents</b>		<b>60</b>

These above figures give rise to a number of issues. First. Since Agenzija Sapport was set up, on average, the Agency introduced 6.4 ISL placements annually. At the current pace of ISL placement rollout this means that it will take the Agency at least 3.5 years to provide an ISL



home placement for the 23 persons<sup>126</sup> who have been approved but are still waiting to be allocated such a placement.

Indeed, if one had to assume that 25% (17 persons) of the 69 persons<sup>127</sup> who are yet awaiting to have their request for residential services successfully approved this would mean that it would take the Agency 6.25 years to be able to allocate these disabled persons with an ISL home placement – unless, of course, a placement opportunity arises due to the death or transfer of a current resident.

Second. The average cost of ISL services – that is both individual support as well as costs relating to the operations of a residency – across the six residencies is €37,928.24. As discussed earlier, the increase in the 2011 financial estimate for the Agency on the 2010 vote amounted to €370,000. The number of ISL residencies in 2010 did not increase and it is, therefore, safe to assume that the 2010 vote covers all known operational and employment direct and indirect costs.

Thus, should one further assume that the increase of €370,000 in the 2011 Agency's budget is utilised solely to finance an increase in the ISL residential placements managed by the Agency, this would mean that Agency could increase its residential placement capacity on the basis of a four tier level of ISL care as modelled earlier in the report) by 12.5 persons annually.

Thus, had the Government to allocate an additional budget of €370,000 (adjusted for RPI and COLA) annually over a period of 10 years (an investment of €3,700,000 without a RPI and COLA adjustment) total residential capacity would increase by 125.5 placements.

A third concern is that despite the considerable increases in the Agency's budget since 2007 – with the exception of 2009 which experienced a slight dip – the investment made by the Agency in ISL home placements has reduced.

Thus, for a total financial budget of €4,097,000 between 2002 and 2006, the Agency invested in 44<sup>128</sup> ISL placements. This compares strongly with the investment in 16 ISL home placements since 2007, where the total financial budget for the Agency - excluding a constant expenditure base of €3,469,000 for Day Services – stood at €12,080,000.

Thus, the Agency between 2002 and 2006 opened a residential ISL placement for every €93,114 when compared to an ISL placement for every €755,000 allocated to it since 2007.

Whilst it is understood and recognised that the services provided by the Agency are, and should be far more comprehensive and embracing than solely limited to the provision of ISL residential placements, this disparity in terms of the investment channelled towards ISL placements is disconcerting.

It leads one to conclude that within a holistic environment for the provision of support and services to disabled persons within the current financing parameters there can be no continued and sustained policy approach to roll out ISL placements on an on-going basis.

The impression garnered is that the current financing envelope permits the Agency only to operate in spurts: an aggressive approach between 2002 to 2006 to establish an ISL residential framework potentially by sacrificing other support services; and the converse since 2007, wherein the priority focus was less the continued introduction of an ISL residential placement environment and more the introduction and / or strengthening of services and support which may have previously been placed on the back burner.

It is the considered opinion of this report that a robust and sustained ISL policy framework that expands, incrementally, to embrace all disabled persons who seek to exercise their right in this regard, cannot be attained within the current financial budget – unless, of course, such an ISL policy framework replaces other activities carried out by Aġenzija Sapport.

This report recommends the following as an alternative mechanism for the financing of an ISL policy framework.

As an important step the report recommends that an ISL Fund is established. It is to be noted that in Consultations held a minority of Government stakeholders underlined their discomfort with the creation of such a funding mechanism and whether this is the appropriate vehicle that should be adopted.

Be that as it may, no alternative financing vehicle was proposed. In the absence of a workable alternative as well as the fact that the concept of

an ad hoc fund, although new to Malta, is successfully applied in overseas jurisdictions<sup>129</sup> the report maintains its position in this regard.

The creation of an ISL Fund will secure a number of key objectives. First, it will ensure that revenue assigned for the implementation of the ISL policy framework is ring-fenced and is used for such purposes only.

Secondly, as a result of the creation of the ISL Fund, financing of the Fund by Government through national budgeting is now decoupled from the Consolidated Fund. This will ensure that savings or funds that are not utilised in a particular year are not lost but are retained within the Fund.

Thirdly, the Fund will provide the appropriate legitimacy and assurance for private financing that may be directed towards the Fund given that a ring-fenced Fund denotes that the Government cannot, for legitimate reasons or otherwise, take over control of private financing made for a specific purpose.

It is recommended that whilst the Fund should be managed by Aġenzija Sapport, it should have a separate Board of Governors and that access by Aġenzija Sapport to income within the Fund should be on the basis of a business and financial plan. The Fund should be examined annually by the National Audit Office.

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## **Policy Recommendation 22**

This report recommends that a ring-fenced Independent Supported Living Fund is created under independent governance, under annual external scrutiny by the National Audit Office, and access by Aġenzija Sapport to income within the Fund should be on the basis of a business and financial plan.

The proposed ISL Fund should be constituted of four funding sources. The **first** funding source should be government financing.

The State has a role and an obligation to ensure that minorities as well as disadvantaged groups are mainstreamed in society and hence there should be no doubt or hesitancy on the fact that the State is to assume the majority of the cost. Government's portion of the Fund will constitute of:

- (i) A payment of the total combined cost of managing the residential units and the financing of Dar Pirotta and the Arka Foundation Respite Centre which in 2010 totalled €2,001,887 and its continued financing together with the appropriate adjustments relating to Inflation and COLA. This would be cost neutral.
- (ii) The allocation of the appropriate funding to:
  - Launch the pilot covering a different mix of levels of care, disabled persons and types of housing. This entails a proposed investment of €300,000 for 2012 and 2013 (total of €600,000) respectively and thereafter the Government maintain its continued financing together with the appropriate adjustments relating to Inflation and COLA.
- (iii) The allocation of an additional €300,000 as from 2014.

This will facilitate growth of an ISL home community by a further 10 persons on different levels of ISL care in 2014 following the assessment and closure of the pilot project; and the continued operations of the ISL policy framework thereafter.

- (iv) A further allocation of €300,000 annually should be channelled to the proposed ISL Fund between 2015 and 2021 in order to support the growth of an ISL disabled community by 10 persons on different level of care annually.

Thus, total investment for the period 2012 to 2021 (adjusted to reflect an annual 2% increase in inflation) on the basis of the above recommendations is as shown in the Table hereunder.

**Table 42: Proposed Investment (adjusted to reflect an annual increase of 2% inflation) in an ISL Environment between 2012-2021**

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	
Pilot	300,000	306,000									
Maintaining ISL Environment Introduced in Pilot			312,120	318,362	324,730	331,224	337,849	344,606	351,498	358,528	
Introducing an ISL Framework post Pilot			300,000	306,000	312,120	318,362	324,730	331,224	337,849	344,606	
Annually Increasing ISL Community				250,000	255,000	260,100	265,302	270,608	276,020	281,541	
					250,000	255,000	260,100	265,302	270,608	276,020	
						250,000	255,000	260,100	265,302	270,608	
							250,000	255,000	260,100	265,302	
								250,000	255,000	260,100	
									250,000	255,000	
										250,000	
<b>Total</b>	<b>300,000</b>	<b>306,000</b>	<b>612,120</b>	<b>874,362</b>	<b>1,141,850</b>	<b>1,414,687</b>	<b>1,692,980</b>	<b>1,976,840</b>	<b>2,266,377</b>	<b>2,561,704</b>	<b>13,146,920</b>

### Policy Recommendation 23

This report recommends that the main source of income to the Independent Supported Living Fund should be the Government as the guarantor and custodian of social inclusion and that existing Independent Support Living financing is to be complemented by €13,146,920 between 2012-2021 as follows

- Two year investment in the pilot - €606,000.
- Operations of ISL homes / services previously under the pilot assessment framework - €2,678,916
- Launching of ISL Policy framework following pilot calibration and continued operations - €2,574,891
- Annual increase of the ISL community and continued operations - €7,287,113.

The **second** source of financing should be the disabled person. In this regard it is recommended that the current condition in the SSA, discussed earlier, that caps and subsequently reduces the disability pension in the event that a person earns more income than the National Minimum Wage is removed not only for persons who will qualify for an ISL home placement but also for all disabled persons.

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## **Policy Recommendation 24**

This report recommends that the Social Security Act is amended so that a disabled person, irrespective of whether he or she is living in an Independent Supported Living home or otherwise, draws the full maximum disability pension entitlement irrespective of the value of the income earned or received.

It is pertinent to underline that the estimation of costs discussed earlier in the report account for expenditure related to daily living – food, water and electricity, etc. Thus, it is proposed that 60% of the pension earned by a disabled person who is living in an ISL home placement provided by Aġenzija Sapport will be paid into the Fund. The remaining 40% will be held by the disabled person as income for his or her personal expenditure.

In the event that a disabled person living in an ISL home provided by Aġenzija Sapport is in employment, irrespective of the income earned 25% of that said income is to be paid into the Fund as a peer-solidarity contribution for those disabled persons living in an ISL home who are not in employment.

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## **Policy Recommendation 25**

This report recommends that a disabled person living in an Independent Supported Living home provided by Aġenzija Sapport is to:

- pay 60% of their disability pension to the Independent Supported Living Fund to contribute to expenses related to food, water and electricity, transport, et al.
- pay 25% of income earned or received to the Independent Supported Living Fund to contribute to expenses related to food, water and electricity, transport, et al.

A disabled person who opts for the personal budget mechanism as an access to an ISL home will pay 45% of his or her disability pension to the ISL Fund to contribute for expenses that Aġenzija Sapport will incur with regards to the undertaking of the newly created services to support this mechanism: certification of Personal Support Assistants, et al.

Income earned or received by the said disabled person, however, will be retained by him or her.

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## Policy Recommendation 26

This report recommends that a disabled person who opts for the personal budget mechanism as an access to an Independent Supported Living home will pay 45% of their disability pension to the Independent Supported Living Fund to contribute for expenses that Aġenzija Sapport will incur with regards to specific services directed to support this mechanism.

Given the potential mix of disabled persons who will secure an ISL home through Aġenzija Sapport or through the personal budget mechanism as well as a number of persons in employment and income earned, it is not possible to approximate the revenue that will be directed to the ISL fund through this income source.

A potential approximation is the contributions made today by disabled persons living in the six residencies of Aġenzija Sapport who today contribute 60% of their respective pension income to the Agency. In 2010 total contributions amounted to €163,776.

The **third** source of income should be that of encouraging private persons to act as beneficiaries either during their life time or after their death to the ISL Fund. The integration of disabled persons within the community, as discussed earlier, is a right. As shown in this report, however, the cost of this integration does not come cheaply.

The proposed investment of €13,146,920 between the period 2012 and 2021 will only provide for an additional 74 ISL home placements (on the basis of a average cost of 4 tiers as modelled in this report).

It is evident that Government financing alone will not suffice; and in such a situation a 'divide' will continue to exist between those disabled persons who would be 'lucky' to qualify for a placement as against those who will never have an opportunity as a placement may never become available.

It is pertinent to add here, that whilst families should be encouraged to finance an ISL environment for their disabled child or children as shown in this report, the annual costs to achieve this are beyond most families – including upper middle class.

Thus, this report recommends the introduction of fiscal incentives directed to private individual persons who may wish to act as benefactors during their life time or following their death including the following:

- A one-off tax deduction of up to a maximum of €100,000 income bestowed to the ISL Fund by an individual during his or her lifetime.
- Exemption from the payment of succession taxation of up to maximum of €200,000 income bestowed to the ISL Fund by an individual on his or her death.

Moreover, it is further recommended that the above measures are complemented by providing corporations or other legal entities with a one off tax deduction of up to a maximum of €250,000 bestowed to the ISL Fund.

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### **Policy Recommendation 27**

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This report recommends that it is evident that Government financing alone will not suffice to secure the right to Independent Supported Living to all disabled persons and to overcome any 'divides' in this regard the Government should encourage private financing, either as private benefactors or as corporate social responsibility measures to the Independent Supported Living Fund through the introduction of the following incentives:

- One-off tax deduction of up to a maximum of €100,000 income bestowed to the Independent Supported Living Fund by an individual during his or her lifetime.
- Exemption from the payment of succession taxation of up to maximum of €200,000 income bestowed to the Independent Supported Living Fund by an individual on his or her death.
- One off tax deduction of up to a maximum of €250,000 bestowed to the Independent Supported Living Fund by a corporation or legal entity.

This report recommends that the **fourth** source of revenue to the ISL fund should be the National Lotteries Good Causes Fund that operates



under the terms of Section 50(7) of the Lotteries and Other Games Act, 2001.

It is to be noted that during consultation this recommendation was criticised by some stakeholders. Two arguments were mainly brought forward. The first underlined that the potential financing of an ISL framework through the Good Causes Fund constitutes 'charity' and the acceptance of this principle may result in the gradual abdication by the State to meet its responsibilities to disabled persons by seeking substitute financing through charity.

The second argument presented is that by seeking a stream of revenue through the Good Causes Fund one is reducing the importance of the disability policy domain to a base level.

Following due consideration, both arguments are refuted. The report underlines, strongly, that the primary responsibility for the financing of the disability policy sector rests unequivocally with the State. This, however, does not mean that a purist approach is adopted that forfeits the consideration of complementing State funding with third party financing including funding instruments such as the Good Causes Fund.

Secondly, The National Lotteries Good Causes Fund is, indeed, designed to help individuals, agencies or organisations that have a social, cultural, educational, sports, philanthropic or religious activity through the charging of a percentage contribution accrued from the amount of tax payable and unclaimed prizes.<sup>130</sup> This report argues that the provision of an improved quality of life to a disabled person is without doubt an important good cause.

Whilst, undoubtedly other government as well as NGO can make a case that the policy area they own and the sector they operate is no less in importance in terms of the beneficial value it brings to society, the fact remains that the disability sector compared to other policy sectors has been relatively underfunded and it is only in the past 25 years or so that this sector started to accrue a sizeable critical mass to influence, reshape and mould both the perception by which disabled persons were regarded as well as in mainstreaming disabled persons.

As repeatedly stated in this report, one potential major difference between this sector and other social and non-social sectors is the high costs involved to Government to maintain a sustainable ISL policy

framework, not to mention the economic burden that an individual family must must to retain a disabled son or daughter to live at home let alone in an independent environment.

An average annual cost of €29,476 (modelled on four different tiers of ISL care) or for the matter the annual estimate cost of €14,632.8 as estimated by an NGO Foundation to enable a disabled person to integrate in society is an insurmountable figure for all but the very wealthy in Malta's society. Seeking to obtain income through the Good Causes fund for the individual financing of the ISL environment of a disabled person – assuredly a good and worthy cause – is complex and unwieldy.

Thus, this report recommends that the Good Cause Fund legislation is amended so that 10% of the annual revenue within the Fund is directed towards the ISL Fund.

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### **Policy Recommendation 28**

This report concludes that the average annual cost of average annual cost of €29,476 (modelled on four different tiers of Independent Supported Living care) or for the matter the annual estimate cost of €14,632.8 as estimated by an NGO Foundation for a disabled person to be integrated in an Independent Supported Living home is an insurmountable figure for all but the very wealthy in Malta's society and the seeking of financing through the Good Causes Fund for such an assuredly good and worthy cause is complex and unwieldy an individual basis. It, therefore, recommends that the Good Cause Fund legislation is amended so that 10% of the annual revenue within the Fund is directed towards the Independent Supported Living Fund.

One final policy matter that requires consideration is how are parents are to be encouraged to provide financing during their life time or following their death to render it more feasible for them to finance, independently or in partnership with Aġenzija Sapport, an ISL home environment for the child.

As discussed above, the estimated average cost for full ISL home support to a disabled person at €29,476 (modelled on four different tiers of ISL care) or for the matter the annual estimate cost of €14,632.8 as estimated by an NGO Foundation renders it expensive for most families – including high middle income earners – to maintain on the short as well as the long term.

As further discussed in this report, the current SSA framework negatively penalises disabled persons in employment who earn income beyond the national minimum wage as well as disabled persons who have means beyond that established by law.

This report has already proposed that the current restrictions established by the SSA with regards to the capping of earned income, with regards to a disability pension, to the national minimum wage and the test of means as a disqualifying criteria for eligibility to support.

Not only, therefore, does the SSA render it difficult, if not impossible, to facilitate independent living for a disabled person, the report is of the considered opinion that there is no positive legislative framework that allows parents of a disabled child to build a sustained income basis that would act as a separate income stream for their during their lifetime or following their death.

It is correct that a potential vehicle that could be applied in this regard exist. This can be achieved through the constitution of a Private Trust which parent can set up for the disabled child under the Trust and Trustees Act. The law recognises all the main types of trust one normally finds in traditional common law jurisdictions. Thus, Maltese trusts can take the form of fixed interest trusts, accumulation and maintenance trusts, protective or spendthrift trusts, charitable trusts, implied resulting or constructive trusts and discretionary trusts.

The Act, however, does not seem to have provisions that relate directly to disabled persons. The closest references to disabled persons are<sup>131</sup>:

- (i) the definition of “charitable purposes” which is defined to mean “any charitable or philanthropic purpose ... includes in particular ... (c) social and community advancement; ... social purpose organisations, including federations of such organisations; or any other purpose as may be prescribed by the Minister by means of regulations made by virtue of this Act; and
- (ii) Section 6A(1) which states that “in the case of a trust governed by Maltese law, where the law of Malta contains provision with regard to the following matters: (i) the protection of minors or incapable parties; ... (iii) succession rights, testate and intestate, especially the indefeasible shares of spouses, ascendants and descendants ... which cannot be derogated from by voluntary act, shall prevail over

the terms of the trust unless otherwise expressly provided in this Act or in other provisions of applicable law relating to trusts and related matters”.

The situation where the beneficiaries of a trust are minors, incapacitated or absent is consistent with the principle in Civil Law, where an equivalent role is played by the institutes of tutorship or curatorship<sup>132</sup>. It is pertinent to underline that motivated by the aim of creating checks and balances in the functions of the respective offices, Article 163 of the Code prevents trustees of such trusts also being appointed as tutors or curators for those same beneficiaries.

Article 5(1)(A) of the Income Tax Act defines “gains or profits arising from a transfer of the beneficial interest in a trust” as a “Capital gains derived by a person from the transfer of a capital asset shall be charged under article 4(1). Section 5(2)(g) establishes rules in relation to gains and profits relating to a transfer “by donation, settlement of property in trust, or distribution or reversion of property settled in trust means the difference in the market value of the property at the time of the donation, settlement, distribution or reversion and the cost of acquisition of the property at the time of acquisition of the property by the donor, settlor or trustee as the case may be. The relevant instrument pursuant to which the said transfers were effected shall include a declaration of the said market value.”<sup>133</sup>

The rate of taxation of a trust is charged upon the chargeable income in relation to the income attributable to the said trust. This establishes the rate of charge at thirty-five cents (0.35) on every euro of the chargeable income.

It is pertinent to underline, however, that the Act does assign a sole special tax status that to a particular institution. This special status is assigned to “any foundation, bequest, trust, institution, or other organisation or body of persons the income whereof is specifically due to be wholly applied in providing income to members of the clergy” where-in the tax charged is at the rate of twenty cents (0.20).<sup>134</sup>

Although this report is not competent to carry out a technical assessment of the Trusts and Trustees Act and the implications of succession and income tax legislation on income and capital generated by trusts, it is, nevertheless, correct to conclude that the current legislative framework provides no special designation to disabled

persons. Such special status, as it exists, is limited only to ecclesiastical bodies.

The report, therefore, recommends that the appropriate competent authorities in discussion with KNPD and other interested parties should introduce an appropriate framework that provides special favourable conditions with regards to the income generated by the Trust given that the purpose of such a Trust is clearly not to achieve tax avoidance or other indirect benefits but rather to secure an improved quality of life for a disabled person by rendering it possible for parents and families to be in a position to achieve this.

Given that this report recommends the current constraints relating to income and means vis-a-vis the maximum disability pension that can be received, the ISL policy environment should see a state of play where financing is can be carried out directly by a family of a disabled child through such a Trust or in partnership with Aġenzija Sapport, where-in the Agency could top up the Trust income through the proposed ISL Fund.

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### **Policy Recommendation 29**

This report recommends that the competent authorities, in discussion with KNPD and other interested parties, should introduce an appropriate framework that provides special favourable conditions with regards to the income generated by the Trust given that the purpose of such a Trust is clearly not to achieve tax avoidance or other indirect benefits but rather to secure an improved quality of life for a disabled person by rendering it possible for parents and families to be in a position to achieve this.

## **Appendix A: Independent Supported Living: A Model of Good Practice.**

The following is an interview with a couple, both of whom are disabled persons, about their experience of independent supported living.

### **How did the opportunity to live independently come about?**

We got married 5 years ago. Before we got married, one of us used to live on her own while the other was living with his parents.

In order to live on my own, I had various personal Assistants to come to help me at different times during the day. I had also support from family members. Then when we decided to get married we did all necessary arrangements and employed a support worker from the Philippines. Thanks to our personal assistant, we are living 100% independently from our families and are enjoying our life as a married couple. We can decide what to do, where to go when we want. Of course we still need the necessary support but it's great living an independent life.

### **How has this experience changed your lives?**

This experience has changed our life drastically. We can say that there is a big difference with living with a full time live-in personal assistant.

A: When I used to live on my own having personal assistants coming over to help me up in different times, I had too many limitations. I was not able always to decide certain things but now we can decide what to do whenever we want.

B: As for me, from when I was born I used to have my parents always by my side. They were so overprotective that I was missing the concept of independence even when I grew up. When I say independence, I mean the right to choose.

### **What were the initial challenges that you faced when you made the decision to living in an ISL environment? How did you overcome these challenges?**

We think that the challenges that we faced were mostly from our families. It was not so easy for them to accept the fact that we will get married and go to live on our own, far from them.

Of course before we took such decision, we did our homework well and planned everything. We made the necessary contacts so we can bring our personal assistant to Malta in time. In fact she came here one month before our wedding day, so we gave her the training that she needed.

Another big challenge was the financial aspect. Until 2005 in Malta we had a situation that if two disabled persons who receive the disability pension get married, they will stop having the pensions and will have only one pension. We always felt that this was not fair and we wrote to the Prime Minister and KNPD about this fact. Thank God, our voices were heard and from January 2006 this situation changed and now when you get married you can keep the both pensions.

**What forms of support - personal assistance, community, etc - did you find when you started off and how has this evolved over your experience?**

Both of us are very active in a disabled people's organisation. We are very lucky that this organisation always gave hours of personal assistance to those members that really need this support.

In fact we are very proud that it was our organisation that started this idea in Malta and it was our members who had the first foreign live-in personal assistants. Both of us benefit from this assistance.

We are also benefiting from the community service through direct payment from the Agenzija Sapport.

**What institutional measures do you believe should be in place over and above those provided you?**

We believe that there should be more hours of community services from Agenzija Sapport. Of course this depends on the funds that the Government give to the Agency.

The more funds the Agency has, the better is the possibility that disabled persons continue living independently in the community with the support they need.

## **Appendix B: List of Persons and Entities Consulted**

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### **Consultations with Non-Governmental Organisations**

Ability for Disability Association

Dar Arka

Dar Pirotta

Dar tal-Providenza

Dar il-Wens

Equal Partners Foundation

Fondazzjoni Hajja Indipendent

Gozo Association of the Visually Impaired

Gozo Federation for Persons with Disability

Individual disabled persons and family members

Individual University Students

Kumitat Konsultattiv tal-Persuni b'Dizabilità Intellettuali tal-KNPD

Kummissjoni Hidma Morda u Persuni b'Dizabilità tal-Azzjoni Kattolika

Maltija

Malta Society of the Blind

National Parents' Society of Persons with Disability

STARS

### **Consultations with Political Parties**

Representatives of the PN

Representatives of the PL

Representatives of the AD

### **Consultations with Government Stakeholders**

Aġenzija Sapport

Department of Social Security

Housing Authority

Malta Financial Services Authority

Ministry for Gozo

Ministry of Education, Employment and the Family

Ministry of Health, Elderly and the Community

Mount Carmel Hospital

Office of the Prime Minister

Saint Vincent De Paule Residence

University of Malta



## Appendix C: Independent Supported Living in Europe: Select Case Studies

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### 01. Review of Supported Independent Living Policies in Europe

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This document reviews supported independent living policies in seven countries within the European Union (EU). Although a broad review of policy frameworks with regards to supported independent living policies was undertaken, the prime research source for this document is based on work carried out by the Academic Network of European Disability Experts (ANED) on supported independent living.

During 2009, ANED reviewed and evaluated national policy developments in comparative assessments to understand the state-of-the-art and to learn lessons from good practice. Given the comprehensiveness of the work carried out and the fact that such work is recent it was considered there will be little value added by seeking to develop new research material.

The following are key observations with regards to supported independent living policies in Europe:

- The majority of member states appear to have developed mainstream policy where there are clear statements supporting options for independent living including direct payment schemes: Estonia, Netherlands, Iceland, Slovakia, Ireland, United Kingdom, and Spain).<sup>135</sup>
- Some countries have developed individual pieces of legislation which articulate specific aspects of support for independent living, such as the right to personal assistance: Finland, Sweden, Denmark, Poland, Italy, and Spain.<sup>136</sup>
- Some countries have developed individual pieces of legislation which articulate specific aspects of support for independent living, such as personal budgets: Germany, Netherlands, and United Kingdom.<sup>137</sup>
- Others, such as Portugal, are at an early stage of developing an independent living project that will include personal assistance.<sup>138</sup>

- For some countries, independent living does not appear to be specifically supported, as a concept or philosophy, at policy level: Czech Republic, Greece, Malta, Austria, Bulgaria, and Latvia.<sup>139</sup>
- In some of these countries there is no discourse of self-directed support or a clear statement regarding the dismantling of existing institutions: Greece, and Czech Republic.<sup>140</sup>
- It appears that access to services and support for independent living is not restricted (at least in theory) to any particular impairment groups: Sweden, Slovakia, Norway, United Kingdom, and Iceland – although Iceland and Slovakia point out that anecdotal evidence may not bear this out in practice.<sup>141</sup>
- Even in countries where there is strong policy support for independence, choice and control some groups of disabled people (notably people with intellectual disabilities) are often subject to measures of legal / mental capacity which have the potential to exclude them from benefiting from support to live independently - Germany, Netherlands and Denmark, Ireland, France, Belgium, Italy, Spain.<sup>142</sup>
- In some countries a continued reliance on institutional care, and/or relatives and extended family members as ‘carers’ of disabled people is not consistent with a commitment towards self-directed support and independent living: Malta, Greece, Romania, Bulgaria, Latvia, Lithuania.<sup>143</sup>
- Six countries appear to have matched their levels of strategic commitment to implementation at local and practice level: Germany, Netherlands, Norway, Sweden, United Kingdom, and Belgium.<sup>144</sup>
- It appears that strategic commitment is not borne out in practice, or that full implementation of support for independent living for all disabled people is limited by local resources and regional interpretation of national policy. For the following countries, the rhetoric does not match the reality. There is a vision, but no clear direction, leadership or mandate to put this into practice at local level. Slovakia, Iceland, Finland, Denmark, Ireland, Portugal, Spain, Italy.<sup>145</sup>

- Just one country is supporting self-directed personal assistance, with (predominantly) use of mainstream services as the main delivery option for disabled people: Sweden. It is in fact suggested that Sweden is offering its disabled citizens full choice and control over the support they need to live independently, with (almost) equal access to the same mainstream services as other non-disabled citizens.<sup>146</sup>
- Twelve countries are currently providing 'twin-track' support, where options for self-directed personal assistance for independent living co-exist alongside more traditional service-led and directed options: Slovakia, Finland, Netherlands, Denmark, Austria, Germany, Ireland, United Kingdom, Spain, Belgium, Norway, and France. It is suggested that these eleven countries are offering their disabled citizens partial choice and control over the support they need to live independently, with some degree (albeit limited in some places) of equal access to the same mainstream services as other non-disabled citizens.<sup>147</sup>
- Nine countries are also offering co-existing support as above, but where the personal assistance element is **not** self-directed (i.e: disabled people can access some sort of personal assistance via a variety of means, but have no control over its planning or implementation in terms of recruiting staff, planning activities, managing the staff and the budget, etc): Poland, Estonia, Italy, Bulgaria, Romania, Latvia, Lithuania, Portugal, Iceland.<sup>148</sup>
- In the following countries, the concept of personal assistance is at a very early stage of development - Poland, Lithuania, Latvia - or is not widespread - Bulgaria, Italy - or is significantly limited in its scope - Portugal, Iceland, Bulgaria.<sup>149</sup> In these countries, it is suggested that they offer their disabled citizens very little choice and control over the support they need to live independently.
- In the 22 countries where some form of personal assistance is available, it appears that for the vast majority, this is focussed predominantly on support at home, and in some cases support to access social and recreational activities. Support at home would include support with tasks such as: house-keeping (laundry, cleaning, paying bills, correspondence, etc); food planning, shopping, preparation and cooking; personal care (washing, dressing, etc). It seems that in only two countries (Iceland, Belgium) does personal assistance to disabled people include

support with caring for children, so it is unclear whether this is an area of need that is supported more widely or not. In some countries personal assistance sometimes includes an information, advice and advocacy component, but details on this were scarce.<sup>150</sup>

- Twelve countries specifically mentioned that personal assistance could be accessed for support with employment. Similarly seven countries said that personal assistance was available to disabled people to support education and training.<sup>151</sup>
- In many countries, it does appear that personal assistance covers 'activities outside the home' and can be used very flexibly, but the absence of specific details make it difficult to judge to what extent disabled people may access personal assistance for employment or education / training purposes.<sup>152</sup>
- Seven countries - Finland, Netherlands, Austria, Bulgaria, Spain, Estonia, and France - appear to have systems based on a medical model of assessment, where access to personal assistance is assessed in terms of the nature of a person's impairment and their overall likely need for support in terms of hours per week, or per month. In this case, several country experts noted that personal assistance thus tends to be weighted towards people with physical/sensory impairments, as opposed to people with learning disabilities or mental health support needs, since the nature of the formers' impairments may be more likely to meet assessment criteria which emphasis 'substantial physical care needs', as opposed to the social support needs more commonly highlighted by the latter two groups.<sup>153</sup>
- Seven countries - United Kingdom, Denmark, Norway, Slovakia, Germany, Ireland, and Sweden - indicated that any disabled person (and some cases other non-disabled people like carers and older people) can apply for personal assistance services under their eligibility criteria. However, even in these countries, inequality in access is an issue to be tackled<sup>154</sup>:
  - In Slovakia, there are no explicit exclusion criteria but anecdotal evidence suggests that social workers were not encouraging people with learning disabilities and their families to apply due to assumptions about their capacity to manage the system.

- In Norway, Belgium and the United Kingdom, the right to services is rationed, and people's access to personal assistance will depend on how much, and what type, of services have been deemed 'available' in their locality.
- In the United Kingdom, eligibility to direct payment and individual budgets (to pay for personal assistance) is based on individual assessment, but this is underpinned by set thresholds for eligibility, which can change in response to what level of resource is available.
- In Belgium, this is fairly mechanistic, in that a set number of personal budgets for personal assistance are agreed each year in certain localities.
- Nine countries appear to be using a system whereby personal assistance is funded via a personal budget or a direct cash payment to the disabled person themselves, or the organisation managing the support: Germany, Belgium, Netherlands, United Kingdom, Denmark, Slovakia, Sweden, Finland, and France. Within this group, practice varies greatly by country, as one might expect. Five countries - Sweden, France, United Kingdom, Germany, and Denmark - support the use of direct payments or personal budgets for disabled people to employ family members as personal assistants, if they wish – although in Slovakia, Finland this is only permitted in exceptional circumstances.<sup>155</sup>
- Disabled people are entitled to self-direct either the funding system and/or the organisation of the personal assistance it pays for, if they wish, and are also eligible to tailored support to do so: Germany, Belgium, Netherlands, United Kingdom, Denmark, Slovakia, Sweden, Finland, and France.<sup>156</sup>
- In seven countries, disabled people receive personal assistance as a service, in terms of an allocation of hours, rather than as a budget, or a cash payment: Portugal, Italy, Norway, Estonia, Romania, Ireland, and Bulgaria.<sup>157</sup>
- In nine countries - Germany, Netherlands, Sweden, Slovakia, United Kingdom, Denmark, Bulgaria, France, and Spain - family members can be paid directly for caring for their relative. Each country that has this form of support has different regulations. For example, in Slovakia the care has to be for a minimum of 8 hours

and in Sweden there are no limits and it can be used alongside other forms of support.<sup>158</sup>

- Benefits paid to family members was the other financial issue that was commonly cited - (Slovakia, Norway, Finland, Germany, Netherlands, Austria, Ireland, Poland, Denmark, United Kingdom). These benefits could be in the form of direct care allowances or benefits (Slovakia, Norway, United Kingdom, Netherlands, Ireland, Poland, Portugal) or payment of pension contributions (Germany, Austria).<sup>159</sup>
- Another form of support that families could benefit from is 'respite care' (short breaks). This is available in ten countries (Slovakia, Iceland, Czech Republic, Netherlands, Malta, Austria, France, Spain, Portugal and United Kingdom). In Sweden the allowance is 30 days per year, plus eight hours of home care services monthly and in Iceland families could have 48 hours per month.<sup>160</sup>

## **02. Review of Supported Independent Living Policies in Select EU Countries**

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### **(a) United Kingdom<sup>161</sup>**

#### Legal and Policy Context

Since the 1990s there have been significant developments in the policy and legal framework to support independent living, many of which may be regarded as positive and progressive.

There has been considerable movement to separate the provision of support from specific types of service or particular physical buildings (e.g. through more flexible purchasing arrangements in a mixed economy of care, and the provision of direct payments to more disabled people).

Innovative local schemes for supporting independent living through accessible housing and direct payments were pioneered with small numbers of users by centres for independent living and user-led organisations of disabled people from the early 1980s.

A national pilot scheme for direct payments, The Independent Living Fund, was established in 1998 and extended in 1993. This provided further examples of real life outcomes and success stories. Knowledge

sharing and lobbying was also enhanced with the establishment of a National Centre for Independent Living.

## Key Policy Documents

*Improving the Life Chances of Disabled People* (<http://www.odi.gov.uk/working/independent-living/strategy.php>)

Putting People First (at: <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>)

## Support for Independent Living

Most personal assistance and equipment/adaptations for daily living are provided through the community care system. Adults with physical, sensory, learning or cognitive impairments, mental health difficulties, older people and parents/carers may be eligible for such support.

The mechanism for receiving publicly funded support depends on an assessment, usually carried out by the local authority social services department. More recently there has been increased emphasis on working in partnership with disabled people and on active participation.

To receive support to meet their social care needs, applicants must apply to their local authority to request an assessment of their circumstances. Funding decisions are made under a national procedure called 'Fair Access to Care', which identifies four levels of risk: critical, substantial, moderate and low.

In practice, due to funding restrictions, most English authorities have raised their eligibility thresholds for assistance to the 'substantial' or 'critical' level of need. An independent review of eligibility criteria for public funding of social care needs (CSCI 2008) queried both the criteria used and the overall amount of funding available, which results in a quality of life divide between those who receive assistance and those who do not.

Since the 1990s, user-controlled personal assistance services have increasingly been provided through the mechanism of 'community care' and 'direct payments'.

Direct payments refer to money given by local authorities in place of community 'care' services. Disabled people take responsibility for employing their own personal assistants and / or commissioning their own services, as well as dealing with local authority accounting requirements.

Personal budgets have been introduced more recently. They are similar in that they are based on an assessment of eligibility for services and involve an allocation of money, but recipients do not have to make a straight choice between managing their own support (with help if wanted) and leaving this up to the local authority.

Essentially, funding to purchase personal assistance is made available in respect of support services and is offered to any eligible older or disabled person aged 16 or over (including those with short as well as long term needs) or to people with parental responsibility for disabled children and to 'carers' aged 16 or over.

The most important gateway to eligibility is assessment. To gain access to direct payments or individual budgets to pay for user-controlled personal assistance, a disabled person must be assessed by the local council as needing social 'care' (or support) services. In carrying out assessments, councils have to use a framework based on meeting the needs required to achieve and maintain the independence of an individual over time.

There are possibilities for some disabled people to receive user-controlled personal assistance in the context of their employment or higher education. Payment may be made directly from the funding agency to the personal assistant, but the disabled person can decide who to employ and how the assistance will be carried out on a daily basis.

In a national survey of all but two English local authorities reported that on 31 March 2009, almost 93,000 people were receiving personal budgets.

## **(b) Sweden<sup>162</sup>**

### Legal and Policy Context

The Swedish Personal Assistance Act of 1994 has in many ways been extremely successful in enabling disabled persons to live in the



community, in self-determination and dignity, with choices equal to others, and to take their rightful place as children, parents and citizens. It is a reform that is the envy of many representatives of the international independent living movement and stands out like a 'golden standard'.

The Act legally entitles currently about 15,000 eligible persons to a non taxable, fully accountable budget from the tax-funded national Swedish Social Insurance Agency for purchasing personal assistance services to support a person in all aspects of life. The budgets' amount is based not on income or wealth but solely on need of practical assistance by others as determined by physical, cognitive or psychiatric limitations, a person's family obligations, work and leisure activities.

Recipients are free to purchase assistance services from local governments, private for-profit companies and assistance user cooperatives or to employ their personal assistants themselves.

### Key Policy Documents

Legislation referenced above.

### Support for Independent Living

A person can obtain assistance allowance if he/ has substantial and durable impairments and needs personal assistance to cope with his daily life with regards to basic needs such as washing, dressing, eating, communicating and moving about. To obtain the allowance a person must need assistance with his / her basic needs for more than 20 hours a week. Those who need personal assistance for their basic needs are also entitled to assistance for other personal needs. Family members can be employed as assistants and can get full payment for any help they provide as assistants.

To be entitled a person must belong to one of the following three groups:

1. Persons with a cognitive impairments, autism or related disability.
2. Persons with a considerable and durable impaired intelligence after brain damage in adult years caused by violence from an external source or physical illness.
3. Persons with other durable physical or mental disabilities, which are evidently not caused by normal ageing.

The impairments must be substantial and cause considerable difficulty in daily life.

The government sets a standard amount for assistance allowance every year. In 2009, the amount is SEK 247 per hour. A person can apply for a higher amount if he/she has special reasons. The highest amount in 2008 is SEK 276. Special reasons may, for example, be that the user needs a specially trained assistant who demands a higher payment than the standard amount.

Personal assistance means personally designed assistance provided in different situations by a limited number of people. It means that users have control over how services are organised and can custom-design their services according to their individual needs and also decides who is employed as personal assistant, when and how aid should be given.

### **(c) Ireland<sup>163</sup>**

#### Legal and Policy Context

While the issue of independent living for people with disabilities has been addressed and highlighted as a desirable goal in a number of policy documents, there is no definitive statement of a policy imperative to move away from providing support in segregated residential institutions to independent living in the community. The right to 'independent living' in Ireland has no legal status in the Constitution, in statute or in administrative law.

The provision of support to disabled people in Ireland still relies to a relatively significant degree on residential institutions especially with respect to those with intellectual disabilities. Although a small number of people with physical or sensory disabilities remain in these institutions, a far higher number of those with intellectual disabilities are living in segregated residential institutions.

The number of people in such institutions increases with age and, in the case of people with an intellectual disability, with the severity of the disability.

Significant barriers arise in relation to support for people with disabilities who want to live in their own homes but cannot afford to buy a property. While in theory they have the same entitlements to social housing as

other members of the community, in practice the limited supply of accessible and adaptable local authority or voluntary sector social housing is a substantial barrier to people with disabilities living independently in their own homes. Furthermore, additional disability related costs mean that the cost of living for people with disabilities is higher than for other members of the community, a fact that may also operate as a barrier to independent living.

The provision of support services to enable people with disabilities to live independently in their own homes, such as Personal Assistant Services and Home Help Schemes is also problematical. Despite the identification of such services as fundamental to facilitating independent living for people with disabilities, they remain underfunded.

Furthermore, access to such services is uneven given waiting lists of differing lengths across the country. This underfunding and uneven access to services may indicate that Ireland is falling short of the standards required by Article 19 (b) of the UN Convention on the Rights of Persons with Disabilities.

Other issues of concern include the absence of any formal processes or safeguards to ensure that people do not enter or remain in institutions against their choice, as well as the absence of any mechanism or legally binding standards for measuring the quality of community based assistance and services. Furthermore, as community or voluntary organisations administer funding for Personal Assistance services, people with disabilities in Ireland do not have the opportunity to effectively control their own financial budgets for these supports for independent living.

#### Key Policy Documents

Report of the Commission on the Status of People with Disabilities – 1996

Towards Equal Citizenship – 1999

Equal Status Act – 2000

National Disability Strategy – 2004

Disability Act 2005

Disability as a Core of the Social Partnership Process – Towards 2016  
Ten Year Framework Agreement 2006-2015  
([http://www.taoiseach.gov.ie/attached\\_files/Pdf%20files/Towards2016PartnershipAgreement.pdf](http://www.taoiseach.gov.ie/attached_files/Pdf%20files/Towards2016PartnershipAgreement.pdf))

Disability in the Programme for Government 2007-2012

National Action Plan for Social Inclusion: 2007-2016  
(<http://www.socialinclusion.ie/documents/NAPinclusionReportPDF.pdf>)

### Support for Independent Living

Personal Assistant services are generally administered by voluntary or community organisations. Two service packages are available to Leaders.

With the self-directed or leader-managed package the person with the disability acts as the leader or service manager. This involves recruiting his / her own Personal Assistants, organising their weekly rosters, returning their timesheets, arranging holiday cover, etc. The leader can consult the service coordinator when necessary.

With the supported package, the service coordinator takes responsibility for some or all of the management, delivery and operation of the service.

With both options the Leader has significant input regarding who is employed as their personal assistant. The Leader will provide most of the Personal Assistant's training, although the service provider will provide essential health, hygiene and safety training.

Individuals can apply directly to service providers to access Personal Assistant services or alternatively they can contact the Disability Area Manager in their local Health Services Executive area.

Currently there is no system of direct payments for Personal Assistant services in Ireland – where-in direct payment would allow funding to follow service users rather than the service provider thereby ensuring that “choice, control and funding” would lie with people with disabilities. Indeed, as of yet, there has been no official response from Government to these calls for the introduction of a Direct Payments option.

Personal Assistant services are funded by the Health Services Executive or Community Employment Schemes. The person with a disability

wishing to access a Personal Assistant service will make an application for funding to the Health Services Executive or Community Employment Scheme and once funding is allocated to the individual, they will enter into negotiations with service providers to provide them with a Personal Assistant service. The service user can demand full transparency in relation to the application of this funding, but there is anecdotal evidence that such transparency is not being achieved.

#### **(d) Germany<sup>164</sup>**

##### Legal and Policy Context

In Germany the main national policies that provide choices for disabled people to live independently in their own homes in the community include:

- Payments of pensions due to full or partial reduction of earning capacity and basic income in order to provide an existence minimum for people with disabilities who cannot earn a (sufficient) living on the general job market
- Integration support as part of the social assistance system (Sozialhilfe) including personal budgets and personal assistance
- Assistance at schools, universities and the work place as part of vocational rehabilitation
- Long-term care, including home care, in the case of comprehensive care needs due to age, chronic illness and/or disability
- Assistive technologies.

##### Key Policy Documents

None identified. The key national laws that defines the rights and access by disabled people who need home help, home care, technological aids and/or modifications of their home in order to manage daily life are the following:

- Social Code Book XII – Social Assistance (Bundesministerium für Justiz 2003)

- Social Code Book XI – Compulsory long-term care insurance (Bundesministerium für Justiz 1994)
- Social Code Book IX – Rehabilitation and Participation (Bundesministerium für Justiz, 2001)
- Additionally, the national systems of compulsory health insurance (Social Code Book V, 1989), old age insurance (Social Code Book VI, 1992) and accident insurance (Social Code Book VII, 1997) are relevant.

### Support for Independent Living

In Germany personal assistance services for independent living that are controlled and directed by disabled people themselves - and 2008 disabled persons have been legally entitled to personal budgets which are a direct payment scheme. Today, the services include (i) personal care; (ii) assistance in housekeeping; (iii) mobility assistance; (iv) assistance at the job place, in apprenticeship or at university; and (v) assistance in recreational activities.

Since the concept of personal assistance was originally developed from activists of the disability rights movement, it involves the philosophy that disabled people must be in control of these services. This is based on the “employer model” philosophy which implies that only services which follow the following principles are called personal assistance services:

- Disabled people control and manage staffing (“Personalkompetenz“): They close contracts with their assistants and decide about the working conditions including the salary. Disabled people are free either to function as employers or use the service of a personal assistance agency.
- Disabled people control the ways in which personal assistance is carried out. They instruct their assistants and decide which services are carried out and which not (“Anleitungskompetenz“).
- Disabled people are in control of the services’ budget and its management (“Finanzkompetenz“).
- Disabled people are free to decide about the organisation and practice of personal assistance according to their needs and wishes (“Organisationskompetenz“).

- Disabled people are the ones who decide in which room or at which place assistance is carried out (“Raumkompetenz”): Personal assistance can take place in private homes, in the public, at the workplace, at a holiday resort, paying visits to friends etc.

In principal, all persons with severe disabilities and in need for comprehensive assistance are entitled to personal assistance on the basis of a means test.

The disabled person may if he / she so wish, remain a client of a social service agency that organises the support for him or her as against managing his or her personal budget. If a person chooses the personal budget, he or she manages the work him- or herself. In the case of guardianship the person who acts as a guardian will overtake the management. According to individual needs, the management of the lump sum can be financed (as extra money) as part of the budget; this is an option especially for people with cognitive disabilities.

Part of the personal budget is also the instrument of agreeing goals (Zielvereinbarung): the responsible agency and the disabled person (or his/her guardian) negotiate and agree on the purposes and needs which the lump sum is supposed to cover. This written contract also covers specific implementation and evaluation details relevant for the individual case.

Whilst personal assistance is open to any disabled person traditionally it has long been the domain of people with physical impairments. Nevertheless use by persons with intellectual disabilities is on the increase although in this case it is recognised that they may need the help of their parents or guardian who may have to take over the management involved with both the personal budget and personal assistance.

### **(e) Denmark<sup>165</sup>**

#### Legal and Policy Context

The context of reform in Denmark for independent living took place within the social system and rather than through the emergence of an Independent Living movement. It has resulted in legislation on technological aids, housing modifications and practical assistance and care in the home.

The system is such today that there persons with disabilities have opportunities to choose a different service deliverer instead of the municipality, or to have a friend or relative engaged by the municipality to provide personal assistance.

In 1998 the concept of an institution was abolished and institutions were modified so that each resident got 2 rooms with a kitchen, became receivers of their own disability pension and paid for housing, meals and other services if they wanted them. This reform has had a large impact mostly with regards to intellectually disabled people in residences.

User governed personal assistance (BPA) started as an experiment in the municipality of Aarhus in 1976. In the 1980s it was incorporated into social service law; however it remained the case that more than half of the 300 users were from Aarhus. The conditions for entering this scheme were strict: people should have a higher than average level of activity outside the house and be young.

The Law on BPA was amended in 2000, with design directed to render the BPA scheme more relevant to a much broader group of users. It provides for personal helpers for up to 24 hours a day, 7 days a week. Therefore it gives people with a high degree of disability a real alternative to living in a residence. It also requires the person to take the role of employer in relation to the helpers.

It should be noted that BPA has not replaced ordinary home help and care for disabled people, but it is only a supplementary scheme that is used for persons needing the most assistance.

From 2009 persons using BPA have been able to choose a private firm or a user-governed organisation to act as the employer. The Danish disability organisation (DH) has established a non-profit user-governed organisation; LOBPA, for this purpose. The intention is that LOBPA will not just administer the helpers for the individual member, but also engage in recruitment and education of helpers and negotiation of working agreements with trade unions, etc. The intention is to make arrangements so that the members get the most possible independence out of it, and the helpers at the same time have acceptable working conditions.

It is recognised that intellectually disabled people have not been able to make use of this opportunity and thefore mentioned changes are also



introduced to render the scheme possible also for intellectually disabled people too.

## Key Policy Documents

Legislation referenced above.

## Support for Independent Living

Whilst the municipality must offer care and practical help in the home to persons with temporarily or permanently reduced physical or psychological functional abilities, the person that is entitled to such help may choose to select the person to provide the assistance. This person must then be approved by the municipality, which then draws up an employment contract with him or her.

If a disabled person needs more than 20 hours of help a week, he or she may choose to receive a cash sum as a contribution towards paid help that the disabled person himself or herself employs. In special cases the municipality can decide that the help must be given in kind, or that the amount should be paid to someone close to the person.

If the disabled person needs an exceptional amount of support, the municipality must give a contribution that covers the engagement of helpers for care, surveillance and escort. This is in instances where the disabled person is able to administer the scheme, engage the helpers and take the responsibility for the daily work organisation.

The municipality pays for this support and there is no means testing or personal contribution. There is however a ceiling on the finances available for help and support for each person in the form of:

- in cases where expenditure for help and support exceed €80,000 / year the state refunds 25% of the expenses over this amount.
- in cases where expenditure for help and support exceed €161,000 / year the state refunds 50 % of the expenses over this amount.

## **(f) Italy<sup>166</sup>**

### Legal and Policy Context

With regards to the right of disabled people to live in the community or in an institution, there seems to be no general policy. It is understood that the decision with regards to the possibility of “institutionalisation” is left up to the interested person, to relatives or the support administrator. The kind of assistance supplied to a person with a disability, depends on the person’s needs, verified through an integrated approach, in agreement with the resources available by the local agencies.

Even if usually the person with disability with his own directly interested relatives is included, there is little or nothing stated with regard to personal or living assistance preferences. Law 162/98, which modified the previous law 104/92, reviews measures in support of persons with serious handicap, through appropriate financing for implementing interventions with regard to the “support of the daily life” and “independent life”.

From a normative point of view, the first reference to Independent Living of disabled people is in article 39, section 2, of the law 104/92 which states that the “law for the assistance, the social inclusion and the rights of handicapped and disabled people” and subsequently in the Law 162/98 “Modifications of the law 5 February 1992, n.104, concerning support measures towards people with serious handicap. This considered in particular the “discipline, with the scope to guarantee the right to have an independent life for disabled people with a grave and permanent personal autonomy in the performance of essential functions of living, not surmountable with assistive technology, the way of realisation of programmes for helping people, managed in a direct way, also through customised plan for people who ask for, with the audit of the services distributed and of their efficacy”.

Be that as it may, both the law 162/98 and the article 14 of the law 328/00, mostly in the southern regions of Italy, were literally neglected and ignored by regional government, most of whom have not recognised them. In some situations, national funding designed to this aim, has been amalgamated in Area Social Plans (established by the Framework Law No 328/00 in order to implement the “integrated system of interventions and social services”) or in other projects which almost always have nothing to do with Independent Living.

It is recognised that where there are good models based on the concept of “Independent Living”, this is due to the work done by the disabled people’s associations, and the effort of more sensitive local administrators.

## Key Policy Documents

Legislation referenced above.

## Support for Independent Living

There is no uniformity in Italy with regards to the type of support available to people with disabilities in order to let them live in their homes within the community. Frameworks in this regard vary depending on the region of residence.

In most cases the municipality of residence provides a kind of direct assistance, through the payment for a specified number (minimum) of hours of home care for an assistant to the person with disabilities who lives at home (alone or with his family).

To determine the number of hours to give the disabled person, the Municipality performs a dual investigation, through an Integrated Evaluation Unit – which looks at both the social context and the medical aspect with regards to the specificity of the impairment. On this basis the capacity and the specific needs of the person are identified and the resulting assessment sets the hours to be allocated to a disabled person.

The provisions of such services are normally means tested.

Most often the work involved is contracted by a municipality to a cooperative of the territory, which then contracts with their staff, selected and managed according to a national collective agreement, in relation to the type of professional employed.

It is to be noted that with this type of assistance, the person with disabilities, as well as his family has no say and is not personally involved in the management of their care. Not only the person with disability almost never can choose the people who will be employed, but most often can not decide which sex the worker should be.

It is pertinent to underline that there are some important pilot projects with regards to supported independent living. One recent measure is the provision of grants for Independent Living; they are ideally based on the ability to organise and manage personal autonomy and are provided on the basis of an individual project and the calculation of the financial

commitment. All the money spent has to be justified and an employment contract has to be given in the case of personal assistants. Once again though, much depends on the will of Regions regarding the financing, managing and regulation of this form of assistance.

### **(g) The Netherlands<sup>167</sup>**

#### Legal and Policy Context

Physically disabled people have a long history of independent living in the Netherlands. Government policy aims at enabling disabled persons to live independently as long as possible. A number of laws support independent living for disabled adults in the Netherlands, some of which are very recent or have been recently amended.

The general thrust of the new legislation is to decentralise the administration of the support necessary to enhance independent community living and also to support the informal networks people with disabilities need and fall back on in order to remain in their own homes and live independently. Municipal authorities are now entrusted with delivery of household support, transportation, the provision of support devices and making accommodations to dwellings.

Both the Social Support Act (Wet op maatschappelijke ondersteuning, WMO) and the 2009 newly revised Act on Extraordinary Healthcare Costs (Algemene wet bijzondere ziektekosten, AWBZ, provide Personal Budgets (Persoonsgebonden budget, PGB). The WMO PGB is available to people living independently. A disabled person can qualify for a PGB (personal budget) pursuant to the Social Support Act to finance the stimulation of development and activities in the home to support independent living. PGBs are often pooled by recipients to finance independent group living arrangements, such as the 63 Thomas houses located throughout the Netherlands which are set up for people with intellectual disabilities.

Another important development which could enhance prospects for independent living is extension of the Dutch Equal Treatment Act for Disability and Chronic Illness (Wet gelijk behandeling op grond van handicap en chronische ziekte, WGBH-CZ) to the area of housing. Effective March 15, 2009, the Equal Treatment Act now prohibits landlords and sellers of dwellings from discriminating on the basis of disability. In addition, rental support (huur toeslag) is also available for

disabled persons and priority in occupying scarce municipal social dwellings can be given to disabled persons.

## Key Policy Documents

Legislation referenced above.

## Support for Independent Living

People who wish to remain in their own homes are to be supported in the first place by their informal networks, especially family, but also neighbours, friends and volunteers.

Disabled people who qualify for a Personal Budget are allowed to purchase the care they see fit, and accountability is required to be given afterwards in an annual reporting system. One has discretion and control over how the Personal Budget is spent as long as the expenditures can be accounted for and fall within the general guidelines of the ZZP. The budgets are not open-ended but are awarded in one of 21 different categories of support and concomitant financial level, depending on the level of impairment and support required (resulting in a 'weighted care package' or ZZP).

This means that disabled persons themselves can hire the people they choose, if they choose to do so. This kind of budget requires administration by the recipient or his or her guardian or mentor and additional support is available by MEE. Personal Budgets or PGBs are available to finance care for all kinds of disabilities, including physical, intellectual and psychiatric disabilities. WMO Personal Budgets are intended to compensate milder disability and provide support in housekeeping and other services such as adaptations to the physical home environment and transport.

Family members and other informal support network members are now formally recognised in government policy and the Social Support Act as important to enabling persons to remain in the community. The Ministry of VWS estimates that 1.6 million caregivers take care of a disabled family member, friend or neighbour.

One is defined as a caregiver if he or she cares for longer than 3 months for a person in need of such care. Local governments are encouraged to provide training for non-professional caregivers, to reward them with a 'compliment' (set at €250 in 2008), and provide other services to enable

caregivers to take a rest when necessary. The Personal Budget may also be used to pay family members and other non-professional caregivers.

In order to qualify for WMO (Social Support Act) one must be assessed by the local authority, and to qualify for AWBZ benefits one must be assessed by a centre for care referral (CIZ). Both procedures involve application, possible interview and review of medical and diagnostic records. Eligibility requirements are complicated.

## **Appendix D: Roles and Responsibilities Relating to Personal Service Assistance and Skills Identification**

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The responsibilities and skills set of the positions involved in personal assistance are shown hereunder:

### **01. Programme Co-ordinator – Supported Independent Living Unit**

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**Purpose:** Manages, plans, controls and co-ordinates the resources and operations of the Supported Independent Living Unit. The Programme Co-ordinator is responsible for the provision of high quality supported independent living services.

**Responsible to:** Chief Executive Officer  
Agenzija Support

**Position Title:** Programme Co-ordinator – Supported Independent Living Services Unit

**Position Status:** Position is Full-time

#### **Responsibilities**

Provides input to the preparation of the Unit's contribution to the Agenzija Support Strategic Plan and Budget

Develops short, medium, and long-term Business Plans for the Unit

Manages the staff resources assigned to his / her responsibility area having due regard for the need to provide direction to them, to monitor their performance, and to assist and manage them as may be required to ensure their motivation, professional development, and general well-being

Evaluates the abilities and performance of senior subordinate staff, preparing written assessments of their performance, discussing their performance with them, and pointing out areas in which improvements are needed

Ensures the delivery of the services and overall responsibilities of the position within approved budgets

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Contributes the development of a knowledge / management information system respecting the work of his / her responsibility area

Maintains management control over, and responsibility for, the operations of his / her responsibility area and its component units, ensuring the attainment of performance target

Develops the framework for the provision of supported independent living

Develops policy options on matters related to the provision of supported independent living

Develops and maintains sustained support and peer networks for families and persons provided with supported assisted living

Establishes institutionalised networks and relationships with related stakeholders, NGOs, et al to secure sustained critical mass with regards to the provision of supported independent living

Champions, develops and maintains channels for the raising of charity and private financing to complement State financing to sustain and expand the provision of supported independent living

Develops proposals for EU / international financing

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The following are perceived to be the skills required by Programme Co-ordinator of the Unit:

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Skill	Skill Level
Written and verbal communication skills	High
Interpersonal and presentation skills	High
Set and manage priorities judiciously	High
Networking	High

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Negotiation	High
Leadership	High
Self-motivation	High
Analytical, evaluative and problem-solving	High
Ability to influence, promote and market ideas and initiatives	High
Understanding of disabilities	High

It is proposed that the persons identified for the position should hold or be requested to obtain a Higher Level Qualifications Level 4 Higher Professional Diploma in Learning Disability Services (4456) as provided by City and Guilds.<sup>168</sup>

## **02. Team Leader – Supported Independent Living**

It is proposed that a Team Leader will be assigned the following responsibilities.

**Purpose:** To plan, provide and monitor the appropriate supporting framework to enable people with a physical and / or learning disability to live their lives to the full in an independent setting

**Responsible to:** Supported Independent Living Co-ordinator  
Supported Living Persons Assigned

**Position Title:** Team Leader – Supported Independent Living

**Position Status:** Position is Full-time

### **Responsibilities**

Assists the supported person in choosing where he or she will live

Together with the person who is to be supported and his or her family designs an individual plan that will allow the said person to

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live independently

Together with the person who is to be supported and his or her family designs a 360° life style for mobility within the neighbour and to and back from key locations such as work, parents residency, etc

Identifies arising wants and needs and plans changes together, with the assisted person and his or her family, the Supported Independent Living plan as to reflect such arising wants and needs

Identifies potential assistive technology that can facilitate independence living for the assisted person

Supports the assisted person with employment, education, financial, etc planning

Carries out core pre-independent training programmes for the assisted person and his or her family

Ensures quality, health and safety for the assisted person

Plans and assigns work to the Personal Services Assistant

Monitors the work of the Personal Services Assistant

Trains and supports the Personal Services Assistant as appropriate

Manages the 24\*7 Emergency Support Cluster

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The following are perceived to be the skills required by a Team Leader, Supported Independent Living:

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Skill	Skill Level
Understanding of disabilities	High
Communicate and listen	High
Ability to empathise and be sensitive to situations and people	High
Organisational	High

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Planning	High
Networking	High
Positive and caring attitude	High
Work with other individuals	High
Leadership	High
Trustworthy	High
Imbues confidence	High
Manages relationships	High

It is proposed that a person appointed to the position of Team Leader – Supported Independent Living should obtain certification in the following City and Guilds credits<sup>169</sup>:

Unit Accreditation Number	City and Guilds 4200 Number	Unit Title	Credit Value
L/601/6442	4300-210	Support person centred thinking and planning	5
K/601/6285	4200-212	Principles of positive risk taking for individuals with disabilities	2
T/601/8654	4200-215	Principles of supporting individuals with a learning disability to access healthcare	3
A/601/6274	4200-328	Principles of supporting individuals with a learning disability regarding sexuality and sexual health	3
J/602/0053	4200-334	Support individuals with self-directed support	5
T/601/8637	4200-204	Support independence in the tasks of	5

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		daily living	
R/601/8578	4200-313	Support individuals in their relationships	4
T/601/8282	4200-316	Support Individuals with specific communication needs	5
M/601/7907	4200-317	Support individuals during a period of change	4
H/601/8147	4200-319	Work in partnership with families to support individuals	4
K/601/5313	4200-209	Understanding the context of supporting individuals with learning disabilities	4
H/601/3451	4200-221	Contribute to the support of the use of assistive technology	3
F/601/5160	4200-222	Support individuals to negotiate environments	4
L/601/8028	4200-308	Provide support to maintain and develop skills for everyday life	4
L/601/8644	4200-309	Support individuals in learning or development activities	5
M/601/9611	4200-310	Prepare to support individuals within a shared lives arrangement	4
H/601/3546	4200-402	Support individuals to access education, training or employment	4

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### **03. Personal Services Assistant**

It is proposed that a Personal Services Assistant is assigned the following responsibilities:

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**Purpose:** To provide effective support to enable people with a physical and / or learning disability to live their lives to the full in an independent

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setting

Responsible to: Team Leader  
Supported Living Persons Assigned

Position Title: Personal Services Assistant – Supported Living

Position Status: Position can be Full-time or Part-time depending on needs as established by the Supported Person's Independent Living Personal Plan

Assigned Personal Assistant / s is scheduled according to the assisted person's individual schedule and pattern of life or routines

### Responsibilities

Provides physical, emotional, social and material well-being, support and assistance to people served with disabilities in their home

Assists the supported person served in expanding his or her opportunities to participate in community life as he or she chooses

Assists the supported person in learning new skills

Assists the supported person in having new experiences

Assists the supported person in choosing where he or she will live

Identifies arising wants and needs and brings these to the attention of the Team Leader

Ensures that the supported person is safe and protected from harm

Supports the person in his / her intimate and personal care consistent with his / her individual needs including:

- bathing
- bladder / bowel care
- dressing
- eating

- 
- grooming
  - medication administration
  - transfers

Supports persons in the day-to-day tasks involved in ordinary living including:

- cooking / washing dishes
- dusting
- grocery shopping
- ironing
- laundry
- light secretarial duties
- mopping floors
- vacuum cleaning
- runs errands
- assists with transportation

Assists the assisted person to achieve his or her full potential

Understands and respects the relationships which are important to the assisted person

Develops and maintains effective relationships with relatives, carers and others to promote trust and partnership

Ability to provide on call emergency response service not necessarily limited to the person to whom he or she is assigned

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The following are perceived to be the skills required by a Personal Services Assistant:

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Skill	Skill Level
Understanding of disability of the person assigned to assist	High
Communicate and listen	High
Ability to empathise and be sensitive to situations and people	High
Organisational	Medium

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Networking	Medium
Positive and caring attitude	High
Work with other individuals	High
Identify training opportunities	Medium
Trustworthy	High
Imbues confidence	High
Manage relationships	High
Understanding of main disabilities	Low

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It is proposed that persons who are employed for the position of Personal Services Assistant should obtain certification in the following City and Guilds credits<sup>170</sup>:

Unit Accreditation Number	City and Guilds 4200 Number	Unit Title	Credit Value
Y/601/3446	4200-223	Introductory awareness of models of disability	2
Y/601/7352	4200-211	Provide active support	3
H/601/5703	4200-224	Principles of supporting an individual to maintain personal hygiene	1
K/601/6285	4200-212	Principles of positive risk taking for individuals with disabilities	2
J/602/0036	4200-214	Contribute to supporting individuals with a learning disability to access healthcare	3
M/601/7048	4200-335	Principles of self-directed support	3

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A/601/8025	4200-205	Provide support for journeys	2
A/601/7926	4200-206	Support individuals to access and use information about services and facilities	3
L/601/9471	4200-207	Contribute to supporting group care activities	3
L/601/6117	4200-217	Understand physical disability	2
D/601/7904	4200-314	Support individuals to manage their finances	3
T/601/7908	4200-318	Support individuals to prepare for and settle in to new home environments	3
T/601/8637	4200-204	Support independence in the task of daily living	5

This publication is supported by the European Union Programme for Employment and Social Solidarity - PROGRESS (2007-2013).

This programme is implemented by the European Commission. It was established to financially support the implementation of the objectives of the European Union in the employment, social affairs and equal opportunities area, and thereby contribute to the achievement of the Europe 2020 Strategy goals in these fields.

The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA-EEA and EU candidate and pre-candidate countries.