



Personal Assistance for persons with disabilities in Malta

The Status Quo and the Way Forward

Prepared by:

Dr Lara Bezzina

Commissioned by:

**Malta Federation of Organisations
Persons with Disability (MFOPD)**

FEBRUARY 2024

LIFE



Personal Assistance for persons with disabilities in Malta

The Status Quo and the Way Forward



“This project has been funded through the Voluntary Organisations Project Scheme managed by the Malta Council for the Voluntary Sector supported by the Ministry for Inclusion and the Voluntary Sector (MIV). This project/publication reflects the views only of the author, and the MCVS cannot be held responsible for the content or any use which may be made of the information contained therein”

Acknowledgements

A huge thank you goes to the invaluable inputs and recommendations, suggestions and questions raised by the research participants, who took the time out of busy schedules to speak to the researcher with sincerity and a will to make things better. Most of them could not be mentioned by name due to anonymity reasons, but that does not mean all the ideas within the study are the researcher's.

A special mention goes to Rita Vella Borg, a disability activist and one of the pioneers of PA users in Malta who sadly passed away in June 2023. Rita – who was the chairperson of the Muscular Dystrophy Group – advocated for the right of persons with disabilities to live an independent life, including by living an independent life herself with her husband Kevin Vella, and, after he passed away, on her own. Both Rita and Kevin had their own PA, who supported them in their own house on a 24/7 basis. Unfortunately, the researcher's interview with Rita could not be terminated, but the essence of her knowledge and experience are reflected in the findings and recommendations.



“Research is formalized curiosity. It is poking and prying with a purpose.”

Zora Neale Hurston

Foreword:

MARTHESE MUGLIETTE

MFOPD President

The Malta Federation of Organisations Persons with Disability (MFOPD) is the one voice of all the persons with disabilities in the Maltese islands.

Throughout the years, persons with disabilities made various efforts to change things at national level, for them to be able to live their life to the full and as respectful as possible. Among others, they fought, and are still fighting for an independent life with the necessary support. ‘Personal Assistance is a tool which allows for independent living’ (ENIL).

This study has been conducted by an unbiased and competent person, Dr Lara Bezzina, who ‘poked and pried’ on our behalf with the sole intention to come up with the right recommendations for a good and strong national Personal Assistance Reform.

This study is of interest to all. It relates directly to persons with disabilities and Personal Assistants, but it also connects with the public as Personal Assistance is paid with national funds. It must be ensured that we get the true value for the money spent for the full benefit of the service users.

**Self-determination is about you being able
to be yourself and live your life however you want.**

STIL, 2023



Table of Contents

Foreword: Marthese Mugliette, MFOPD President	4
List of Figures.....	7
Executive Summary	8
List of Acronyms & Abbreviations	10
1. Introduction.....	11
1.1 Research Objectives	12
1.2 Report Structure.....	12
2. Personal Assistance: a tool for independent living.....	13
2.1 What is Personal Assistance?	13
2.2 Personal Assistance across Europe	15
2.3 Personal Assistance in Malta and Gozo	17
From its Origins to the Present Day.....	17
The Status Quo	18
3. Research Methodology.....	21
3.1 Desk Research	21
3.2 Key Informant Interviews (KIIs)	22
3.3 Data Analysis	25
3.4 Validation of Conclusions and Recommendations.....	25
3.5 Dissemination	25
3.6 Ethical Considerations	25
3.7 Limitations.....	26
4. Findings and Analysis.....	27
4.1 Relevance	27
4.2 Impact.....	29
4.3 Efficiency.....	31
4.4 Effectiveness.....	34
4.5 Inclusivity.....	39
4.6 Sustainability	39

5. Conclusions and Recommendations.....	41
5.1 Legislative Framework.....	41
5.2 Budgeting and Expenditure	42
5.3 Decision-Making.....	43
5.4 Personal Assistance Provision.....	45
5.5 Information about Personal Assistance	46
5.6 Challenging assumptions and shifting the mentality.....	47
5.7 Complementing Personal Assistance: working in tandem with other sectors	48
Annex I – Information Sheets & Consent Forms.....	51
Annex II – Questionnaires	63
Annex III – Validation Workshop Agenda	69

List of Figures

Figure 1: Type of research participants	23
Figure 2: Participants with disability - Type of impairment.....	24
Figure 3: Participants with disability - Gender	24



Executive Summary

Personal assistance (PA) is a tool which allows for independent living. It is the decisive factor in ensuring that everyone's right to live their life in the manner they want is being guaranteed. In Malta, Aġenzija Sapport is the national agency that provides subsidies for personal assistant services through the Independent Community Living (ICL) scheme. PA services in Malta, however, while providing support to many and supporting persons with disabilities to live independently, do not appear to meet the full needs of all persons with disabilities. There was thus a great need to explore the extent to which current services are enabling independent living in the community, as well as how these services could be improved. It is in this context that the current research study was commissioned by the Malta Federation of Organisations Persons with Disability (MFOPD).

The qualitative study, carried out over the course of 2023, included desk review of pertinent documents, over 60 interviews with key stakeholders (including decision-makers, service users, service providers and disability experts - both local and regional), as well as a validation workshop during which the findings and recommendations were discussed and validated with the same (local) stakeholders.

The research findings indicate that the current ICL scheme is **very consistent with the contextual needs of persons with certain types of disabilities**, such as persons with multiple complex physical impairments. The majority of interviewees who fit this profile make use of a live-in PA and would otherwise be unable to live independently. The ICL scheme is also very relevant for – and meets the needs of – many adults and children with intellectual disabilities who are supported in activities of daily living, leisure activities, therapeutic follow-up (in the case of children) and, to a lesser extent, their studies. However, **the ICL scheme is not reaching all persons with disabilities**: despite publicity on various media, **many interviewees were still unaware of the scheme**. Factors contributing to this are misinformation (e.g. on the meaning of PA) and the inaccessibility of Aġenzija Sapport's website. Furthermore, the reach of the ICL scheme is affected by the fact that **persons with mental health difficulties are not eligible** to apply. Another challenge encountered is the **mindset of many legal guardians of adults with intellectual disabilities**, who – rather than engage a PA to support their child in having control over their life – prefer to continue taking care of their child until they are unable to do so anymore.

In terms of **efficiency, interviewees' experiences vary from finding the process efficient** – such as in terms of providing emergency PAs when needed – **to not efficient**. The latter is mainly due to the **long waiting time experienced by potential service users from their first contact with Aġenzija Sapport to the time they are allocated a social worker/ICLM executive** to carry out the needs assessment. This is largely due to the **social workers' huge caseload**. Furthermore, among other aspects,

service users find the process of employing a personal assistant burdensome, overwhelming, and sometimes beyond their capability, with many interviewees indicating that they need, and would like to have, support in this process. Finally, the ICL scheme is not efficient in terms of maximising the use of available financial resources, largely because of the excessive fees paid to private care companies to whom many persons with disabilities are compelled to resort to since they find it challenging to find a suitable PA themselves. Nonetheless, the PAs provided by such companies are also largely unsuitable for working with persons with certain types of disabilities, particularly intellectual ones. The challenge in finding suitable PAs is also linked to the current low subsidy (9 euro per hour) granted to persons with disabilities who need weekly hours of assistance. This is not enough to cover a PA's salary and related expenses, making it difficult for many interviewees to bridge the gap between the subsidy and the actual expenses.

With regard to decision-making, the biggest hurdle is the ICL Appeals Board, which was found to be lacking on multiple aspects, including communication, timeliness, efficiency, and knowledge of disability and of the ICL scheme. The ICL Board, on the other hand, has improved its efficiency in recent times, although challenges remain, particularly in terms of communication between the Board and the needs assessment team. Furthermore, neither of the Boards' members include persons who themselves make use of personal assistants, and each Board has only one person (the Chair) who is a person with disability. The ICL scheme was thus found to lack meaningful inclusion of persons with disability in decision-making.

Based on these findings, the study makes multiple recommendations on the following aspects:

- To develop and implement – together with persons with disabilities – a legislative framework which clearly defines the personal assistant's role and job specifications, the rights and obligations of both service user and personal assistant, and the type of service providers. The framework should also include the immediate enforcement of the Personal Autonomy

Act and the Protection of Adults in Situations of Vulnerability Act

- To enable – in terms of adequate funding and support with the employment process if necessary – persons with disabilities who need PA services to engage a personal assistant.
- To render the process inclusive of persons with disabilities – particularly those with lived experiences of making use of personal assistance – particularly in decision-making posts, in accordance with the social model of disability.
- To improve the efficiency and communication processes of the ICL and ICLA Boards, with the latter needing to be completely restructured.
- To curb the exorbitant private care agencies fees and incentivise and strengthen user-led non-profit organisations to provide such services.
- To provide widespread and accessible information on personal assistance, related schemes, service providers and all aspects related to such services.
- To raise awareness on personal assistance with – and educate – persons with disabilities and their relatives, the professionals and other workers who work with them, and decision-makers.
- To improve the working conditions of social workers in order to enable them to work effectively.
- To bring to an end the opening of new residential institutions for persons with disabilities.
- To work in partnership with other sectors such as those providing educational, employment, leisure, family, mental health, assistive technology, transport, infrastructure and housing services in order to enable persons with disabilities to truly live independently.



List of Acronyms & Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activity of Daily Living
ASD	Autism Spectrum Disorder
CEO	Chief Executive Officer
CfR	Commissioner for Revenue
CRPD	Commission for the Rights of Persons with Disability (Malta)
DIER	Department for Industrial and Employment Relations
EDF	European Disability Forum
ENIL	European Network for Independent Living
EU	European Union
ICL	Independent Community Living
ICLA (Board)	Independent Community Living Appeals (Board)
ICLM	Independent Community Living Monitoring
IEP	Individualised Education Plan
LSE	Learning Support Educator
KNPD	<i>Kummissjoni Nazzjonali Persuni B'Dizabilita`</i>
MCAST	The Malta College of Arts, Science and Technology
MFOPD	Malta Federation of Organisations Persons with Disability
MIV	Ministry for Inclusion and the Voluntary Sector
MIVC	Ministry for Inclusion, Voluntary Organisations and Consumer Rights
NAO	National Audit Office
NGO	Non-Governmental Organisation
OPD	Organisation of Persons with Disabilities
PA	Personal Assistant
PCP	Person-Centred Planning
PE	Permission to Employ
STIL	Sweden Cooperative for Independent Living
UK	United Kingdom
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UoM	University of Malta

1. Introduction

Personal assistance is a tool which allows for independent living. The European Network for Independent Living (ENIL)¹ specifies that personal assistance differs from home care and other types of support services in that it should be controlled by disabled people themselves.²

In Malta, *Aġenzija Sapport*³ is the national agency that provides services for persons with disabilities, including subsidies for personal assistant services. These services, while providing support to many and supporting persons with disabilities to live independently, do not appear to meet the full needs of all persons with disabilities in Malta in all spheres of life. Disability organisations lament the lack of professional personal assistance service, which in its current state does not provide services to all those who require it and / or does not meet many persons with disability's required number of hours of personal assistance.⁴ For example, the Commission for the Rights of Persons with Disability (CRPD Malta)⁵ notes in its Shadow Report submitted to the Committee on the Rights of Persons with Disabilities in 2018,⁶ persons with

disability should have access to leisure time at all times. This, however, is not possible unless there are personal assistants (PAs) who can accompany them during leisure activities. It also notes that people with intellectual disabilities, who are not allowed to vote in privacy, may require personal assistance during voting. At the time of writing (December 2023), persons with intellectual disabilities are assisted by the assistant electoral commissioners to vote.

Thus, as a study commissioned by the CRPD Malta in 2021⁷ recommends, a greater effort needs to be made in order to move away from institutionalised care and invest more in services such as personal assistance, which allows persons with disabilities to live independently and participate fully and actively in society, as advocated by Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁸ to which Malta is party. Article 19, *Living independently and being included in the community*, states that State Parties should ensure that:

persons with disabilities have access to a range of in-home, residential and other community support services, **including personal assistance necessary**

1 <https://enil.eu>

2 ENIL. 2022. Personal Assistance. <https://enil.eu/personal-assistance>

3 <https://sapport.gov.mt>

4 Faculty for Social Wellbeing, University of Malta (for CRPD Malta). 2021. *Service Provision and Persons with Disability*. <https://www.crpdmalta.org/resources/research>

5 <https://www.crpdmalta.org>

6 CRPD. 2018. *Submission to the Committee on the Rights*

of Persons with Disabilities in Advance of its Consideration of Malta's 1st Periodic Report. <https://www.crpdmalta.org/uncrpdmalta/uncrpdmalta>

7 Faculty for Social Wellbeing, University of Malta (for CRPD Malta). 2021. *Service Provision and Persons with Disability*. <https://www.crpdmalta.org/resources/research>

8 UN. 2006. *Convention on the Rights of Persons with Disabilities*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>



to support living and inclusion in the community, and to prevent isolation or segregation from the community [bold added by author].

To date, however, very little research has been carried out on personal assistant schemes and services and their effectiveness in Malta. There is thus a great need to explore the extent to which current services are meeting persons with disabilities' needs and enabling their independent living in the community, as well as how these services could be improved. Indeed, the Malta National Disability Strategy⁹ calls for a gap analysis and for taking stock of the current situation in the field of independent living in the community. It is in this context that the current research study was commissioned by the Malta Federation of Organisations Persons with Disability (MFOPD),¹⁰ which also responds to ENIL's suggestion for governments across Europe to support research initiatives into personal assistance – led by disabled people and their representative organisations – to identify all characteristics of PA schemes and policies at national level, with the aim of bringing them in line with the UNCRPD.¹¹

1.1 Research Objectives

The objectives of this research study are thus two-fold:

- To evaluate the current personal assistance scheme(s) and services in Malta and Gozo (hereafter referred to as 'Malta')
- To explore the best scenario of personal assistance in Malta in supporting persons with disabilities to live independently.

1.2 Report Structure

Following this introductory chapter, this report is structured as follows:

- **Chapter 2** gives an overview of the meaning and significance of personal assistance, delving into salient PA services in Europe, before going into the Maltese context both historically as well as the current scenario.
- **Chapter 3** delves into the methodology employed in each stage of the study, including data collection and analysis, validation, dissemination, ethical considerations and limitations.
- **Chapter 4** discusses the findings and evaluates them in terms of the current services' relevance, impact, efficiency, effectiveness, inclusivity, coherence and sustainability.
- **Chapter 5** brings together the conclusions emerging from the study together with recommendations for the way forward with regard to the legislative framework, expenditure, decision-making, PA provision, information dissemination, mentality shifting and the necessity of working together with other sectors.
- **Annex I** and **Annex II** contain the different information sheets, consent forms and questionnaires used in the data collection phase; while **Annex III** contains the validation workshop agenda

9 Ministry for Inclusion and Social Wellbeing (Malta). 2021. *Freedom to Live: Malta's 2021-2030 National Strategy on the Rights of Disabled Persons*. <https://inclusion.gov.mt/wp-content/uploads/2023/04/Disability-Doc-ENG-SEP-21.pdf>

10 <https://www.mfopd.org>

11 ENIL. 2020. *Independent Living Survey – Summary report*. https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf

2. Personal Assistance: a tool for independent living¹²

Personal assistance is, evidently, only one facet of independent living. This report, however, focuses mainly on PA, while acknowledging that PA provision schemes, services and regulations do not – and cannot – exist in a vacuum, and all aspects of life in the community need to be rendered accessible and inclusive in order for independent living to truly be possible.

This chapter explores the concept of personal assistance more deeply, after which it gives an overview of PA services and legislation across Europe. The last section of the chapter then, delves into the Maltese scenario with regard to the origins of PA services in Malta and the current scene, including the legislative framework and PA in practice.

¹² This chapter does not aim to give a holistic scrutiny of personal assistance, either in Europe or in Malta. It is rather aimed at giving an overview of salient aspects of the service.

2.1 What is Personal Assistance?

Provision of personal assistance and other community supports and services, a barrier-free environment and adequate technical aids... [make] full citizenship possible.

ENIL, 2022

Personal assistance (PA) is considered as “one of the most significant innovations in the disability policy over the last several decades.”¹³ It is the decisive factor in ensuring that everyone’s right to live their life in the manner they want is being guaranteed. This is self-determination.¹⁴

Personal assistants accompany persons with disabilities for as much time during the day as necessary, and support them in the areas of activities required, including – but not limited to – dressing, bathing, cooking, reading, driving, visiting friends, attending educational studies, and going on business trips.¹⁵ Persons with disabilities should be able to decide who their assistants are, what

¹³ Sanden, F. (ENIL). 2022. *Personal Assistance as a Break-through innovation in Disability Support*. <https://enil.eu/personal-assistance-as-a-break-through-innovation-in-disability-support>

¹⁴ STIL. 2023. *Welcome to STIL – The Founders of Independent Living in Sweden*. <https://www.stil.se/en-english>

¹⁵ Sanden, F. (ENIL). 2022. *Personal Assistance as a Break-through innovation in Disability Support*. <https://enil.eu/personal-assistance-as-a-break-through-innovation-in-disability-support>



they help them with, when they work and how the support is given.¹⁶ According to the results of a key study on PA across Europe published in 2019, the most important elements for PA users are:

- being able to choose the personal assistant themselves
- having opportunities to appeal the outcome of the needs assessment
- having control over the timing of the assistance.¹⁷

Indeed, according to the Independent Living Movement, a system or policy that does not have certain characteristics such as an adequate level of funding and being able to hire one's PA should not even be referred to as personal assistance.¹⁸

ENIL – a user-led network of disabled people across Europe, advocating for independent living practices, values and principles¹⁹ - sets out the criteria of personal assistance (PA) for persons with disabilities, which:

- is purchased through cash allocations enabling the person to pay for the needed assistance;
- should be provided on the basis of an individual needs assessment, and depends on the life situation of each individual;
- should be recruited, trained and managed by persons with disabilities themselves, if they so choose. Adequate support should be provided for this if needed. Persons with disabilities should also be the ones that

choose the employment model which is most suitable for their needs;

- should be paid according to the wage rates in the particular country – thus the rates allocated for PA should take this into account, as well as other costs such as employer contributions and administration costs.²⁰

ENIL's guidelines are in line with the UN Committee on the Rights of Persons with Disabilities, which – besides the points indicated above – also states that:

- individualised PA services should not result in a reduced budget or higher personal payment;
- persons with disabilities should have the option to custom design their own service;
- PA is a one-to-one relationship, that is, it should not be shared unless it is with the consent of the person granted the PA;
- persons with disabilities can freely choose the degree of personal control over service delivery;
- persons with disabilities must have full self-determination and self-control over their PA: "package" service delivery, that is, linking the availability of one service to another / oblige two or more persons to live together / can only be provided within special living arrangements, are not in line with Article 19 of the UNCRPD.²¹

16 STIL. 2023. *Welcome to STIL – The Founders of Independent Living in Sweden*. <https://www.stil.se/in-english>

17 Mladenov. T. 2019. *What is good personal assistance made of? Results of a European survey*. <https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1621740>

18 ENIL. 2020. *Independent Living Survey – Summary report*. https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf

19 ENIL. 2022. *Proud, Strong and Visible. European Network on Independent Living*. <https://enil.eu>

20 ENIL. 2022. *Personal Assistance*. <https://enil.eu/personal-assistance>

21 UN Committee on the Rights of Persons with Disabilities. 2017. *General comment No. 5 on Article 19 – the right to live independently and be included in the community*. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>

2.2 Personal Assistance across Europe

This section provides a brief overview of PA schemes in Europe, both with regard to practice and governance, as well as in terms of legislative frameworks. The section focuses on particular cases which are either best practices and/or have encountered challenges which are useful to learn from.

At an EU-level, the new EU Disability Strategy 2021-2030²² states that persons with disabilities “old and young, have an equal right to live independently and be included in the community, with choices equal to those of others about their place of residence and with whom they live” (p. 11). The Strategy also includes, as one of its Flagship Initiatives, issuing “guidance recommending to Member States improvements on independent living and inclusion in the community” (p. 12), including on personal assistance schemes. At the time of writing (December 2023), this guidance has not yet been issued, and the provision of personal assistance services across Europe varies from one country to another, both in practice and in governance.

An independent living survey administered by ENIL across Council of Europe Member States in 2020 found that the majority (33 out of 43) countries have PA schemes in place. However, the vast majority of respondents evaluated PA schemes in their countries as inadequate or as requiring improvement. The study also found a lack of awareness on the differences between PA and home care services, even among disabled persons and their organisations.²³

Historically, Sweden and the United Kingdom (UK) were the first to introduce personal assistant schemes in 1994 and 1996 respectively.²⁴ The Swedish national PA scheme was the most highly rated²⁵ one by persons with disabilities participating in a pilot PA checklist created by ENIL in 2018.²⁶ Nonetheless, in 2019, Sellin reported that in the previous ten years, the right to personal assistance in Sweden had been reduced multiple times through the Supreme Court judgements, leading thousands of people losing their right to personal assistance and having their lives broken. In her article, Sellin appeals for rapid legislative changes, which would restore the right to personal assistance.²⁷

Legal frameworks governing PA across countries in Europe range from non-existent (e.g. Malta) to countries which have long-standing ones in place. Sweden, for example, introduced the Personal Assistance Act (LASS)²⁸ in 1994. Assistance allowance is granted to people with severe functional disabilities if their disability arose before the age of 65 and if the person requires at least 20 hours a week of basic support. Assistance allowance is payable as a standard amount per hour to the entitled recipient. The recipient engages an assistance provider. Usually, the provider chosen is the municipality, a user cooperative or a private company. The local municipality finances the first

22 European Commission. 2021. *Union of Equality. Strategy for the Rights of Persons with Disabilities 2021-2030*. <https://ec.europa.eu/social/main.jsp?catId=1484&langId=en>

23 ENIL. 2020. *Independent Living Survey – Summary report*. https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf

24 Sanden, F. (ENIL). 2022. *Personal Assistance as a Break-through innovation in Disability Support*. <https://enil.eu/personal-assistance-as-a-break-through-innovation-in-disability-support>

25 The target countries of the pilot were Belgium, Bulgaria, Croatia, Ireland, Italy, Norway, Serbia, Slovenia, Spain, Sweden and the UK.

26 ENIL. 2019. *PA Checklist – a Tool for Assessing Personal Assistance Schemes*. https://enil.eu/wp-content/uploads/2022/03/Web_PA-Checklist-report.pdf

27 Sellin, K. (ENIL) 2019. *Swedish PA Users at Risk of Losing Support*. <https://enil.eu/swedish-pa-users-at-risk-of-losing-support>

28 Ministry of Social Affairs (Sweden). *Act (1993:389) on assistance compensation*. <https://rkrattsbaser.gov.se/sfst?bet=1993:389>



20 assistance hours per week for each beneficiary, whereas the rest is funded by the state.²⁹

Other countries introduced such legislation much more recently. In Slovenia, for example, the Personal Assistance Act (PAA)³⁰ started being implemented in 2019, after a long battle by the disability movement for personal assistance provision for persons with disabilities.³¹ The Act obliges the state to, among others:

- develop personal assistance services and coordinate them with other areas of social security
- ensure uniform organisation, accessibility and efficiency of such services across the country
- provide conditions for education and training; and
- finance the service of personal assistance.³²

The PAA also defines the type of providers who can provide PAs, which are charitable organisations, self-help organisations, organisations of persons with disabilities (OPDs), institutes and self-employed providers. Providers – whose details are kept in a register of PA providers kept by the Ministry of Labour, Family and Social Affairs – have to be non-profit in nature.³³

This is not to say that such laws did not encounter any challenges in their implementation. Some of the challenges encountered in Slovenia, for example, are enumerated below:

- One of the greatest challenges was the lack of society's understanding of what a PA is and how it contributes to a person's independent living. Thus "the old logic of help, care and protection" was "simply implemented under a new name" (Pecaric, 2023: n.p.).
- Furthermore, because there are no complementary services on this scale, the PAA became a solution for everything persons with disabilities need, including solving family social hardships. As Pecaric³⁴ suggests, Slovenia needs a range of community services that would meet persons with disabilities' different needs, such as domestic help and assistance with escorting.
- Another challenge is the fact that since family members can also be PAs, persons with disabilities who used to attend sheltered work centres – which, while being institutions, still provide some people's only interaction with the outside world – were discharged from such centres in order for them to employ one or two family members, thus receiving greater number of assistance hours while also employing a relative. This means that the disabled person's quality of life is actually decreased rather than increased.
- Large PA providers in Slovenia have a triple role in that they can legally represent the user, be the legal representative of the PA providers and be personal assistants to their own child. This not only involves conflict of interest, but also allows the vast

29 Sellin, K. (ENIL) 2019. *Swedish PA Users at Risk of Losing Support*. <https://enil.eu/swedish-pa-users-at-risk-of-losing-support>

30 President of the Republic of Slovenia. 2017. *Personal Assistance Act (PAA)*. <http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO7568#>

31 Poropat, K. (YHD – Association for Theory and Culture of Handicap). 2021. *Personal Assistance in Slovenia*. Presentation delivered at conference in Poland on 24.02.2021

32 President of the Republic of Slovenia. 2017. *Personal Assistance Act (PAA)*. <http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO7568#>

33 Poropat, K. (YHD – Association for Theory and Culture of Handicap). 2021. *Personal Assistance in Slovenia*. Presentation delivered at conference in Poland on 24.02.2021

34 Pecaric, E. (ENIL). 2023. *Personal assistance in Slovenia and the problem of understanding Independent Living*. <https://enil.eu/personal-assistance-in-slovenia-and-the-problem-of-understanding-independent-living>

majority of service providers to implement PA as a kind of home help rather than as a personal assistant, going in the opposite direction to the concept of independent living.

2.3 Personal Assistance in Malta and Gozo

From its Origins to the Present Day

The actual origins of PA services in Malta are not completely clear, partly due to the fact that personal assistance was (and still, at times, is) not termed as such at the time. There were several sporadic initiatives which started the PA discussion – and eventual services – in Malta. These included a person with disability ending up residing in an elderly people's home due to lack of alternatives, who was then given a financial package by a charitable foundation in order to be able to employ a PA. The Muscular Dystrophy Group of Malta³⁵ – founded in 1980 – also began to lobby for PA services.³⁶ Indeed, the first Maltese person who had a PA – around 30 years ago – was a person with muscular dystrophy.³⁷

In 2011, CRPD Malta (then KNPDP³⁸), published a report on independent living which included a series of recommendations towards building a robust and sustained policy framework for independent supported living for persons with disabilities. Recommendations included the collection of disability-disaggregated data; the introduction of legislation for independent

supported living; and embracing personal assistant services, assistive technology support, and property adaptation regarding accessibility. The report also recommended that a person's eligibility for independent living services is not means tested; but also that the disability pension framework is revised to be sufficiently adequate to allow a person with disability to live independently. Specifically with regard to personal assistant services, the report recommended that a disabled person should have access to a personal budget which would allow them to: choose a PA; request support in managing payments; request Aġenzija Sapport to make arrangements for support; identify the person with whom they wish to live; and identify the location and building they wish to inhabit. Finally, among other important recommendations, the report also made suggestions as to how such services can be funded (mainly by the government, together with part of the person's disability pension and possible private financing, among others.)³⁹

Following this landmark report, the government gave a budget to Aġenzija Sapport for personal assistant services.⁴⁰ For a time, this budget was administered under three different schemes/Boards:

- **Personal Assistance Fund (PAF).** This fund catered mainly for live-in carers for persons with disabilities needing more than 30 hours a week of ongoing personal assistance.
- **Direct Payment.** Under this scheme, a financial package was offered to persons with disabilities who needed less than 13 hours per week of services, to enable them to employ a personal assistant or carer.
- **Independent Community Living (ICL) Scheme.** Similar to Direct Payment, the ICL was a financial package offered to persons

35 <https://www.facebook.com/profile.php?id=100070257240262>

36 Interview with Fred Bezzina (KNPD Executive Director 1987-2009), July 2023

37 Interview with Rita Vella Borg, May 2023

38 CRPD Malta was founded in 1987 as the National Commission Persons with Disability (NCPD), which changed its name to *Kummissjoni Nazzjonali Persuni b'Dizabilita`* (KNPD) in 1993. It was officially established through the Equal Opportunities (Persons with Disability) Act of 2000. In 2016, when the legislation was amended, the name was changed to its current one.

39 Spiteri Gingell, D. (KNPD). 2011. *Policy on Independent Supported Living for Disabled Persons in Malta*. <https://www.crpdp.org.mt/resources/research>

40 Interview with Fred Bezzina (KNPD Executive Director 1987-2009), July 2023



with disability to live independently / provide more assistance in more intense situations, and covered services provided by a live-in carer or an amount of hours which exceeded the maximum offered through the Agency's own human resources or Direct Payment.⁴¹

The Status Quo⁴²

Needs Assessment. Persons eligible to apply for the ICL Scheme are persons with disability under 60 years of age. In the current scenario, a person with disability is initially assessed by a social worker after making contact with Aġenzija Sapport. This initial (intake) assessment is carried out either via the phone or at the agency's office. The needs assessment team considers, among others, how the disability affects the person's life, their age, and whether they have already identified a person to be their PA.

Once the assessor confirms that the person needs a personal assistant, the person with disability is placed on a waiting list to be allocated a social worker or a member of the ICLM team (made up of professionals graduating from various degrees such as psychology, social policy and criminology), depending on the person's background.⁴³ Once this takes place, the social worker⁴⁴ conducts a deeper assessment, usually at the person with disability's home. This assessment reviews the

intake information and goes into detail on aspects such as how the disability manifests itself in the person's life, how the PA would support the person, and other services the person is benefiting from. The social worker draws up a report based on this information, together with the proposed PA hours the person needs. The report is then submitted to the ICL Board.

The ICL Board. At the time of writing (December 2023), personal assistant services in Malta are subsidised by the Aġenzija Sapport through the **Independent Community Living (ICL) Scheme**, with the three different Boards mentioned in the previous section having been merged into one in recent years.

The current ICL Board was established in November 2021. Its eight members (plus one substitute member) are appointed by the Minister for Inclusion and the Voluntary Sector.⁴⁵ The current members hail from different professions and backgrounds including occupational therapy, physiotherapy, social work, education, academia, consumer services and parents of persons with disability. Only the chairperson is a person with disability, and – besides a mother of a woman with disability – no other members are disabled and none of the members have a personal assistant themselves. Some of the Board Members are also employed by Aġenzija Sapport in various roles.

The ICL Board meets bi-monthly and plans the yearly schedule by December of the previous year. The minimum number of persons required at every meeting is four: three members plus the secretary, and some members sometimes attend via video call.

The person with disability and their social worker appear in front of the ICL Board (after the latter would have reviewed the report submitted by the social worker), where the Board decides the number of PA hours to be allocated to the person. The ICL

41 Interview with Oliver Scicluna (Aġenzija Sapport CEO), July 2023.

42 Unless otherwise specified, the information in this section was obtained from interviews with ICL Board Members, Social Workers & ICLM support executives

43 If the person with disability who needs the ICL scheme also has social problems, they are allocated a social worker. Otherwise, they are allocated an ICLM support executive.

44 This can be also an ICLM support executive. However, 'social worker' is often used in this report to cover all needs assessment team, in order to maximise reading flow.

45 <https://inclusion.gov.mt/minister>

Board also reviews – generally yearly (unless the service user / social worker asks for an appearance before, for e.g. to request an increase in PA hours) – those benefiting from the subsidy in order to see whether any changes need to be made.

The ICLA Board. If the person with disability (and the social worker) do not agree with the amount of hours allocated by the ICL Board, they can appeal this decision with the ICLA Board. The person and social worker appear in front of the ICLA Board for the final decision. The composition and work procedure of the ICLA Board remain rather unclear at the time of writing.

The Subsidy. The current subsidy granted to persons with disabilities to engage a PA – which comes out of public funds, with the total budget granted for 2023 being €4.2 million – is that of €9 per hour, which was increased from €6.50 per hour in May 2023. At the end of each month, the service user submits the necessary forms to the ICL Finance department at Aġenzija Sapport, who then reimburse the service user for the hours used during the previous month. Persons who have a live-in PA, however, have the PA expenses paid in full by the ICL scheme. There are currently approximately 380 persons using personal assistance services in Malta and Gozo.

Engaging a PA. A person with disability can choose their own PA, whether it be a friend, a person identified through advertising, or a carer engaged through a private company (see below). The ICL Board generally does not accept that the PA is a close family member, partly due to the reason that parents can also be eligible to receive the carer's grant.⁴⁶

A person with disability who needs a live-in personal assistant can also bring over someone from

the Philippines themselves. The contact is usually initiated through Maltese people who go to the Philippines or through a Filipino person residing in Malta. In recent years, however, it is mostly private care companies (see below) who are bringing over Filipino persons to work as carers in Malta.⁴⁷

The Private Care Companies. There are currently an increasing number of private care companies who provide carers for persons with disabilities. With the exception of one,⁴⁸ none of the private care companies⁴⁹ checked out by the researcher mention, on their websites, that they provide *personal assistants for persons with disabilities*. The services indicated on their websites are targeted mainly at elderly people, for whom they provide care.

While representatives of the companies interviewed – with the majority of companies not responding to the researcher's request for interview – indicate that they do, indeed, provide personal assistance for persons with disabilities, the overwhelming evidence from service users themselves, their relatives, the ICL Board and Aġenzija Sapport representatives speaks to the contrary, in the sense that employees of these companies are not personal assistants but rather carers.

Persons with disabilities who go to a care company for a PA generally pay much higher fees than if the PA is employed directly by the service user themselves. A live-in PA who is brought over to Malta – generally from the Philippines, but also, more recently, from South Asia – by a private company, costs around €10,000 more than if the person with disability conducts the process themselves. Furthermore, such companies require further charges including for a replacement PA (e.g.

46 <https://socialsecurity.gov.mt/en/information-and-applications-for-benefits-and-services/non-contributory-benefits/carers-grant>

47 Interview with Rita Vella Borg, May 2023

48 Villa Anna Teresa: <https://villaannateresa.com>

49 Examples include: 3cMalta (<https://3cmalta.com/services>); Healthmark Care Services (<https://www.healthmark.com.mt>); OZO Group Malta (<https://ozogroup.com>); Uniplural (formerly Apex) Group (<https://uniplural.com>)



when the actual PA is on vacation or sick leave) and administrative costs.⁵⁰

Thus, while care companies do have their advantages – relieving the service user from often burdensome paperwork and bureaucracy surrounding the employment of a PA, and from having to find a replacement themselves when the main PA is unavailable – the increasing fees demanded by such companies are out of reach for many. One company, for example, charges a rate of €18 hourly on Sundays and public holidays; while another charges €21, with the rate going up to €25 if the public holiday falls on a Sunday.

Legislative Framework. There is currently no law governing personal assistance services in Malta. However, living independently in the community is one of the 13 Objectives of The National Disability Strategy. Indeed, one of the actions to be taken under this Objective (10) is strengthening personal assistance and community living schemes by 2026. In partial response to this, the (then-) Ministry for Inclusion, Voluntary Organisations and Consumer Rights (MIVC)⁵¹ launched the personal assistance reform document for public consultation⁵² in October 2023, as part of the PA reform process currently underway.

50 Interviews with ICL Board Members (April-September 2023); Interviews with persons with disabilities who have live-in PA (May-September 2023)

51 The Ministry was changed in January 2024, following a cabinet re-shuffle, to the Ministry for Inclusion and the Voluntary Sector.

52 Agenzija Sapport. 2023. *Public Consultation Document - Personal Assistance Reform: Laying the foundation for a Personal Budgets system for persons with disabilities*. <https://www.gov.mt/en/publicconsultation/Pages/2023/NL-0037-2023.aspx>

3. Research Methodology

The research study was conducted between March and December 2023. It employed a qualitative approach and consisted mainly of five separate but interlinked phases, as detailed below.

3.1 Desk Research

The first phase consisted of reviewing existing literature from both international, regional (European) and national sources, including, but not limited to:

- UNCRPD recommendations, state reports and shadow reports
- EU-level reports, recommendations and directives (including reports produced by the European Disability Expertise - EDE, previously known as Academic Network of European Disability Experts – ANED)
- Pan-European disability organisations' (e.g. European Network on Independent Living - ENIL, European Association of Service Providers for Persons with Disabilities – EASPD, European Disability Forum - EDF) reports and recommendations

- National-level disability-related strategies, policies and legislation
- National-level research and recommendations (e.g. published by CRPD Malta, the University of Malta (UoM), OPDs and non-governmental organisations (NGOs) working in the disability field; news items).

The desk research helped set the stage for the subsequent phase (see section 3.2) and identified gaps in knowledge to be explored during interviews with various stakeholders. However, the desk research was not be confined solely to the first phase of the study, but was carried out throughout the whole of the research process, and incorporated any documents / information identified by interviewed stakeholders.



3.2 Key Informant Interviews (KIIs)

The questions that were asked to interviewees were developed following the desk research, in order to identify the most pertinent questions to be asked. The questionnaires (see Annex II) for the interviews were semi-structured in nature: while a pre-set list of questions was drawn up for each target group, targeting the areas pertinent to the research, it was also imperative to allow the interviewees to have the opportunity to “bring up their own ideas and thoughts”.⁵³ This ensured that the interviewees could elaborate on aspects which are important to them, which the interview might otherwise not have covered.

The second phase of the study consisted of fieldwork, or **interviews with a range of stakeholders** involved in, or affected by, personal assistance services, as described below. These were carried out **between April and November 2023**. The first part of the fieldwork consisted in conducting exploratory, or scoping, interviews with key stakeholders who could shed an overview of the current services and help the researcher refine the questions for the rest of the stakeholders, which consisted of:

- **Persons with disabilities in Malta and Gozo who currently have a PA (whether on a live-in or on ‘hours’ basis).**⁵⁴ This target group consisted of persons with different types of disabilities (physical, intellectual and sensory), genders and age groups (adult, youth and children). It also includes those who have been allocated the ICL subsidy for a number of hours but feel they need more; as well as those who had a PA in the past but no longer have one. In

the case of children using or applying for the ICL scheme, one or both of their parents were interviewed.

- **Persons with disabilities who have been allocated the ICL subsidy and are currently looking for a PA.**
- **Persons with disabilities who are on the waiting list for the needs assessment.**
- **Persons with disabilities who might apply for the ICL scheme in the near future.**
- **ICL Board members and ICL Appeals (ICLA) Board members.**
- **Aġenzija Support: management and needs assessment team.** Interviews with this target group enabled the researcher to triangulate the data gathered from the interviews with persons with disabilities and obtain a clear picture of the selection process, eligibility, types of activities supported, funding and accountability related to personal assistance.
- **Personal Assistants.** A small number of interviews were held with personal assistants themselves, in order to gauge their employment situation, the work they engage in and their views on the services offered.
- **Private care companies providing PAs for persons with disability.**
- **OPDs and NGOs working in the disability and mental health sectors.**
- **Representatives of the (then-)MIVC⁵⁵ and the Engage Board.**
- **Disability experts and academics.** Interviews were held with disability studies academics from the Faculty for Social Wellbeing at the UoM and key stakeholders with vast experience in the disability sector in Malta.
- **ENIL representatives.**
- **European Union (EU) Member States Best Practices: Sweden and Slovenia** in order to further explore the personal assistance situation in Europe and identify best practices that could be adapted to the Maltese context.

53 Willis, K. (2006) ‘Interviewing.’ In Desai, V. and Potter, R. (eds.) *Doing Development Research*. London: SAGE Publications.

54 A distinction is being made between individuals who benefit from the service of a live-in PA and those who benefit from a number of hours of PA services per week.

55 <https://inclusion.gov.mt>

Recruitment of participants was carried out with the support of Agenzija Sapport and MFOPD, who sent out a call for participants to their respective networks. Snowballing was also used in order to recruit more persons with disabilities and ensure that the sample consisted of persons of different ages, genders and impairment type.

Participants with disability. As Figure 1 indicates, a total of 62 interviews were carried out. In this figure, whether the interview was carried out with the person with disability themselves or with a relative, the interview is labelled as being with a person with disability.

Figure 2 then zooms in on the potential / service user segment, detailing the type of impairment. It is to be noted that the figure rather simplifies the reality, in the sense that a number of participants have more than one disability, or have congenital or neurological diseases, which were simplified here to physical / intellectual / multiple disabilities. Figure

3 demonstrates the gender of the participants with a disability. The ages of participants with disability range from 6 to 53 years.

Both Figures 2 and 3 show the details, evidently, of the potential / service user, even when the interview was held with a relative. When a service user as well as their relative were interviewed, these were also counted as one interview, even when the researcher spoke to them separately. However, some of the parents interviewed have more than one child with disability (who is a service user / potential service user) and thus the number of participants with disability shown in these two figures are larger than the ones shown in Figure 1.

Besides the KIIs, data was also gathered from the validation workshop (see section 3.4) participants, both during the workshop itself, as well as from feedback sent by participants to the researcher after the workshop.

Figure 1: Type of research participants

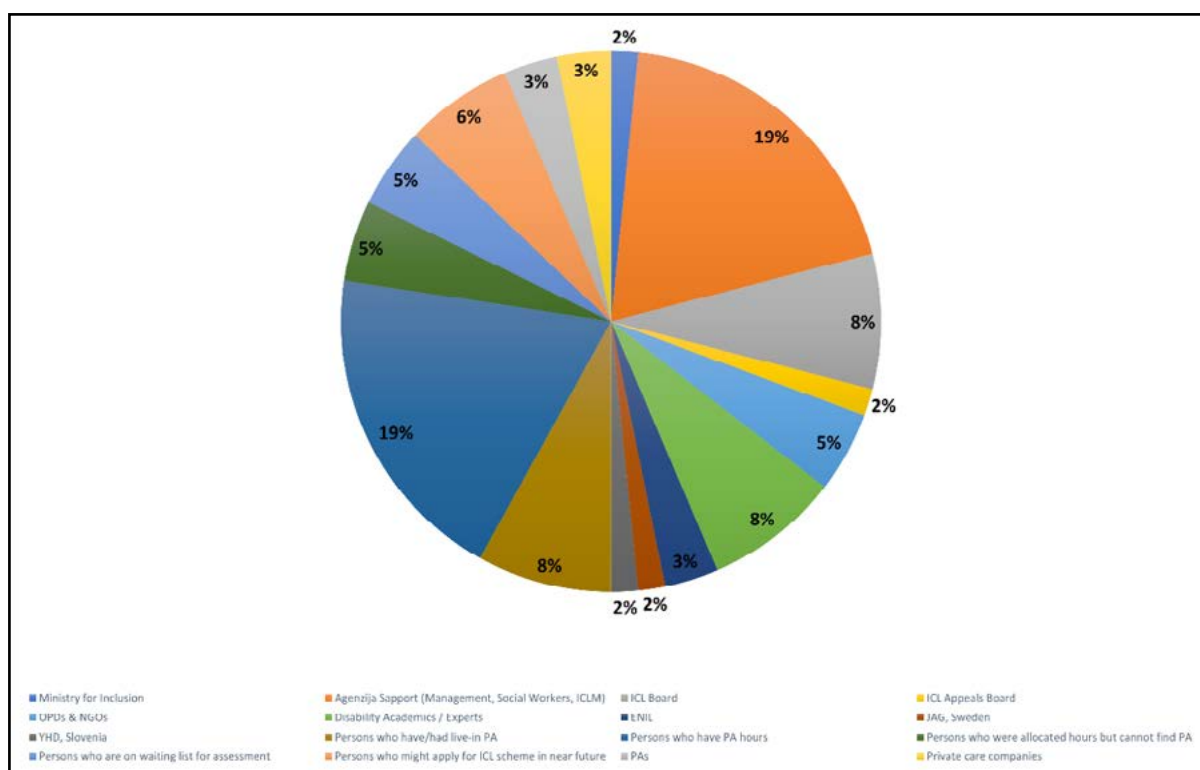




Figure 2: Participants with disability - Type of impairment

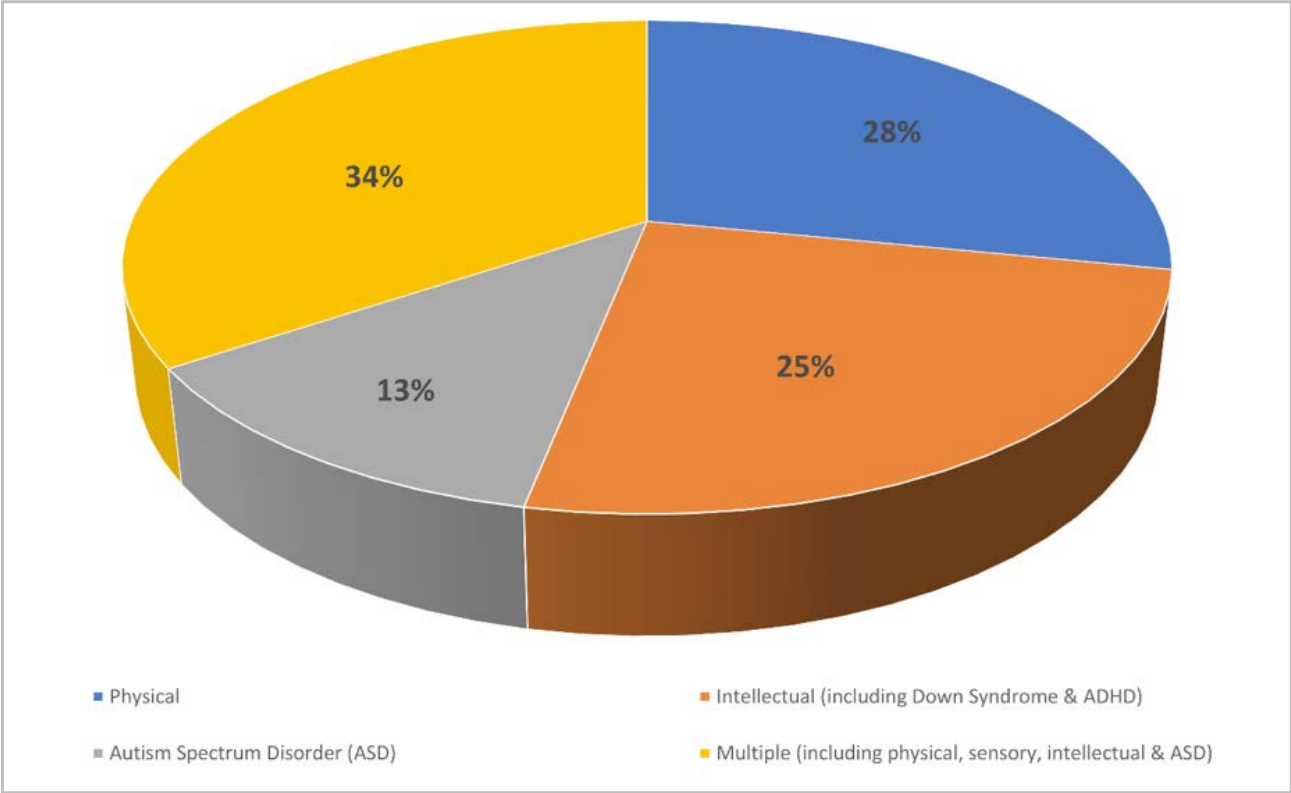
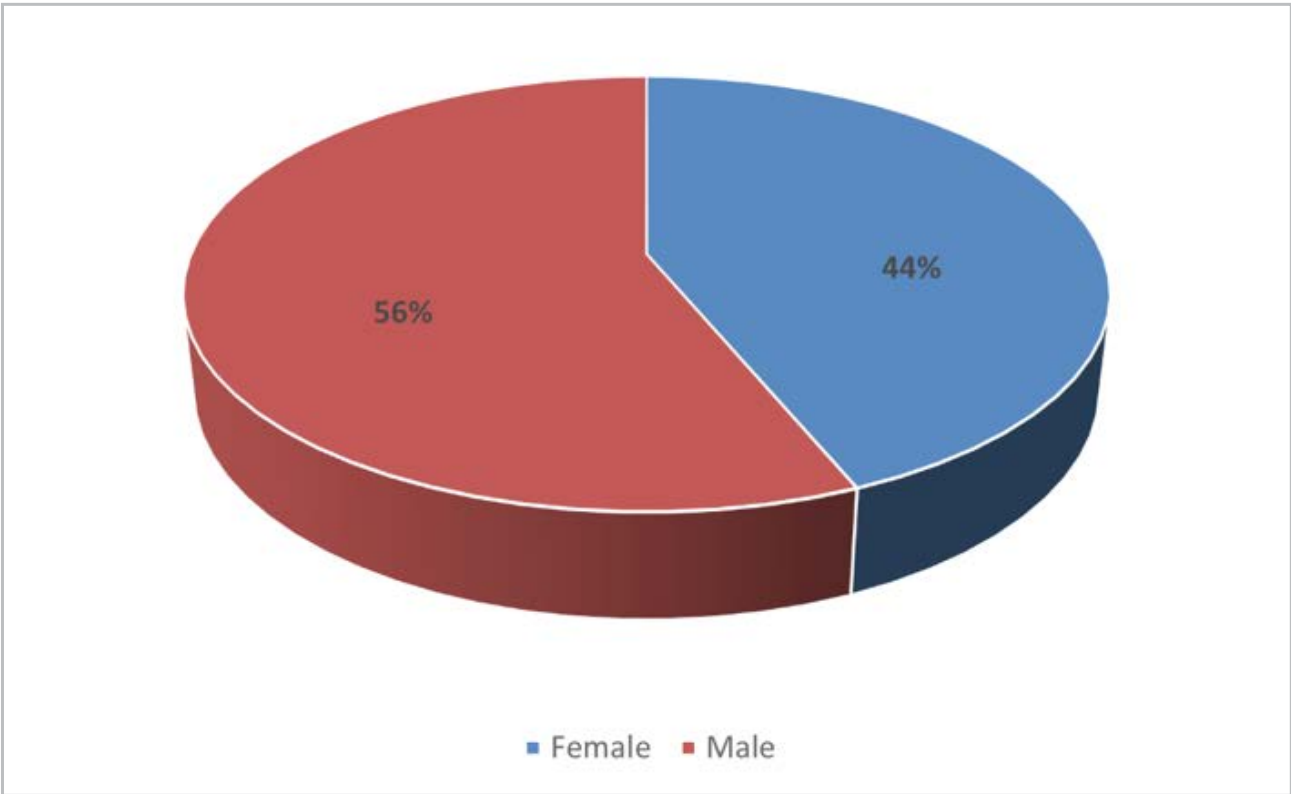


Figure 3: Participants with disability - Gender



3.3 Data Analysis

Following the interviews and their transcription, the data analysis was carried out. The analysis was guided by the principles of triangulation to ensure reliability of the gathered data. The triangulation approach was based on comparison of acquired data on the same question/issue across different sources of information. The researcher applied triangulation through three steps by:

- identifying potential sources of information for a particular question at hand;
- using each feasible source of information to obtain evidence on the same question; and
- comparing and assessing all data from different sources.

By comparing different sources of information, the researcher avoided subjectivity and partiality in data processing conclusions. As such, the triangulation was helpful not only to cross-validate the findings but also to see different dimensions of the same question. Where triangulation was not feasible e.g., due to limited sources of data available to the researcher on a given question, this was acknowledged accordingly in the findings.

To be able to coherently process all the data gathered during the data collection phase, the researcher used the data analysis software MAXQDA, which enable her to analyse the collected data based on pre-defined codes and drawing on the research questions.

Based on this analysis, the subsequent chapter was then developed.

3.4 Validation of Conclusions and Recommendations

Towards the end of the research study (October 2023), a validation workshop was organised (see Annex III), for which the following stakeholders were invited: OPDs, NGOs working in the sector, persons with disabilities and their family members,

Aġenzija Support and CRPD representatives, ICL Board members, representatives from the (then-) MIVC and from the Ministry for Gozo, shadow minister and disability spokespeople from other parties. The workshop's aim was to discuss the recommendations emerging from the study and possible solutions. The workshop was participatory in nature and was facilitated by the researcher.

3.5 Dissemination

As an umbrella organisation, with 41 enrolled member organisations, MFOPD is able to involve its members with the dissemination of the research results, which will also be published online (on the MFOPD website and social media) and in hard copy. Furthermore, even prior to the finalisation of the report, the research findings and recommendations were – in draft format – being disseminated and discussed with key stakeholders through meetings with authorities and decision-makers that MFOPD participated in.

MFOPD will also use its networking, especially through its membership with the European Disability Forum (EDF)⁵⁶ and the European Network on Independent Living (ENIL), to disseminate information and have further impact.

3.6 Ethical Considerations

The researcher ensured that the following ethical principles are in place throughout the course of the study:

- **Accessible information and consent.** Participants and potential ones were provided with an information sheet and consent form (in English or Maltese, as requested) detailing the aims of the research and use / dissemination of results. Easy to Read format of these documents were also available for those who needed

56 <https://www.edf-feph.org>



them (see Annex I). The researcher made sure that the participants understood why they are participating, that they can opt out at any time they wish to, and that they can refuse to answer any question posed to them. The participants who requested it were also sent a draft of the report before it was finalised, in order for them to be able to review their contribution.

- Interviews were carried out in the **language of choice (Maltese or English) of the interviewee**. While the majority of the interviews were – with the consent of the interviewees – held online, interviewees were asked if this is convenient for them. When the **interviewee requested a face-to-face interview, their request was granted**.
- **Anonymity**. The researcher made sure to omit the names of the participants (who remained known only to the researcher), and as much as possible, to render them unidentifiable in the report and presentations given as part of the study.
- **Security of data**. The raw data collected was only available to the researcher. It was kept on a password-encrypted computer and was erased after the end of the research study.

3.7 Limitations

As in any qualitative study, there were limitations and challenges encountered during its implementation. Below is a non-exhaustive list of such issues as well as the efforts that were made to mitigate them where possible:

- The researcher was often unable to obtain **direct access to participants with intellectual disabilities**, thus many service users with intellectual disabilities were not interviewed directly. Interviews were either held with a relative (parent or sibling) or

with both the relative and the person with disability. While the researcher tried to speak individually to the latter when the person communicates verbally, the majority of the parents / siblings were reluctant to do so. In other instances, the person with disability themselves chose to have a relative present. Thus many interviews were conducted with only the relative, or with the relative present.

- **Availability of participants**. Quite a number of potential participants who were contacted by the researcher were either unavailable, did not turn up to the scheduled interview, or did not respond to the researcher's multiple requests. These mainly consisted of persons with disabilities, private care companies, and personal assistants themselves. The latter group was the hardest to reach, both because reaching out to them depended mostly on indirect contacts (i.e. the researcher depended on others to put her in contact with them / ask them if they wish to participate); and also because many PAs work long hours and are thus less available to hold an interview. Nonetheless, the amount of interviews conducted, together with the validation workshop, helped validate the data gathered.
- **Addressing intersectionality**. Regrettably, none of the calls for participants resulted in participants from ethnic minorities, the LGBTIQ community or other minorities. Following the validation workshop however, a person from a religious minority approached the researcher to be interviewed.

4. Findings⁵⁷ and Analysis

This chapter presents the findings of the data collection effort⁵⁸ in an evaluative manner. The findings⁵⁹ were analysed according to the following criteria: relevance, impact, effectiveness, efficiency, inclusion and sustainability. Other aspects of personal assistance and independent living in Malta (such as external coherence) are discussed in the final chapter (see Chapter 5) since this deals more with recommendations, rather than findings from this study.

4.1 Relevance

To what extent is the current ICL scheme consistent with the contextual needs of persons with disabilities and their families?

57 The actual findings emerging from the study are much vaster than those reported here. Nonetheless, some aspects were not incorporated (e.g. those which are not immediately relevant to the PA reform, or which needed a much deeper analysis than can be included here) in this report in order to render it as succinct as possible.

58 The names of research participants are omitted, except when they are public figures or when they are quoted from speeches they have given publicly.

59 The findings presented in this chapter emerged from the interviews carried out for this study, as detailed in section 3.2 of this report.

I don't know what I would do if it weren't for her [the PA].

Woman with physical disability (live-in PA)

I can continue living on my own thanks to the PA and Support. I cannot thank them enough that I can continue living in my own home thanks to this [ICL] scheme.

Woman with physical disability (live-in PA)

The current ICL scheme is **very consistent with the contextual needs of persons with certain types of disabilities, such as persons with multiple complex physical impairments** (e.g. persons with muscular dystrophy and other persons who are unable to use more than one of their limbs).⁶⁰ The majority of interviewees who fit this profile make use of a live-in PA and **would otherwise be unable to live independently** (i.e. live in the community and have control over their lives). In such cases, the PA mainly assists / supports the person with the Activities of Daily Living (ADLs) such as personal hygiene, dressing, eating, transfers/bed mobility, locomotion and bowel and bladder control. As demonstrated

60 This is not to say that all persons who fit such a profile need / make use of a PA.



by the quotations⁶¹ of two interviewees, the PA is essential in the lives of persons who need assistance with these activities and is a game-changer in terms of independent living.

I believe that the ICL scheme is supporting the majority of the individuals.

It is very flexible and it can cater for a variety of needs.

Social Worker, Aġenzija Sapport

The ICL scheme is also **very relevant for – and meets the needs of – many adults and children with intellectual disabilities, especially those persons whose impairment is less complex** (e.g. persons on the lower end of the ASD and persons with Down Syndrome who communicate verbally, are in employment, etc.). In such cases, the needs of the interviewees generally fall into the following interlinked categories:

- **Support with ADLs:** All the interviewees with intellectual disabilities are supported in daily living activities, although the extent to which this is needed differs according

61 All quotations cited in the report are in English: those which were said in Maltese have been translated to English for ease of reference. The quotations are also as true to the original as possible (except where, for example, the sequence of words / phrases had to be changed in order for the quotation to be understood) and thus reflect the interviewee's way of interpretation and speaking (e.g. 'I applied for a PA' might mean 'I applied for the ICL scheme subsidy on behalf of my child'.) The information in the brackets following the details of the interviewees with disability or their relatives indicates the type of PA services they had at the time of the interview, whether it is a live-in PA or hours of PA services, whether they are on the waiting list at Aġenzija Sapport (often referred to as simply 'Sapport') to be assigned a social worker or ICLM support executive, whether they are in the process of applying for the ICL scheme, or whether they might apply for the ICL scheme in the near future.

to the person's needs. While interviewees with physical disabilities mentioned earlier often need the PA to *do* certain activities for the person (e.g. bathing, cooking, etc.), adults with not-so-complex intellectual disabilities most often need **support in learning how to**, for example, cook simple meals. Others need **reminding to** bathe or to take medication.

- **Support in leisure activities:** This support is very much linked to the point above. All interviewees with intellectual disabilities need accompaniment in their leisure activities, whether it is to be:
 - supported in budgeting, danger awareness, socialising; or
 - able to choose the type and place of activity they would like to engage in; or
 - accompanied to the place of the activity (e.g. when attending music/drama lessons, etc.).

More often than not, these support needs in adults with intellectual disabilities are interlinked, as demonstrated by the quotation below. The subsequent quotation on the next page demonstrates the importance of personal assistance in being able to have control over one's life.

Before, I used to do nothing... I can go out with my mum but mum is always in a hurry. She has her own things to do. [The PA] gives me her time, asks my opinion.

Woman with intellectual disability (PA hours)

The carers [at the residential home] take him out as a group. So when I asked him if he wants a PA, he said yes – to take him out. He depends on people – and if they cannot do what he wants to... on his own he cannot go out because he doesn't have the concept of time

Sister of man with multiple disabilities
(plans to apply for PA)

The PA helps her in all the right ways – it is a success! She helps her with self-sufficiency: undressing, dressing, holding the cutlery during mealtimes, goes out with her, talks to her, does the tasks that the Early Interventionist sets for her, reads to her...

Mother of daughter with multiple disabilities
(PA hours)

- **Therapeutic follow up** (mostly for children with disabilities): The PA supports the child with continuing, at home, the work conducted during therapy sessions such as speech, physio and occupational therapy.
- **Support in studies:** Due to the non-existence of learning support educators (LSEs) at post-secondary education level, persons with intellectual disabilities who would like to further their studies need personal assistance in supporting them, both during lectures as well as in homework. At the time of writing, subsidies to engage a PA have been allocated to some service users, however sporadically. Nonetheless, as shown in the next quotation, there is a great need for support for persons with disabilities who would like to study at post-secondary level.

There is a great discrimination against persons with disabilities who want to continue studying at post-secondary level, where there are no LSEs: they may be brilliant but still need support. But they are brought to the horizon and then told 'no more!', no opportunities for you because there is no support at post-secondary level.

Sister of man with multiple disabilities
(plans to apply for PA)

4.2 Impact

4.2.1 What are the outcomes of the ICL scheme?

As alluded to in section 4.1, the ICL scheme has – and is – **making it possible for persons who would otherwise have no choice but to live in an institution, to live independently**. This is especially true for **persons with complex / multiple physical disabilities** and is the biggest impact the ICL scheme has had to date. The scheme is also making it possible for adults with not-so-complex intellectual disabilities to have more control over their own lives while also learning the necessary skills to live independently.

4.2.2 To what extent is the scheme reaching persons with disabilities in Malta and Gozo?

The scheme is reaching persons with disability in Malta and Gozo **to a certain extent**. While the ICL scheme has been publicised on public media (TV being the one most cited by interviewees), quite a number of interviewees and potential interviewees were either still unaware of the ICL scheme before the researcher spoke to them, or came to know about it coincidentally (e.g. by word of mouth). This is due to a number of factors:



- **The Aġenzija Sapport website page** providing information on the service.⁶² The website, which is already hard to find, has minimal information about the ICL scheme and how it works, thus making it difficult for people who do not know the system to understand exactly what is provided and how they can access it. Furthermore, the page is under the title 'Carers Scheme', which misinforms the public about the difference between a carer and a personal assistant. The title continues with 'Independent Community Living Monitoring Services' which is also rather confusing as this only refers to the monitoring side of the services rather than first describing the actual service.

From the website I couldn't understand what I have to do [to apply for the ICL scheme]... so I asked [someone from Sapport management].

Woman with physical disability (PA hours)

- **Lack of targeted / effective publicity.** While some interviewees did get to know about PA services from public advertisements, most of them (see quotations below) came to know about the scheme through informal means (e.g. from other service users), through events organised by NGOs, or through making contact with Aġenzija Sapport regarding other services (e.g. community services).

I had no idea [the ICL scheme] existed...I know PA exists in other countries because I went for a conference....in Germany. So I asked about PA with other parents.... and [she] told me PAs exist in Malta.

Mother of son with intellectual disability
(on waiting list)

An ex-student of mine told me about this [scheme] because she was working at Sapport. I had no idea!... There is no outreach about the services that exist!

Mother of daughter with multiple disabilities
(in process)

- There is still **widespread misinformation / lack of information** – even among service users themselves – about what a PA is, either confusing it with carer services (see first point in this section) or simply not knowing the meaning of personal assistance, as evidenced by the quotation below.

The first two years we were with [a private care company] who was changing the carer all the time... so it wasn't good for [my son]. So then we found one ourselves but I didn't know it was called a PA. We call them 'carer'.

Mother of son with multiple disabilities (PA hours)

62 <https://sapport.gov.mt/services/carers-scheme-independent-community-living-monitoring-iclm-services>

- **Persons with mental health difficulties are not eligible for the ICL scheme**, unless they also have a disability (intellectual, physical, sensory, etc.). This is partly due to the ‘separation’ of mental health and disability in legislation⁶³ and services in Malta. Persons with mental health difficulties are not generally registered with CRPD Malta’s register of persons with disabilities,⁶⁴ which is a pre-requisite for eligibility for the ICL scheme. They also do not normally receive services from Aġenzija Sapport, but from other entities such as Richmond Foundation,⁶⁵ none of whose clients contacted by the researcher knew about the ICL scheme, much less benefit from it.

4.3 Efficiency

4.3.1 To what extent is the ICL scheme efficient?

Experiences of interviewees who applied for the ICL scheme **differ in terms of efficiency**. While some interviewees state that their needs were responded to immediately – for example, one interviewee with physical disability speaks of the **efficiency with which he was provided with emergency PAs when needed** - many others voice their frustration at various aspects of the ICL scheme:

- **Long waiting time:** The majority of the interviewees – as demonstrated by the quotations below – state that once they

I applied with Sapport two years ago...Other parents told me it will take a long time. When I applied, they told me that there is a long waiting list... I went again to ask about my application. They told me I am still on the waiting list.

Mother of son with intellectual disability
(on waiting list)

We applied for a PA with Aġenzija Sapport more than a year ago... we are on the waiting list and they told me that they would contact me later... Then when no one got back to me, I phoned them again and they told me there is a long waiting list. So this is a phantom service. Why do you have a service and advertise it? If I have to wait for more than a year, then there is no service. If there is no follow-up, you will fall out of the system.

Father of son with intellectual disability
(on waiting list)

get in touch with Aġenzija Sapport, they are left to wait for a long time, without any communication whatsoever. This is partly related to the **huge caseload of social workers at the agency**. In recent years, this has been partly mitigated by introducing the ICLM team, who take over the needs assessment of potential/clients if these do not also have social problems (see section 2.3 of this report). Furthermore, according to a number of interviewees, the **efficiency of the ICL Board has generally improved** in recent

63 Malta has separate laws and strategies for mental health, such as the *Mental Health Act* (<http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=11962&l=1>) and the *Mental Health Strategy for Malta 2020-2030* (https://health.gov.mt/wp-content/uploads/2023/04/Building_Resilience_Transforming_Services_A_Mental_Health_Strategy_for_Malta_2020-2030_EN.pdf)

64 <https://www.crpdm.org.mt/services/eu-disability-card>

65 <https://www.richmond.org.mt>



years, with the waiting time for clients to appear in front of the Board being reduced to approximately a few weeks. Nonetheless, due to such factors as, for example, there being urgent cases needing to appear in front of the ICL Board prior to those who were already scheduled, some cases might still take a lengthy time to appear in front of the ICL Board.

- Persons with disabilities who are approved by the ICL Board to receive the subsidy **lose the funds if they do not use them within a certain time period**. While this is understandable from a finance management point of view, and for reaching as many persons with disabilities in need of a PA as possible, it also ignores the reality of the challenges encountered by many to actually find a PA or one suited to their needs (see section 4.4).
- **Burdensome paperwork.** Accountability evidently requires paperwork. Nonetheless, monthly paperwork that service users need to submit to Agenzija Sappport can be daunting for some, either timewise or capability-wise, especially when it involves multiple forms to be filled which could potentially be reduced.

Every month I have to fill in five papers: timesheet, invoice, receipt, declaration.... Why do you need five papers?

Woman with physical disability (PA hours)

The fact that you have to provide three or four documents every month is too much. Per quarter would be good, especially for someone like me who does not use a lot of PA hours.

Man with physical disability (PA hours)

The biggest bureaucratic process that provides challenges for persons with (any type of) disabilities, however, is the employment of the PA, as demonstrated by the quotations below.

The main stumbling block was getting in this thing of the self-employed. [The PAs] asked me questions which I didn't know how to answer on VAT, tax, etc. I don't understand these things... So [the PAs] were reticent about [taking on the job]... Sometimes people want to help out... but I didn't know how to go about the employment process. I want us to have the choice of the PA but we need support with the employment documents, process, etc. because these papers scares the potential PAs off.

Mother of son with intellectual disability
(PA hours)

I found a person to [be my PA]... I was very optimistic about it... But then he asked me if he will be taxed on the payment he receives. I have never worked in my life so I had no idea how this works. I asked the social worker and she said that Sapport does not go into that. She sent me to Jobsplus and DIER. The CfR said that since the person is employed on a full-time basis and would be employed as a PA on a part-time basis, he would have to pay 10% from his part-time income and 25% from his full-time one. Apart from all the bureaucracy, I have to go to Jobsplus to apply for a PE number for the PA. So without ever working myself, I am an employer! It was really overwhelming for me.

Man with physical disability (PA hours)

- **Conflict of interest.** In Malta it is nigh impossible to avoid some conflict of interest. Being such a small country, many of the country's inhabitants are either related or know / of each other, whether directly or indirectly. Nonetheless, certain aspects of conflict of interest with regard to some Board Members' dual roles make this aspect more challenging. For example, two ICL Board Members are also Aġenzija Sapport employees. Furthermore, there are occasions where the person with disability is known by an ICL Board Member, which can make it uncomfortable for the applicant to disclose aspects of their private life. This over and above the apprehension and anxiety felt by several interviewees when appearing in front of a board who will pass a judgement on them and make a decision concerning their lives.

- **ICL Appeals Board.** There is almost unanimous agreement by the interviewed professionals who have appeared in front of the ICLA Board with / representing service users that the Appeals process is **not efficient**. The main aspects that came out of the interviews relating to the ICLA are the following:

- **Lack of communication / response.** Social workers and ICLM support executives interviewed denote a range of between four to seven months from the time of the social worker's outreach to receiving a response from the ICLA or to the case actually appearing in front of the Board.
- **Lack of timeliness (before and after).** Similarly, there are cases which took a year (from the initial application to the communication of the decision) to be finalised.

The Appeals Board has a disastrous communication system – they never reply to emails asking them to set a date. For them to issue a decision letter it sometimes takes a year. Sometimes it takes such a long time that we tell the client they might have to give up – because by the time they get a date to appear in front of the Appeals Board, the situation of the client would have completely changed.

ICLM Support Executive, Aġenzija Sapport



The ICL Appeals Board needs to be made up of persons who are in touch with the reality out there. And this is a cause of a lot of frustration for us and the client. We send the report to the Appeals Board including the other services that we have explored with the client. But the Board does not read the report and starts asking questions about the services we would have already written about in the report. And the client feels misunderstood...

Decisions take months – even 5 months. Meanwhile clients do not know what to do... [they] still need the services. This causes lots of anxiety for them which also transfers to us. And [the ICLA] give no feedback. It is very unethical.

All of my cases have been declined so far. One case, for example got declined – I asked what the reason was so we see if we can re-appeal but I got no answer. It's like they forget that we are working with human beings.

Social worker, Agenzija Sapport

4.3.2 To what extent have the modes of intervention and the implementation of the ICL scheme made it possible to achieve its objectives maximising the use of available resources?

To a certain extent. As mentioned earlier (see section 2.3), private care companies ask for exorbitant fees. In the case of live-in carers, since the PA package is paid in full by the ICL scheme, financial resources that could be used to subsidise PA salaries for other persons with disabilities are instead taken up by these companies, who continue raising their fees.

4.4 Effectiveness

4.4.1 To what extent is the ICL scheme effective and thus achieving its objectives?

To a certain extent.

- It is commendable that the ICL scheme is not means-tested: personal assistance is a human right.
- Among interviewees, there is unanimous consent that it is difficult to find PA, or at least an appropriate one. Challenges include:
 - **Difference in language** (if the PA is foreign): many individuals with intellectual disabilities do not speak English.

I didn't contact the [private care companies] because I know who they are – my sister teaches them English. They are total beginners: it's scary. How can they communicate with my daughter?

Mother of daughter with multiple disabilities
(in process)

- Finding a PA who **understands the person's disability**. Carers coming from private care agencies do not have any experience in working with persons with disabilities. While this might not always provide a difficulty, PAs need to have the willingness to learn. This also links, however, to the working conditions of the PA, who deserves to be paid an adequate salary as well as have the right job conditions (see section 4.6).

It is really difficult for us parents to find a PA. Some of them do not know what autism is. None of them have training on how to deal with ADHD, autism: they only have certification in elderly care. Or are not available during the hours I need.

All carers are foreign and my children do not always understand English.

Mother of three children with multiple disabilities (looking for PA)

Support told me I cannot have high expectations. But how can that be? My child is aggressive. Some PAs were too weak. Others were not appropriate: they either do nothing or else shout at my children....

Mother of three children with multiple disabilities (looking for PA)

- **Precarity of service continuity.** If, for example, the live-in PA decides to leave their employment, it takes a while to bring another live-in PA – who are generally Filipino nationals – over to Malta, leaving the person with disability either without a PA or else with stop-gap ones who would not know their client. This is over and above the fact that, as mentioned earlier, private care companies usually provide carers who do not know the needs of with persons with disabilities. This

is linked to the fact that at times, persons brought over from the Philippines come to Malta under the impression that they will be working in other sectors (e.g. the hospitality sector) and thus are unwilling to work as a live-in PA.

- **Lack of appropriate service providers.** Besides the points mentioned above, when a person with disability wants / needs to engage a PA from a private care agency, they are obliged to engage them for a minimum of three / four hours at a time, even if they do not actually need these amount of hours.

I met with a lot of problems because the amount of hours I need were few, so I couldn't meet the minimum requirements from the [private care companies] of 3 hours per day.

Man with physical disability (PA hours)

I have PAs for a period of time, then they leave. And I cannot have that – changing the PA all the time. Every time the PA changes, I spend six weeks working from home to train the new one. I do not go to work until I am sure that they are ok. I do this from my unpaid leave.

Mother of three children with multiple disabilities (looking for PA)



During Covid, for example, some carers took a year to come from abroad. And sometimes the person with disability pays money to the [private care company] to get a carer and the carer doesn't come within the time promised; or else they give the carer to someone else, for example while the other is in hospital. Then the latter comes out of the hospital and has no one to help her settle down at home.

Social Worker, Agencija Sapport

- **The subsidy is not enough** to engage a PA for many individuals interviewed, as evidenced by the quotations below. This is due to a number of factors, some of which have been already mentioned (e.g. lack of PAs pushes persons with disabilities to turn to expensive private care agencies). Furthermore, if a person has no income apart from the disability pension, paying a PA salary and their expenses proves challenging. This is further exacerbated if there is more than one person with disability in the family, thus increasing expenses. Indeed, the 9 euro subsidy makes it difficult for the employer to employ someone legally and pay their taxes, social security contributions and other related expenses. At the same time, low pay also deters potential PAs from taking on the job.

The subsidy is not enough – I pay [the PA] 10 euro per hour and reimburse him for petrol, and wear and tear [of the car].

Mother of three children with intellectual disabilities (PA hours)

To find a... PA is not cheap....with the subsidy there are so many hours one can have at one's disposal, per month. To lure [the current PA] in, I offered him 15 euro per hour, which is a lot. Then I also pay for his food, cinema tickets, etc...

Mother of son with multiple disabilities (PA hours)

I take the PA with me to different therapy sessions, so that she knows what is happening during these sessions. So it is a lot of time and money that I have to spend this way.

Mother of daughter with multiple disabilities (PA hours)

One of the problems [to engage a PA from a private care company] was the cost: 13 euro per hour. And Sapport gives only 9 euro per hour. This is not enough for us.

Man with physical disability (looking for a PA)

Other interviewees mention the fact that it is difficult for them to pay the PA from their own pocket, that is, until they are reimbursed at the end of the month. On this last point, commendably, one such case was solved by Aġenzija Sapport offering to process a person's documents weekly, rather than monthly, thus enabling them to engage a PA and pay them regularly.

- **The need for a mentality shift.** This refers to multiple aspects at different levels of society in Malta:
- **Parent over-protection** (especially of persons with intellectual disability). This topic has been explored in other studies which confirm this phenomenon in Malta.⁶⁶ In the present research study on personal assistance, it emerged that over-protection – while well-meaning – can impede persons with intellectual disabilities in accessing the ICL scheme: many parents are of the idea that the best option is for them to continue taking care of their (adult) children until they are

My [26-year old] son lives with me. I take care of him and his medication... I had gone to Sapport and Sapport had offered me a PA for some hours... I said no because at that time it was ok. I am not thinking of applying for a PA for him unless something happens to me.

Father of man with intellectual disability

no longer able to do so, at which point their children will then go to reside in a community residence. As shown by one of the quotations below, this mentality is rather understandable; nonetheless, if Malta is going to shift towards deinstitutionalisation,⁶⁷ there needs to be a mentality shift among parents.

Most of my clients' parents are elderly. They are coming from a generation when ICL was not a thing. They always felt reassured that as they start to grow up, their child will move into a residential home. Hence now this is very overwhelming for them.

Social Worker, Aġenzija Sapport

⁶⁶ See, for example: Callus, A-M., Bonello, I., Mifsud, C. & Fenech, R. 2019. *Overprotection in the lives of people with intellectual disability in Malta: knowing what is control and what is enabling support*. Disability & Society. DOI: 10.1080/09687599.2018.1547186

⁶⁷ CRPD Malta. 2023. *Towards the Deinstitutionalisation of Persons with Disability in Malta*. <https://www.crpdmalta.org/mt/towards-the-deinstitutionalisation-of-persons-with-disability-in-malta>



- Linked to parent over-protection is also the **assumption by legal guardians that they know the preferences, needs and capabilities of the person with disability**. This naturally leads to resistance to considering the option of their (adult) child living independently.
- **Resistance to having strangers at home**. This resistance is found both in relatives as well as persons with disabilities themselves. Nonetheless, whereas the latter prefer having a PA at home – though at times uncomfortable – and living independently; when parents / legal guardians are the decision-makers, the person with disability does not have a choice but to be assisted by them.
- **Persistence in opening new residential homes for persons with disabilities**. Many interviewees expressed confusion at the fact that while on the one hand parents are being told that their children with disabilities will not be able to reside in a residential home when they need to because Aġenzija Sapport – as part of the move towards deinstitutionalisation – will not be opening new residences; on the other hand other entities – such as ALS Malta⁶⁸

– are opening new residences (housing more than 10 persons in each) with the financial support of the government.⁶⁹

4.4.2 *To what extent is the management of the scheme effective?*

- While some interviewees acknowledge that the **management of the ICL scheme has improved in recent years** and that their experiences with the application process and the ICL Board are positive, there **remain some challenges**, particularly regarding the **communication between the ICL Board and the needs assessment team** (social workers and ICLM support executives). This appears to be a two-way challenge: on the one hand, ICL Board members feel that the needs assessment team does not always present the correct picture of the applicant to the Board (e.g. in terms of the report submitted to the ICL Board). On the other, the needs assessment team feel that the communication from the ICL Board could be improved, especially with regard to the justification of decisions taken when less hours than applied for are approved, for which the ICL Board does not give a reason.
- Lack of communication is felt still more with the **ICLA Board**, as alluded to earlier (see section 4.3). Interviewees lament especially the ICLA Board Members':
 - **Lack of understanding of the ICL scheme** (e.g. the Board asking for a service user's payslips when the ICL scheme is not means-tested; asking a social worker to apply for more hours than needed to compensate for extra expenses).

68 <https://alsmalta.org>

69 See, for example, the opening of a new home by ALS Malta in May 2023, with the support of the (then-)MIVC: <https://alsmalta.org/il-ftuh-ta-dar-bjorn-zebbug>

I have nothing positive to say about the Appeals Board. I have no idea how they were appointed. It is shameful how they behave. I don't think they are even aware of the aims of the service – the questions they ask are not relevant to the ICL scheme. And I felt that they had not even read the report – they were asking questions that were already answered in the report... I had asked the Appeals Board if they need an updated report [from the one I had submitted to the ICL Board]. They said no. A few days before [we appeared in front of the ICLA Board], they asked me for the report, which I had sent them months before.

Social Worker, Agenzija Sapport

- **Lack of knowledge of disability** and of the particular needs of persons with disabilities (e.g. suggesting that a service user, who has no sense of danger, works in the construction sector).
- **Lack of etiquette** (e.g. Board members do not introduce themselves when service user & professional appear before the Board; ICLA Board sends decision letter to the professional and not the service user. The latter is also linked to the Scheme's inclusivity – see section 4.5).

4.5 Inclusivity

To what extent are persons with disabilities involved in the management of the ICL scheme?

Persons with disabilities are **partially involved in the management** of the scheme. Their **meaningful inclusion and participation can be much improved**

in the process – from the allocation of funds through to the appeals:

- **Less than half of the ICL and ICLA Board members are persons with disability** (see section 2.3) and none of the members have a PA themselves. The composition of the Boards has elements of medical model of disability: while professionals are needed, and most ICL Board members have vast experience in disability and, to a lesser extent, the human rights model of disability, there is still a strong element of **non-disabled experts making decisions for disabled service users**.
- **Persons with profound disabilities are not represented** on either Board. This is being mentioned as a separate point to the first one due to the fact that persons with profound disabilities are often more marginalised than persons with other disabilities and rarely have the space to speak out and be heard. This aspect also came out clearly during the validation workshop (see section 3.4) and needs to be emphasised.
- As mentioned in section 4.4, **applicants are often left in the dark on the reasons for decisions** taken by the Boards.

Thus **persons with disabilities are not genuinely empowered in decision-making** at an stage of the ICL scheme process.

4.6 Sustainability

To what extent is the ICL scheme sustainable and how?

The sustainability of the current PA services in Malta could be improved, due to several factors, some of which have already been discussed in the previous sections:



- Live-in PAs are usually persons who come from the Philippines due to the higher salaries in Malta. Nonetheless, there is no certainty that people from the Philippines will continue wanting to come and stay in Malta. This is also linked to the fact that, as the quotation below indicates, **persons from the Philippines working in Malta are easily subjected to inadequate working conditions.**

[The private care companies often] pay the carer the minimum wage: around €879 a month. And [sometimes] they cannot get out of the contract and their passport would have been taken away. It is a legal form of human trafficking.

ICL Board Member

Such statements echo recent bids by the Honorary Consulate of the Philippines to push for a labour agreement that would help prevent immigration scams and the exploitation and abuse of Filipino workers in Malta,⁷⁰ whose number has doubled (with figures still rising) over the past few years,⁷¹ bringing the total of Filipinos in Malta to around 12,000 people.⁷²

70 Cummings, J. (Times of Malta). December 11, 2023. *Philippines wants its workers in Malta protected against abuse. Agreement would ensure Filipinos experience 'less exploitation and abuse'.* <https://timesofmalta.com/articles/view/philippines-wants-workers-malta-protected-abuse.1072317>

71 Consulate of the Republic of the Philippines to Malta. 2023. <https://www.csbgroup.com/consulate-of-the-republic-of-the-philippines-to-malta>

72 Cummings, J. (Times of Malta). December 11, 2023. *Philippines wants its workers in Malta protected against abuse. Agreement would ensure Filipinos experience*

- The **low subsidy** – and thus many persons with disabilities' inability to bridge the gap between the subsidy and actual PA expenses – **makes the scheme unsustainable** in that potential PAs are not being encouraged to work in this field; and persons with disabilities are not aware of when / if the subsidy will be increased at par with the cost of living.
- Similarly, the **challenging work undertaken by social workers and their dwindling numbers** need to be taken into account: social workers need to have job conditions matching their studies, experience and in-work challenges in order to encourage more social work graduates and social workers to work in the field.

'less exploitation and abuse'. <https://timesofmalta.com/articles/view/philippines-wants-workers-malta-protected-abuse.1072317>

5. Conclusions and Recommendations

Based on the findings of this research as well as invaluable inputs from interviewees⁷³ themselves who contributed to this chapter (whether directly or indirectly), the following recommendations for the improvement of the PA system in Malta and Gozo are being presented here. In view of the changing scenario (i.e. the ongoing PA reform at the time of writing (December 2023), different recommendations apply to different possible scenarios).

The recommendations are divided into the following sections for ease of reference: legislative framework; budgeting and expenditure; decision-making; personal assistance provision; information about personal assistance; challenging assumptions and shifting the mentality; complementing personal assistance: working in tandem with other sectors. However, they are interlinked and depend on the implementation of the other recommendations.

5.1 Legislative Framework

The right to personal assistance should be protected

⁷³ The majority of the interviewees could not be cited by name due to anonymity purposes.

by national legislation. Encouragingly, the Personal Assistance Reform which is – at the time of writing (December 2023) - under way, proposes, as part of the implementation plan, a strong legislative framework that focuses on the rights of personal autonomy and a user-led approach, amongst others. It is important that this framework:

- is fully in line with **Article 19 of the UNCRPD** and **General Comment No. 5** of the Committee on the Rights of Persons with Disabilities.
- is co-designed and co-produced with **persons with disabilities** themselves (particularly those who have personal assistants) and **developed in close and meaningful consultation with OPDs, civil society and stakeholders** working closely with persons with disabilities.
- is implemented as soon as possible, with **clear and adequate timeframes and monitoring** systems of its various implementation stages.
- **clearly defines who is eligible for a personal assistant** and the eligibility criteria (while allowing for the uniqueness of each individual's needs), including in terms of age (see section 5.7).
- clearly defines **what a personal assistant is and what it is not** (e.g. a carer), as well as the **responsibilities and rights of both personal assistant and service user** (including the activities that the personal assistant is



obliged and not obliged to do). This is necessary – together with information and awareness raising (see sections 5.5 and 5.6) in order to clear any misconceptions on the role of personal assistants.

- **clearly defines the occupation of personal assistant.** This needs to be accompanied by a mainstream **job description developed by** the public employment agency **Jobsplus**⁷⁴ (in conjunction with the relevant stakeholders) in its Occupational Handbook,⁷⁵ which details the **job description, duties, work environment, qualifications, knowledge and skills which are required by the person holding the job; as well as the related career opportunities, median pay and job outlook for the coming years.**⁷⁶ Such description should also include probationary periods and **the specific rights and job conditions of live-in personal assistants** (including opt-out contracts with the possibility of opting back in to the national maximum weekly working hours,⁷⁷ daily paid hours of leave, emotional support and **housing in case of a person coming to Malta specifically to work as a live-in PA**). PA also wages need to be revised regularly according to the rise in cost of living. Finally, a PA system which depends on migrants who come to Malta under the impression that they will do another job or else who are here only for a few years is not quite sustainable. The

PA job thus needs to be regularised and job conditions which are attractive and adequate to the job requirements need to be developed, in order to attract more people to such jobs.

- **clearly defines which type of entities can provide personal assistants** (see section 5.4).
- is implemented together with the two other complementary legislations: the **Protection of Adults in Situations of Vulnerability Act** which was published for public consultation in 2017;⁷⁸ and the **Personal Autonomy Act**, which was already being drafted in 2018.⁷⁹ While these two legislations are much needed in their own right – and also need to be developed in close and meaningful consultation with OPDs and relevant stakeholders – they are also necessary in tandem with the implementation of widespread personal assistance services **in terms of curbing abuse, protecting the person with disability's wellbeing and supporting the service user in PA management.**

5.2 Budgeting and Expenditure

- While **PA services should not be means tested** – they are a fundamental right – findings show that **not all persons with disabilities**

74 <https://jobsplus.gov.mt>

75 Jobsplus. 2018. *Occupational Handbook*. <https://jobsplus.gov.mt/job-seekers-mt-MT-en-GB/guidance-services/occupational-handbook-2018>

76 Currently this Handbook does not include Personal Assistant as one of the Occupations detailed within, and limits itself to describing home-based and institution-based care workers.

77 DIER. 2020. *Normal Hours of Work*. <https://dier.gov.mt/en/Employment-Conditions/Hours%20of%20Work/Pages/Normal-Hours-of-Work.aspx>

78 This Act was published for public consultation under a different name in 2017: Ministry for the Family and Social Solidarity (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing). 2017. *The 'Protection of Vulnerable Older Persons and Adult Persons with Disability' Act – Closed Consultation*. https://meae.gov.mt/en/public_consultations/mfss/pages/consultations/theprotectionofvulnerableolderpersonsandadultpersonswithdisabilityact.aspx

79 CRPD Malta. 2018. *Submission to the Committee on the Rights of Persons with Disabilities in Advance of its Consideration of Malta's 1st Periodic Report*. <https://www.crpdmalta.org.mt/uncrpd-det/uncrpd>

can afford to pay the difference between the **subsidy** they receive from Aġenzija Sapport and the **personal assistant wages**. One way to mitigate this is through the proposed personal budgets,⁸⁰ which would **cover the expenses of the PA's salary, tax, social security contributions and other related expenses**. Without this, it is impossible to truly enable independent living for all.

- Whether through personal budgets or otherwise, the **PA's expenses incurred due to work-related matters** such as meals when eating out with service user, transport, event tickets, etc. **also need to be covered by the provider** (not out of the service user's pocket).
- These expenses can be covered from the money that could be saved from the exorbitant private care companies' fees (see section 5.4) and from the cost of housing persons with disabilities in institutions and supported living residences. Currently, it costs Aġenzija Sapport around €10,000,000 annually to manage its 11 supported living residences, which house 80 residents.⁸¹ Should these 80 residents transition to independent living, the cost of financing personal assistants would amount to much less than what is currently being spent. Evidently, for persons with disabilities to live independently, there are other preconditions to be taken into account, such as affordable and accessible housing (see section 5.7).
- The ICL scheme expenditure should also be audited by the National Audit Office (NAO)⁸² in

order to identify how best this budget could be spent and to promote best practices.

5.3 Decision-Making

- The **'Nothing about us without us'** philosophy needs to be re-introduced in the decision-making process of the PA system. As it currently stands, less than half of the composition of the ICL and ICLA Boards are persons with disability and none are persons who have a PA themselves. Should these still remain in place after the reform, it is quite **imperative that more persons with different types of disabilities themselves (and, where necessary – such as when persons have profound disabilities and cannot articulate clearly their preferences – their legal guardian⁸³) are members of both Boards, particularly persons with lived experiences of personal assistance**. The reason for the latter is that no one better than persons living the experience can better understand the needs of others in similar situations. This is not to say that non-disabled professionals should not be involved if deemed necessary, but rather that, in keeping with the social model of disability, persons with disability should be the majority in such decision-making roles. If professionals are involved, they should be strictly persons who work in the disability sector, understand disability issues and have disability etiquette.
- In order to ensure service continuity and efficiency, **ICL Board members need to meet more frequently than on a bi-weekly basis, in order to be able to meet according to the waiting list requirements, particularly if the number of persons with**

80 Aġenzija Sapport. 2023. *Public Consultation Document - Personal Assistance Reform: Laying the foundation for a Personal Budgets system for persons with disabilities*. <https://www.gov.mt/en/publicconsultation/Pages/2023/NL-0037-2023.aspx>

81 Interview with Oliver Scicluna (Aġenzija Sapport CEO), October 2023.

82 <https://nao.gov.mt>

83 Or, once the Personal Autonomy Act (see section 5.1) comes into effect, the person supporting the person with disability in supported decision-making.



disabilities making use of such services is envisaged to increase in view of the current move towards de-institutionalisation. Such engagement would also accommodate the priority given to emergency cases without pushing too far back other cases which are not deemed as urgent.

- Similarly, the **ICLA Board** needs to meet **more frequently in order to accommodate, in a timely manner, appeal requests and ensure timely correspondence** with the service user and social worker.
- Such **Board(s) members should be engaged through a transparent process, include only persons with appropriate qualifications and experience** (see previous point in this section on this) and **have clear roles and mandates (including the timeframes within which decisions are taken and a basis on which decisions are to be made) which ensure no conflict of interest** (e.g. if a person who is well-known by a Board member is appearing in front of the Board, the Board member should be replaced by another member for that particular case. Both Boards should be also independent of Aġenzija Sapport). Having Board members appointed by the Ministry also implies the possible changing of members with changing governing political parties and thus less continuity. The responsibilities of each Board member should be clear and made public (e.g. on the public service website⁸⁴), and be subject to probation, renewal of contract, etc.

- **Transparency and open communication** is also crucial in decision-making of both Boards. Besides having clear criteria on which to base decisions – albeit each person with disability's needs being unique – the **ultimate decision needs to be communicated to the person with disability with clear reasons as to why such a decision was taken**. This is not only in line with the social model of disability, but also with showing respect to both service user, their family members and the professionals (social workers, ICLM support executives) who would have worked hard to prepare the necessary documentation before appearing in front of the Board, as well as at times going out of their comfort zone (especially service users). Meanwhile, regular updates on the position of their application – starting from the first contact made with Aġenzija Sapport up to being assigned a social worker – should be communicated to the (potential) service user.
- **Transparency and timely communication is also essential to – and with – the professionals (e.g. social workers, ICLM support executives) working with service users every day**. These are the ones who meet the service users and know their lives, challenges and needs; and thus need to be aware of **decisions being taken and changes being made (both of which should also include such professionals before being finalised) - especially in this time of reform - in order for them to be able to provide the service users with the right information and guide them on their path**.
- **Channels for service users to give anonymous feedback** on their ICL & ICLA Boards' experiences should also be put in place.
- Given the above recommendations, **the**

84 <https://www.gov.mt/en/Government/Government%20of%20Malta/Ministries%20and%20Entities/Officially%20Appointed%20Bodies/Pages/Boards/Independent-Community-Living-Board.aspx>; <https://www.gov.mt/en/Government/Government%20of%20Malta/Ministries%20and%20Entities/Officially%20Appointed%20Bodies/Pages/Boards/Independent-Community-Living-Appeals-Board.aspx>

current ICLA Board should be completely **restructured** in terms of its composition, mandate, frequency of meetings and **way of working** (with an emphasis on timely and adequate correspondence with professionals and service users, compassionate and well-informed sessions with professionals and service users, and clear reasons on the decisions made.)

5.4 Personal Assistance Provision

- Should they still be PA providers after the reform, **private care companies providing ‘personal assistants’ need to be regulated** (see section 5.2) in terms of:

- **Exorbitant, ever-rising fees** (including carer salaries, replacement carer salaries, administration fees). **Regulations** (including those **limiting the maximum fees⁸⁵ and rate of fee-raising that can be allowed**) **need to be put in place in order to protect consumer rights and wellbeing.** At the same time, these companies also need to **regulate PAs’ salaries, which are currently much lower than the actual fees they charge service users, in order to safeguard personal assistants’ job conditions.**
- **Personal assistant experience and qualifications.** **Regulations also need to be put in place with regard to the kind of PA that such companies – or any other – can provide.** Companies should provide

personal assistants rather than carers, and where needed, training (e.g. on how to work with persons with intellectual disabilities, challenging behaviour, non-verbal communication, etc.) should be provided by the company itself at its own expense. This includes **language training** where the service user prefers to communicate in Maltese.

- The **path that workers from the Global South take to come to Malta needs to be researched and regulated**, including the expenses such workers undertake and their awareness of the job and the job conditions that awaits them here.
- One manner in which the provision of PAs could be regulated is by incentivising **non-governmental organisations, cooperatives, or social enterprises to provide personal assistants:**
 - This would ensure that the service is being provided by non-profit **organisations whose main aim is to support persons with disabilities in living independently, rather than making profit.** As mentioned in section 5.2, public funds which are currently being used – indirectly – to be given to private care agencies, as well as those being spent on residential homes, can be used to fund such NGOs’ human resources, capacity-strengthening, administrative functions and PA salaries.
 - Such organisations should be **user-led** (thus ensuring that the provider understands the realities of the user

⁸⁵ For example, through price capping regulations, given that personal assistance is an essential service.



and ensure the meaningful inclusion of persons with disabilities), and **provide a 'pool' of PAs for persons with disabilities who would be supported / assisted in finding the right match of a PA for them**, as well as in **learning how to manage / supervise their PA**. This would meet one of the biggest challenges faced by service users and potential ones: finding a (suitable) PA, who would, in the proposed scenario, be interviewed and selected by the service user themselves after the provider 'matches' a potential PA with a service user.

- The service providers would also support the service user, if required, **in the process and bureaucracy of employing a PA, offering the possibility of the PA being employed by the service provider while still being managed/supervised by the service user** (with support, when needed, by the service provider.) This would also meet another big challenge that current service users are facing – that of dealing with the paperwork, process and legalities of employing another person – while still allowing the service user to be in control of the service.
- **Monitoring of the service (including the PA's work, the wellbeing of both PA and service user, as well as identifying abuse of the service)** would also be the service provider's responsibility.
- The service providers would also be in charge of **providing user-led training to PAs**. While some types of a PA's responsibility would not necessarily need training (e.g. where the service

user needs are more care-based), many PAs would still need training in how to work with service users (e.g. with regard to keeping boundaries). **Such training can be carried out in a collaborative manner between service users and personal assistants and include training to service users in managing a PA.**

- **Referrals to such service providers could be made directly by the professional carrying out the assessment – together with the person with disability** – of the service user's needs and number of hours of assistance needed.

5.5 Information about Personal Assistance

- As mentioned in section 5.1, while the law will define what a PA is, there needs to be **widespread accessible information** – including information which can be accessed easily via different means of communication such as telephone or a reference person within Local Councils – on the meaning of personal assistance and what it can / cannot be used for.
- The **website containing information on personal assistance** needs to:
 - **be fully accessible** for people with all kinds of disability (thus including Easy Read versions of the information within, subtitling and captioning of videos, read-aloud features, as well as the possibility of changing font, text size and page contrast, among others).
 - be in **both Maltese and English**, in order to ensure a wider outreach.

- **provide – in a simple and accessible manner – all the information possible within** (this would serve both to make the service transparent as well as to reduce the number of calls / drop-ins to the service provider), including the services and support that the service provider provides, how the allocated money is spent, the process of obtaining a personal assistant and of changing the PA, and what happens in different unexpected but common scenarios (e.g. if the service user ends up in hospital for some time).
- As mentioned in the first point, the **website needs to be accompanied by the promotion of both website and service** (see also section 5.6) **not only on public media but also through NGOs, OPDs** and other stakeholders who regularly come into contact with persons with disabilities.

5.6 Challenging assumptions and shifting the mentality

- Personal assistance services are a relatively recent development in Malta. Thus it is evident that the **public in general, and persons with disabilities and their relatives specifically, as well as those who regularly work / come in contact with persons with disabilities**, need to be **educated about the meaning of – and reason for – personal assistance**, and the difference between this and other services (e.g. community services). This includes **changing the misconception that living independently means doing everything oneself**.
- Such awareness raising also needs to target the much-needed **shift in the mentality in**

which parents are the default option for persons with disabilities until they are no longer there. As Professor Callus⁸⁶ indicates, in order for the shift towards independent living to take place, there is a need to move away from the question of ‘what will happen to my child when I am not here?’ to ‘**what will happen when my child wants to live independently from me?**’ The focus – from all relevant stakeholders, including decision-makers, residential support workers, professionals, parents and the person with disability themselves – needs to shift to **what the person with disability prefers and needs**.

- Challenging assumptions and supporting a shift in mentality needs to take place on two counts:
 - **Raising awareness, educating and providing best practice examples / ‘role model’** examples of persons with disabilities who live independently with assistance from a PA on the one hand; and on the downsides of living in institutions and not having control over one’s life on the other.
 - **Bringing to an end the state (and public) financial support to institutions and residences for persons with disabilities which are being opened currently or are planned to open in the near future.** Such financial support and the backing of charity initiatives by policy-makers to newly opening institutions give **mixed messages** to the public, persons with disabilities and their families, and other relevant stakeholders.

⁸⁶ Interview with Prof Anne-Marie Callus (Department of Disability Studies, UoM), August 2023.



5.7 Complementing Personal Assistance: working in tandem with other sectors

- Evidently, **PA services cannot function in a vacuum and need to be complemented with others** such as the availability of assistive technology devices, accessible housing, accessible information, accessible transport, accessible infrastructure and access to goods and services.
- **Accessible housing is of utmost importance:** for persons with disabilities to be able to live independently, housing needs to be made available which is accessible not only in physical terms but also financially. Furthermore, should the practice of having a live-in PA continue, those persons who make use of such service need housing which accommodates the PA as well.
- **At policy-making level, independent living services** for persons with disabilities need to be **implemented and monitored** not only by the responsible ministry, but **also in collaboration with other relevant ministries** including those responsible for **education, employment, children's rights, social policy, housing, transport, infrastructure, public works and enterprises**.
- According to the UNCRPD, persons with mental health difficulties are also persons with disabilities. In Malta, there is still a **distinction - in terms of both legislation and services – made between persons with disabilities and persons with mental health difficulties**. Services to these two 'groups' are provided by different entities, thus excluding persons with mental health difficulties from benefiting from personal assistants. Nonetheless, PA services should be available for persons with mental health difficulties as well.
- Depending on whether the reformed PA system allows for PAs for children with disabilities, **the reform discussion needs to also focus on whether children with disabilities and their families will have separate services (i.e. family support services rather than PA services)**. This might help clarify the distinction between personal assistance (solely for independent living) and family support, where the latter would include support to families of children with disabilities who evidently require support to care for their children which is over and above that of families who do not have a child with a disability. Such services could include support with homework, support with ADLs, working on exercises set by therapists at home, and accompanying children during playtime.
- **Depending also on whether the Ministry for Education⁸⁷ provides LSEs or a similar type of support for youth with disabilities wishing to continue studying after the end of compulsory education (i.e. at Junior College,⁸⁸ Higher Secondary,⁸⁹ MCAST,⁹⁰ University), the PA reform discussion should also focus on whether PA support will also entail support in education. While there is definitely a great need for this type of support, it might not be a PA's role to provide this**, as this would require the need for certain qualifications from the PA's side (similar to the qualifications required by LSEs). This brings us back to the earlier point of **collaboration with other ministries in order to provide the services needed**

87 <https://education.gov.mt>

88 <https://www.jc.um.edu.mt>

89 <https://edumalta.gov.mt/en/schools/post-secondary-institutions/giovanni-curmi-higher-secondary-naxxar>

90 <https://mcast.edu.mt>

and to ensure that these services work in tandem with each other.

- **Depending also on whether a PA accompanies a person with disability to the place of work as a workplace personal assistant, supported employment will need to be revised / restructured in conjunction with Jobsplus.**
- The key to the above points and to enabling an individual to live their life according to their preferences and needs is **person centred planning (PCP)**, where a package of what an adult person can do in their life is put together. An example could be that a person with intellectual disability attends a Day Centre (whether public⁹¹ or private) twice a week, goes to the gym with her PA another two days of the week, while on another day she attends a course in photography, or does voluntary / paid work. However, the seed for PCP should start when the child starts going to school, that is, through the Individualised Education Plan (IEP) meetings.⁹²
- At needs assessment level, **the vast lack of social workers** (who are invaluable in their work with persons with disabilities) needs to be addressed in terms of:

- **existing social workers' wellbeing:** social work is an intense and stressful work which can easily lead to burnout,⁹³ thus not allowing social workers to carry out their job well, and increasing the risk of leaving the social work profession for a less stressful one with better job conditions.
- **job prestige:** the social work profession needs to start being acknowledged – in terms of salary, other job conditions, etc. – as the invaluable work that it is.

- Finally, **further research building on the present one needs to be conducted, looking especially at personal assistance and the intersection between disability and ethnic/religious minorities; and disability and the LGBTIQ community.** Such research is needed in order to promote the inclusion – not simply rhetorically, but also at policy-level – of persons with disability who also 'form part' of other marginalised groups.

91 <https://sapport.gov.mt/services/day-services>

92 Interview with Prof Anne-Marie Callus (Department of Disability Studies, UoM), August 2023.

93 Times of Malta. *Editorial March 9, 2023.* <https://timesofmalta.com/articles/view/editorial-safeguard-social-work-now.1017987>



Annex I

Information Sheets & Consent Forms



RESEARCH ON PERSONAL ASSISTANCE IN MALTA INFORMATION SHEET

[Date]

The Malta Federation of Organisations Persons with Disability (MFOPD) has commissioned Dr Lara Bezzina to conduct a research study on personal assistance for persons with disability in Malta and Gozo. The research is being funded by the Malta Council for the Voluntary Sector (MCVS) through the Voluntary Organisations Project Scheme (VOPs) and is being implemented throughout 2023.

The aims of this research are to **evaluate the current personal assistance services** and funding available in Malta and to **explore the best scenario of personal assistance** in supporting persons with disabilities to live independently.

To this aim, the researcher is conducting interviews with key stakeholders, including: persons with disabilities who currently have a personal assistant or are on the waiting list for one, persons with disabilities who have applied for personal assistant hours and were deemed not eligible, personal assistants themselves; as well as social workers, ICL (Independent Community Living) Board

representatives and pan-European independent living organisations.

The data collected from participants will be transcribed and analysed collectively through a qualitative analysis software. The findings of the research will be presented in a published report and during a validation workshop with key stakeholders towards the end of the implementation period.

Interviewees can choose to remain anonymous: in this case, your name will not appear in the report and all means necessary will be taken to render the interviewees unidentifiable. Interviewees' personal data will not be disclosed to anyone by the researcher, if they so wish. Interviewees also have the right to access, rectify, and, where applicable, erase the data concerning them. Any data collected during the research process will be used exclusively for the purpose of this research. Once the research is complete, all data will be erased.

Interviews will not take longer than one hour. Your contribution to this study would be greatly appreciated and serve to propose recommendations in ameliorating the personal assistance scenario in Malta, towards enabling independent living for all persons with disabilities.

Should you require any further information and / or clarifications, do not hesitate to contact Lara Bezzina on bezzinalara@gmail.com or the MFOPD president, Ms Marthese Mugliette on marthesemugliette@gmail.com

Marthese Mugliette

Lara Bezzina

RESEARCH ON PERSONAL ASSISTANCE IN MALTA

CONSENT FORM

STATUS QUO AND THE WAY FORWARD

After having read the Information Sheet, kindly fill in the consent form below and return it to Dr Lara Bezzina on bezzinalara@gmail.com.

- I have read the information sheet on the Personal Assistance research project and have understood all the information provided. ☐
- I understand the aims of the research and how the report will be used and disseminated. ☐
- I freely give my consent to be interviewed. ☐
- I understand that even after I give my consent, I can withdraw my participation without giving a reason for my withdrawal. ☐
- I understand that I can refuse to answer any question posed by the researcher, without giving a reason for the refusal. ☐
- I understand that I can stop the interview at any time I wish. ☐
- I understand that I have a right to remain anonymous and that if I request it, the researcher will make sure that I remain unidentifiable in the published research report. ☐
- I understand that the interview may be (audio) recorded if I give consent. ☐
- I understand that all data collected will be stored securely, be only accessible to the researcher, and will be destroyed after the end of the research study implementation. ☐
- I understand that I can access and rectify the data concerning my contribution to the research report. ☐
- I understand that the data collected will be exclusively used for the purpose of this specific study. ☐

Name

Signature

Date



RIĊERKA FUQ L-ASSISTENZA PERSONALI F'MALTA

DOKUMENT TA' INFORMAZZJONI

[Data]

Il-Malta Federation of Organisations Persons with Disability (MFOPD) ikkummissjonat lil Dr Lara Bezzina biex tagħmel riċerka fuq l-assistenza personali għall-persuni b'diżabilità f'Malta u f'Għawdex. Il-fondi għal din ir-riċerka ġew mogħtijin mil-Malta Council for the Voluntary Sector (MCVS) - Voluntary Organisations Project Scheme (VOPs) u qed tigi implimentata matul is-sena 2023.

L-għanijiet ta' din ir-riċerka huma li **tevalwa s-servizzi attwali ta' assistenza personali u l-finanzjament disponibbli f'Malta** u li **tesplora l-aħjar xenarju ta' assistenza personali** biex tappoġġja lill-persuni b'diżabilità biex jgħixu b'mod indipendenti.

Għal dan il-għan, ir-riċerkatriċi qed tagħmel intervisti ma' persuni b'diżabilità li bħalissa għandhom assistant/a personali jew li jinsabu fuq il-lista ta' stennija għal wieħed/waħda, persuni b'diżabilità li applikaw għal sigħat ta' assistenti personali u li tqiesu mhux eliġibbli, assistenti personali nfushom; kif ukoll ħaddiema soċjali, rappreżentanti tal-Bord tal-ICL (Independent Community Living) u organizzazzjonijiet Ewropej li jaħdmu fuq il-ħajja indipendenti.

L-informazzjoni miġbura mill-partekipanti se tigi traskritta u analizzata kollettivament permezz ta' softwer ta' analiżi kwalitattiva. Is-sejbiet tar-riċerka se jiġu ppreżentati f'rapport ippubblikat u waqt workshop ta' validazzjoni ma' daww li jaħdmu f'dan il-qasam jew jgħixu dawn l-esperjenzi, lejn tmiem il-perjodu ta' implimentazzjoni tar-riċerka.

Il-persuni intervistati jistgħu jagħzlu li jibqgħu anonimi: f'dan il-każ, ismek mhux se jidher fir-rapport u ser jittiehdu l-mezzi kollha meħtieġa biex l-intervistati ma jkunux jistgħu jiġu identifikati. Jekk jixtiequ, l-informazzjoni personali tal-persuni intervistati ma tigi żvelata lil ħadd mir-riċerkatriċi. L-intervistati għandhom ukoll id-dritt li jaċċessaw, jirrettifikaw, u, fejn applikabbli, iħassru l-informazzjoni li tikkonċernahom. Kwalunkwe informazzjoni miġbura matul il-proċess tar-riċerka se tintuża esklussivament għall-iskop ta' din ir-riċerka. Ladarba r-riċerka titlesta, l-informazzjoni kollha ser tigi mħassra.

L-intervisti mhux se jieħdu aktar minn siegħa. Il-kontribut tiegħek għal dan l-istudju jkun apprezzat ħafna u jservi biex jipproponi rakkomandazzjonijiet għat-titjib tax-xenarju ta' assistenza personali f'Malta, biex ikun possibbli l-għajxien indipendenti għall-persuni kollha b'diżabilità.

Jekk teħtieġ aktar informazzjoni u/jew kjarifiki, toqgħodx lura milli tikkuntattja lil Lara Bezzina fuq bezzinalara@gmail.com jew lill-president tal-MFOPD, is-Sinjura Marthese Mugliette, fuq marthesemugliette@gmail.com

RIĊERKA FUQ L-ASSISTENZA PERSONALI F'MALTA

FORMOLA TA' KUNSENS

Wara li tkun qrajt id-dokument ta' informazzjoni, inti ġentilment mitlub/a biex timla l-formola ta' kunsens hawn taht u tirritornaha lil Dr Lara Bezzina fuq bezzinalara@gmail.com.

- Qrajt id-dokument ta' informazzjoni dwar il-proġett ta' riċerka dwar l-Assistenza Personali u fhimt l-informazzjoni kollha pprovduta. ☐
- Nifhem l-għanijiet tar-riċerka u kif ir-rapport se jintuża u jitqassam. ☐
- Jien liberament nagħti l-kunsens tiegħi biex niġi intervistat/a. ☐
- Nifhem li anke wara li nagħti l-kunsens tiegħi, nista' nirtira l-partecipazzjoni tiegħi mingħajr ma nagħti raġuni għall-irtirar tiegħi. ☐
- Nifhem li nista' nirrifjuta li nwieġeb kwalunkwe mistoqsija magħmula mir-riċerkatriċi, mingħajr ma nagħti raġuni għar-rifjut. ☐
- Nifhem li nista' nwaqqaf l-intervista fi kwalunkwe ħin li nixtieq. ☐
- Nifhem li għandi dritt li nibqa' anonimu/a u li jekk nitlobha, ir-riċerkatriċi se tiżgura li nibqa' mhux identifikabbli fir-rapport ta' riċerka ppubblikat. ☐
- Nifhem li l-intervista tista' tiġi rreġistrata (awdjo) jekk nagħti l-kunsens. ☐
- Nifhem li l-informazzjoni kollha miġbura se tinżażen b'mod sigur, tkun aċċessibbli biss għar-riċerkatriċi, u se tinqered wara t-tmiem tal-implimentazzjoni tal-istudju tar-riċerka. ☐
- Nifhem li nista' naccessa u nirrettifika l-informazzjoni li tikkonċerna l-kontribut tiegħi għar-rapport ta' riċerka. ☐
- Nifhem li l-informazzjoni miġbura se tintuża esklussivament għall-iskop ta' dan l-istudju speċifiku. ☐

Isem

Firma

Data



Riċerka fuq l-Assistenza Personali f'Malta

Research on Personal Assistance in Malta

[Date]

Informazzjoni fuq ir-Riċerka / Information Sheet

Għażiż/a [isem tal-partecipant/a] / Dear [name of research participant]



Kif taf, jien qed nagħmel riċerka fuq l-assistenza personali f'Malta.

As you know, I am doing research on personal assistance in Malta.



Jien qed nagħmel din ir-riċerka għall- Malta Federation of Organisations Persons with Disability.

I am doing this research for the Malta Federation of Organisations Persons with Disability.



Din ir-riċerka qed issir biex inkunu nafu kif nistgħu intejbu s-servizz ta' l-assistenza personali għall-persuni b'diżabilità'.

This research will help us to know how personal assistance services for persons with disability can be improved.



Peress li int applikajt għal
assistent/a personali,
jien nixtieq nitkellem
miegħek.

*Since you applied for a person-
al assistant, I would like to talk
to you.*



Ser inkun qed insaqisik
xi mistoqsijiet fuq
l-esperjenzi tiegħek.

*I will ask you some questions
about your experience.*



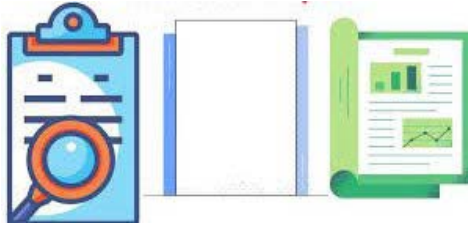
Waqt l-intervista, jien ser
inkun qed nikteb xi noti
dwar dak li tghidli.

*During the interview, I will
write down what you tell me.*



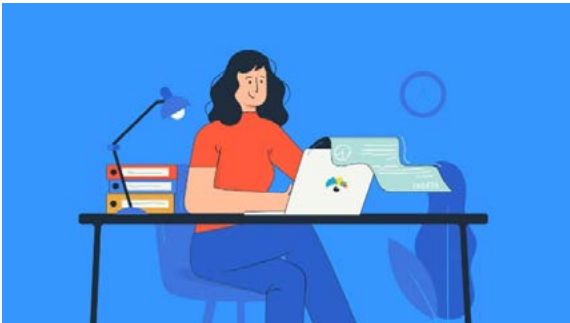
Jekk inti tagħtini
permess, jista' jkun li
nirrekordja l-intervista.

*If you give me permission, I
may record the interview.*



Wara li nispicċa l-intervisti, jien ser nikteb dak li sibt f'rapport li ser ikun ippublikat.

Once I finish all the interviews, I will write the findings in a report, which will be published.



Jien ser nuża l-informazzjoni li tagħtini waqt l-intervista għal din ir-riċerka biss.

I will use the information that you give me during the interview only for this research.



Din l-intervista ser issir f'ħin, gurnata u post komdu għalik.

This interview will take place at a time, day and place of your choosing.



Inti tista' tirrifjuta li tagħmel din l-intervista.

You can refuse to have this interview.



Jekk tixtieq tistaqsini xi
ħaġa, tista' ċċempilli fuq
79888331.

*If you would like to ask me
anything, you can call me on
79888331.*

Grazzi / Thank you.

Marthese Mugliette
(MFOPD President)

Lara Bezzina
(Researcher)



Consent Form

After reading the information above, please:

- 1) tick the boxes below where you agree with the corresponding statement
- 2) sign at the bottom.

I understand what this research is about and what it will be used for.	
Lara has told me about what she will do with my interview.	
I understand that Lara will use the information that I give her only for this research.	
I understand that I can ask Lara not to use the information that I give her.	
I would like my interview to remain confidential.	
I would not like my interview to remain confidential.	
I understand that if I choose to have my interview remain confidential, Lara will not write down my name in the research report, but some people may identify me when reading the report.	
I give permission to Lara to record my interview.	
I do not give permission to Lara to record my interview.	
I agree to take part in this research.	
I do not agree to take part in this research.	

Name & Surname of research participant

Signature of research participant

Date

Formola ta' Kunsens

Wara li taqra l-informazzjoni t' hawn fuq, jekk jogħġbok:

- 1) immarka l-kaxxi hawn taħt fejn taqbel mad-dikjarazzjoni korrispondenti
- 2) iffirma fil-qiegħ.

Nifhem fuq xiex inhi din ir-riċerka u għalxiex se tintuża.	
Lara qaltli x'se tagħmel bl-intervista tiegħi.	
Nifhem li Lara se tuża l-informazzjoni li nagħtiha biss għal din ir-riċerka.	
Nifhem li nista' nitlob lil Lara biex ma tużax l-informazzjoni li nagħtiha jien.	
Nixtieq li l-intervista tiegħi tibqa' kunfidenzjali.	
Ma nixtieqx li l-intervista tiegħi tibqa' kunfidenzjali.	
Nifhem li jekk nagħżel li l-intervista tiegħi tibqa' kunfidenzjali, Lara mhux se tikteb ismi fir-rapport tar-riċerka, iżda xi nies jistgħu jidentifikawni meta jaqraw ir-rapport.	
Nagħti permess lil Lara biex tirrekordja l-intervista tiegħi.	
Ma nagħtix permess lil Lara biex tirrekordja l-intervista tiegħi.	
Naqbel li nieħu sehem f'din ir-riċerka.	
Ma naqbilx li nieħu sehem f'din ir-riċerka.	

Isem u Kunjom tal-parteeipant/a

Firma tal-parteeipant/a

Data



Annex II

Questionnaires⁹⁴

⁹⁴ The questionnaires included in this Annex are the broad ones used for each target group, from which there were variations according to the sub-target group member being interviewed (e.g. the questionnaire for persons with disabilities was adapted accordingly to whether the person already has a PA, is looking for a PA, etc.). Other interviews, such as those with disability experts (national or otherwise) were more open-ended - focusing on the interviewee's expertise - with the researcher asking follow-up questions.



Questionnaire for Persons with Disabilities

Interview:

Date:

- 1) What is your family & housing situation (e.g. who do you live with; is your house your own, etc.)?
- 2) How did you get to know about the PA (ICL) scheme?
- 3) How did you find the application process (e.g. easy, challenging) and decision-making process? Why?
 - 3.1 Do you feel this process could be improved? Why?
 - 3.2 If yes, how?
- 4) What type of PA services do you benefit from (e.g. hours, live-in, etc.)?
 - 4.1 If it is live-in, how do you find having a PA living with you 24/7?
 - 4.2 Do you have a room for her/him?
 - 4.3 What about intimate situations (e.g. having a quarrel with someone) – do you have the ability to tell PA to leave?
- 5) How did you choose the PA?
 - 5.1 Does this method suit you? Why?
 - 5.2 If it doesn't suit you, what other method would you prefer?
- 6) Are you satisfied with the choice of PA? Why?
 - 6.1 If not, what would you change?
- 7) What is the most important characteristic of a PA for you? Why?
- 8) Do you feel that you can live independently (being yourself and living in the manner you want) with the current PA services you have? Why?
- 9) How have the payments / services improved your opportunities for education, employment, social life, family formation?
- 10) Do the PA services you currently have meet all your needs at the time that you want / need them?
 - 10.1 If yes, what needs are met (e.g. bathing, driving, working, etc.) and to what degree (e.g. do you still need relatives, friends or volunteers to support you in living independently)?
 - 10.2 If not, why? What needs are not being met?
- 11) If the PA hours you currently have do not meet all your needs, have you requested more hours from the ICL Board?
 - 11.1 If yes, did you have a satisfactory reply?
 - 11.2 If not, why did you not request it?
- 12) Did you have the opportunity to appeal the decision?
 - 12.1 If yes, did you? How did you find the appeals process?
 - 12.2 If you did not appeal, why?
- 13) Are you accountable for the use of the services / funds, and how?
- 14) Do the funds received cover the expenses (salary, etc.) of the PA? If not, how do you mitigate this?
- 15) Do you think the PA system could be improved? Why?
 - 15.1 If yes, how?

Questionnaire for Personal Assistants

Interviewee:

Type of employment (e.g. hours / live-in, etc.):

Date:

- 1) Please tell me a bit about yourself and your background.
- 2) Why did you choose to become a PA?
- 3) How did you become a PA for your client / employer (e.g. were you employed by the person with disability, by a company, etc.)?
 - 3.1 (if applicable) How did you come to Malta (e.g. specifically for the PA job)?
 - 3.2 (if applicable) Did you know what kind of job you were going to do once in Malta? Did you meet your employer beforehand?
- 4) What kind of assistance (for which activities, what type of support, etc.) do you provide for your client / employer?
- 5) How do you find working as a PA? Why?
 - 5.1) If you are a live-in PA, does this arrangement suit you? Why?
 - 5.2) How do you find your job conditions (workload, wages, leave, social security, etc.)?
 - 5.3) Are you happy with your job? Why?
- 6) Do you feel there is anything that can be improved in the system (e.g. job finding, job conditions, etc.)? Why?
 - 6.1 If yes, how can these be improved?
- 7) Is there anything else that you would like to add?



Questionnaire for ICL Board Members

Interviewee:

Designation:

Date:

1) Who are the members of the ICL Board (professions, background, etc.)?

- 1.1 How were they selected?
- 1.2 How often does the Board meet?
- 1.3 How does the Board work?

2) Can you please give an overview of the ICL scheme and how it works?

- 2.1 What kind of disabilities do applicants usually have?
- 2.2 At what stage of the process do applicants appear before the Board? What goes on during this meeting?
- 2.3 How does the Board decide on how many PA hours to approve?

3) How are the funds disseminated among applicants?

- 3.1 Are ICL scheme recipients accountable for the use of the funds, and how?
- 3.2 Are there any persons with disabilities in Gozo who have personal assistants?

4) Which activities are/not supported by the ICL scheme, and to what degree (for example, do recipients still depend on family members, friends or volunteers?)

- 4.1 Are there times when they would need personal assistance but have no assistants?
- 4.2 Are relatives (not close ones like immediate family members) accepted as PAs? Why?

5) How have the subsidies / services improved the recipients' opportunities for education, employment, social life, family formation?

6) Who are the personal assistants and what are their job conditions?

7) Do you think the PA system could be improved? Why?

- 7.1 If yes, how?

Questionnaire for Agenzija Sapport Needs Assessment Team

Interviewee:

Designation:

Date:

- 1) Can you please give an overview of ICL scheme and how it works?**
 - 1.1 Are these services also being provided in Gozo?
- 2) At what stage do you, as a social worker / ICLM support executive, enter into the picture?**
 - 2.1 What is your role?
- 3) How is the applicant assessed?**
 - 1.1 Is there a form for this assessment?
- 4) Are there any challenges you meet in this process?**
 - 4.1 If yes, what are they?
 - 4.2 How are these challenges mitigated?
- 5) Do you think the current ICL scheme is meeting the independent living needs of persons with disabilities?**
 - 5.1 If yes, how?
 - 5.2 If not, why?
- 6) Do you think the personal assistance system could be improved? Why?**
 - 6.1 If yes, how?
- 7) Is there anything else you would like to mention about personal assistance in Malta?**



Questionnaire for Private Care Companies

Interviewee:

Company:

Designation:

Date:

1) What kind of services do you provide?

1.1 What kind of services (e.g. carers, personal assistants) do you provide for persons with disabilities?

1.2 Do the service users usually make use of the Aġenzija Support subsidy?

2) How do you first make contact with the service user/does the service user first make contact with you?

2.1 What happens then?

3) What does the agreement between your company and the service user contain?

3.1 Does the service user choose their own PA? If yes, how does this take place? If not, who chooses the PA?

3.2 What are the costs incurred by the service user when being provided with a carer / PA from your company?

3.3 What happens to the service user when the PA is on leave?

4) Are PAs / carers trained to work with persons with disabilities?

1.1 If yes, what kind of training do they receive and by whom? Who pays for the training?

1.2 If not, why?

5) What are the job conditions of personal assistants / carers in terms of salary, leave, etc.?

6) Do you provide live-in carers?

6.1 If yes, where do the live-in carers generally come from, and how do they come to Malta?

7) Can service users give feedback on the services provided? How?

Annex III

Validation Workshop Agenda



PERSONAL ASSISTANCE IN MALTA: *The status quo and the way forward*

Validation Workshop Agenda

Date: Wednesday October 25, 2023

Time: 9:00 – 12:30

Venue: St. Joseph's Home (Santa Venera)

No.	Item	Duration
1	9:00 Introduction a. Introduction by MFOPD President Ms Marthese Mugliette b. Introduction to the research study by researcher Dr Lara Bezzina	20 mins
2	9:20 Presentation of the Research Findings Presentation of the findings by Dr Lara Bezzina Q&A	40 mins
	Coffee Break @ 10:00	20 mins
3	10:20 Recommendations: Discussion & Co-Creation Presentation of draft recommendations by Dr Lara Bezzina Discussion of recommendations: feasibility & sustainability Co-creation of further recommendations	90 mins
4	11:50 Conclusion Further comments from participants Wrap-up: summary of discussion by Dr Lara Bezzina Next steps	30 mins
5	12:20 Closing speech by Minister for Inclusion, Voluntary Organisations and Consumer Rights - the Hon. Julia Farrugia Portelli	10 mins
	Total	3.5 hours

L-ASSISTENZA PERSONALI F'MALTA: Is-sitwazzjoni kurrenti u dik futura

Workshop ta' Validazzjoni - Programm

Data: L-Erbgħa 25 t'Ottubru, 2023

Ħin: 9:00 – 12:30

Post: Dar ta' San Ġuzepp (Santa Venera)

Nru.	Attività	Tul ta' ħin
	9:00	
1	Introduzzjoni Introduzzjoni mill-President tal-MFOPD Ms Marthese Mugliette Introduzzjoni għar-riċerka mir-riċerkatriċi Dr Lara Bezzina	20 min.
	9:20	
2	Prezentazzjoni tar-Riżultati tar-Riċerka Prezentazzjoni tar-riżultati minn Dr Lara Bezzina Mistoqsijiet u tweġibiet	40 min.
	Brejk – Te' u Kafe' @ 10:00	20 min.
	10:20	
3	Rakkomandazzjonijiet: Diskussjoni u Ħolqien Prezentazzjoni tal-abbozz tar-rakkomandazzjonijiet minn Dr Lara Bezzina Diskussjoni tar-rakkomandazzjonijiet: fattibilità u sostenibilità Ħolqien flimkien ta' rakkomandazzjonijiet oħrajn	90 min.
	11:50	
4	Konkluzjoni Aktar kummenti mill-partecipanti Għeluq: sommarju tad-diskussjoni minn Dr Lara Bezzina Il-passi li jmiss	30 min.
	12:20	
5	Diskors tal-għeluq mill-Ministru għall-Inkluzjoni, il-Volontarjat u d-Drittijiet tal-Konsumatur, l-Onor. Julia Farrugia Portelli	10 min.
	Total	3.5 sigħat



Malta Federation of Organisations Persons with Disability (MFOPD)

“This project has been funded through the Voluntary Organisations Project Scheme managed by the Malta Council for the Voluntary Sector supported by the Ministry for Inclusion and the Voluntary Sector (MIV). This project/publication reflects the views only of the author, and the MCVS cannot be held responsible for the content or any use which may be made of the information contained therein”