One Voice

Official Voice of the National Federation for the disability sector

Issue 7 – January 2024

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THERE IS NO GREATER DISABILITY IN SOCIETY THAN THE INABILITY TO SEE A PERSON AS MORE.

ROBERT M. HENSEL

Credits and the President's Message:

One Voice is a magazine published by the Malta Federation of Organisations Persons with Disability (MFOPD).

As its title implies, the magazine is the official, unified voice of Malta's civil society working in the disability sector. It portrays the mission and vision of the various Organisations active in this sphere as represented by their umbrella Federation.

One Voice

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Marthese Mugliette
President MFOPD

One voice can change a room, and if one voice can change a room, then it can change a city, and if it can change a city, it can change a state, and if it can change a state, it can change a nation, and if it can change a nation, it can change the world. Your voice can change the world.

Barak Obama

Each person with disability is important to our sector. The non-governmental organisations within our sector in the Maltese islands are the voice of all persons with disabilities. MFOPD is the platform where ideas and views on disability issues are exchanged among its 41 member organisations.

For this reason, it is crucial for persons with disabilities to enrol with an NGO which identifies with their situation. NGOs can make a difference and this thanks to the individual members they represent. It is also crucial for the NGOs working within our sector to come together under the national umbrella organisation for the disability sector, MFOPD, to be the **one voice** for our sector.

MFOPD is the **one voice** of all persons with disabilities in the Maltese islands. MFOPD is made up of 41 non-governmental organisations, all working for and with persons with disability. Each member organisation has the responsibility to be the voice of each of its individual members. MFOPD has the same responsibilities vis-à-vis its member organisations.

MFOPD's member organisations should assure unity within the sector. They should speak with a unified voice on same issue. Our **one voice** can change our lives. Let us use this voice to make the lives of all persons with disabilities better!

Unfortunately, sometimes some still choose to repeat the statement that 'the disability sector is fragmented'. This is not true. MFOPD's role is to ascertain this is not the case. If it is the case that some individuals are sending out negative messages, this does not mean fragmentation within our sector.

MFOPD augurs that the **one voice** of the 41 enrolled NGOs remains unified and has the desired, effective weight.

EU FUNDED STUDY VISIT ON PERSONAL ASSISTANCE

Personal Assistance (PA) for persons with disabilities has been on MFOPD's agenda for quite some time. Finally, things started moving on this issue and for the first time ever, the national 2022 budget allocated a substantial amount of money for PA, which was also topped further in the national 2023 budget; discussions involving MFOPD and ENIL on a PA reform took place and a public consultation on PA reform was launched. The Malta Federation of Organisations Persons with Disability (MFOPD) wanted to make a step further and wanted to inform itself about good practices on the subject.

This year MFOPD benefitted from an EU funded project in the field of Adult Education whereby MFOPD had the opportunity to learn how Personal Assistance is being implemented in Slovenia. With the help of ENIL, the Association for Theory & Culture of Handicap (YHD) was chosen as the organization to host the Maltese delegation. YHD developed services that enable users to lead a high-quality and active lives despite their disability. It established methods and guidelines for the implementation of these services, both for users and personal assistants. It also gives great importance to educating, raising awareness, and providing information about independent living for people with disabilities.

The main aim of this study visit was to inform ourselves about the good practices, the role of a personal assistant and understanding how the coordination of personal assistance is carried out. Furthermore, this study visit helped us get a clear definition of the rights of the user, the sharing of responsibilities and the possibility of other support measures that could be provided to support the user.

During this unique experience, we learned mostly on how a PA can change a person's life for the better. We heard about

the great change in the lives of persons with disabilities from living in an institution to living independently in the community with the support of a PA. We also met and visited persons with disabilities living independently, benefitting from personal assistance provided by YHD. These meetings were special and moving for us as the persons described in depth how it was like, living in an institution with limited options and unrealized expectations. It was common with all the persons we met, that they were ready to conquer their own fear which was conditioned by the years of living within an institution, to find the courage to take the necessary step. Their determination to live on an equal footing with everyone else, take decisions about their life and to have the chance to manage all their everyday activities was powerful enough for them to overcome all hurdles along the way.

We were also given an overview of the Personal Assistance Law of Slovenia, whereby it states that PA service providers can be charitable organisations, self-help organisations, disabled people's organisations, institutes and self-employed providers. In Slovenia an agreement is signed between the State and the NGOs whereby the latter are funded for the provision of this service by the government. Included in the law are the main tasks of a Personal Assistant which includes the basic needs of the person with disability, household and daily tasks, escorting, tasks at the workplace of the person with disability and in his/her education process.

Sharing their experiences about the running of the service of personal assistance was beneficial to all. YHD had its' trial-and-error moments until they found the best system to run the service. Presently they are providing the service of personal assistance to around seventy persons with disability. As requested by the PA law, they also give a yearly 6 hour training to the personal assistants and to the persons with disabilities making use of the PA.

We were very surprised to see that they have accessible maps and a 'Ljubljana by wheelchair app'. One could easily notice the fully accessible environment, particularly if one chooses to explore the surroundings on foot.

On our return to Malta, we immediately started making the necessary appointments with the Minister and all authorities and people concerned to share our experience and all that we learnt with them, with the sole intention to have a better Personal Assistance Reform here in Malta.

Venera Micallef - Secretary

Co-funded by the European Union

MFOPD'S STUDY VISIT TO YHD –

ASSOCIATION FOR THEORY AND CULTURE OF HANDICAP, SLOVENIA

FUNDED UNDER ERASMUS+
PROGRAMME KEY ACTION 121

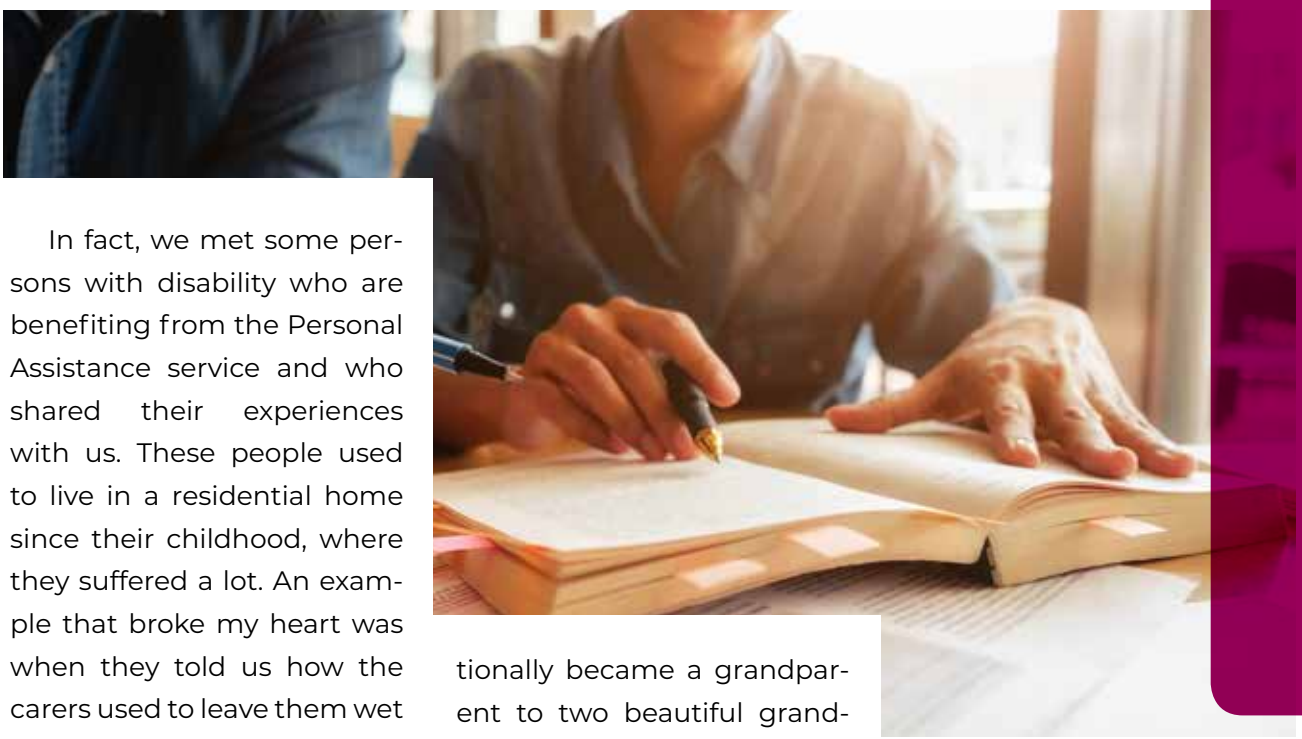
My name is

Jeanette Micallef.

I am 32 years old, and my full-time job is that of a Learning Support Educator (LSE). I work with children who have severe multiple learning disabilities. As a part-time job, I give Personal Assistance to Gayle, a 36-year-old who has Down syndrome.

During the last week of September 2023, I was one of a group of 8 persons who spent a week in Ljubljana Slovenia at the YHD - Society for the Theory and Culture of Disability. This was a study visit about Personal Assistance (PA) organised by the national umbrella organisation for the disability sector, the Malta Federation of Organisations Persons with Disability (MFOPD). As a PA myself, my experience in Slovenia was very interesting and hopeful. I am using the word 'Hope' because the people we met in Slovenia made us aware of the significant positive impact that this service is leaving in their lives, allowing them to live an independent life.

They showed us the beauty of independence for a person with a disability, whoever the person may be and whatever disability they may have; that everyone deserves to have a better life and to be given the opportunity to work and fulfil their dreams in the best way they can.



In fact, we met some persons with disability who are benefiting from the Personal Assistance service and who shared their experiences with us. These people used to live in a residential home since their childhood, where they suffered a lot. An example that broke my heart was when they told us how the carers used to leave them wet with their urine for a long period of time. In fact, some of these persons got emotional when they were telling us about their experience. Now that they have the Personal Assistance, they are living their lives completely and with dignity.

Those who are benefiting from the PA service, are succeeding, like you and me. They are living and not just existing. I'm saying this because, for them, the PA is that person who is helping them, in some cases to be their hands and feet, so that they can do the things we normally do every day like for example cooking, gardening, going to work, shopping, etc... Some of the PA service users are working in different fields such as in a factory, in an office, self-employed; one of them also got married, has a beautiful daughter, and additionally became a grandparent to two beautiful grandchildren. Benefitting from the support of Personal Assistance made the lives of the whole family much better, very beautiful and happy.

My heart rejoiced when I saw so many theories being put into practice and not left written on paper. Thanks to these people with disabilities themselves who run the YHD organisation, who come from different backgrounds but came together for a good cause, work is ongoing to offer others a better life. They are giving others an opportunity to be independent despite having a disability.

I am hoping that as a country, we learn and work together so that these practices will one day start being offered to all people with disabilities, so that they can be more independent and be able to fulfil their individual dreams.

From this experience, I learned how important it is that when you see a person with a disability, you don't just see them from the outside but also recognize that, that person is just like you and me – has feelings, thoughts, has different desires and dreams, just like us. So why shouldn't we continue to support and help them reach their full potential and live an independent life? What is stopping us from doing this? Why is it that difficult to do?

I feel proud that I am a PA because I know that there is a person who is 'living her life' because of my support. This is what she, and those around her tell me. I am making a difference in someone's life. And this must be our motto as human beings!

Jeanette Micallef

DE-INSTITUTIONALISATION

Rhoda Garland
Commissioner for the Rights of Persons with Disability

One of the fundamental principles of the disability rights movement has been the phrase

‘Nothing About Us Without Us’.

It has been the message reiterated by disability activists since the early 1980’s in the UK and informed the creation of the UNCRPD which was written by a group of disabled people.

It is an easy mantra to say but often is ignored when it comes to really important areas of the lives of disabled people, where non-disabled people still believe that the provision of the service for the disabled person is the most important aspect and that disabled people’s thoughts about the construction and procedures involved in the service are secondary.

This is particularly evident when it comes to institutionalisation where disabled people are seen as being irrelevant to the discussion simply because they are the subjects for whom the institutionalisation is required and are therefore considered as being without opinions due to their levels of functionality.

Following the passing of the UNCRPD Act in 2021 there is a requirement for the Government of Malta to move towards ensuring disabled people are able to live independently in the community with appropriate levels of support and that a process of deinstitutionalization should take place. This

has been acknowledged and de-institutionalisation is included in the National Disability Strategy for 2021 to 2030. The strategy states that by the end of 2030 there should be a strategic plan in place for moving towards deinstitutionalization. On first reading a period of 9 years to create a plan may seem to be an overly long time, however when consideration is given to the number of provisions that need to be ramped up or created from scratch, it becomes quite a challenge.

For the last 18 months CRPD has undertaken a piece of research into the current state of play in residences and institutions in Malta to see what is happening and what will need to be put in place to enable those people living in the institutions to be supported to live in the community with support. It was important to gain the thoughts, not only of the professionals who run the institutions but also the residents, keeping in mind the mantra of 'Nothing About Us Without Us'. The results of this research will provide the base situation for which a strategic plan can be put in place to move towards de-institutionalisation.

The findings of the research were at times troubling; rigid regulations control the ability of the residents to live their lives in a manner of their choosing in many different areas. Residents were often not given a choice of what they wanted to eat, or the time they were to eat; they were told when to get out of bed, bathe and when to go to bed; what leisure activities they would take part in, or would have to take part in, and what relationships they were permitted to have. The institutions were run for the benefit of the staff in the residence rather than the residents themselves.

There are many barriers which hinder progression towards deinstitutionalization, which must be addressed.

Probably the most obvious one is the lack of personal assistants who will be required to support the disabled people as they move into the community. These PAs will also need to take a different approach away from that of controlling the disabled person to one of empowering them to make their own decisions to the best of their ability, this is a tricky cultural shift, but one which must take place if we are to enable disabled people to live independently. Training will be required for disabled people themselves in independent living skills and also re-training of those who currently work in institutions to provide a supportive and empowering role for the disabled people they work with. Maltese people need to be encouraged to work in this area which most likely require employment package improvements and the perception of the job to be seen as a worthwhile fulfilling role which is admired by the wider community.

The PA Reform Bill which has just completed its public consultation period will provide a more holistic approach

towards the provision of Pas and will also include Personal Budgets further empowering disabled people to have more control over their lives. There will, of course also be a need to increase the provision of other services and also accessible housing if the process of deinstitutionalization is to be successful.

Currently parents request that their children are put on waiting lists for residential care, so that they are satisfied their children will be taken care of should they die. It is therefore essential that the gaps in service provision are addressed so that these parents can be confident that their children will be catered for in the community with the correct level of support in the future.

Some parents may think that there is no way that their children will be able to live independently with support in the community, but there are countries who have been able to completely close down their institutions so that all disabled people, however complex and severe their situation is are able to live supported independent lives. It can be done. Malta is reaching out to these countries to understand the process they undertook, we do not pretend we have all the answers but we are willing to learn.

De-institutionalisation is a complex and long process, however it is possible and it is surely better that a disabled person lives in the community where they feel included and supported and able to make their own decisions rather than live in an institution where their lives are governed by the staffing rotas of those who are there to run the institution.

The longest journey starts with a first step, I do not know if de-institutionalization will be fully implemented by the end of my time as Commissioner, but I am fully committed to make sure that we keep taking steps to move towards it and begin the preparation work to fill in the gaps to ensure that in the future disabled people have the best possible opportunity to live a fully inclusive life in a Maltese community which appreciates, respects and supports them to live their lives to their full potential.

MFOPD appreciates and thanks ***Mr Keane Cutajar*** *for this article. The European Parliament for Persons with Disabilities is a very important event for our sector, an event which locally, has only been given such an exposure by the Malta Daily.*

700 DISABILITY ADVOCATES CALL ON THE EU TO ENSURE

"NOTHING ABOUT THEM WITHOUT THEM"

The Malta Federation of Organisations Persons with Disability (MFOPD) made a significant impact at the 5th European Parliament of Persons with Disability.

The event, which took place in the hemicycle of the European Parliament in Brussels, brought together 600 disability advocates from across the European Union to discuss the advancement of disability rights within the EU.

During the event, Gayle Mugliette represented MFOPD and delivered a powerful speech. She shared her positive personal experience of being supported by a Personal Assistant and expressed her hope that all individuals with disabilities would have access to such assistance without encountering any obstacles. She also highlighted a concerning issue in Malta: some persons with disabilities are still unable to exercise their right to vote in secrecy.

The European Parliament of Persons with Disability marked a significant milestone with the adoption of the European Disability Forum's Manifesto on the 2024 European Elections.

This manifesto serves as a roadmap for the European Disability Forum's campaign for next year's elections and emphasises the movement's demands to be fully involved in the political process.

Key elements of the manifesto include ensuring the right to vote and stand as candidates for persons with disabilities in European elections, the establishment of strong services focusing on disability rights within EU institutions, the creation of a new European agency for accessibility, the adoption of an EU-wide Disability Card for mutual recognition of disability status, and the introduction of legislation to guarantee the availability and affordability of assistive technologies.

Additionally, the manifesto emphasises the need for further protection of women and girls with disabilities, support for Ukrainians with disabilities, and the inclusion of disability considerations in the EU's budget, green transition, and digital transformation.

The participation of the Malta Federation of Organisations Persons with Disability at this event reflects their dedication to advocating for the rights of persons with disabilities at both the national and European levels.

CONCLUSIONS OF THE RESEARCH ON PERSONAL ASSISTANCE FOR PERSONS WITH DISABILITES IN MALTA AND THE RECOMMENDATIONS FOR THE PA REFORM

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(disability, international development, participatory video)

Based on the findings of this research as well as **invaluable inputs from interviewees[1] 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.

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

1.1 LEGISLATIVE FRAMEWORK

The **right to personal assistance should be protected 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 1.7**).
- 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 1.5** and **1.6**) 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**[2] (in conjunction with the relevant stakeholders) in its Occupational Handbook,[3] 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**.[4] 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,[5] 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 wages also 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**.

2 https://jobsplus.gov.mt

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

4 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.

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

- **clearly defines which type of entities can provide personal assistants** (see **section 1.4**).

- is implemented together with the two other complementary legislations: the **Protection of Vulnerable Older Persons and Adult Persons with Disability Act**[6] which was published for public consultation in 2017; and the **Personal Autonomy Act**, which was already being drafted in 2018.[7] 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**.

1.2 BUDGETING AND EXPENDITURE

- While **PA services should not be means tested** – they are a fundamental right – findings show that **not all persons with disabilities 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,[8] 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 1.4**) 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.[9] 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 1.7**).

- The ICL scheme expenditure should also be audited by the Na-

6 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

7 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.crpd.org.mt/uncrpd-det/uncrpd

8 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

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

tional Audit Office (NAO)[10] in order to identify how best this budget could be spent and to promote best practices.

1.3 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 guardian[11]) 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

10 https://nao.gov.mt

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

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 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 website[12]), 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 docu-

12 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

> **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.**

mentation 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 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.)

1.4 PERSONAL ASSISTANCE PROVISION

- Should they still be PA providers after the reform, **private care companies providing 'personal assistants' need to be regulated** (see **section 1.2**) in terms of:

    - **Exorbitant, ever-rising fees** (including carer salaries, replacement carer salaries, administration fees). **Regulations** (including those **limiting the maximum fees**[13] **and rate of**

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

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 1.2**, 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 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.

1.5 INFORMATION ABOUT PERSONAL ASSISTANCE

- As mentioned in **section 1.1**, 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 1.6**) **not only on public media but also through NGOs, OPDs** and other stakeholders who regularly come into contact with persons with disabilities.

1.6 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 Callus[14] 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.

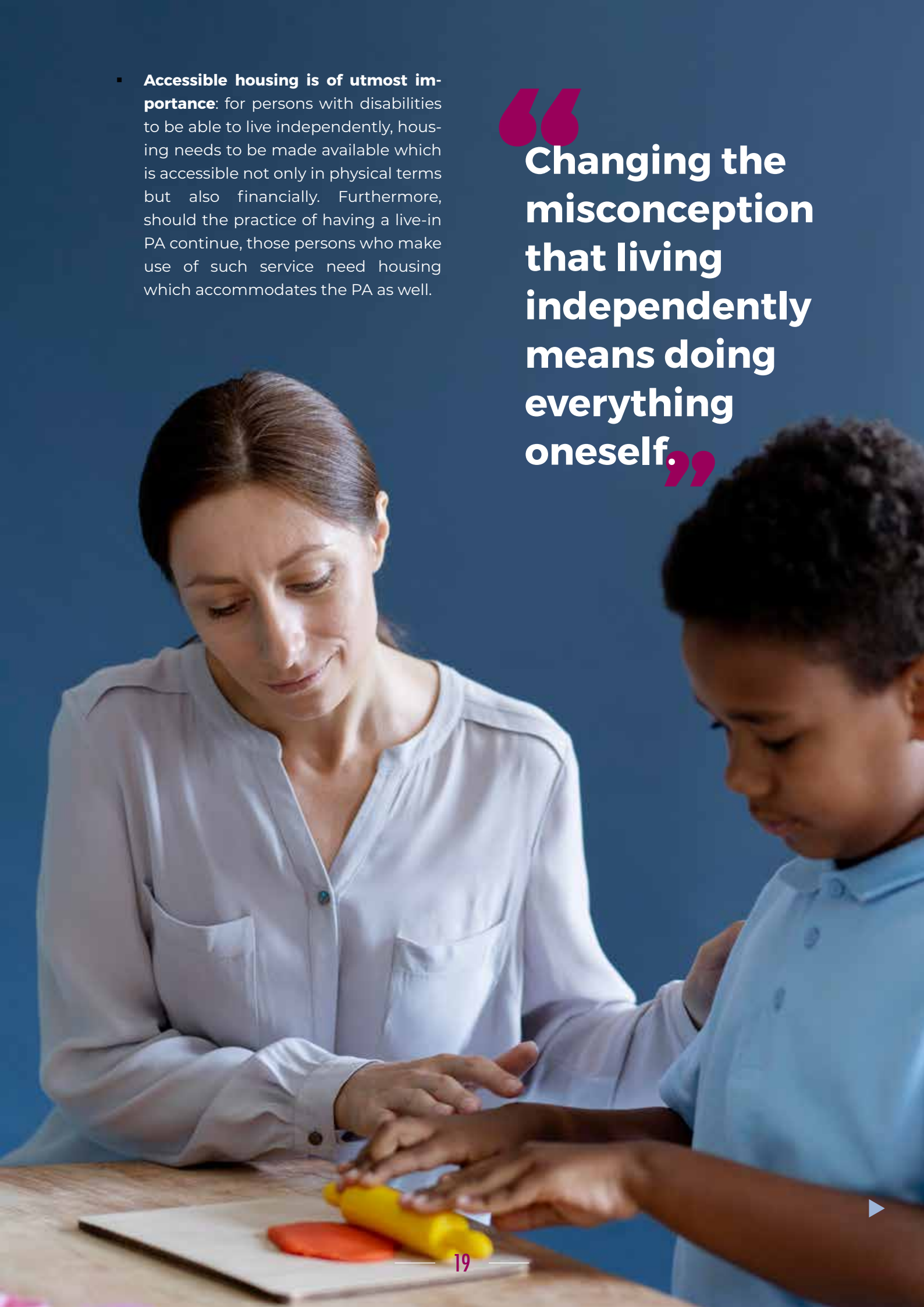
1.7 COMPLEMENTING PERSONAL ASSISTANCE: WORKING IN TANDEM WITH OTHER SECTORS

- 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.

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

- **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.

> **“Changing the misconception that living independently means doing everything oneself.”**



- **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 Education**[15] **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,[16] Higher Secondary,[17] MCAST,[18] 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 and to ensure that**

15 https://education.gov.mt

16 https://www.jc.um.edu.mt

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

18 https://mcast.edu.mt

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 public[19] 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.[20]

- 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' well-being:** social work is an intense and stressful work which can easily lead to burnout,[21] 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.

19 https://sapport.gov.mt/services/day-services

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

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

A BELATED HAPPY CHRISTMAS AND A HAPPY NEW YEAR 2024!

Dr Denis Vella Baldacchino
Commissioner for the Promotion of Rights of Persons with Mental Disorders

Most of us just had a merry period of time, exchanging a lot of warm greetings, having family and friend reunions, lunches, dinners, parties, and exchanging gifts and best wishes.

All the home and street decorations helped us all get in the festive mood, and why not? Some travelled abroad to break from the routine and possibly to explore distant lands or exotic places. I am sure our social media feeds were flooded with posts of such festive goings-on. But were the same festivities also shared by people living in the Middle East and in Ukraine? Promptly one may answer, what do we have to do with these people far away from our reaches and shores? Truly this may not be in the spirit of true Christmas. Now shifting our focus to the reality within our shores, did our brothers and sisters sufferring from any chronic health condition enjoy the same festive spirit? Although the festivities should be for everybody to enjoy, persons with mental health issues may feel worse off and their solitude may increase at a time when most of us are enjoying the Christmas spirit. Even loved ones who care for them at home (the informal carers) may have passed through this period of difficulty. Is this social justice? The various solidarity fundraising activities reflect a true community spirit; a time where we stop and think about these people, who through no fault of theirs, are sufferring from various health conditions. The voluntary organisations who give them support need desperate funding and these fundraising events can help them try and make ends meet. The organisation of the yearly Christmas lunch by Caritas hosted at the Curia in Floriana, for people who are alone, as well as, the distribution of a warm lunches to people in need at their home are strong initiatives to be applauded. A big applause goes to the volunteers who committed their personal time, away from their families and loved ones

to bring joy to these people. These should all collectively be awarded the National Order of Merit for participating in these initiatives. This is true community spirit.

But did we manage to reach all people who are alone? Did we reach all those who, through no fault of theirs, are disconnected from reality, those that are admitted involuntarily to the various licensed mental health facilities, or are being kept there for long periods of time on court orders? The same applies to those in the correctional facilities. All these do not enjoy the freedom which we may all take for granted. Are these persons entitled to enjoy the true Christmas ? Did we manage to give them hope; to look for a brighter future in the new year 2024?

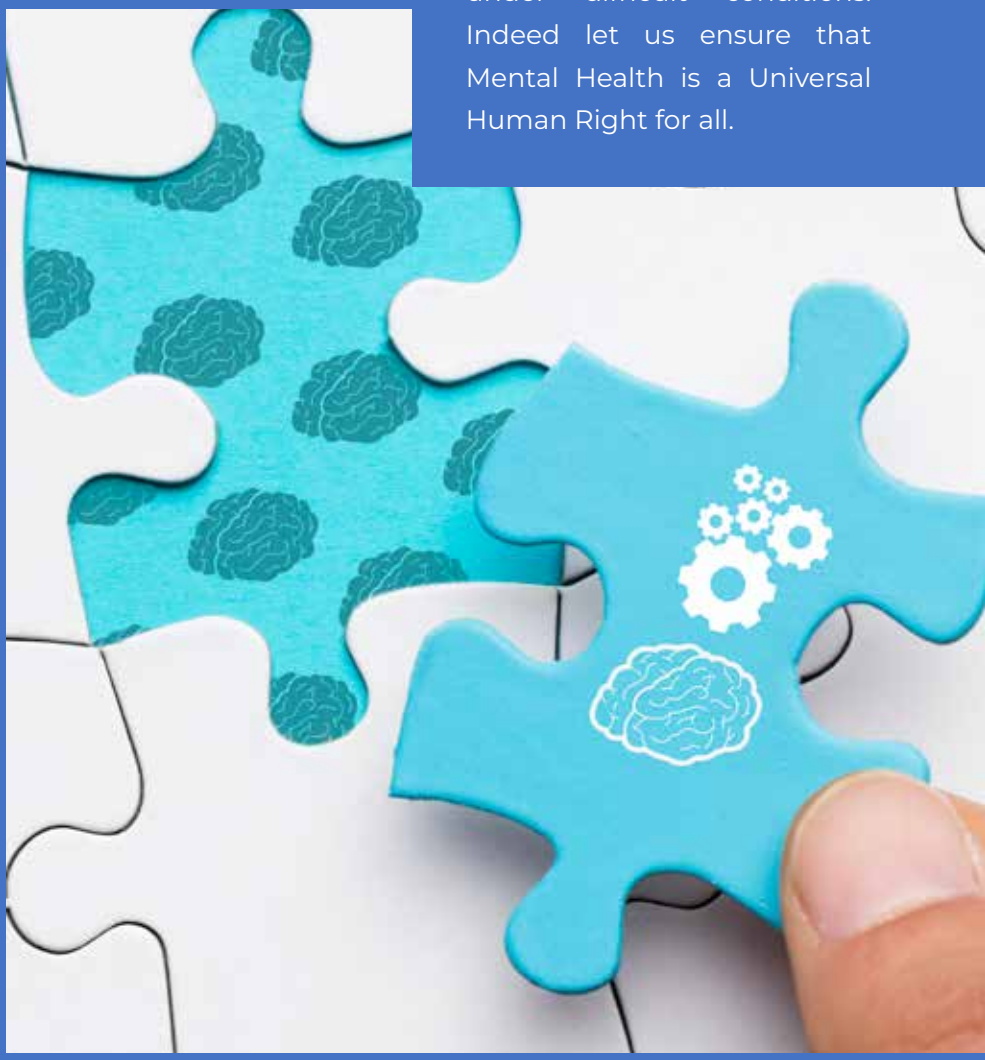
We are all increasingly speaking about mental health well-being and focusing our attention more towards the preservation of mental health in all stages of our lives.This calls for a whole-of-government approach, with the participation of all the leaders in our community as well as in places of work. But who is ensuring that such preventive measures are being implemented and followed upon? Who is ensuring that adequate funding is being committed to support and sustain these initiatives? It may be misleading to assume that everyone is pulling in same direction. Various unions have embarked on initiatives to support their members when it comes to problems related to mental health. These need to be applauded. But how many members are actually seeking this help? Is everyone aware of the universal human right of mental health as declared by the World Health Organisation? An increasing number of persons of young age are having problems related to mental health. Various research studies are identifying possible contributory factors. Are these factors been looked into and the associated recommendations implemented? Are we monitoring the efficacy of these measures? Are we actually providing informative sessions to improve mental health literacy, as well as, building resilience of our younger generations to address the challenges of mental health issues? It would have been commendable that in the new Cabinet that has just been announced, this monitoring role could have been assigned under the portfolio of the Office of the Primeminister. It is such a great overarching responsibility

We all know that the physical environment impacts the mental health well-being of our community. The green initiatives being undertaken to try and rectify the negative impact of urban over-development are a step in the right direction. The issue of excessive traffic congestion has been raised on a number of occassions especially in the run-up to elections. But have we managed to control the situation? Can these traffic problems be conducive to the various instances of road rage incidents? Are these accentuating the stress

levels in the community? Failure to understand the possible impact of a negative environment on mental health well-being does not catalyse improvements. Is the level of pollution in our environment, whether in the air or in noise levels, actively being followed up and redressed? An authoritative body to ensure that corrective measures are being taken across the whole-of-government, as well as, in the community is urgently called for. Urban development should not take precedence on any of the corrective actions. So many authorities are already in place to regulate the situation, however, all should have this overarching mandate to preserve and sustain the mental health well-being of all.

Mental health will be affected if physical health is compromised. Hence more efforts should be in place to promote physical activities in whatever form. Local councils should take more initiatives to promote physical activity in their respective communities. Although various initiatives are already being done to increase local sports facilities, more efforts are needed to ensure better accessibility of to People of all ages. We need to be mindful of our ageing population. Are our roads safe enough to encourage persons with mobility problems to go for walks? Investment should be done to preserve our diminishing countryside and develop safe and accessible paths or trails to encourage persons to go for relaxing walks, possibly organised, supported and led by our community leaders rather than organising sedentary coffee mornings. And why not encourage dancing, singing and supported community gardening targeting especially those with mental health problems or limited financial means? Some may argue that these are frivolous suggestions but the link between engaging in such activities and mental health improvement is backed up by research in the area.

We need to take control of our mental health and understand that everyone can be susceptible to the many contributory factors around us which can impinge on our mental wellbeing. Mental health challenges are a reality that can affect each and everyone of us. These are not challenges that merely happen to the less fortunate others. Let us make 2024 the year of concrete action to help People with mental health issues and to prevent mental health problems. Let us stop and think about our younger and elder generations and about the foreign workers that may be working and living under difficult conditions. Indeed let us ensure that Mental Health is a Universal Human Right for all.



Personal Assistance for persons with disabilities in Malta has been on MFOPD's agenda for years.

MFOPD managed to secure funding through VOPS to cover the costs of this very important and needed study. VOPS is managed by MCVS.

Following the official launching of the research publication the research will be uploaded on MFOPD's website www.mfopd.org

LIVING WITH AN RMD IN ALL STAGES OF LIFE

MARY VELLA, PRESIDENT ARAM

This year's World Arthritis Day (WAD) campaign was focused on highlighting the lifetime journey of a person with an RMD (Rheumatic and Musculoskeletal Disease), possibly starting from a paediatric patient or young child to living with the disease as an adult. It includes its impact on all aspects of life, like growing-up, working, caring for others, and/or ageing. This highlighted the role rheumatologists and diverse healthcare professionals in rheumatology play in the lifelong treatment of persons living with rheumatic diseases.

Recently, Arthritis & Rheumatism Association Malta (ARAM), became a member of Malta Federation of Organisations Persons with Disability (MFOPD). The MFOPD President, Ms. Marthese Mugliette attended this conference, and was very much impressed when she heard from the Rheumatology Specialists invited as well as from the General Practitioner and the patients themselves, how disabling this condition can be, even though this can be an invisible disease.

Therefore, what is Arthritis?

Arthritis is a complex and prevalent medical condition that affects millions of people worldwide. It's estimated that around 120 million people in the European Union are affected by RMDs. It is an umbrella term of a group of disorders characterized by inflammation of one or more joints, resulting in pain, swelling, stiffness, and reduced joint function. Arthritis can have a profound impact on the individual's quality of life, which entails an understanding of its different forms, causes, symptoms, and available treatments.

Types of Arthritis

There are more than 200 different types of arthritis, with osteoarthritis and rheumatoid arthritis being the most common. Osteoarthritis (OA) is a deteriorating joint disease that occurs when the protective cartilage that cushions the ends of bones wears down over time. On the other hand, Rheumatoid arthritis (RA, is an autoimmune disorder where the immune system mistakenly attacks the lining of the membranes that surround the

joints (synovium) of the persons themselves.

Symptoms and Diagnosis

The symptoms of arthritis can vary from one person to another, depending on the type and severity of the condition. Common signs, include joint pain, swelling, stiffness, and a decreased range of motion. Diagnosing arthritis can be a lengthy process which involves a combination of medical history, physical examinations as well as laboratory and imagining tests. Early diagnosis is crucial for effective management and treatment as well as prevention of further joint and organ damage.

Causes and Risk Factors

The onset of this condition which causes arthritis can stem from genetic, environmental and lifestyle factors, including, age, family background, gender, obesity, joint injuries, and infections. Both the Rheumatologist and the patient, through shared decision making, can understand better these factors to prevent and adopt a proactive approach to a better quality of life.

Management and Treatment

While there is no cure for most types of arthritis, various management strategies aim to alleviate symptoms, improve joint function, and enhance the overall quality of life for individuals affected. Treatment options may include medication, physical therapy, lifestyle modifications, and in some cases, surgical interventions. Patient education and self-management play a crucial role in empowering individuals to cope with their condition and make informed decisions better about their health.

Lifestyle and Coping Strategies

Adopting a healthy lifestyle can play an important role in the progression of arthritis and enhance the overall well-being of the patient. Regular exercise, a balanced diet, and maintaining a healthy weight are crucial steps for arthritis management. Additionally, individuals with arthritis benefit from learning stress-management techniques, seeking social support, and staying informed about the latest advancements in arthritis research and treatment.

Conclusion

Arthritis is a very prevalent and challenging medical condition that requires a multidisciplinary team for its effective management. Through increased awareness, early diagnosis, and a combination of medical interventions and lifestyle adjustments, individuals with arthritis can lead fulfilling lives while reducing the impact of the disease on their day-to-day activities. Ongoing research continues to provide hope for new treatment options and improved outcomes, emphasizing the importance of a collaborative effort between healthcare professionals, patients, and the community at large in the journey towards better joint health.

As a supporting NGO, the main goal of ARAM is the advancement of health and education for a better quality of life for patients suffering from RMDs on both national and international level. For more information, reach out to us!

Are you feeling any of these symptoms? Take the necessary action ...
We are here to support you!
Mob: 9925 9532 / 77019970
E-mail: aramalta@gmail.com / Website: www.aramalta.com
Facebook: Arthritis & Rheumatism Association Malta – ARAM
Twitter: @ArthritisMalta /
Instagram: @aramalta

THE 2024 ACCESS CITY AWARD
goes to San Cristóbal de La Laguna

The Spanish island town gets high marks for creating an urban environment fully inclusive of people with disabilities

Today, the Spanish city of **San Cristóbal de La Laguna received the 2024 Access City Award**, for its comprehensive approach to accessibility and its dedication to improving the quality of life of persons with disabilities. The award was presented this morning at the Access City Award Ceremony by European Commissioner for Equality Helena Dalli.

San Cristóbal de La Laguna, located on the island of Tenerife, has prioritised the accessibility of persons with disabilities across urban spaces, transportation systems, and social activities. For example, all vehicles and all stations of the city's tram network are fully accessible, and the city centre has acoustic traffic lights and tactile paving to guide visually impaired people.

In 2021, the municipality launched **Orange Point, a mobile space with resources for inclusive and accessible events**. Orange Point provides sign language interpreters, anti-noise systems, and trained staff, as well as easy-to-read materials. The city's commitment to accessibility is also exemplified by various other initiatives, including the adoption of an institutional declaration for the defence of the rights of persons with disabilities to promote positive actions in this area.

In addition, a **disability council and an ombudsman for persons with disabilities** have been created. The Disability Council directly involves persons with disabilities in decision-making through their consultative work, while the Ombudsman provides independent advice to the City Council, coordinating and promoting the city's accessibility initiatives in collaboration with the Council.

Other European cities distinguished for accessibility policies

The city of **Łódź (Poland)** was awarded the second-place prize for implementing comprehensive standards of accessibility to guide all municipal investments, and the city of Saint-Quentin (France) won the third place for improving accessibility of the city's public transport network.

In addition, **Tübingen (Germany)** received a special mention for its city development aligned with the principles of accessibility and the New European Bauhaus.

South Dublin County (Ireland) was also awarded a special mention for landscape and playground areas, recognising their commitment to ensuring play areas have varied landscapes incorporating natural elements, all while remaining accessible.

https://www.themayor.eu/en/a/view/the-2024-access-city-award-goes-to-san-crist-bal-de-la-laguna-12231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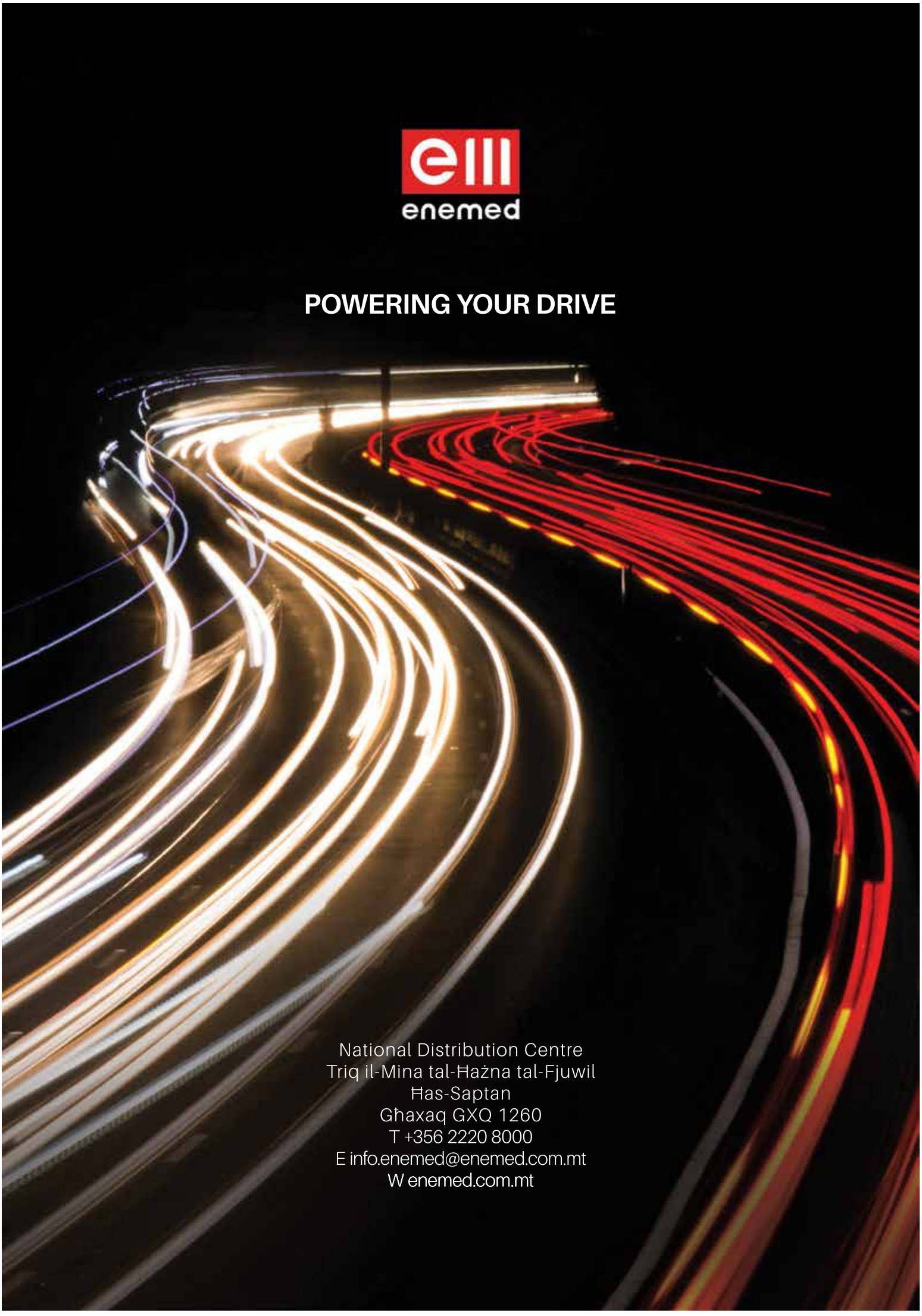
BEING DISABLED MEANS TAKING A SLIGHTLY DIFFERENT PATH, BUT IT DOESN'T HINDER OUR POTENTIAL.
ROBERT M. HENSEL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