One Voice

Official Voice of the National Federation for the disability sector

Issue 6 – January 2023

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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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Editor:	Venera Micallef
Published by:	MFOPD
Artwork:	Ryan Bezzina
MFOPD Add:	Level 3, Verdi Court, Parata Street, Sta Venera SVR 1310
Web:	www.mfopd.org
Email:	info@mfopd.org
Tel:	7707 5555 / 2707 5555
Facebook:	Malta Federation of Organisations Persons with Disability

VO/0042

Marthese Mugliette
President MFOPD

The theme of the 5th edition of the European Parliament for persons with disability is "Building an inclusive future for persons with disabilities in the EU". This event is being held at the European Parliament on the 23rd May, 2023.

Persons with disability coming from all over the EU can voice their concerns and make their suggestions and statements at this high-level meeting. The topic for the event was not chosen by accident. Notwithstanding the United Nation Convention on the Rights of Persons with Disability (UNCRPD) which was signed and ratified by all EU members, persons with disability are enduring a difficult life, some much more than others, because of lack of serious interest and attention to them by their governments. The UNCRPD entered into force for the European Union on January 22nd, 2011. This means that every country, Malta included, must protect the rights of persons with disability.

How can we build an inclusive future for persons with disabilities here in Malta? The key words are 'disability inclusion'. This means "*understanding the relationship between the way people function and how they participate in society and making sure everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires*".

Disability is not a stand-alone issue. It is not a topic to be discussed on its own. It should be considered at all discussions and policy making on any subject affecting the society and this by all Ministries and authorities.

The involvement of persons with disabilities and their representative organisations in the decision-making which affects them lies at the heart of the UNCRPD, reflecting the slogan of the disability movement 'nothing about us without us'. It is of utmost importance for this to be understood by our policy makers. Unfortunately, we are still seeing decisions taking place without our involvement and sometimes even without our knowledge.

Each Minister must be responsible to assure that, in accordance with the UNCRPD, persons with disability and their organisations are participants in the discussions which affect them. Until this is well understood by our authorities, and they act accordingly, Malta would not be in a position to build an inclusive future for its citizens with disabilities. Building an inclusive future for persons with disability here in Malta entails Government's continuous collaboration and engagement with us.

Are all our Ministers responsible enough to make this happen for the full benefit of all persons with disability?

Conference:

PERSONAL ASSISTANCE FOR PERSONS WITH DISABILITY

On the 11th April, 2022, the Malta Federation of Organisations Persons with Disability (MFOPD) organised a national conference about 'Personal Assistance for persons with disability'.

The keynote speaker Dr Adolf Ratzka gave very interesting in-depth information about the subject. Following is the feedback reported by Prof Elena Tanti Burlo' who was the moderator at this conference:

SCAN ME

1. **We need to emphasize that personal assistance should be given to any person who needs it to be able to live an autonomous and full life. A life they choose to live. Individuals with developmental disabilities and mental health problems should be encouraged to live inclusive lives supported by a personal assistant of their choice.**

a. There should be direct funding so that the person needing assistance will be able to hire and fire their own personnel;

b. Control on one's life is only possible if there is direct payment

c. Real choice is only possible if there is direct payment

2. **We need to emphasize that, and here I quote Adolf Ratzka: "People only move into residential institutions *(and here I would add special schools/ resource centres/ hubs/learning zones and nurture groups or any other segregating services)* if they are forced to for lack of acceptable alternatives in the community *(and here I add in ordinary schools/classrooms).***

3. **We need to move away from:**

a. the predominant medical model which dictates all our services including our educational system; and the

b. charity model where disabled individuals and their families are made to beg for taxpayers' money for services they should receive by right. Services need to be given according to the level of need and no one should be in a situation where they need to either pay themselves for services or beg money from other institutions or charities; and

c. move toward the human rights model of disability.

4. **Dr Ratzka gave a very useful distinction between the PA and the caregiver:**

a. Within a PA system, the in-

dividual receiving support is the PA's BOSS : the decision making is in the hands of the individual hiring the PA. Research conducted by Soresi, Nota and Wehmeyer demonstrates that the higher one's level of self determination the higher is one's quality of life. Therefore the development of self determination is essential;

b. The individual receiving care from the caregiver is the object of care. The individual's needs are interpreted by the caregiver.

5. **How can we convince policy makers that individuals have a right to PA? How can we convince policy makers that the PA has a right to be paid competitive wages with adequate employment conditions? The amount of money given for the employment of a PA needs to cover competitive wages and not form part of what is sometimes described as equivalent to "slave trade". Foreign PA can also result in language and cultural misinterpretations.**

Dr Ratzka explained how direct payments are not to be seen as costs but as an investment. Living in institutions is capital intensive with land and buildings while living in the community is wage intensive.

Direct payments are an investment and not costs.

6. **We need to make sure that all individuals especially those living with disability and mental health issues develop high levels of self-determination and autonomy. The W.H.O., back in 1997, highlighted the benefits of including life-skills education in schools which includes skills such as:**
    - Decision making
    - Problem solving
    - Creative thinking
    - Critical thinking
    - Effective communication
    - Interpersonal relationship skills
    - Self-awareness
    - Empathy
    - Coping with emotions
    - Coping with stress

How much are these skills taught and practiced outside the confines of the PSED class?

How involved are students in their IEP?

7. Not everyone can administer their PA alone and some need support for decision making (**Supported decision making**). Schools should be a training ground for this. Peers, as friends, are extremely important. Peers may form part of the circle of friends who may also give support for decision making.
8. Direct payments should cover all the costs and UNCRPD states that there should not be any co-funding of services.
9. Dr Ratzka insisted that the laws for the rights of persons with disability exist but they need to be used. The state needs to provide the financial support to implement the laws on the rights of persons with disability (UN-

Conference:

PERSONAL ASSISTANCE FOR PERSONS WITH DISABILITY

CRPD) and to, also, provide individuals easy access to the financial and legal backing to challenge any institution or agency falling short of implementing the UNCRPD.

10. The UNCRPD has been rectified by Malta, however we are seeing that often only lip service is given to it. The definition of inclusion, in every sphere of life, needs to reflect real inclusivity, real participation in everyday activities. The creation of services for "homogenous" groups has no place in an inclusive society.
11. Fulfilling and meaningful lives based on self-determination: I will end by quoting Dr Ratzka again which summarizes his contribution. "In a residential home I would have died decades ago".

Prof Elena Tanti Burlo'
Dept for Inclusion and Access
to learning
University of Malta
Vice President
Equal Partners Foundation

CRPD

GOVERNMENT OF MALTA
MINISTRY FOR INCLUSION, VOLUNTARY ORGANISATIONS AND CONSUMER RIGHTS

GOVERNMENT OF MALTA
MINISTRY FOR GOZO

VisitMalta

MEMO

To: **Hon Julia Farrugia Portelli, Minister for Inclusion, VO & Consumer Rights**
Ms Nancy Caruana, Permanent Secretary, Ministry for Inclusion, VO & Consumer Rights
From: **The Malta Federation of Organisations Persons with Disability (MFOPD)**
Date: **10th May, 2022**
Re: **Problems being encountered by persons with disability**

THE MALTA FEDERATION OF ORGANISATIONS PERSONS WITH DISABILITY (MFOPD) IS THE NATIONAL UMBRELLA ORGANISATION FOR THE DISABILITY SECTOR. IT WAS FOUNDED FIFTY TWO YEARS AGO AND AS AT TODAY, IT HAS 35 NGOS AND 10 INDIVIDUAL MEMBERS ENROLLED WITH IT.

All the members have been asked to forward their list of problems to be included in one document and presented to your good selves. The list below starts with those mentioned by the committee of MFOPD followed by the feedback received from the members and this in alphabetical order.

MFOPD assures that all the voices are heard and thus included all the feedbacks received. This means that there is duplication of points.

MFOPD :-

1. Need for professional Personal Assistance for persons with disability
2. Need for professional Supported Employment service for persons with disability and to include NGOs in providing this service.
3. There is lack of leisure places fully accessible for persons with disability where they can meet up and make new friends.
4. The parents' right to decide about the education of their children must be assured.
5. The lack of a trans-disciplinary team / approach throughout the students' educational years is leaving negative effects on the lives of the students with disability.....
6. LSE's to be very knowledgeable on 2 or 3 disabilities / conditions and to work with such cases
7. Students with disability are finishing their compulsory scholastic years not yet ready for employment and for the life outside school.
8. Education in Malta is compulsory between the ages of 5 and 16 years**.** Students with disability, due to their condition / disability, need more time to learn and thus their learning should not stop

at 16 years of age.

9. Resource Centres should be part of the schools and not a drive away from schools.
10. Lack of Lifelong Learning for persons with disability.
11. Lack of accessibility – both physically and of information.
12. We are still in a situation where some persons with disability cannot exercise their right to vote independently.
13. Persons with disability are being offered generic medicines which are not as much effective as the original ones.
14. Persons with mental health issues should benefit from the disability allowance as the lack of this is putting these persons in a frustrated and helpless situation.
15. There is a lack of statistics of the disability sector and then obviously, its analysis.
16. We are not getting the value for the money being spent on disability.
17. An evaluation of all the services for persons with disability should immediately take place and remove what is not working and improve where necessary.
18. All persons with disability have a right to live a full, dignified life....not only the rich!
19. It is unacceptable to continue having persons with disability put on waiting lists to benefit from a service needed by them.
20. As is done in some other EU countries, we should have retained our national disability card (the yellow card) and upgraded its benefits parallel with the EU disability card. “The aim of the EU disability card is to facilitate travelling to another Member State for persons with disabilities. This card will allow persons with disabilities to access certain discounts for culture, leisure, sport, and transport under the same conditions as the nationals with disabilities of that country”.
21. MFOPD should be one of the participants in the monitoring of the UNCRPD (see CRPD Annual Report 2020, page 36)
22. ENGAGE, the civil society participation mechanism in line with Article 4(3) of the Convention, General Comment No. 7 as mentioned in the National Strategy for the Rights of Persons with Disability (2021-2030) – MFOPD is not aware of its establishment, let alone of its (MFOPD’s) participation
23. Being the national umbrella organisation for the disability sector, MFOPD should always be a participant in all decision making which directly or indirectly effect persons with disability. This by whoever and from wherever such decisions, including policies, are being taken.

24. Medication

- lack of variety in ADHD medication, generic medication is changed without advising people who use it - although medication seems the same chemically, different people are affected differently. Patient feedback isn't taken into consideration (NOTHING ABOUT US WITHOUT US!!). There are times of year when medication runs out! This is not ok and creates havoc.

- POYC - considering the organisational difficulties (executive function deficits) that are part of ADHD, the entire POYC process is too complicated and tiring, thus making the process to access medication a very tough one.

- *Suggestion :- Perhaps there should be written guidelines explaining the procedure or the pharmacy / psychiatrist could fill in the papers online to help the person with ADHD access the system*

25. Services

- CYPS and CDAU, are unfortunately less effective due to lack of staffing. This leads to inefficient following up of patients and long waiting lists.
- As yet, there are no allowance/benefits/tokens available to be used for therapy/ assessment /support even though this issue has been identified and in discussion for 20+ YEARS. This leads to further burdens on the system and ever-growing waiting lists. It also leads to families having to pay a lot of money on support that would be offered free should the public services be more efficient.
- No support structure for youths with problems due to ADHD - there is a gap in services
- Whilst some professionals have an awareness of ADHD, there are quite a number who are insensitivity towards the condition and its symptoms, leading to ADHD being unseen, patients not being listened to, and not receiving the right treatment and support. Professionals need to keep up with the latest research on ADHD and medication.

- ADHD (inattentive type) is being discriminated against at the Statementing Board (inattentive types are excluded from needed support, with LSEs being removed at stages where they really need the continuation of this service (e.g. grades 10/11). If there are no behavioural issues with ADHD, unfortunately it is not supported, even when educational psychologists recommend support. There is stigma attached to ADHD as a disability - Statementing Board argues that ADHD (inattentive type) cannot be considered to be a disability, whereas research shows otherwise - this shows statementing board lacks understanding of the condition
- Whilst there used to be an adult clinic, this was closed and the lack of ADULT / family clinic for ADHD is felt.
- training of employers to be aware and more understanding of ADHD in the workplace - both needs and strengths
- improvement of medication access and services for this life-long condition.

26. Education
    - support services in school that recognise ADHD and truly understand it (a number of families are sent to family therapy - whilst they may/may not need it, seeing the family as the cause of ADHD-related issues at school is unfair and mortifying for many families who are doing their utmost, and struggling, who need proper support and not judgement)
    - training of educators in what ADHD is in truth and not simply on what they can see - a greater understanding of the internal reasons behind the behaviour and practical ways of reaching the students, supporting them and helping them reach their potential is necessary.
    - training to create an awareness of executive dysfunction and how students need to be scaffolded
    - when there are difficulties / the students appear to be struggling, look like they do not care about how they are doing, or there is the suspicion that they are experimenting with illicit substances, schools should recommend students to be screened for ADHD

27. Others
    - A national guideline on ADHD is needed (like in other EU countries)
    - Local statistics on ADHD should be available.

Caritas Malta Epilepsy Association

28. the urgent need for a specialised epilepsy nurse both for adult and paediatric neurology clinics
29. the long overdue request for the availability of Buccal Midazolam
30. for the relevant committee to consider the availability of Epidiolex(r) for rare types of refractory epilepsies in certain patients, as indicated and approved by EMA

Down Syndrome Association

31. Health
    - Lack of professionalism on breaking the news at birth to new parents
    - Lack of therapies and therapists at CDAU, thus parents have to carry the burden of these costs and / or remain without
    - This lack is bringing about lack of continuation of service.
    - The urgent need to alleviate the burden of these costs.

- Lengthy procedure to finalise and sign (renew) the MoU for the Adult Down Syndrome Clinic between the Down Syndrome Association, which was the mind behind this very important and needed clinic, the Ministry for Health, the Ministry for Inclusion and the Ministry for Active Ageing
- the Association is not aware of any services and monitoring with regards the ageing of persons who have Down syndrome and whose ageing effects start at a very early stage

32. Education
    - Lack of proper inclusion
    - No lifelong learning and continuation
    - In some cases, LSEs are acting as babysitters
    - IEPs and transitions are not being followed in the Resource Centres
33. Our children need professional Personal Assistance, which is not available now, and this is affecting them negatively
34. There is lack of professional Supported Employment to help our youths get and maintain a job according to their abilities
35. Lack of jobs for our adults with intellectual disability
36. Lack of accessible leisure places where they can meet up and make new friends

Inspire Foundation

37. Enough suitably trained and qualified therapists (Occupational Therapy, Physiotherapy and Speech Therapy) available on the market – a collective effort needs to be made to recruit youngsters and encourage them to train as therapists
38. Access to additional hardware and software for school-age children who can benefit from technology to help support their development
39. Creation of formal channels of commu-

nication with all relevant stakeholders including health, mental health, social services etc. Many times, families encounter several problems which are addressed by different professionals. Better visibility and communication will result in better quality service as well as a more efficient and effective use of resources all round.

40. Practical and easily accessible consultation services by other professionals (e.g. financial, legal etc) who can facilitate the day-to-day issues encountered by parents/guardians
41. More enforcement where regulations protecting persons with disability are concerned (e.g. facilitating access to persons with physical disability, protecting parking places etc)

MALTA SOCIETY OF THE BLIND

42. The inability of people with visual impairment to have a person of their trust to help them vote so that they can vote in private instead of the officials. A lot of countries allow voting even by post and in Malta you must go to a place and vote in front of people you don't know.
43. A lot of obstacles at eye level such as trees having long branches outwards on the pavements.
44. Most pavements are too narrow especially when houses have steps on the actual pavement. People with guide dogs find it difficult to navigate especially when there are garbage bags as well. *Some of our members put forward suggestions such as, where possible, as is the case with apartments with porches and houses with drive ins, garbage bags can be left in these spaces to avoid inconvenience.*
45. Lack of zebra crossings in main roads.
46. A lot of traffic lights do not have sound which lets a person with visual impairment know that they can cross.

MENTAL HEALTH ASSOCIATION MALTA

47. Mental Health Act to be reviewed to give adequate recognition to family caregivers
    - gives carers the right to receive support if they have eligible needs. This support is identified through a carer's assessment.
    - if you care for someone, you have a legal right to have your caring needs assessed.
    - a carer's assessment should look at all your needs. This includes the things you would like to be able to do in your daily life. Your needs should be written down in a support plan.
48. Disability recognition
    - discriminative practice that individuals with mental illness are not eligible for SDA (Severe Disability Allowance).
    - The medical board unfortunately is not using the appropriate tool to scale mental health
    - Social Assistance (SA) if living independently, in a hostel or sheltered accommodations or at Mt. Carmel Hospital. But not for individuals living with their parents. This situation is untenable.
49. Monitoring of Mental Health Services
    - Quality of mental health service provided should be assessed by independent bodies (regulator) preferably including the service users themselves and their representative organizations as recommended in the United Nations Convention on the Rights of persons with disability (Article33)

MULTIPLE SCLEROSIS SOCIETY

50. Accessibilty - new developments or buildings and areas undergoing refurbishment should be made accessible to all persons for example in BOV Mosta there are steps to access the elevator

and its difficult to maneuver wheelchair to get inside.

51. Homecare assistance- the idea to have an assistant so that many people with disability can still live at home rather than live in an institution/ hospitals. It will reduce burden on families.
52. Private residential homes culture (clients are seen as numbers instead of individuals). These practices need to be changed.
53. MS nurse - a specialised nurse on MS where the patients can easily reach the nurse and communicate with her/him their needs instead of waiting for the appointment with the neurologist. This person can be the bridge between the patient and the neurologist.
54. Medication related to MS - we would like that the range of medication related to MS is increased by making available other medicines than those listed in the medical formulary
55. Special ID card - it would ease the issue if persons with disabilities can use the special ID card for all public services and areas

National Parents' Society of Persons with Disability

56. Education

- Services like Breakfast Club, 3-16, lifelong learning, other education services provided by NGOs servicing the Educ Ministry should be made available for all students with disabilities irrespective of the school they attend, including resource centres
- The long-term objective is to close all resource centres and all children and "specialised" services to be given within mainstream schools

57. Residential

- the long-term objective is to close all institutions that provide residential services to more than 3 people
- Community homes should be within the locality of the individual.
- Local councils should also be part of the planning of community services

58. Agenzija Sapport

- A financial capping system/tax credit/ or other financial exemption needs to be in place to ensure that families receiving a subsidy for ICL and other services of Sapport, do not incur unnecessary and expensive burdens to meet the bureaucratic essentials.
- All recently introduced new procedures through the updated agreements at Sapport, should be revised and only essential items kept, ensuring extra costs to the user for compliance shall be covered and there would be continuity of services.
- Exemptions should be introduced for ALL individual (not company engaged) personal assistant service givers not exceeding 5 hours per week for any personal assistant engaged. Example if there are two personal assistants giving 3 hours and 4 hours service to one person with disability in a week these would be exempted from requirements for leave, bonuses, sick leave, paying NI, tax etc.
- The agreements signed with NGOs to provide services such a LINC, respite, adult services etc should be made public. We are not interested in the amount that is being spent but we want to know what services the clients are to expect for transparency and accountability
- Adult Services should be age appropriate and should follow a constructed programme and should not be just caring and babysitting
- Persons with Disability should be given adequate support so that that when Sapport Day centres have half days in summer months this would not cause hardship to parents who need to work.

59. Carers Rights

- The carers' allowance needs to be just for those parents who cannot go out to work because they have to care for their child on a full-time basis
- The gov has introduced a grant for parents of persons with severe disability and cannot work due to care giving. Clear guidelines and criteria must be published
- The grant needs to be realistic and reflect the cost of living. The E300/500 annually is charity not a right.
- Benefits, such as special leave and schemes for recognised full time employed parents caring for their disabled child

Voice for Inclusion Association Gozo :-

60. Need of provision of sports for children with disabilities for all ages in Gozo
61. Need for full time CDAU services provided under one roof including dentistry and paediatrician in Gozo, and not one-off visits.
62. Need for facilitation of service providers coming from Malta to provide therapies
63. The Hydrotherapy pool in Sannat which we had lobbied for the past 4 years is still in existent
64. **Suggestion** - *there should be a tax credit for therapies we parents pay. In the tax return, there are tax deduction for childcare services and tax deductions for sports activities but none for child therapy services which for us are a daily burden and a must!*

Individual Members

65. Complaints by persons with disability and/or their parents/guardians/ carers should be taken seriously and acted upon professionally.
66. It is very important to ensure that the funding of the agreements with service providers is being used genuinely and correctly. Certain NGO's ask for costly monthly fees (not yearly memberships), from their clients, irrespective that their services are paid by the Government.

67. No places and no availability for our children to make friends.
68. The disability allowance is not enough for a person with disability to live independently.
69. Our cultural heritage areas, such as Malta's historic museums and creative areas should be free of charge for persons with disability and their parents/ guardians/carers
70. It is a nightmare for some parents to attend to their children's hospital appointments and this because the EU disability card is not always accepted at the hospital.
71. Our children getting services from Agenzija Support pass through a very hard time whenever their professional workers change, and this happens quite a lot.
72. When our children go into an Agenzija Support residence, they do not consider age and abilities, example my 30-year-old son shares a room with a 60 year old man.

DEVELOPING THE POTENTIAL AND SKILLS of Vulnerable Persons

The Malta Association of Supported Employment (MASE) embarked on an ESF funded project 'Developing the Potential and Skills of Vulnerable Persons'. This project was implemented over a period of 22 months. The last day of the project was 31st December, 2022.

MASE was established by, and is a branch of, the Malta Federation of Organisations Persons with Disability (MFOPD). The sole aim of MASE is to monitor the employment of vulnerable persons and act accordingly.

The increase in the number of persons at risk of poverty and social exclusion, the imbalances in the labour market due to discrimination and unequal treatment together with the lack of tailor-made education, training and support services to support vulnerable persons prompted MASE to embark on this project.

This pilot project focused on persons with disability and with mental health issues. The project trained the administrators and the job coaches who supported the project's beneficiaries - the persons who for some reason are falling through the cracks of the services which are already in operation in the market.

In our opinion, one of the key reasons as to why these persons are falling out of the current systems operating in the market is due to a lack of individualised support. In some cases, current service providers are not catering for their needs. This results in persons with disability remaining on unemployment lists for a significant length of time and as a result, they turn to the services of MASE to

quicken the process. Also persons turn to the service of MASE after they lose their jobs due to incorrect job matching.

Through this project MASE targeted this gap in the market. This pilot project targeted this need as although the programme focused on the 5 stages of Supported Employment, specific focus was put on certain stages of Supported Employment. This focus increased these persons' ability to not only find work, but also to maintain it.

This ESF funded pilot project provided another option in addition to what already is in the market to persons with demanding needs, to obtain gainful employment.

The project has ended and MASE internally assessed and evaluated the pilot project. MASE reports the following findings:

1. The major part of the project's beneficiaries, notwithstanding being of a young age, were not yet ready for work
2. They lacked the skills and competences to find the right job
3. They lacked information about different types of jobs and so were unable to decide which jobs they wished for and are fit for them
4. The pandemic changed what jobs are now available and, in some cases, this is affecting vulnerable persons negatively
5. The calls for vacancies are sometimes written in a way that they discriminate against persons with intellectual disability
6. The need for such a professional Supported Employment service for persons with intellectual disability and with mental health issues

Venera Micallef
MASE Project Officer

Operational Programme I - European Structural and Investment Funds 2014-2020
"Fostering a competitive and sustainable economy to meet our challenges"
Activity part-financed by the European Regional Development Fund
Co-financing rate: 80% European Union; 20% National Funds

June 27, 2022

FOLLOWING IS MFOPD'S INTERVENTION WITH REGARDS THE AMENDMENTS TO THE IVF BILL AT THE COMMITTEE FOR THE CONSIDERATION OF BILLS OF LAWS

Late last night, Sunday 26 June, I arrived back in Malta, after attending the AGM of the European Disability Forum (EDF). The MFOPD represents Malta on this European forum. I took the opportunity and discussed with EDF the Bill of Laws that amends Various Laws on Assisted Procreation.

I would like to share this information with you so that you are better informed in this regard.

Malta has signed and ratified the CRPD - the Convention on the Rights of Persons with Disabilities. It is the duty to observe it in all its aspects.

In addition, it is worth recalling that the Maltese Parliament approved the UNCRPD Act. This legislation was intended to ensure that the Convention becomes an integral part of Maltese law.

The deliberate screening of human beings in the embryonic stage, their segregation during the freezing process and the elimination of their chances for pregnancy and birth is unacceptable and goes against the spirit of the Convention.

This will position people with genetic defects as second class citizens.

With this medical model, we will start to classify and decide which human lives should be given the opportunity to continue living according to their state of health.

Everything that the disability sector has achieved over the last few years is threatened by this proposed amendment of the PGT-M.

The social model of disability is a way of looking at the world; developed from the perspective of a person with a disability. The equality strategy is based on this model which says that people are disabled by the obstacles in society and not by their condition or difference.

This model argues that society is built to meet the needs of the majority of people who do not have a disability.

It is with this social model that this Committee, and all Members of Parliament, should look after and see people with disabilities.

It is good to be informed of the concerns of the CRPD of the United Nations in relation to Poland, which concern is set out in the Concluding observations on Poland regarding genetic testing - under Arts. 1-4. I am mentioning this because it applies to what we are discussing today. Allow me to quote word for word some information from this document.

The CRPD Committee of the United Nations makes the following observations in the article below and the conclusions which information is highlighted in yellow in the document you have in your hands:

Poland (CRPD/C/POL/C/1)

The Committee is concerned at the: ...

(b) Variety of disability assessment mechanisms, including separate mechanisms for children until 16 years old, as well as the variety of definitions of disability,

which are not consistent with the purpose (art. 1) of the Convention, and are all based on a medical-model disability, using derogatory terminology and vague concepts such as "mental retardation", "incapacity to work", "inability to perform social roles" or "dependent or lacking ability to be autonomous";

(c) Lack of awareness of professionals and civil servants on the rights of persons with disabilities and the State Party's obligations under the Convention;

(d) Selective and limited involvement and meaningful consultations with organizations of persons with disabilities in policy making;

(e) Legal provisions promoting prenatal genetic testing as primary prevention of future impairments of a foetus;

The Committee recommends that the State party:

(a) With the wide participation of organisations of persons with disabilities, develop a strategy and action plan for implementation of obligations under the Convention, ensuring the comprehensive paradigm shift from a charity model to the human-rights model of disability across its national, regional, local and sectoral policies, considering persons with disabilities as human rights holders;

(b) Ensure a disability assessment which fully incorporates a human rights model of disability and takes a human rights based approach by inter alia:

- Involving Organisations of persons with disabilities in the design of disability assessment mechanisms;
- Engaging persons with disabilities in generating the information on which disability assessments are made;
- Eliminating multiple methods of assessment;
- Making information on assessments requirements accessible and user-friendly.

(c) Eliminate all negative terminology across all existing and drafted regulations and replace it with a terminology which fully respects the dignity and autonomy of persons with disabilities;

(d) Ensure active and full-scale involvement and meaningful consultations with various organizations of persons with disabilities, including but not limited to women, children, refugees and asylum-seekers, LGBT+ persons, persons with psychosocial and/or intellectual disabilities, with hearing and visual impairments, persons living in rural areas and persons in need of high level of support, in designing of new laws and strategies to ensure that legislation complies with the Convention, as well as in the implementation, monitoring and reporting on the Sustainable Development Goals;

(e) Provide trainings to professionals, including judges and law enforcement officials, health care professionals, teachers as well as personnel working with persons with disabilities to raise their awareness of the rights under the Convention;

(f) Refrain from including information on primary disability prevention in future report, as primary prevention of impairment is not a measure contributing to the implementation of the Convention;

(g) Consider withdrawing its interpretative declaration and its reservations to the Convention and ratify the Optional Protocol to the Convention.

Each of you will be given copy of this information. As you can notice, the marked parts are also contradictory in the proposed amendments of the PGT-M because they touch on the same principles.

Therefore, the MFOPD asks you to consider the implications of the introduction of PGT-M and stop with the maximum of polar body biopsy.

Thank you for giving me this opportunity.

Marthese Mugliette
President

GOZO ROUND TABLE CONFERENCE

Another 50th anniversary celebration was the Gozo Round Table Conference held on 7th October, 2022 in Gozo.

The aim of this conference was to raise awareness about the United Nation Convention on the Rights of Persons with Disability (UNCRPD) especially

Article 19 – Independent Living and being part of the community

Article 24 – Education

Article 27 – Work

The reason behind the organisation of this Gozo event was for MFOPD to start and to facilitate good communication among the Maltese and Gozitans on the same issues.

The event was attended to by Maltese and Gozitan persons who engaged well throughout the event.

The discussion was professionally conducted by Mr Lelio Spiteri. There was a very good interaction between the audience and the professionals present.

Hon Julia Farrugia Portelli, Minister for Inclusion, Voluntary Organisations and Consumer Rights, Hon Clint Camilleri Minister for Gozo, Hon Dr Alex Borg MP Shadow Minister for Gozo and H.E. Rev Anton Teuma, Bishop of Gozo addressed the conference. Their presence was very much appreciated and means a lot to the disability sector.

Scan me to access video of event.


GVERN TA' MALTA
MINISTERU GHALL-INKLUŻJONI, IL-VOLONTARJAT U D-DRITTIJIET TAL-KONSUMATUR
Rikonoxximent f'għeluq il-50 sena anniversarju tal-Federazzjoni Maltija tal-Organizzazzjonijiet għal Persuni b'Diżabilità (MFOPD).
Mogħti mill-Ministru għall-Inklużjoni, il-Volontarjat u d-Drittijiet tal-Konsumatur
Julia Farrugia Portelli

Literacy, learning and assessment
21ST CENTURY PERSPECTIVES

This article has been adapted from: Falzon, R. (2022) The meaning of literary in the 21st century: Implications for learning and assessment. In H. Goodsall & S. Flohr (Eds) The Dyslexia Handbook 2002. The British Dyslexia Association. pp.110-123.

Profs. Ruth Falzon,
University of Malta
MDA Secretary

Historically, literacy has only been part of human civilisation for about 10,000 years, compared to 100,000 years of human language. Civilisations who utilised literacy have connected with world leaders and other civilisations who form part of the United Nations (UN). Further, literacy became available to all around 160 years ago, when nations started to focus on education and literacy for all as opposed to the few elite. Literacy now pervades every part of our lives and affects wellbeing .

Reading is gleaning meaning from print - reading accurately and fluently to access meaning. The ability to decode single words - simultaneously recognising letter/s (graphemes representing phonemes) and blending them into words accurately - does not automatically lead to the ability to read paragraphs with fluency and ease to enable comprehension. If decoding is not an automatic process, then reading comprehension is affected. For example, if it takes one ten seconds to read 'indicate' or 'cerebral', can one equate this with the ability to access print fluently and effortlessly? As you are reading this text, you may want to reflect on how many words you are actually decoding or recognising. You are probably an efficient reader with a lot of practice. This has led you to amass thousands of sight words, which you recognise automatically. You will only decode unfamiliar words (e.g. machairophyllum latifolium) or made-up words (e.g. phlograthompinantation). How would you cope reading a paragraph full of unfamiliar words?

Likewise, spelling is the ability to automatically transform words into their written format. Accomplished and efficient readers and spellers have sight word vocabulary banks which lead them to recognise rather than de-

code (read) and retrieve rather than encode (spell) words. This automaticity is vital for accessing meaning from and transforming thoughts into written language. Expected adult reading fluency to easily glean meaning for print is loosely rated at around 200-250 words per minute and average adult writing speed at 25 words per minute.

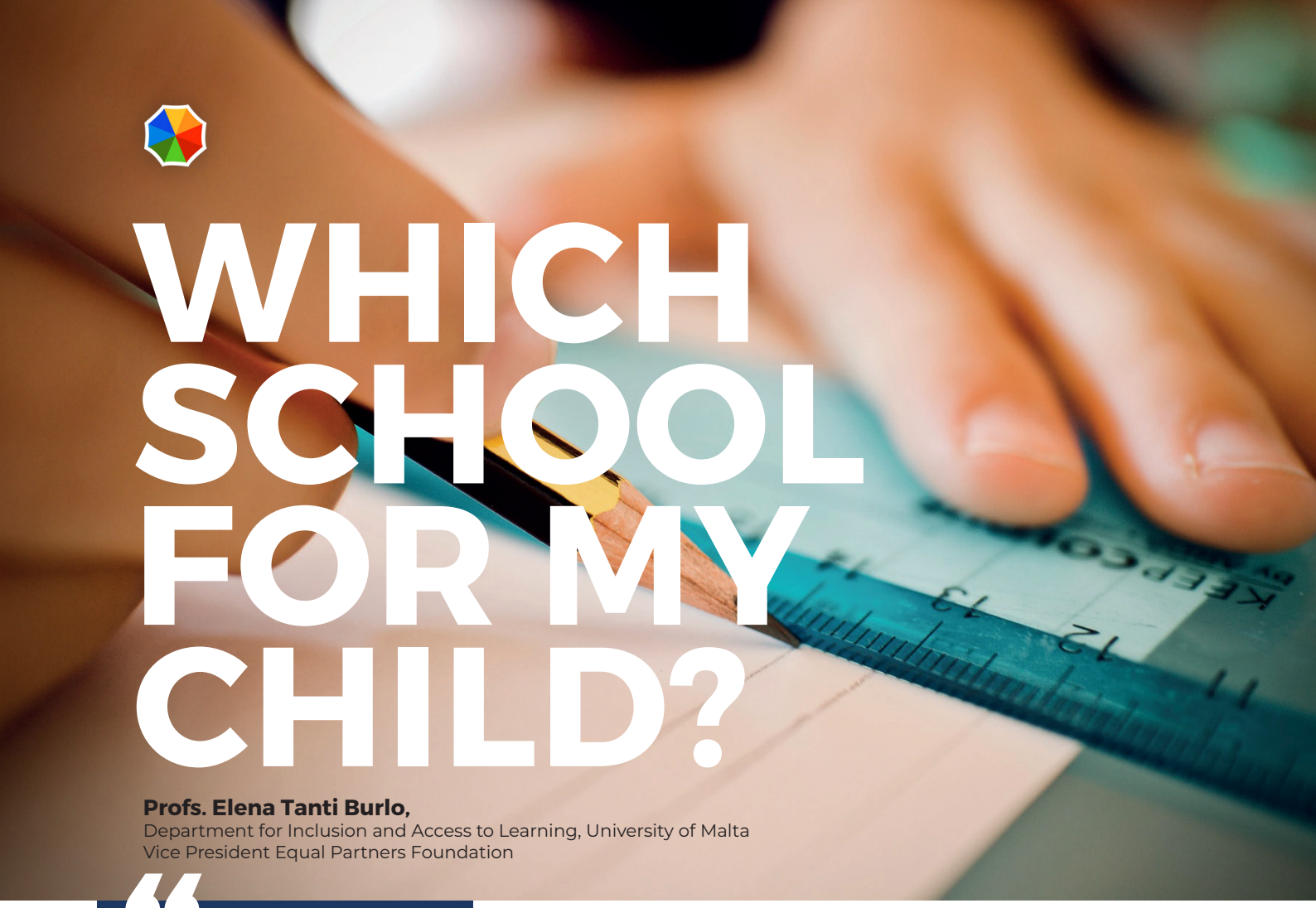
Good education equips one with literacy skills for life. In most countries literacy skills are fundamental to daily living and affect citizens' social, political, civic, economic and personal lives. Where literacy still does not have a fundamental function, oppression and poverty prevail. Eradicating poverty, reducing child mortality, addressing population growth, achieving gender equality and ensuring sustainable development, peace, democracy and empowerment are some good reasons why literacy is essential.

Early literacy success needs effective and expedient teaching techniques. Early-literacy-classroom instruction is considered a core contributor to high incidences of literacy challenges. Research findings attribute poor classroom instruction to lack of basic understanding of concepts related to language structure. Excluding other reasons for failure, including insufficient teaching techniques, a conservative 10% of populations has specific challenges with literacy – dyslexia, whilst coping with other areas of learning. Notwithstanding having access to education, people with dyslexia may experience barriers to learning, certification and employment if their literacy challenges are not appropriately addressed. When addressing and supporting literacy challenges for such a population, one needs to address intervention from two perspectives: access and improving literacy skills.

Technology has improved so much, that schools must consider its use to access and produce print. Information and communication technolgoies bridge interactive features of speech and archival characterists of writing. Gutenberg's printing press (c. 1440) introduced printing, which took centuries to truly infiltrate and affect society with the advent of industrial Revolution (c.1760). The transition between Print and Technology was faster: we have transitioned from an industrial to an informative economy in mere decades.

Since the speed and effectiveness of early literacy learning affect success in learning, technology to access and present print needs to be utilised for those struggling with literacy. Standard computers themselves already incorporate adaptations to address all aspects of literacy, now also in Maltese. Indeed, whether candidates should sit for examinations orally, typewritten, or handwritten should be as basic a choice as wearing or not wearing prescriptive glasses. Examination objectives are not compromised if aural input and oral output are used, unless reading and spelling themselves are being assessed.

In as much as literacy has to be given priority in education, for those with neurological challenges to access it, technology must be used as a compensator strategy. Literature clearly evidences the negative effects challenges with literacy have on wellbeing. Educational systems and educators must avoid unnecessary suffering by challenging their definition of learning and performance in examination and knowledge. Clinton's 1997 International Literacy Day message implored: 'Literacy is not a luxury, it is a right and a responsibility. If our world is to meet the challenges of the 21st century we must harness the energy and creativity of all our citizens".



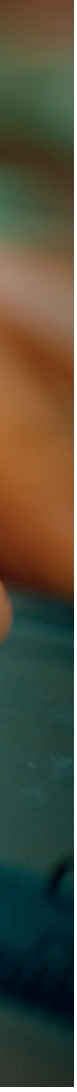
WHICH SCHOOL FOR MY CHILD?

Profs. Elena Tanti Burlo,
Department for Inclusion and Access to Learning, University of Malta
Vice President Equal Partners Foundation

"Which school should I enroll my child in?". This is a question I am frequently asked by parents to a child with disability. This is a serious question for any parent. I usually start by stating that there are pros and cons to every school. Schools are the reflection of their heads, principals and senior management teams. Sometimes, if the head of school changes the philosophy and the dynamics, the school could change; to the better or to the worse, as we have witnessed.

The most appropriate school for a child with disability is, I belief, the most appropriate school for any child. It's simple! A school based on respect of basic human rights; where relationships are welcome and nurtured; where all children are taught in the same class irrespective of their test marks, background, beliefs, gender, socio-economic status, abilities and disabilities. That is inclusive education!

To go back to the original question asked by parents. Technically the parents should have no cause of concern as we are told that our educational system is an inclusive system! The Maltese data provided to the European Agency for Special and Inclusive education for 2019-20 indicate that 66 and 56 students attended primary and secondary/ post-secondary education outside mainstream education. These are the children who were attending special schools (our resource centres) in 2019-20; The data also indicates that no children/learners were attending alternative forms of education; and all children/ learners educated with their peers in mainstream groups/ classes were said to be there for 80% or more of the time. This means that there were NO students, not even ONE, who was not with their peers for more than 6 hours a week!



I will not comment further but perhaps we need to look again at this data and also whether we are implementing the UN Convention on the Rights of Persons with Disability and more specifically article 24 on education (UN, 2006).

How inclusive are our schools? The fact that the children in Malta are: banded, set, streamed according to their marks; pulled out from their classrooms and hosted in, amongst others structures, like nurture groups, multisensory rooms, resource rooms, learning zones; placed in differentiated classrooms, alternative programmes; sent to 'hubs' and special schools (our "resource centers") as well as other day programmes outside school, I find it difficult to say that our educational system is an inclusive one. In fact not even our typically developing learners are included especially those attending state schools.

I had already made my concerns known back in 2010 and I quote

"Most of our Maltese children with disability are said to be attending ordinary schools. We now need to make sure that they are in inclusive settings, and remain there, learning with their peers with an empowered general education teachers equipped with the necessary teaching tools and supported by qualified personnel so that they will be fully engaged in the inclusion of all the children (Tanti Burlo', 2010, p.216).

The situation got worse. We failed to make sure that our children are in inclusive settings, and that our educators are empowered and supported by qualified personnel. The meaning given to inclusive education, in Malta, perhaps, copying what happens in England, has incorporated "special" and segregating "services" where the emphasis is on trying to "fix" the child. A far cry from the need to create an environment where all children could learn together.

The European Agency for Special Needs and Inclusive Education has shifted it's emphasis "away from a narrow focus on learners' special educational needs and special needs education as specific provision, **towards extending and improving the quality of support for learning that is generally available to all learners".** The External Audit report commissioned to the Agency by the Maltese government published in 2015 highlighted the need to remove barriers to inclusive education in Malta, namely by removing selectivity and segregation and shifting to an inclusive pedagogy based on Universal Design for Learning. It also stated that there was a need of a clear understanding of what inclusive education really is and is not.

Inclusive education is for all with no if and no buts. Inclusion does not happen on its own. We need to develop our skills "to identify diversity, to respect and celebrate it" (Sores, Nota in Tanti Burlo' 2020, 2019) . We need to learn these skills ourselves as educators while teaching these skills to our students . We learn about inclusion when we fully engage with it. "Just by doing it" as Vianello would say. Diversity is part and parcel of life.

"There are no short cuts to inclusion. Cutting corners may easily lead us straight into segregating environments thinking they are the only way forward, as they lose hope and optimism" (Tanti Burlo' 2020). Often the right boxes are ticked but....

THE WEAKEST LINK IN OUR EDUCATION SYSTEM

- A parent of the National Parents Society of Persons with Disability

The Policy on Inclusive Education in Schools: Route to Quality Inclusion (2019) states that the National School Support Services (NSSS) should provide support, especially for students who have individual needs and are at risk of exclusion. Specialised centres should ideally be located within mainstream schools. This includes assistance provided to teachers in mainstream education settings by educators working in specialised centres.

Mainstream school educators believe that they embrace inclusion. Due to the discriminatory nature of the 'one size fits all' approach, our children who are considered to have challenging behaviour are becoming lost in the system as educators in practice have shut the doors to diversity and acceptance. This causes families like mine to bear an even greater burden when we are forced and not choose to look at other ways for our children to get their right to education. After the schools were closed due to the COVID-19 pandemic, Felix*, my 6-year-old son, had a very difficult time returning to school. He had trouble adjusting to the routine and was unsure of what was expected of him or how he should act in class. This caused him to miss most of the day's lessons which prevent him from gaining any education. He is now attending a specialised program with five other boys on the spectrum of autism.

"My 6-year-old son, had a very difficult time returning to school. He had trouble adjusting to the routine and was unsure of what was expected of him or how he should act in class.

The breaking point for us was when last year Jason* my 12-year-old son, was being repeatedly excluded by his class teacher, who would yell that he wanted Jason removed from the class. Jason was only permitted to return to eat his lunch. His LSE subsequently requested a transfer in the middle of the year. He was afterwards moved to a resource centre.

Instead of funding the segregation of these children, money would be better spent on resources and training in disability studies in mainstream schools and their educators, which ought to have the means to meet the needs of all students.

While the constitution states that inclusive education and inclusive learning environments apply to all children, however, as each year passes, more specialised programs are being funded which leaves more children at risk of being segregated and excluded from their community once they reach adulthood.

Quality of Life & Support Services: From words to action

EASPD INTERNATIONAL CONFERENCE 2022

From Words to Action! This was the objective of the Quality of Life and Support Services conference on 13th and 14th October 2022 held in Malta.

The international conference was hosted by the European Association of Service Providers for Persons with Disabilities (EASPD)[1] and Aġenzija Sapport[2] with the aim to inspire support services to implement modern quality measurement models focusing on improving the quality of life of the people they support. The event further showcased how such innovative models can help service providers move towards high quality, empowering and person-centred forms of support, aligned with the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Following the recent launch of the European Care Strategy[3] and in light of the upcoming initiative of the European Commission to develop an EU Framework for Social Services of Excellence[4] by 2024, the conference provided an opportunity for more than 300 participants and 70 speakers from across Europe and beyond to discuss what is needed to improve the delivery of disability services across Europe. It further provided participants with the opportunity to participate to workshops focused on different elements relevant to service development and improvement, such as modernising human resources and organisational management, person-centred and family-centred planning, innovative quality frameworks, self-advocacy in service delivery and development, promising funding models for social services, among others.

1 www.easpd.eu

2 www.sapport.gov.mt/en/Pages/default.aspx

3 www.ec.europa.eu/commission/presscorner/detail/en/ip_22_5169

4 www.ec.europa.eu/social/main.jsp?catId=1484

"We need innovative quality assurance systems reflecting the development and delivery of person-centred forms of support for persons with disabilities, aligned with the rights and principles of the Convention", was among the concluding remarks.

HIGHLIGHTS OF THE CONFERENCE

Three panel discussions and fifteen workshops sparked conversations among service providers, persons with disabilities, public authorities representatives, researchers and other relevant stakeholders.

The 2022 edition of the EASPD Innovation Awards[5] further highlighted that monitoring and improving the quality of services is a dynamic activity which encourages constructive reflection and creative thinking, both of which are necessary for innovation. Even, if measuring the quality of services for persons with disabilities can be a challenging mission for most service providers, it was agreed that it is a fundamental part of support services that can bring plenty of opportunities. This was further strengthened by representatives of Scotland and Malta highlighting the need for partnerships between public authorities, persons with disabilities and service providers to ensure the development of high-quality services.

The questions on how to assess quality support, how to organize services to provide quality support and how to work with partners to achieve this objective were in the center of the conference. "*...both authorities and service providers need to invest far more into making their quality systems useful instruments for self-learning and self-improvement, but also for making the most of often limited public spending and staff resources"*, pointed out James Crowe, president of EASPD.

MOVING FORWARD

Among the participants of the conference were members of the EASPD Taskforce on Quality Services. Composed of service providers, persons with disabilities, public authorities, international networks, as well as researchers and other relevant stakeholders. The Taskforce is working to contribute to the development of the EU Framework for Social Services of Excellence and during the conference, the group presented their first reflections of the key elements that an EU Framework on Social Services of Excellence need to include[6]. Their discussions will continue after these two days and quality of social services will be included in the future work of EASPD and its members.

"The way forward should be more involvement of persons with disability", highlighted Oliver Scicluna, CEO of Aġenzija Sapport, and he further referred to the need of discourse to move on to cover the right of access to normal life, beyond education and employment. *"Discussions on sexuality, family life and socialisation should also make it to the agenda to ensure that the social partners move from words to action on what really matters for the service users."*

"Using existing European Funding programmes, as well as the Disability Platform and Social Protection Committee, among others, the EU has a number of tools at its disposal to support Member States" concluded Maya Doneva, Secretary General of EASPD.

Ms Konstantina Leventi
Senior Policy Officer
EASPD

5 www.easpd.eu/publications-detail/easpd-innovation-awards-october-2022-quality-of-life-support-services-from-words-to-action/

6 www.easpd.eu/publications-detail/eu-framework-on-social-services-of-excellence-for-persons-with-disabilities-input-of-the-task-force-on-quality-of-services/

ENIL's Freedom Drive 2022

From the 26th to the 28th of September 2022, the European Network on Independent Living (ENIL) held its 10th Freedom Drive in Brussels. MFOPD is a member of ENIL and attended this event specially to support the demands.

For this **Freedom Drive 2022,** ENIL put together the following demands for the European Union, its Member States and other European countries. MFOPD had the opportunity to present a copy of these demands to Hon Roberta Metsola, President of the European Parliament. At the conference organised by ENIL for this event, the Malta delegation met Dr Helena Dalli, EU Commissioner for Equality. The following information is excerpted from ENIL's Freedom Drive 2022 Demands document.

Improve access to Personal Assistance

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that all disabled people have "the equal right [...] to live in the community, with choices equal to others". This does not mean that disabled people have to live alone and without support. According to Article 19(b), "persons with disabilities [must] have access to a range of in-home, residential and other community support services, including personal assistance".

To close down institutions, governments must increase access of disabled people to community-based services, especially personal assistance (PA). All services must be run according to the human rights model of disability. General Comment No 5 defines PA as "person-directed, user-led human support". Personal assistants (PAt) provide one-on-one support to disabled people, enabling them to access the same opportunities as non-disabled people.

End institutionalisation of disabled people

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) "recognises the equal right of all persons with disabilities to live in the community with choices equal to others ". In 2017, the Committee on the Rights of Persons with Disabilities adopted the General Comment No. 5, which states that "state parties have the immediate obligation to [...] replace any institutionalized settings with independent living support services."

According to General Comment No 5, all countries that ratified the UNCRPD should "adopt clear and targeted strategies for deinstitutionalisation". Strategies or plans of action for deinstitutionalisation should contain "specific time frames and adequate budgets, in order to eliminate all forms of isolation, segregation and institutionalisation of persons with disabilities".

Use EU funds for community-based supports and services

General Comment No 5 states that "no new long-term institutions should be built and that older long-term care residential institutions should not be renovated beyond the most urgent measures necessary". In addition, "state parties should ensure that public or private funds are not spent on maintaining, renovating, establishing, building or creating any form of institutions or institutionalization"

According to Article 17 of the EU Treaty, the European Commission must "oversee the application of Union law". The CRPD is part of EU law. The CRPD Committee also recommended to the EU "to strengthen the monitoring of the use of the European Structural and Investment Funds", in order "to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions".

Decrease the disability employment gap

Article 27 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) says that "States Parties recognize the right of persons with disabilities to work, on an equal basis with others [...] States Parties shall safeguard and promote the right to work".

Article 19 of the UNCRPD recognizes "the equal rights of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right".

According to General Comment No 5, independent living means that disabled people exercise choice and control over their lives. It adds that: "Personal autonomy and self-determination are fundamental to independent living, including access to [...] decent employment".

There is a big disability employment gap in all EU countries. This means that disabled people are much less likely to be unemployed, compared to non-disabled people. In the EU as a whole, 50,6% of disabled people are employed, compared to 74,8% of non-disabled people. For people with certain impairments, the situation can be even worse.

Empirical evidence confirms that sheltered workshops are not a good transitional measure into regular employment. Active labour market policies that use sheltered employment actually decrease disabled people´s likelihood to find a job in the open labour market. They therefore increase the disability employment gap. On the other hand, good employment protection legislation increases disabled people´s job opportunities.

“Together, we overcome the challenges for people with disabilities”

This was the theme of the Parliament event MFOPD organised whereby member organisations of MFOPD had the opportunity to make their voice heard at this highest institution, the Maltese Parliament.

The event was held on Wednesday 7th December with the following eleven organisations addressing the event: Caritas Malta Epilepsy Association, Down Syndrome Association, Equal Partners Foundation, Malta Association of Crohn’s & Colitis, Malta Association of Supported Employment, Malta Dyslexia Association, Mental Health Malta, ME<CFS & Fibromyalgia Alliance Malta, Multiple Sclerosis Society, Prisms Malta and the National Association of Pensioners.

Following is MFOPD President’s address for the occasion.

Honourable Mr Speaker, Honourable Minister for Inclusion, Members of Parliament, Commissioners, representatives from the Directorate for Disability Affairs and the Maltese Council for Voluntary Organisations, Colleagues, I greet you and welcome you to this meeting where today, the Associations within the Federation are being given the opportunity to have their say in the place where the decisions that affect us are taken.

Honourable Mr Speaker, thank you for this opportunity and thank you Honourable Minister and Members of Parliament for accepting our invitation.

Today’s is another round of celebrations of the fiftieth anniversary of the establishment of the Federation. The fiftieth anniversary was in 2020, the year when the pandemic began. We had to postpone every activity that we had planned for later. All the activities that were planned for that year, were organized during this year.

MFOPD is the national umbrella organization for the disability sector, with thirty-seven (37) non-governmental organizations, all working with and for persons with disability, enrolled with it. There are also ten individual members on a personal basis.

This chamber has just seen the approval of the measure in the Personal Assistance budget for persons with disabilities. The Federation has been pushing for a long time to have Personal Assistance for people with disabilities and finally this assistance has been recognized in this budget. For this I would like to thank our Minister, the Honourable Julia Farrugia Portelli and the Permanent Secretary who I am convinced have worked hard so that this assistance was included in this budget. Personal Assistance is the tool for the independent life of persons with disability.

Now we want to see, and there is a need for, the good will of the other Ministers.

This measure is very important for persons with disabilities, but alone it does not work miracles. Parallel to this assistance, persons with disabilities must find the services they need in the community and not segregated services: the services must be provided professionally when and when they need them and not benefit from them according to a waiting list: the Personal Autonomy Bill must come into effect as soon as possible: the information, services, public transport, roads, sidewalks, beaches, buildings and other public places must be accessible to everyone: the television programs must be accessible to everyone: education must be of quality for persons with disabilities: employment opportunities for persons with disabilities must not continue to decrease and this for no reason : technology, assistive and digital, must be available and accessible to everyone, informed to everyone and most important, that it is affordable because it helps a lot in the independent life of persons with disabilities.

Everyone has a right to a clean and safe environment. The air pollution that we have, among others due to the dust of the exaggerated construction and also due to the many cars that we have on our roads, is having negative effects on the physical and mental health of people: the erosion of the natural environment, which I dare to describe as a frantic race with who will succeed in stealing the most from our environment, is putting restrictions on people with disabilities: the race to tear down and raise buildings - all this is affecting our mental health. No one deserves to live in anxiety because whenever s/he opens a window, now s/he finds a wall or galleries staring at him: or that a person can no longer see the natural light from her/his room because of the tall structures. The open spaces are important, but they are not the solution to eliminate the anxiety that people are forced to go through due to the disaster in the natural and structural environment.

Disability is not a stand-alone issue. It forms part of each Minister's portfolio, and it is therefore necessary and important that all Ministers consult with the Minister for Inclusion on anything that directly affects the public. The picture I just gave shows that there is no synergy in this regard.

People with disabilities and their Associations should always, at all times and at all moments and by

> **Together, we overcome the challenges for people with disabilities**

everyone, be considered as important stakeholders in any discussions related to everything that affects them. This is emphasized in the Convention for the Rights of Persons with Disabilities to which Malta is a signatory. I can say that from the side of our Minister this is happening but certainly not from the side of other Ministries.

The fact that there are no statistics for our sector worries me a lot. Statistics are very important because through them it will be known whether we have progressed, and how much we have progressed, and also, we will be able to plan and take decisions. I hope that in the very near future, we Associations will be in a better position to continue our work with the help of the statistics that will begin to be available for the sector.

The Federation has been representing the disability sector on the Civil Society Committee within the MCESD for years. Despite the various requests of the Federation to create the mechanism through which discussions in MCESD also address how that particular theme affects people with disabilities, this has not yet happened. Article 11 of the EU Treaty recognizes participatory democracy as a fundamental democratic principle and calls for the creation of a meaningful dialogue with civil society. This article emphasizes what the Federation has been asking for.

On another note, MFOPD would like to take this opportunity to confirm its position on three issues: MFOPD is against abortion, MFOPD is in favour of IVF but against embryo testing to choose who lives and who doesn't. And here I quote the concern of the Committee for the Rights of Persons with Disabilities of the United Nations in relation to Poland, which concern is set out in the Concluding observations on Poland regarding genetic testing - under Arts. 1-4. This observation says this: *The Committee is concerned at the Legal provisions promoting prenatal genetic testing as primary prevention of future impairments of a fetus;*

I would like to clarify that this information has been passed on to MFOPD by the European Disability Forum of which we are members.

With this quote, I close by once again appealing for goodwill on the part of everyone for the full benefit of people with disabilities. I ask all Members of Parliament, even those who are not here, to listen to what is said today and more than that, so that everything they say and every decision they take, leads to improvement in the true sense of the word, in the life of people with disabilities.

Thank you
Marthese Mugliette

LUXEMBOURG CITY:

SCAN ME

2022 Access City AWARD WINNER

The **Access City Award** is one of the activities within the **Strategy for the Rights of Persons with Disabilities 2021-2030** which is organized by the European Commission and the European Disability Forum. Its goal is to build Europe without barriers.

The **Access City Award** attempts to encourage cities to collaborate and exchange positive examples, with the ultimate goal of ensuring a **safer and more inclusive future for people with disabilities.** The prize is granted to the city that has significantly improved accessibility in core aspects of daily life and also has concrete plans to improve further.

On December 3, 2021, it was announced that the 2022 Access City Award would go to **Luxembourg City**. According to a press release published by the European Commission, the city was recognized by an expert jury for its wide range of innovative ideas and enhancements to increase accessibility for people with disabilities.

This cosmopolitan city, which is also home to the European Court of Justice, has made accessibility one of its main priorities. Luxembourg City has set up a variety of infrastructure and equipment to help persons with disabilities feel safer and more independent. By doing that, the city confirmed its commitment to inclusion and once again demonstrated it is willing to work hard in order to make sure the needs of all residents are met.

Low-floor buses with ramps, as well as visual and audio announcements on buses and at bus stops, are all available throughout Luxembourg's capital. Furthermore, Luxembourg City makes major council meetings available in sign language, in addition to spoken language and accessible transcription, so that each and every resident is able to stay up-to-date with the newest political decisions.

Helena Dalli, European Commissioner for Equality, stated: "Imagine that you want to take a bus, but you cannot board it. Or that your child is unable to play with other children because the playground is not accessible. Accessibility makes a real difference in daily life. It is about autonomy and equality."

''This is why with the Access City Award we recognize the efforts to make cities more accessible and inclusive. I congratulate this year's winner, Luxembourg City, for its commitment to equal opportunities for persons with disabilities," she continued.

The European Commission received 40 bids for the 2022 Access City Award. The cities of Helsinki, Finland, and Barcelona, Spain, came in second and third, respectively.

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