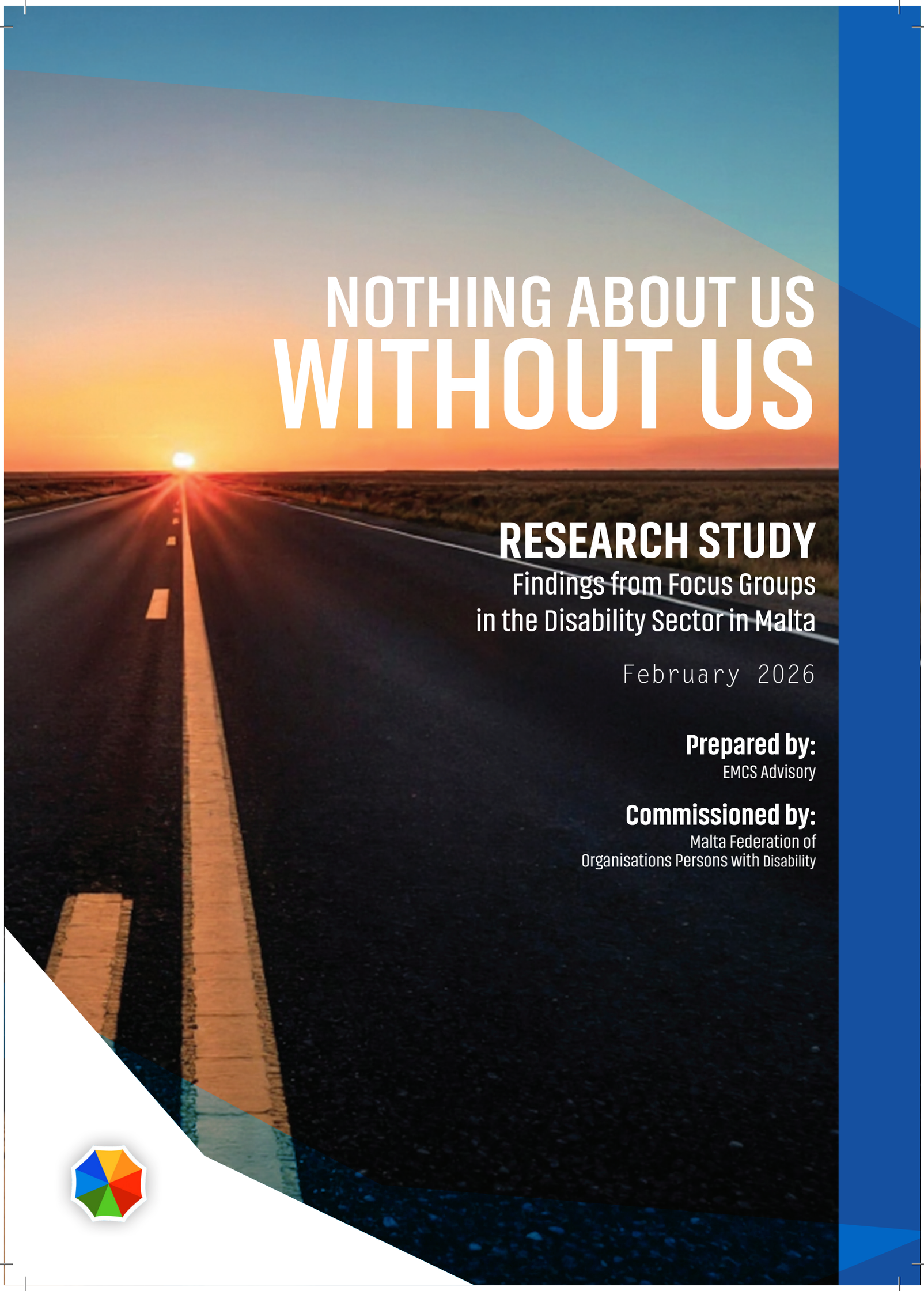

NOTHING ABOUT US WITHOUT US

RESEARCH STUDY

Findings from Focus Groups
in the Disability Sector in Malta

February 2026

Prepared by:
EMCS Advisory

Commissioned by:
Malta Federation of
Organisations Persons with Disability

NOTHING ABOUT US
WITHOUT US

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Acknowledgements

We sincerely thank all persons with disabilities, their family members, and representatives of NGOs working with persons with disabilities who generously shared their time, experiences, and insights. Your contributions were invaluable to this focus group study and have greatly enriched this report.

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Malta Council for the VOLUNTARY SECTOR

VOPS Voluntary Organisations Project Scheme

GOVERNMENT OF MALTA
MINISTRY FOR INCLUSION AND THE VOLUNTARY SECTOR

CONTENTS

LIST OF ABBREVIATIONS

ABBREVIATION	MEANING
MFOPD	Malta Federation of Organisations Persons with Disability
NGO	Non-Governmental Organization
CRPD	Commission for the Rights of Persons with Disability
IACD	Inter-Ministerial Administrative Committee on Disability
DDI	The Directorate for Disability Issues
IEP	Individualised Education Programmes
SDG	Sustainable Development Goals
LSE	Learning Support Educator
PA	Personal Assistant
MRI	Magnetic Resonance Imaging
OT	Occupational Therapy
ME	Myalgic Encephalomyelitis
ADHD	Attention Deficit Hyperactivity Disorder
IDD	Intellectual and Developmental Disabilities

“Nothing About Us Without Us”

Persons
with disabilities

FORWARD

The UNCRPD requires governments to closely consult and actively involve persons with disabilities and their representative organisations in all decisions that affect their lives.

Article 4(3) – Participation in decision-making

States must: closely consult with and actively involve persons with disabilities through their representative organisations in developing and implementing legislation and policies.

This is the legal foundation of “Nothing About Us Without Us”. Governments must consult and involve organisations of persons with disabilities in decision-making.

Article 33(3) – Participation in monitoring

Civil society — especially persons with disabilities and their organisations — must participate fully in monitoring the implementation of the Convention.

The Convention also calls for the full participation of persons with disabilities and their organisations in monitoring. At present, this participation is still limited.

If we are serious about the UNCRPD, we must ensure that organisations of persons with disabilities are meaningfully involved in monitoring its implementation and that persons with disabilities are always at the centre of all decisions.

Marthese Mugliette
President MFOPD

1. INTRODUCTION

This report presents the findings of a series of focus groups commissioned by the Malta Federation of Organisations Persons with Disability (MFOPD) to examine the current state of disability inclusion and support services in Malta. The project is designed to provide a structured platform for critical reflection on existing practices, identify areas for improvement, and collaboratively shape future strategies aimed at enhancing the rights, wellbeing, and quality of life of persons with disabilities.

The focus groups brought together a diverse range of participants, including persons with disabilities, family members/carers of persons with disabilities, representatives from disability-focused non-governmental organisations (NGOs), and professionals/ service providers working in the disability private and public sectors. By drawing on the lived experiences and professional insights the discussions sought to uncover systemic challenges, gaps in service provision, and opportunities for meaningful reform.

The primary aim of the focus groups is to empower participants to contribute actively to the evaluation and development of policies, programmes, and services affecting persons with disabilities. In line with MFOPD's commitment to inclusivity and participatory practice, the project emphasises that all contributions would be treated with full confidentiality and anonymity, ensuring that every voice could be heard openly and constructively.

Overall, this report synthesises the insights from these focus groups to inform policy recommendations and sector-specific strategies. It reflects the collective experiences and perspectives of participants, highlighting both the successes and limitations of existing systems, and providing suggestions for systemic, rights-based, and person-centred reform.

2. PROFILE OF PARTICIPANTS AND PRE-SESSION PARTICIPANT INSIGHTS

A total of 11 focus groups were held with 65 participants. All focus group participants were invited to complete a questionnaire consisting of demographic items and questions directly relevant to the study. This questionnaire was completed prior to the start of each focus group. The questionnaire included the following:

1. **Age**
2. **Gender**
3. **Locality of residence**
4. **Profile of respondent, with the following options:**
    - **Person with a disability**
    - **Family member/carer of a person with a disability**
    - **Member of a disability NGO**
    - **Professional/service provider working in the disability sector**
5. **Type(s) of disability most relevant to the respondent or their family**
6. **In your experience, what are the biggest challenges faced by persons with disabilities in Malta/Gozo today?**
7. **Whether the respondent or someone they support has ever requested assistance from CRPD**
8. **If yes, rating of their experience with CRPD on a scale from 1 (very poor) to 5 (excellent)**
9. **Whether the respondent or someone they support has ever requested assistance from Agenzija Sapport**
10. **If yes, rating of their experience with Agenzija Sapport on a scale from 1 (very poor) to 5 (excellent)**

2.1. Participant Profiles

Responses to the demographic and profile items (Questions 1–5) are presented below, organised according to the focus group each participant attended. The tables provide an overview of each focus group, including the date, the language in which it was conducted, and the demographic profile of the participants. Some participants selected more than one profile in Question 4 of the questionnaire, as they fit into multiple categories. In the tables below, the **'Profile'** column lists the profile(s) for each participant. Each profile is indicated with a bullet point, even if the participant selected only one. If a participant selected multiple profiles, each profile is shown as a separate bullet point. Similarly, if a participant reported more than one type of disability, each type is listed with its own bullet point.

FOCUS GROUP 1:

Date	Tuesday, 4th November, 18:00 – 19:30
Language	Maltese
Participants	8

Participant Profiles of Focus Group 1:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	51	• Person with a disability • Family member/carer of a person with a disability	• Physical	Malta
Female	49	• Family member/carer of a person with a disability	• Sensory (vision, hearing etc.) • Intellectual/developmental	Malta
Female	55	• Family member/carer of a person with a disability	• Psychosocial/mental health	Malta
Female	38	• Family member/carer of a person with a disability • Professional/service provider working in the disability sector	• Intellectual/developmental	Malta
Female	42	• Family member/carer of a person with a disability	• Sensory (vision, hearing, etc.) • Intellectual/developmental • Communication	Malta

Male	41	• Family member/carer of a person with a disability	• Physical • Psychosocial/mental health	Malta
Female	48	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta
Female	72	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta

FOCUS GROUP 2:

Date	**Thursday, 6th November, 10:00 – 11:30**
Language	Maltese and English
Participants	7

Participant Profiles of Focus Group 2:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	27	• Family member/carer of a person with a disability	• Physical	Malta
Female	55	• Person with a disability and member of a disability NGO	• Physical	Malta
Female	39	• Family member/carer of a person with a disability	• Intellectual/developmental • Psychosocial/mental health	Malta
Male	46	• Family member/carer of a person with a disability	• Intellectual/developmental • Psychosocial/mental health	Malta
Female	42	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta

			• Psychosocial/mental health	
Female	67	• Family member/carer of a person with a disability and member of a disability NGO	• Physical • Intellectual/developmental	Malta
Female	71	• Family member/carer of a person with a disability	• Intellectual/developmental • Communication	Malta

FOCUS GROUP 3:

Date	**Friday, 7th November, 10:00 – 11:30**
Language	Maltese and English
Participants	5

Participant Profiles of Focus Group 3:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	65	• Family member/carer of a person with a disability • A member of a disability NGO	• Intellectual/developmental • Psychosocial/mental health	Malta
Female	45	• Professional/service provider working in the disability sector	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental	Malta
Female	34	• Family member/carer of a person with a disability • A professional/service provider working in the disability sector	• Sensory (vision, hearing, etc.) • Intellectual/developmental • Communication	Malta

Male	56	• Person with a disability and a member of a disability NGO	• Physical	Malta
Female	35	• Family member/carer of a person with a disability • A member of a disability NGO	• Neurodevelopmental	Gozo

FOCUS GROUP 4:

Date	**Wednesday, 12th November, 11:00 – 12:30**
Language	Maltese
Participants	5

Participant Profiles of Focus Group 4:

Gender	Age	Profile	Type of Disability	Place of Residence
Male	71	• Family member/carer of a person with a disability • A member of a disability NGO	• Physical • Intellectual/developmental	Malta
Female	55	• Family member/carer of a person with a disability • Member of a disability NGO	• Physical • Intellectual/developmental • Psychosocial/mental health • Communication	Malta
Female	64	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta
Female	55	• Family member/carer of a person with a disability	• Physical • Psychosocial/mental health	Malta
Female	63	• Person with a disability	• Physical	Malta

			• Psychosocial/mental health	

FOCUS GROUP 5:

Date	**Thursday, 13th November, 18:00 – 19:30**
Language	Maltese and English
Participants	6

Participant Profiles of Focus Group 5:

Gender	**Age**	**Profile**	**Type of Disability**	**Place of Residence**
Female	63	• Family member/carer of a person with a disability • A member of a disability NGO	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental • Psychosocial/mental health	Malta
Male	45	• Member of a disability NGO	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental • Psychosocial/mental health	Malta
Female	34	• Family member/carer of a person with a disability • A member of a disability NGO • A professional/service provider working in the disability sector	• Intellectual/developmental • Neurodevelopmental	Malta

Female	31	• Person with a disability	• Physical • Psychosocial/mental health	Malta
Female	50	• Family member/carer of a person with a disability • A member of a disability NGO	• Intellectual/developmental • Psychosocial/mental health	Malta
Female	58	• Professional/service provider working in the disability sector	• Intellectual/developmental	Malta

FOCUS GROUP 6:

Date	**Friday, 14th November, 11:00 – 12:30**
Language	English
Participants	1*

* The participant requested to be interviewed on this subject alone due to potential flare-ups related to her conditions (ME and Fibromyalgia).

Participant Profile of Focus Group 6:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	42	• Person with a disability and member of a disability NGO	• Physical • Psychosocial / mental health	Malta

FOCUS GROUP 7:

Date	Monday, 17th November, 10:00 – 11:30
Language	English
Participants	7

Participant Profiles of Focus Group 7:

Gender	Age	Profile	Type of Disability	Place of Residence
Male	48	• Person with a disability	• Intellectual/developmental	Malta
Other	24	• Person with a disability, member of a disability NGO • Professional/service provider working in the disability sector	• Physical • Intellectual/developmental • Psychosocial/mental health	Malta
Female	27	• Professional/service provider working in the disability sector	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental	Malta
Female	62	• Family member/carer of a person with a disability • Member of a disability NGO	• Sensory (vision, hearing, etc.) • Intellectual/developmental	Malta
Female	72	• Member of a disability NGO	• Neurodevelopmental	Malta
Female	42	• Family member/carer of a person with a disability	• Intellectual/developmental	Gozo
Female	54	• Person with a disability • Member of a disability NGO	• Physical	Malta

FOCUS GROUP 8:

Date	Tuesday, 18th November, 10:00 – 11:30
Language	Maltese and English
Participants	8

Participant Profiles of Focus Group 8:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	39	• Family member/carer of a person with a disability • Member of a disability NGO • Professional/service provider working in the disability sector	• Intellectual/developmental • Psychosocial/mental health	Malta
Female	50	• Family member/carer of a person with a disability • Member of a disability NGO • Professional/service provider working in the disability sector	• Intellectual/developmental	Malta
Female	54	• Family member/carer of a person with a disability • Member of a disability NGO	• Intellectual/developmental	Malta
Male	49	• Member of a disability NGO	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental	Malta

			• Psychosocial/mental health	
Male	67	• Person with a disability • Member of a disability NGO	• Physical	Malta
Male	75	• Family member/carer of a person with a disability • Member of a disability NGO	• Intellectual/developmental	Malta
Female	43	• Family member/carer of a person with a disability • Member of a disability NGO	• Intellectual/developmental	Gozo
Female	53	• Person with a disability • Member of a disability NGO	• Physical • Sensory (vision, hearing, etc.)	Gozo

FOCUS GROUP 9:

Date	**Wednesday, 19th November, 18:00 – 19:30**
Language	Maltese
Participants	6

Participant Profiles of Focus Group 9:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	36	• Family member/carer of a person with a disability	• Psychosocial/mental health	Malta
Female	42	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta

Male	46	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta
Female	34	• Family member/carer of a person with a disability	• Physical	Malta
Female	42	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta
Female	62	• Family member/carer of a person with a disability	• Intellectual/developmental	Malta

FOCUS GROUP 10:

Date	**Thursday, 20th November, 18:00 – 19:30**
Language	Maltese and English
Participants	6

Participant Profiles of Focus Group 10:

Gender	Age	Profile	Type of Disability	Place of Residence
Female	47	• Family member/carer of a person with a disability	• Physical, intellectual/developmental • Psychosocial/mental health	Malta
Male	36	• Family member/carer of a person with a disability	• Intellectual/developmental • Psychosocial/mental health	Malta
Male	43	• Family member/carer of a person with a disability	• Intellectual/developmental • Psychosocial/mental health	Malta
Male	54	• Family member/carer of a person with a disability	• Physical • Intellectual/developmental, • Psychosocial/mental health	Malta

Female	34	• Family member/carer of a person with a disability	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental, • Psychosocial/mental health	Malta
Female	35	• Family member/carer of a person with a disability	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental	Malta

FOCUS GROUP 11:

Date	**Friday, 21st November, 18:00 – 19:30**
Language	Maltese
Participants	6

Participant Profiles of Focus Group 11:

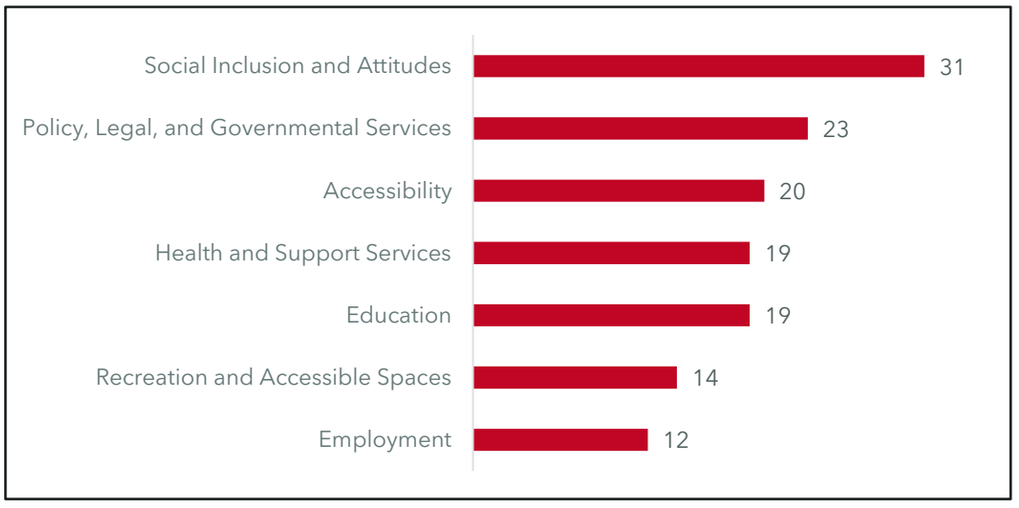
Gender	Age	Profile	Type of Disability	Place of Residence
Female	34	• Family member/carer of a person with a disability	• Sensory (vision, hearing, etc.) • Intellectual/developmental	Gozo
Female	43	• Family member/carer of a person with a disability	• Intellectual/developmental	Gozo
Female	29	• Family member/carer of a person with a disability	• Intellectual/developmental	Gozo
Female	43	• Family member/carer of a person with a disability	• Physical • Intellectual/developmental	Gozo

		• Member of a disability NGO		
Female	41	• Family member/carer of a person with a disability	• Physical • Intellectual/developmental	Gozo
Female	53	• Professional/service provider working in the disability sector	• Physical • Sensory (vision, hearing, etc.) • Intellectual/developmental, • Psychosocial/mental health	Malta

2.2. Pre-Focus Group Session Participation Insights

Biggest challenges faced by persons with disabilities in Malta/Gozo today

In the questionnaire administered prior to the focus group, participants were asked an open-ended question: "In your experience, what are the biggest challenges faced by persons with disabilities in Malta/Gozo today?" Participants were free to identify as many challenges as they considered relevant. The graph below illustrates the total number of mentions for each challenge.



The chart shows clear differences in how often each category was mentioned across all responses. Because participants could list more than one challenge, the figures represent the total number of mentions rather than the number of participants.

Social Inclusion and Attitudes is the most frequently mentioned category, with 31 mentions. This is followed by Policy, Legal, and Governmental Services, which was mentioned 23 times. Accessibility is the next most frequently cited category, with a total of 20 mentions.

Two categories appear at a similar level: Health and Support Services and Education, both of which were mentioned 19 times each. Recreation and Accessible Spaces received 14 mentions, placing it below the previous group but still representing a substantial number of responses.

Employment is the least frequently mentioned category in this dataset, with 12 mentions.

Overall, the distribution shows that mentions are spread across all seven categories, with each category being identified multiple times, but with noticeable variation in how frequently each one appears in the responses.

To facilitate more detailed analysis, participants' responses were analysed and categorised into distinct codes, each with a corresponding description.

1. **Accessibility** (Barriers to mobility, public transport, buildings, digital tools, and other physical or online environments, including lack of digital accessibility for those who are older, illiterate, or not tech-savvy.)

2. **Education** (Limited opportunities for further education (after the age of 15), support, or accommodations in schools, universities, or other learning environments, including lack of training for teachers and learning support staff, lack of inclusive education, and schools being unsuitable for students with special needs.)

3. **Employment** (Limited job opportunities, difficulty retaining employment, workplace accommodations, equal treatment, or inclusive employment practices.)

4. **Social Inclusion and Attitudes** (Negative societal attitudes, stigma, discrimination, lack of awareness about disabilities (including non-visible disabilities), lack of inclusion, tokenism, or segregation from community, social, or educational settings.)

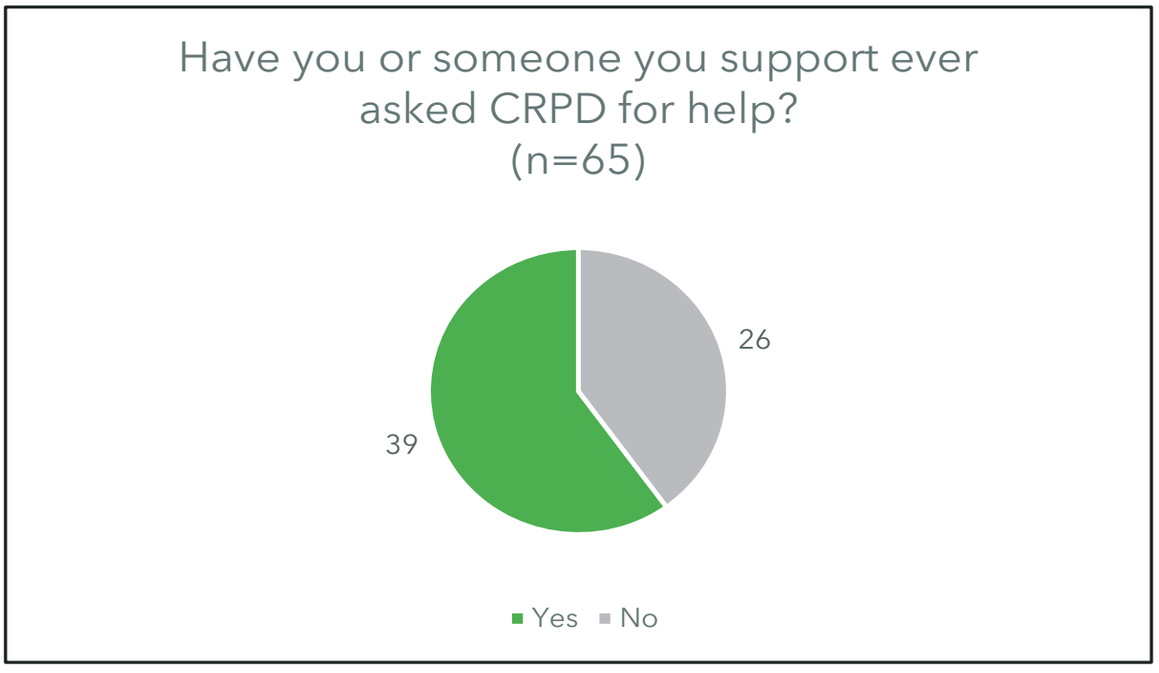
5. **Health and Support Services** (Difficulties accessing healthcare, rehabilitation, personal assistance, social support services, mental health services, specialised services for persons with severe behavioural needs, long waiting lists for limited services, difficulty accessing healthcare professionals (including high costs), and difficulty obtaining necessary medication.)

6. **Policy, Legal, and Governmental Services** (Insufficient enforcement of disability rights, policies, inclusive service design, consultation with persons with disabilities or their families/ NGOs, lack of financial support or welfare provisions, barriers to independent living, bureaucratic or lengthy administrative processes, and lack of awareness of available services among individuals with disabilities and their families.)

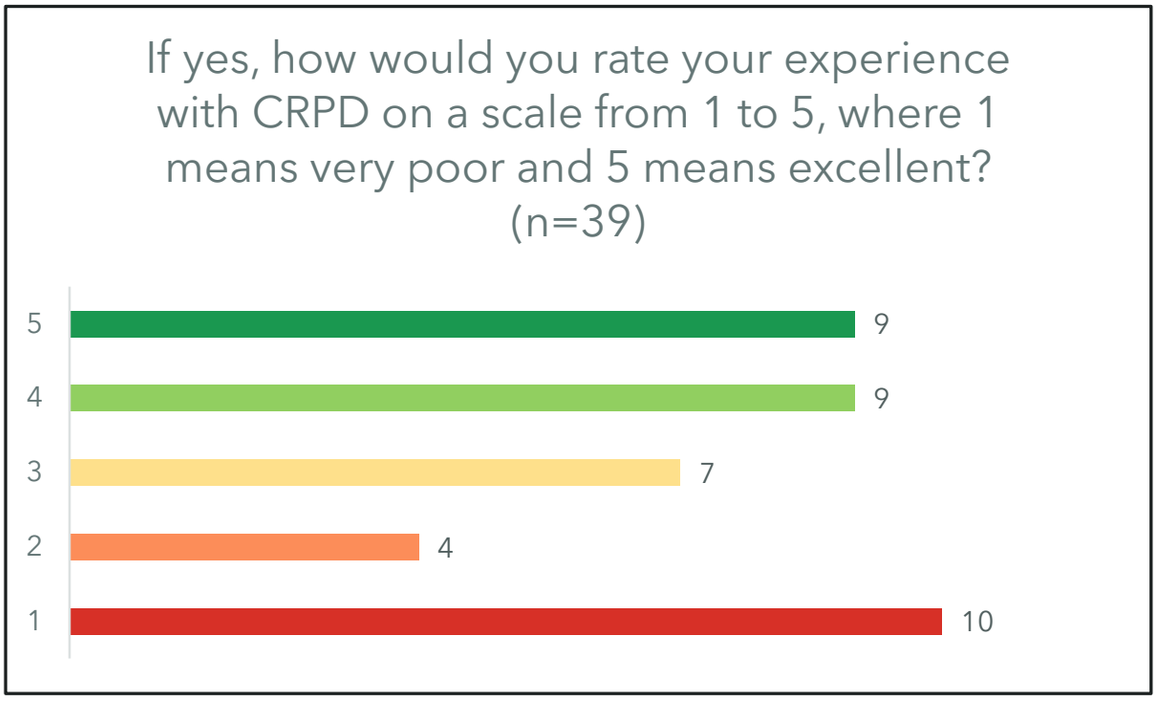
7. **Recreation and Accessible Spaces** (Limited access to leisure, sports, cultural activities, public spaces, sensory rooms, or other facilities designed for persons with disabilities.)

Experience with CRPD and Agenzija Sapport

Finally, participants were asked whether they, or someone they support, had ever sought assistance from CRPD and Agenzija Sapport. If they responded affirmatively, they were asked to rate their experience on a scale from 1 (very poor) to 5 (excellent). The graphs present the results of these questions with regards to CRPD.



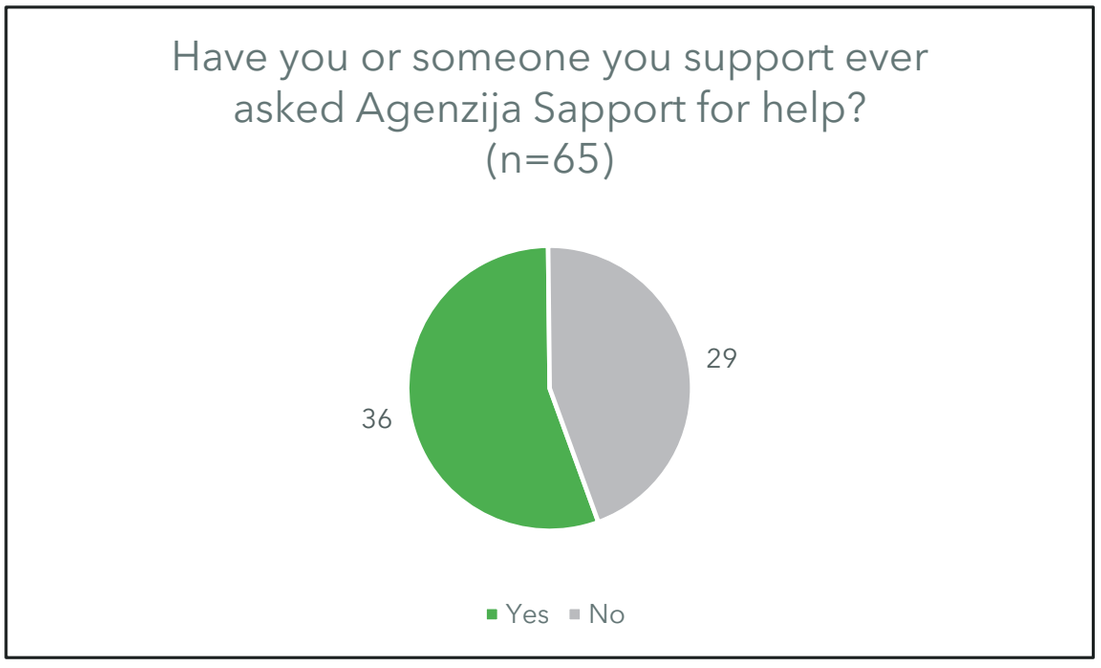
Out of the 65 participants, 39 reported that they or someone they support had asked CRPD for help, while 26 had not. This means that around three fifths of the sample had direct contact with CRPD.



Among the 39 respondents who rated their experience, the full range of scores from 1 to 5 was used. Ten respondents gave the lowest rating of 1, while four rated the experience as 2. Seven respondents selected the mid-point rating of 3. At the higher end of the scale, nine respondents rated the experience as 4 and a further nine rated it as 5. This shows a wide spread of responses, with substantial numbers at both the very low and the higher ends of the scale. The most frequent single rating was 1, but ratings of 4 and 5 together account for 18 out of 39 responses, which is just under half of those who answered this question.

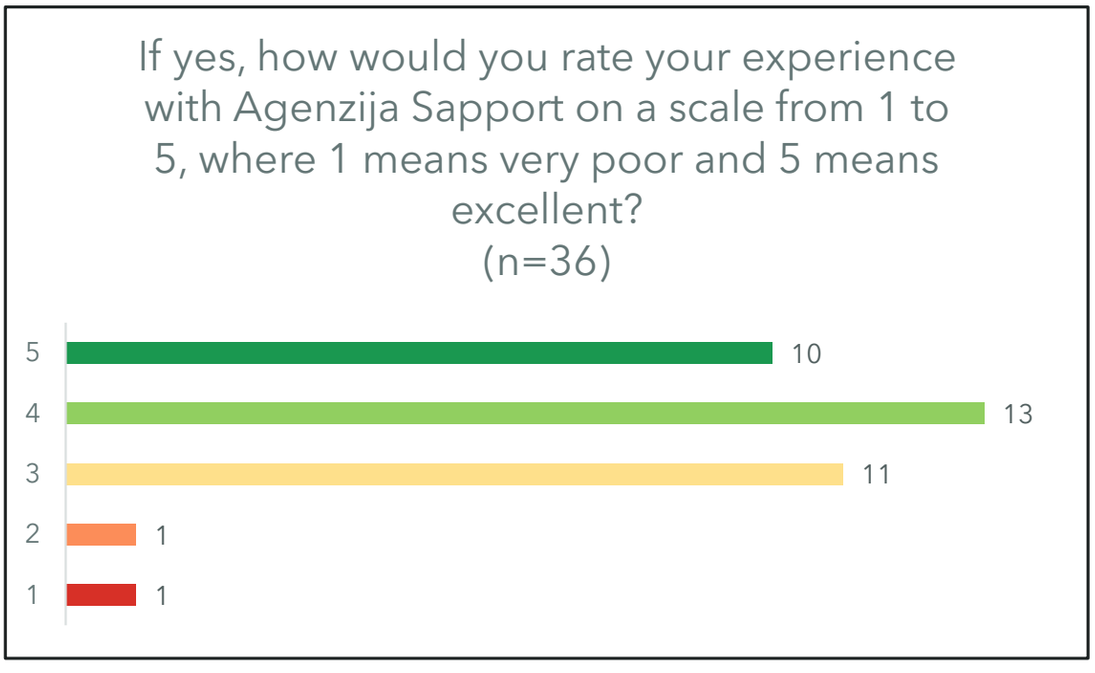
The average rating for CRPD is **3.08** out of 5, indicating a result slightly above the mid-point of the scale, alongside considerable variation in how the service was rated. 10

Then, the participants were asked the same two questions with regards to Agenzija Sapport. The results of these questions are presented below.



Out of the same 65 participants, 36 reported that they or someone they support had asked Agenzija Sapport for help, while 29 had not. This again means that a little over half of the sample had direct contact with the agency.

Among the 36 respondents who rated their experience, most scores were concentrated in the middle to higher part of the scale. Only one respondent gave a rating of 1 and one gave a rating of 2. Eleven respondents selected 3, thirteen selected 4 and ten selected the highest rating of 5.



This indicates that the majority of responses were clustered around ratings of 3, 4 and 5, with relatively few very low ratings.

The average rating for Agenzija Sapport is **3.83** out of 5, which is notably above the midpoint of the scale and reflects a stronger concentration of higher ratings compared to the spread seen in the CRPD results.

The findings presented are based on feedback from a small, non-representative group of respondents. As such, the results should be interpreted with caution. While the responses provide useful indicative insights and help to highlight potential themes or issues, they cannot be considered statistically representative of the wider population. Consequently, the findings should not be generalised and are best viewed as exploratory rather than conclusive.

3. MAIN FINDINGS

3.1 General Experience and Inclusion

Participants were asked to comment on the motto *"Nothing About Us Without Us"* which is central to the Disability Rights Movement. One participant felt that it remains *"a principle and a reminder that real inclusion requires active participation of persons with disabilities…recognising that [they] are experts in their own experiences,"* — a goal that participants felt still has room for fuller realisation. This sentiment was echoed more broadly, with participants reporting that they were often disregarded or made to feel uncomfortable when raising concerns: *"I'm a Learning support Educator (LSE) and I never get consulted. When I try to provide my feedback or suggestions as an educator, I get shut down." Another Learning Support Educator (LSE) explained, the principle of "Nothing About Us Without Us" is far from being upheld, being referred to by said educator as "Everything About Us Without Us."* Similarly, another participant noted, *"When we speak about these things the authorities make you feel uncomfortable because you make them accountable. When I speak, I know it's useless."* Another similarly expressed long-standing frustration: *"We are not inclusive at all, not for the physically or mentally disabled. I've been fighting in this sector for years."* This feeling was commented on also by NGO members, explaining that when the Life Map project (a new programme offered to 16+ students with disabilities, and this includes students who have benefited from an inclusive education in regular schools throughout their educational years) was introduced, it was done so "*without being discussed with NGOs. There is a lack of consistency — sometimes there is consultation, sometimes there is not."* They described a pervasive sense of exclusion and a consistent lack of meaningful consultation in decisions affecting persons with disabilities.

Adding to a lack of consultation, participants also noted a lack of follow-through from institutions, *"everybody listens, but then nothing happens."* One participant who forms part of an NGO commented that, *"we try to see how we can contribute and give our input and sometimes, yes, we're listened to and everyone agrees, and then nothing is done."* This lack of initiative hinders progress and leaves persons or families/carers of persons with disabilities in the dark. This point was highlighted by a participant working as a professional in the disability sector, who pointed out that there are also disabled people and their relatives who *"don't have a clue about what they should do"* or even that *"they have a right to apply for the EU disability card."*

Across the discussions, participants stressed that exclusion extends beyond interpersonal interactions to wider societal and structural levels. Several described a prevailing culture of uniformity that overlooks individual needs in favour of standardised approaches. As one participant observed, *"…in Malta, we have the opinion that if something worked with person A, it will work with person B. They want everything to be uniform."* Such inflexibility often left individuals and families isolated and struggling to navigate systems not designed to accommodate diversity, including those living with invisible or dynamic disabilities. One participant explained, *"I have Myalgic Encephalomyelitis (ME) and Fibromyalgia…Right now, no one can see the pain I'm in."* Another participant with severe Fibromyalgia commented that *"I am facing many problems and feel as though I am alone in a bubble, with no one helping me."*

Hidden disabilities were further discussed in relation to social attitudes and stigma, which were noted

as another key barrier. Participants stressed that although public awareness has increased, it has not translated into widespread understanding, with *"an imbalance between different types of disabilities."* One participant emphasised that conditions such as Fibromyalgia and Epilepsy need more public awareness as they are *"invisible conditions and should be given more attention,"* warning that people suffering from these types of disabilities often *"struggle in silence"* because of a lack of awareness and understanding of the disabilities themselves. These issues are compounded by entrenched stigma, with one participant stating, *"a lot of people still judge kids and even adults with autism."* In smaller communities such as Gozo, the effects were described as particularly acute, where limited privacy means *"everyone knows"* when individuals seek mental health or disability services, leading many to delay accessing support. It was noted that public narratives increasingly focus on visible disabilities, leaving invisible conditions to *"take a back-row seat"* leading to misunderstandings and inadequate accommodation for persons with hidden disabilities. Overall, participants felt that awareness often functioned more as rhetoric than reality. As one participant put it, *"there is awareness, but I feel this is a buzzword nowadays. We're very behind on inclusion, such as in education, healthcare and infrastructure."*

Positive experiences were also discussed, both in terms of resources available and in terms of individual inclusion. One participant working in the disability sector explained some of the programmes available to children with intellectual disabilities, *"I work with Inspire. I come from the education sector and taught for 21 years before working in this job. In my current sector, I work with over 300 autistic learners. We have three main programmes, such as have the Link School which functions like a resource centre, and we have the STAR programme."* Additionally, despite the lack of resources and help in Gozo, as compared to Malta, a parent of a child with an intellectual disability living in Gozo shared her experience of finding a sports coach who took her son's disability into consideration, *"it was an incredible thing…when my son realised that with proper help he could do certain things,"* demonstrating that with some care and attention, disabilities need not hinder individuals from pursuing things they enjoy.

Overall, participants conveyed a shared perception that inclusion remains more aspirational than practiced. Despite increased public discourse, they felt that meaningful change requires listening to lived experiences, valuing diversity, and ensuring that systems respond equitably to the needs of persons with disabilities and those who support them.

3.2 Accessibility and Independent Living

Accessibility and independent living emerged as domains marked by profound structural inadequacies and inconsistent planning resulting in significant constraints on autonomy for persons with disabilities and their families. The overarching finding indicates that, despite policy commitments to inclusion, the built environment, public infrastructure, and support systems remain misaligned with the lived realities of disabled people, producing daily barriers that undermine independence, dignity, and social participation.

Participants consistently described a physical environment that is neither reliably accessible nor designed with disabled persons in mind. One participant explained that *"the pavements and roads are not accessible,"* while another emphasised that *"even when I take my mother out, the pavements aren't wide enough. There's a lot of rubbish and plants in the way. It's very difficult. It's a huge obstacle."* Reports of broken or uneven pavements, ramps that were poorly placed or missing entirely, and obstructions caused by private objects or village feast decorations further illustrated a pervasive lack of enforcement. One participant with a physical disability highlights this issue further, holding that, *"I struggle to walk with a walker because I never know from where I can pass. The pavements don't help, some have ramps, some don't, and some are broken."* Additionally, a parent of a child with a physical disability questioned the lack of road safety for pedestrians, *"When you cross the zebra crossing there's no respect from drivers, not even at the traffic lights. Everyone's in a hurry, and if you're disabled, they treat you like you're in the way. I have to keep my eyes everywhere when I take my daughter out. In this day and age, when we've created so much hype and awareness, how are we still this far behind?"* These accounts underscore a systemic failure to treat accessibility as a basic public requirement rather than an optional accommodation.

The accessibility of public buildings, services, and transport was described as similarly inconsistent, with barriers often embedded in everyday logistics. Several participants highlighted challenges in navigating hospitals and public transport, with one family member of a child with a disability explaining that, *"The blue badge available parking spaces in Mater Dei are not enough. Even with a Blue Badge in Mater Dei, you still have to park far away and take a taxi. I can't carry my son, who weighs about 85kg, even a short distance."* Another family member of a person with a disability explained the challenges of attending appointments at Mater Dei: *"To make it to an appointment at Mater Dei, I have to go at 6 a.m. just to find parking. I park in the outpatient area and still have to go early."* Others noted that physical access to buses was often impossible — a participant with Fibromyalgia explained, *"I used to drive, but because of Fibromyalgia, I cannot drive anymore… the buses do not stop near the pavement, so I cannot get on or off,"* adding that her concerns were dismissed by drivers who told her she was *"young,"* revealing deep misunderstandings of invisible disabilities. Environments such as beaches, playgrounds, shopping centres, and schools were also described as exclusionary. One parent criticised shopping centres for having lifts and escalators *"out of order,"* noting that such *"basic"* features should not be intermittent.

Within schools and educational settings, accessibility concerns extended beyond mobility to include sensory, cognitive, and communication needs. Parents emphasised the lack of appropriate resources and assistive devices, explaining that in mainstream schools there are *"no clickers," "no basic keyboards,"* and difficulties obtaining *"a basic mouse"* restricted children's participation. The account of a mother whose daughter is hearing impaired illustrated the broader dimensions of inaccessibility: *"my daughter is hearing impaired — she needs subtitles, even in mental math she*

needs a live reader to lip read." This highlights that accessibility also encompasses communication, adaptable learning tools, and inclusive pedagogical practices, not solely physical structures.

Housing accessibility and the affordability of home adaptations emerged as additional barriers. Attaining appropriate housing or necessary modifications was described as prohibitively expensive and procedurally inaccessible. One participant described the Housing Department's grant scheme for building a sensory room, noting that while a €6,000 grant was available, local suppliers drastically inflated prices: *"a swing costing €600 in Malta could be purchased for €75 online with the same quality… It's an abuse from the salespersons."* Because online purchases could not be reimbursed, the participant concluded, *"I didn't get the money back… but I was happier that way,"* highlighting how procurement rules can unintentionally undermine cost-effective accessibility improvements. A participant living with ME and Fibromyalgia highlighted how long-term illness and reliance on social security create significant barriers to accessing and maintaining safe housing. Living on her own with no family and approximately €700 per month, her income was largely consumed by essential expenses such as medication, rent, and utilities, and food leaving minimal flexibility to address housing-related needs. She discussed how her ceiling is about to collapse. Although government assistance would cover 50 per cent of the estimated €5,000 repair cost, the remaining €2,500 contribution was unattainable on her income.

A person with disability that tried applying for a blue-badge parking space was left entirely to local political discretion: *"the mayor told me he could not assign another parking space within 50 metres… but when I turned the corner, I found four more."* Such inconsistencies foster perceptions of unfairness, arbitrariness, and gatekeeping.

Economic precarity amplified accessibility barriers, particularly for individuals unable to work due to fluctuating or severe conditions. One participant living with severe ME described social assistance as *"a prison with a death sentence,"* explaining that income restrictions prevented them from working even minimally, while the allowance remained insufficient to meet basic needs: *"I sometimes go without food."* They also described periods of profound cognitive and physical debilitation, made worse by the lack of access to domestic help, *"When I'm having particularly bad days I even forget how to open a door… I go to shower with my clothes on."* This testimony highlights how severe disability-related symptoms, combined with rigid welfare structures, can erode independence and self-sufficiency.

At the heart of many narratives was the desire for community inclusion and the recognition that institutionalisation, whether physical or systemic, undermines autonomy. Families of persons with severe disabilities emphasised the importance of being supported to remain within the community. One mother caring for her 40-year-old son with Down Syndrome and severe autism explained that opportunities were limited and geographically isolating: *"He refuses to go anywhere… I wish there were more opportunities for persons like him to be part of the community, not just placed with others like themselves."* Another participant echoed this sentiment directly: *"They say we should keep the elderly within the community — so why not people with disabilities too?*"

Finally, several participants underscored the lack of consultation and meaningful involvement of disabled people in shaping accessibility. Participants recounted instances where facilities were certified as accessible but failed to meet real needs. As one participant asked, *"These hotels are certified as disabled friendly — but have they ever tested them with an actual wheelchair user? We went to a supposedly disabled friendly hotel but had issues to fit in certain areas with the wheelchair."* Another reflected on schools and public buildings:

"Even new public buildings… are often inaccessible. Our complaints don't reach those responsible for designing these things." These accounts reinforce the idea that accessibility must be co-designed with disabled people rather than imposed through top-down, checklist-driven processes.

The cumulative evidence paints a clear picture: accessibility in Malta remains fragmented, unpredictable, and frequently symbolic rather than substantive. Barriers arise not only from physical structures but from bureaucratic systems, cultural attitudes, economic inequality, resource shortages, and a persistent lack of consultation.

3.3 Education and Employment

Participants described the education and employment systems as falling significantly short of inclusive aspirations. The accounts collectively highlight chronic under-resourcing, a lack of professional training, and rigid structures that fail to respond to the diverse and often complex needs of disabled children, adults, and their families.

Participants consistently characterised the education sector as inadequately prepared to support disabled learners. A dominant theme was the insufficient training and skill level of LSEs. One participant stated plainly that *"LSEs aren't experienced enough when it comes to certain disabilities. They tell them to just sit there, don't move and stay put. They don't help the students with disability become included."* Concerns about competence were further reinforced, with a parent noting that, *"my child's LSE didn't even have one O-Level. They need proper training."* Adding to these issues, an LSE participating in the focus group stated that *"the courses we take do not prepare us"*, with the participant noting that LSEs often lack basic knowledge about different conditions, medication, and current research. Further frustration was noted by another LSE who discussed late diagnoses for children with disabilities, *"there are children in year 5 and year 6 who are just being assessed now. I feel disgusted. Why are us educators afraid to refer children for assessment?"* A parent stressed the worrying point that *"some LSEs don't even know that there are different levels of autism",* and that *"they have no idea what special needs entail…the 10-week training has to happen before LSEs begin working, not after."*

Shortages of specialised staff, closed sensory rooms, and limited adaptive equipment were identified as persistent obstacles. One parent explained that the CRPD fails to enforce solutions: *"we have to wait for multisensory teachers to be trained."* Educator preparedness and classroom management were also called into question, with another parent commenting on the fact that some teachers *"put my son to sleep for two hours,"* causing behavioural issues at home. These issues were noted as being compounded by the constrained communication between families and educators as *"LSEs have a directive from the union to only talk to the parents through a communication book or over teams"*, which can make the communication process difficult and artificial. Nevertheless, participants acknowledged the dedication of many LSEs who invest personal resources and value relevant

training, arguing that de-escalation and disability-informed approaches should be extended to all school staff.

Parents also described a lack of individualised approaches and poor communication from educational professionals, *"I always insist that education should be there for everyone. Autistic children can't do traditional exams and can't be assessed like others."* One parent of a child with multiple conditions explained that practitioners tended to operate within narrow diagnostic frameworks: *"My daughter has more than one condition, but many professionals are limited to just one — for example, they only focus on ADHD, autism, or Down Syndrome. They keep trying the same approaches even when they clearly aren't working."* This parent further highlighted the absence of meaningful feedback, recounting that when their daughter experiences a meltdown, *"all I get is a message saying there was a meltdown — no details, no explanation of what happened before or after, or what the environment was like. If they don't tell me what triggered it, how can we improve?"* Without early recognition of cues or adaptive strategies, they argued, *"we're still at the most basic level."* It was also acknowledged that for those who are not able to keep up with lessons in person there is a feasible way to adapt, with one participant citing Covid-19 as an example. When schooling moved online, *"they could do online lessons, but now they don't offer this option. Why was it possible then but not now?"* This was perceived as indicative of broader institutional inflexibility and failure to account for fluctuating or severe health conditions.

A further concern centred on inappropriate grouping of students with diverse support needs. One person added that, in addition to these educational issues, there are also problems concerning what happens after secondary education: *"In Mtarfa Day Centre, they mixed everyone together — if you have Down syndrome, autism, or another disability, they are all put in one place. You can't lump a person with Down syndrome, a physically disabled person, and an autistic person all together. They have different needs."* Such practices were seen as undermining both the service and the person's wellbeing. One parent described how their non-verbal child's Year Two classroom lacked an educator trained to teach children with his specific needs, noting that despite repeated requests for *"visual education because he is non-verbal,"* lessons remained non-adapted. The parent also found out that the LSE in question did not have a laptop, further hindering the child's ability to learn. Similarly, teachers often relied on single assessments that failed to capture a child's true abilities, with one participant noting that this is not a good standard of examination for her autistic son: if he *"is not in the mood"* he won't cooperate. A father of a son diagnosed with ADHD described a similar issue where the child's ADHD-related needs went unrecognised, compounding academic difficulties: *"It's really tough to do well when there are other kids making outbursts in classes and then my son falls behind."* These experiences illustrate how rigid assessment practices and insufficient training mask competencies and obstruct tailored learning.

Another key concern was the over emphasis on academic subjects at the expense of functional life skills, an imbalance that participants felt has particularly significant consequences for students with intellectual disabilities. While such skills are valuable for all learners, participants stressed that students with disabilities often require more targeted instruction and guided practice to acquire the skills necessary for independent adulthood. As one parent observed, *"we emphasise academia and subjects like Mathematics, Maltese, and English, but where are self-advocacy and sign language?"* Similarly, another parent described resistance to their disabled child dropping certain subjects: *"When my son was in primary and secondary and we asked for history to be dropped; they made a fuss about it."* These experiences describe a curriculum insufficiently adapted to the practical realities faced by students with disabilities as they transition to adult life. Participants highlighted the importance

of explicitly teaching functional life skills, including managing money, cooking, and laundry: *"It would be better if they taught him how to use money, or to cook, or to wash clothes."* Without structured opportunities to develop these skills, students with disabilities risk leaving compulsory education academically focused yet insufficiently prepared for independent daily living.

Some participants described significant financial strain in seeking adequate education. One parent reported resorting to private services to secure appropriate support: *"my daughter wasn't born like this, but she had an operation that went badly. My first hurdle was education. I am aware of the San Miguel Education Resource Centre, but I felt that my daughter was not making significant progress as she spent endless hours in a cot. In fact, they told me that 'whatever we do, her situation won't improve.' Who are they to say that? As a result, I had to find an alternative. Luckily, I found a private institution, but I give them my whole salary. I ended up penniless."*

Participants noted international strategies which have been implemented which are working for children with disabilities, citing Finland as a model for inclusive practice, where schools integrate children with disabilities into mainstream settings and support learning through technology, which participants felt demonstrate that inclusion is achievable when there is commitment.

Issues were also raised when discussing the transition from education into adulthood, characterised by uncertainly and limited options. One participant explained that her *"son is in his second year at Wardija. He has always attended mainstream schools. He has both physical and cognitive disabilities. When he moved to post-secondary level, there was a problem because students with disabilities had nowhere to go afterwards. The only options were Wardija Resource Centre or MCAST. MCAST offers courses for people with disabilities, but since my son always had one-to-one learning at primary and secondary levels, he had to go to Wardija. The issue is what happens after Wardija — how will these young people earn a living? Are they being included in society?"* With regard to MCAST, one parent of a person with a disability commented that the programmes offered for students with intellectual disabilities remain too advanced for some individuals within this cohort.

Participants described the transition into vocational or higher learning as poorly supported, calling for greater collaboration between educational institutions and external organisations, arguing that *"there should be communication between Wardija School and organisations to encourage students to take up crafts or technical jobs"*, noting that this lack of opportunity for persons with disabilities hinders their personal development. Additionally, participants emphasised that *"there aren't post-secondary courses for those with lower intellects"* calling into question what will become of persons with disabilities who have next to no avenues open to them for higher education.

Participants also highlighted profound obstacles in employment for disabled adults. Family members described longstanding exclusion from the labour market, with one parent reporting that when seeking employment opportunities for their 48-year-old daughter with Down Syndrome, they were told that *"there are no opportunities for her — no job opportunities at all."* Another emphasised the emotional significance of participation, sharing that *"my daughter has been telling me that she wants to work. Even something voluntary would be good for her — the important thing is that she's included."* For families living farther from major centres, lack of local accessible options intensified these barriers: *"my daughter wants to work, even on a voluntary basis, but I cannot find her somewhere to go close by."* Similarly, a parent of child with a disability commented on how she *"used the Lino Spiteri Foundation to help find my daughter a job, but there was no continuity…They'd tell her to apply for certain jobs when she didn't even know how to.*

And they'd suggest jobs that were too hard for her. They don't even make a proper assessment of what would be appropriate for her to do."

Family members themselves also faced employment challenges. One participant described being forced out of work due to inflexible systems: *"I was a government officer, but I had to care for my wife full-time. I had to leave my job because they wouldn't let me work from home…They tell you their hands are tied because of the system. The system is failing us."*

Participants noted widespread reluctance among employers to hire persons with disabilities, including instances where employers preferred paying penalties rather than employing inclusively. These attitudes perpetuate exclusion despite policy frameworks intended to promote equality — *"my son has a diploma but could not find proper employment."* Another participant mentioned that her 17-year-old son *"who is autistic, he applied to work with the government as a beach boy with the Malta Tourism Authority. I informed them in advance about his disability. We never heard back… then after a week I called them and they told me he was not being considered because of his disability,"* leading to feelings of frustration and worry about her child's future.

Participants highlighted limitations in both employment and higher education opportunities for young people with disabilities in Gozo. One parent noted: *"After the age of fifteen there aren't opportunities in employment and education, especially in Gozo. Agenzija Sapport has a day programme which is always fully booked, with a 3-year waiting list…Diocese allows for persons with disabilities to work with them, but we can't always rely on them."* In higher education, some parents had to privately fund support personnel for their child, exposing significant access and equity gaps.

For participants with chronic or severely limiting conditions, employment was described as virtually unsustainable. Although some could secure jobs, retaining them was often impossible due to health fluctuations and the lack of flexible work arrangements. One participant situated their experience within wider evidence, referencing research showing that 75% of individuals with ME cannot work.

Taken together, these reflections reveal an employment landscape characterised by structural discrimination, rigid bureaucratic systems, and limited opportunities for meaningful inclusion. As with education, participants emphasised that real progress requires a shift from nominal inclusion to sustained, practical, and adequately resourced support.

3.4 Health and Social Services

Participants consistently described the health system as inadequate and frequently inaccessible, particularly for individuals with complex or non-verbal disabilities. Hospitals were often perceived as unsuitable, with sensory triggers, long waiting times, and a lack of prioritisation for persons with disabilities. While some positive experiences were acknowledged, such as by a participant living with fibromyalgia, who described the emergency department at Mater Dei as *"very good"* and noted that *"they helped me a lot when I was injured or in pain,"* other accounts highlighted systemic gaps in accessibility, empathy, and coordination. A parent of an autistic child described Mater Dei as ill-equipped

to meet the needs of autistic patients, stating: *"Mater Dei as an autism hospital — it's a complete beginner-level service. There isn't even a single quiet room. Everything is loud, waiting times are excessive, and they make you wait even if you tell them your child is autistic."* Inclusive and sensory-friendly environments were seen as essential, with one participant stating, *"it's important that the spaces we create are autism-friendly."*

Concerns were raised about misdiagnosis and poor handling of disability-related health conditions; as one parent described, *"When he was young, they already suspected autism, but the medical professionals mismanaged him. They dismissed his distress as tantrums, gave him painkillers, and ignored our explanations."* Another participant described the lack of awareness among medical staff, *"once, medical staff from Mater Dei sent me to the Floriana polyclinic for fibromyalgia services, but when I went there and asked about it, they laughed in my face because they did not even know that such a service existed."* Knowledge gaps among clinicians were frequently cited, resulting in misdiagnosis, dismissive treatment, and unsafe care. One participant described the challenges in managing ME and the limited treatment options available: *"With ME, many of us are chemically sensitive. In my case, Cymbalta gave me psychosis for three days, and I am allergic to most medications. Tablets often do not help us, which is why we rely on vitamins. There is no support from the government for vitamins. It feels like the only options are tablets that can harm you or nothing at all."*

Similarly, participants reported being mislabelled as psychologically unstable or *"spoiled,"* reflecting a broader culture of invalidation. Structural misalignment of services further compounded these difficulties; for example, physiotherapy and hydrotherapy programmes were described as often unsuitable for people with ME, who may experience deterioration from such exercises: *"what the government offers, people with ME can barely use. What we need is a person to come home to help us with circulation of blood, physical help."*

This participant recounted that during surgery, the clinicians dismissed the relevance of her ME condition to anaesthetic dosing, despite evidence of altered metabolic responses, an oversight that could have led to a *"brain trauma or brain damage. The least they could do is listen. I showed them studies of what they should do in my case, but they completely ignored it."*

Long waiting times were frequently cited, forcing families to rely on private care. One participant noted that their father, who has a disability, experienced long waits for care: *"For my father's psychiatric appointment, we had to wait 3–4 months in Mater Dei, and privately, we got an appointment in a week."* Financial barriers compounded these structural challenges, with one participant reflecting, *"today to have a session with a therapist or a psychologist it is expensive, and if you cannot afford it you won't get the treatment you need…and you will end up isolated and worse than before."*

Gaps in specialist support were particularly acute for non-verbal or complex disabilities, with one parent explaining, *"the worst kind of disability is when they're non-verbal. My child is severely autistic and non-verbal…Doctors don't understand them, and there aren't enough professionals who know how to deal with this type of disability."* Families reported feeling unsafe and unsupported, with a scarcity of specialised medical professionals exacerbating these challenges. One participant noted that *"there is only one neurologist in Malta who sees persons with disabilities,"* creating a fragile system where essential care can be delayed or interrupted. In one case, a parent explained that *"my daughter's doctor retired and there's no one to replace him,"* leaving high-risk conditions unmonitored, while another described the distressing scenario in which, if their child experiences seizures, *"they'll admit him until the doctor gets back"* which leaves the family in a state of stress and unease. One family recounted that, after repeated attempts to clarify MRI-related risks for an implanted device, they were ultimately informed post-anaesthesia that *"Mater Dei does not have the right MRI equipment."* Orthopaedic

care was also cited as inadequate, with delayed consultations and poorly fitting medical devices described as *"a complete disaster… triple the size."* Participants felt that *"nothing is being taken into consideration regarding the health of the children,"* perceiving decision-making as driven primarily by financial limitations: *"everything is about money now."* Additionally, participants mentioned that services such as sensory equipment were prohibitively expensive.

Participants from Gozo pointed out a lack of access to healthcare services and support: *"here in Gozo it's not good; they don't have the things to work with… we've been waiting 6 years for the occupational therapy to be in Gozo with all the resources."* Participants noted that even when services exist, access can be exploitative or inconsistent: *"sometimes they see us as a bank account… it's not fair, you have to be dedicated."* Assistive devices were also sometimes unavailable or inadequately supported, with one parent explaining, *"My son uses a bone anchored hearing aid, and the battery compartment came off. When I took it in, they told me it would take too long to fix and that they had to send it to the supplier. Usually they have a loan device, but this time it had been given to someone else. They advised me to put some tape on the battery compartment. Putting tape on such an expensive device was shocking to me."*

Participants noted that services which were readily available in Malta were harder to access in Gozo, *"Fibromyalgia service and access to pain clinics in Gozo are non-existent which is not equitable in comparison to Malta."* Additionally, *"Gozo does not have equitable access to leisure services. In Malta we can access the public pool for free and in Gozo we have to pay 10 euro for the card and then for each service we use thereafter."* Families noted logistical and financial challenges in attending appointments due to the lack of services in Gozo — *"Because of my daughter's hearing impairment, I go down to Mater Dei, I cannot afford to take leave, we lose a day, because they don't want to provide a programme for hearing aids."* Additionally, specialised supports, such as occupational therapy (OT) and speech therapy, was described by one family member as inconsistent stating, *"I don't believe Gozo has appropriate places where I can take my son. I tried Voice for Inclusion and Occupational therapy but did not find them to be adapted to his needs, there's still a lot of work to be done."*

Administrative and practical barriers further compounded difficulties in accessing services. Rigid assessment processes for disability benefits were described as insensitive, with one participant describing their experience applying for benefits related to their severe disability stating, *"I have ME and Fibromyalgia. These are dynamic and invisible disabilities. Right now, no one can see the pain I am in. I had a problem with work. I had to stop working seven years ago and resign. I thought I could return to work, but I could not. This has created a financial burden. If my husband did not work, we would be in serious trouble. There is a lack of understanding and empathy from the general public. There is also dismissal from healthcare professionals, and we are even being dismissed by the medical assessment boards, the ones meant to qualify us for disability assistance. I was one of those not accepted. The assessment is too rigid. They ask stiff, fixed questions."* Processes for accessing services were described as repetitive and inefficient, particularly in programmes such as Active Ageing, where applicants must repeatedly submit extensive documentation: *"When you apply for their services, you have to fill in a form with your doctor and provide many documents… a year later, I tried applying again for physiotherapy, but I had to start the whole process again."* Participants emphasised the need for strategic planning and investment in specialised services, citing international models as examples, with one participant noting, *"ten years ago, Australia launched a scheme called NDIS. Anyone who is disabled — mentally or physically — gets insurance for life."*

Assessment boards were frequently criticised for intrusive or irrelevant questioning, with one participant noting, *"when I went before*

the Fibromyalgia board, they asked me very inappropriate questions, such as whether I have intimate moments with my husband or whether I go to church. I found this deeply intrusive and irrelevant. How can they decide what support or benefits I am entitled to, based on questions like these?" Such experiences were reinforced by a broader sense of mistrust in official decisions: *"rheumatologists diagnosed me with severe Fibromyalgia, yet the board said there was nothing serious. Are they calling the specialists liars?"*

Access to therapy services was limited by cost, availability, and scheduling delays, with resource constraints particularly pronounced in Gozo: *"Even simple speech therapy in Gozo is difficult because there are very few therapists rotating in schools. Ideally, children should get therapy once a week or every two weeks, but sometimes it comes months later."* Participants called for the provision of specialised health support, including IDD nurses, psychologists, and dieticians: *"Why don't we have IDD psychologists? There should be support, like a psychologist and dietician specifically for IDD persons."*

Mental health services were also discussed, and were widely characterised as outdated, inaccessible, and, at times, dehumanising. One participant reflected on institutional experiences, stating, *"for me Mount Carmel is not a rehabilitation centre. To me it's more like a prison. The things I've seen and experienced, even when I worked as a carer showed me it's like a prison there."* One participant reported experiences of physical mistreatment, including being dragged from ambulances without proper equipment: *"I was taken to Mount Carmel three separate times … the ambulance did not have its footplates for the wheelchair… I still have the physical scars from being dragged across the tarmac."* Others described exclusionary treatment, such as being refused by the Richmond Foundation due to a distant past episode: *"I think it wasn't fair on me that I was judged on something I did many years ago. I told them that I want to better my life, they threw me away like trash. I felt like I was good at nothing at that point. An institution that was supposed to help me broke me."*

Many participants spoke of increasing exhaustion and limited avenues of support for caregivers, both within the families of people with disabilities and among carers and nurses. One participant noted: *"Even nurses and carers need time off because of burnout. We know what it feels like to take care of someone. We need to take care of these people,"* referring to fellow nurses and carers. Similarly, a parent affiliated with a Gozitan NGO described the personal toll of caregiving: *"It causes us a lot of stress. I used to be calm, but now I'm exhausted… We are helping society by taking care of persons with disabilities,"* yet highlighted a lack of support from government institutions, attributed to *"a lack of oversight,"* which results in gaps across education, health, and employment.

Collectively, these accounts illustrate a health and social care system that is under-resourced, inconsistently implemented, and insufficiently responsive to the needs of persons with disabilities.

3.5 Institutions (CRPD and Agenzija Sapport)

Participants described mixed experiences with institutions such as the CRPD and Agenzija Sapport, acknowledging some positive initiatives while emphasising persistent systemic shortcomings. Some participants praised the CRPD for its efficiency, noting, *"I contacted the CRPD about an issue, and they were very helpful. They responded within 24 hours, and the issue was resolved within a week."* Similarly, positive experiences were highlighted with Agenzija Sapport and the MFOPD, with one participant stating, *"I had a positive experience with Agenzija Sapport… the assistants are always helpful and always listen to us,"* and another noting, *"I had a problem with my son's communication device, and I wrote to MFOPD, and they went out of their way to help me. I always received assistance."*

Services such as the provision of personal assistants were widely recognised as valuable. One parent noted, *"Agenzija Sapport provides us with a personal assistant. I work full-time, and my daughter has ADHD. Anyone with a disability can apply, but the waiting list is long."* However, participants frequently raised concerns about the training, competence, and accountability of assistants provided by Agenzija Sapport. A broader shortage of personal assistants and support workers further constrained opportunities for independent living.

Trust, safety, and continuity were ongoing concerns. Some families resorted to surveillance in the home, while others experienced abrupt withdrawal of services — for example, one participant was approved for a personal assistant after a nine-year wait, only to be told shortly afterwards to *"find a personal assistant ourselves"* due to staff shortages. Families frequently bore the responsibility for the assistant's training and integration, with one participant stating: *"The current system puts all the burden on you, except financially. You still need to take ownership and teach the assistant everything."* Instances of theft or neglect further underscored the need for stronger professional standards and oversight. Prolonged delays and administrative barriers were also common; one participant reported that despite applying for Personal Assistant (PA) services *"a year and a half"* earlier, no support had materialised.

Positive initiatives, such as the sibling support group, were praised: *"A positive thing I saw was that Agenzija Sapport had a sibling group. At least I didn't feel so alone,"* one participant said. Nevertheless, participants frequently felt unheard or unsupported by both the authorities and the CRPD, stating: *"We're not being heard by the authorities or by the CRPD… Everyone says 'yes,' but then nothing happens. It's very unfair and uncalled for."*

Participants also emphasised persistent bureaucratic barriers, limited human resources, and gaps in public awareness. One participant reflected, *"We find bureaucracy is huge for NGOs. We work as volunteers, and the least we should do is fill forms each year. It makes life very difficult."* Here, Agenzija Sapport was praised for the use of a single application for multiple services, which was seen as practical — *"when you apply with them, they will use the same application for everything you need rather than giving too many papers."*

Beyond individual agency performance, participants drew attention to broader systemic issues, including fragmentation, lack of coordination, and absence of long-term strategic planning: *"I wish there were benchmarks and milestones with relation to the disability sector in Malta. There are so many issues that need addressing, but we meet and talk about the same things without ever knowing what progress has been made."* The CRPD was described as reporting to the Ministry for Inclusion, which some felt undermined its impartiality: *"because you cannot speak badly about those who pay you."*

Coordination across ministries was described as ineffective, with the Inter-Ministerial Administrative Committee on Disability (IACD) failing to address concerns: *"we would voice our concerns, and nothing is done"* and *"the board is not functioning. It is not*

doing its work." Fragmentation across ministries, agencies, and NGOs was a recurring theme, with participants noting that inter-agency coordination is weak: *"Every minister says something different… how can you take accountability when everyone is looking out for himself… for example if you ask the Ministry for Inclusion, they tell you that mental disability does not fall under our remit."* Participants consistently called for improved leadership, oversight, and strategic planning across sectors, emphasising that, *"There should be leadership in every sector to ensure that people with disabilities are being seen — in education, health, and employment. There should be checks across all areas."*

Overall, the quality and consistency of support were seen to depend heavily on individual staff members rather than on systemic reliability, highlighting the need for comprehensive reform.

4. MFOPD INSIGHTS

The MFOPD provided insights into the 5 key thematic areas explored in the previous chapter, giving their views on what can be improved, and how this can be done.

4.1 General Experience and Inclusion

The MFOPD stressed that the principle 'Nothing About Us Without Us' is not respected in Malta, where Ministries often work in silos and disability is viewed as the sole responsibility of the Ministry for Inclusion: *"Despite meetings held at the end of 2025 with the Permanent Secretary — during which full agreement was reached, including his own proposal to enshrine this principle in law — and a subsequent follow-up meeting that reaffirmed that MFOPD, CRPD, and the Directorate for Disability Issues (DDI) should always be jointly present in discussions on national disability matters (a proposal initiated by MFOPD and approved by all three parties), recent developments indicate that this agreed approach is not being upheld. This meeting was a follow-up for the 55th anniversary round table conference. This round table confirmed that there are so many problems within our sector and this was highlighted by the guest speaker, the Vice President of the European Disability Forum who was present at this meeting. MFOPD believes that it is not only NGOs that should speak the same language and take a unified position on key issues — a process already being facilitated within MFOPD — but that the national focal point and coordinating mechanism for the implementation of the United Nations Convention on the Rights of Persons with Disabilities (DDI), as well as the national regulator for disability issues in Malta (CRPD), should also align with this shared understanding and approach. MFOPD members reported that, on some occasions, meetings related to the disability sector in Malta were held to which certain ENGAGE members were invited, while MFOPD was not. Additionally, MFOPD has already invited both DDI and CRPD to two meetings it managed to secure on two different national issues. They also noted that CRPD and ENGAGE continue to hold independent meetings. These incidents underline a systemic inconsistency: we cannot expect national entities to respect inclusive governance while it is not being consistently practiced within the sector itself."*

Another recurring issue is misrepresentation of participation. Persons with disabilities who attend meetings on behalf of state entities such as Agenzija Sapport, DDI, or the CRPD are often presented as *"community representatives,"* despite only representing their employer or entity. The MFOPD emphasised that representation requires accountability to the community, transparent feedback, and the capacity to bring forward the perspectives of diverse member organisations. Public consultations were described as accessible in principle but inadequate in practice, particularly when held online. Submissions are often minimally reflected in outcomes, yet NGOs still appear at the end of consultation documents, creating a misleading impression of engagement. Moreover, the MFOPD witnessed instances where some authorities gave incorrect information or did not provide any information at all. A critical recent example, the Life Map privatised programme for students transitioning out of obligatory education, was introduced without any NGO involvement, with the NGOs hearing about it through the press.

The evidence suggests a structural gap between formal and substantive participation. The inclusion of individuals *"in their personal capacity"* raises concerns regarding tokenism and accountability. The MFOPD argues for a dual-representation model where both MFOPD and individual NGOs participate, ensuring expertise, community accountability,

and diversity of disability experiences. The current system falls short of participatory governance principles, resulting in decisions taken about disabled people rather than with them.

4.2 Accessibility and Independent Living

Accessibility challenges in Malta remain multidimensional, cutting across physical, institutional, and socio-economic domains.

The MFOPD identified major barriers such as physical and built environment obstacles; transport limitations; digital and communication inaccessibility; educational barriers; employment obstacles; healthcare inequities; attitudinal barriers; and policy and governance deficiencies.

The Personal Assistance system was reported as understaffed, unaffordable for many, and burdened by long waiting lists. Responsibility for securing a PA is left almost entirely to persons with disabilities and their families, which the MFOPD acknowledged is *"tiring and frustrating."*

These barriers reflect a systemic rather than isolated failure, with accessibility still conceptualised narrowly instead of as a universal principle underpinning all public services.

4.3 Education and Employment

Inclusive education in Malta faces structural challenges, particularly in professional support, system accountability, and transition planning. These limitations directly affect employment prospects for persons with disabilities.

The MFOPD reported that teachers and LSEs frequently lack training and ongoing support. Some of them actively request guidance, yet *"continue to be left without it,"* emphasising that inclusive education is now performing worse than it did 35 years ago, despite greater knowledge and policy commitments. Additionally, long-standing recommendation — the establishment of a Transdisciplinary Team to support students and families — has never materialised. As a result, Individualized Education Programmes (IEPs) are often poorly drafted, unmanaged, and unmonitored, contributing to students leaving school without essential life and employment skills. Additionally, parents reportedly fear speaking out due to experiences of bullying or repercussions within the system.

Although an external audit by the European Agency for Special Needs and Inclusive Education was completed in the previous year, the Ministry has not shared the findings with NGOs, nor has the MFOPD been invited to any discussions based on the report.

The transition between compulsory schooling and employment remains severely underdeveloped. The MFOPD stressed that students leave school without skills for employment; the Life Map programme does not equip learners with the competencies needed for the labour market and for independent living; and that existing employment services for persons with disabilities remain unevaluated and unresponsive to actual needs.

The MFOPD proposed concrete measures for improvement, including:

- evaluation of what we presently have and change, remove, introduce new practices where necessary;
- continuous consultations with NGOs;
- professionally drafted and regularly updated IEPs;
- specialised training for LSEs;
- stronger multidisciplinary collaboration;
- the introduction of a professional 16+ educational program for students with disability in an inclusive setting

- structured transition processes;
- professional assessments for jobseekers;
- sustained job coaching;
- employer awareness initiatives.

The disconnect between education and employment in Malta points to a systemic failure in long-term planning. Without cross-disciplinary support and accountable monitoring mechanisms, inclusive education risks becoming nominal rather than transformative. The unshared audit report underscores persistent transparency issues and reinforces concerns that reform is occurring without civil society engagement.

4.4 HEALTH AND SOCIAL SERVICES

Healthcare accessibility challenges apply to both disabled and non-disabled populations, though their effects are amplified for persons with disabilities.

The MFOPD noted that waiting lists, high medication costs, and expensive private alternatives impact everyone. However, for persons with disabilities, each barrier interacts with additional challenges such as mobility, communication needs, or support requirements.

The systemic nature of healthcare delays in Malta requires disability-sensitive approaches rather than separate systems. Universal reforms must incorporate reasonable accommodations to ensure equal access.

4.5 Institutions (CRPD and Agenzija Sapport)

The CRPD is intended to serve as the independent regulator safeguarding disability rights, yet its current operational reality weakens public trust and impact.

The MFOPD identified several issues with the CRPD including long delays in investigations, sometimes spanning years; loss of legal cases (together with the fact that CRPD does not proceed with court cases as much as needed and whenever needed resulting in persons with disabilities left alone to carry the burden of the situation); lack of visible action, leading persons with disabilities to feel unsupported; and insufficient proactive enforcement.

The call was clear: persons with disabilities want the CRPD to be more present, assertive, and timely; *"People want to feel CRPD by their side."*

Similarly, Agenzija Sapport's ability to deliver key services is limited by resource shortages and the absence of cross-ministerial cooperation, with the MFOPD noting a lack of human resources, a lack of capacity to manage existing backlogs and new services, challenges in advancing independent living, and systemic barriers — such as unaffordable housing and urban environments.

Without cross-ministerial collaboration, progress on independent living will remain fragmented. Disability policy cannot be siloed within a single agency or Ministry.

Thus, the MFOPD expressed the importance of having persons with disabilities represented in Parliament with a clear agenda focused on disability rights and wellbeing. The central message for decision-makers remained consistent: *"Nothing About Us Without Us"* and a commitment to *"leave no one behind"* in line with Malta's Sustainable Development Goals (SDGs) commitments. Political inclusion is both symbolic and practical. Representation in Parliament would enhance visibility, accountability, and structural change, ensuring that disability rights form part of mainstream political agendas rather than niche policy areas.

5. CONCLUSIONS AND RECOMMENDATIONS

The focus groups on disability, conducted across Malta and Gozo, reveal a consistent and concerning picture of the lived realities of persons with disabilities and their families. While awareness regarding different disabilities and disability-related issues has grown, genuine inclusion remains largely aspirational, with systemic fragmentation, inconsistent service quality, and bureaucratic obstacles pervasive across sectors.

5.1 Key Findings

GENERAL EXPERIENCE AND INCLUSION

Lack of meaningful consultation:

- Participants consistently reported that their input is ignored or undervalued in decisions affecting persons with disabilities.
- The principle of "Nothing About Us Without Us" is not upheld in practice, with both disabled individuals and professionals (e.g., LSEs, educators, NGO members) often excluded from discussions.
- Initiatives such as Life Map were introduced without NGO consultation, highlighting inconsistent engagement and tokenistic approaches.
- Follow-through is lacking, institutions listen but rarely act on feedback, leaving families members/caregivers without guidance.

Systemic Exclusion and Uniform Approaches:

- A culture of uniformity prioritises standardised solutions over individualised support, failing to accommodate diversity and dynamic or hidden disabilities.

Social Attitudes, Stigma, and Awareness Gaps:

- Individuals with invisible conditions such as Myalgic Encephalomyelitis, Fibromyalgia, and Epilepsy experience isolation and lack of empathy from both the general public and medical professionals.
- Small communities (e.g., Gozo) amplify the effects of stigma due to limited privacy.
- Public narratives tend to focus on visible disabilities, marginalising individuals with hidden or complex conditions.

Structural Barriers and Service Limitations:

- Persons with disabilities, family members/caregivers, NGO members, and professionals in the disability sector all described enduring bureaucratic, financial, and logistical barriers to accessing care and support, which led to reports of high emotional and practical strain, with burnout common.
- Specialist services are often financially prohibitive (e.g., €90 for a 10-minute therapy session) and coupled with long waiting lists due to limited resources (e.g., medical specialists), these services cannot fully address the needs of all persons with disabilities in Malta and Gozo.

Positive Experiences Highlight Potential for Inclusion:

- Targeted, personalised support — such as sports coaches adapting activities to a child's disability — demonstrated that inclusion is achievable with attention and empathy. Participants emphasised that when systems respond effectively, individuals can participate meaningfully and achieve personal growth.

ACCESSIBILITY

Physical Environment and Public Infrastructure:

- Pavements, roads, and public spaces were described as frequently inaccessible due to obstructions, poor maintenance, or improper design.
- Public buildings, schools, hospitals, transport, and recreational spaces often lack reliable accessibility features.

Transport and Mobility Challenges:

- Public transport is often inaccessible, particularly for individuals with mobility limitations or invisible disabilities.
- Parking provisions, even with disability permits, are inconsistent and subject to arbitrary local enforcement.
- Everyday travel — e.g., to schools, hospitals, or recreational areas — is physically and logistically difficult.

Educational and Communication Accessibility:

- Schools often lack assistive devices, adaptive learning tools, and resources for sensory, cognitive, or communication needs, leading to hearing-impaired students facing inadequate accommodations, e.g., no subtitles or live readers, restricting full participation.

Housing and Home Adaptations:

- Accessible housing and home modifications are expensive and difficult to implement. Grant schemes exist but are undermined by inflated local prices and restrictive procurement rules, and those making use of social assistance run into financial issues.

Shortage of Trained Carers and Support Workers:

- Families often have to train assistants themselves due to insufficiently prepared staff.
- Staffing shortages lead to abrupt withdrawal of services, disrupted continuity of care, and safety concerns for the persons with disabilities involved.

Economic Barriers and Welfare Limitations:

- Rigid social assistance systems prevent participation in minimal work, while allowances remain insufficient for basic needs.
- Financial barriers limit access to domestic support, therapy, and adaptive equipment, reducing autonomy.

EDUCATION AND EMPLOYMENT

Insufficient Training and Preparedness of Education Staff:

- Learning Support Educators (LSEs) often lack adequate training and knowledge of specific disabilities.
- Many educators are unaware of variations within conditions (e.g., different levels of autism) or how to adapt teaching strategies.
- Crucially, training is often minimal or delivered only after educators have already begun working with students, leaving them underprepared during the most critical early stages of support. This highlights the urgent need for earlier, comprehensive, and ongoing professional development for LSEs, ensuring they enter classrooms equipped with the knowledge, practical strategies, and confidence required to support students with disabilities effectively and inclusively.

Resource Limitations and Infrastructure Gaps:

- Schools face shortages of specialised staff, adaptive equipment, and open sensory rooms.
- Adult students are sometimes grouped inappropriately with peers having very different needs, undermining learning and wellbeing.
- Lack of communication between schools and families prevents meaningful feedback and adaptive responses to students' needs.

Rigid Curricula and Limited Focus on Functional Skills:

- Academic subjects are prioritised over practical life skills, self-advocacy, and independent living competencies.
- Curriculum flexibility is limited, e.g., requests to drop subjects are resisted despite individual needs.
- Students with disabilities, especially intellectual disabilities, are leaving education unprepared for daily life or post-school opportunities.

Transition to Adulthood:

- Post-secondary school options for education, vocational training, and employment are scarce.
- Lack of coordination between educational institutions and external organisations limits opportunities for skills development and meaningful engagement.
- Individuals with lower intellectual abilities have few avenues for post-school progression available to them.

Employment Challenges for Persons with Disabilities:

- Structural discrimination and rigid employment systems restrict access to meaningful jobs. Employers often prefer to avoid hiring disabled individuals, sometimes paying penalties instead of employing inclusively.
- Non-visible disabilities are particularly prone to discrimination during recruitment.
- Limited opportunities for persons with disabilities, both educational and employment-related, exist in Gozo and outside major centres.
- Chronic or fluctuating conditions make sustained employment difficult.
- Withdrawal of remote work options post-pandemic removed flexibility that previously enabled participation.
- Inflexible workplaces exacerbate feelings of exclusion for persons with disabilities who often require accommodations such as adjusted working hours. These environments also place significant strain on family members/caregivers, who must navigate the tension between maintaining employment and providing care. In response, workplaces should implement clear guidelines and policies to support flexibility and accommodation in such situations.

HEALTH AND SOCIAL SERVICES

Inadequate Accessibility and Unsuitable Environments:

- Hospitals, clinics, and public health spaces often fail to accommodate sensory, mobility, and communication needs. Long waiting times, loud or overstimulating environments, and lack of sensory-friendly areas impede access, particularly for autistic individuals and those with complex or non-verbal disabilities.
- Public health infrastructure is inconsistently accessible across locations, with Gozo facing acute gaps in services.

Knowledge Gaps and Insufficient Expertise:

- Medical staff frequently lack awareness of specific conditions, including ME, fibromyalgia, and non-verbal autism.
- Misdiagnoses, dismissive treatment, and failure to follow clinical guidance are common, sometimes with potentially dangerous consequences.

Limited Specialist Services:

- Shortages of specialised medical professionals, including neurologists, psychologists, and personal assistants create fragile care systems.
- Families often experience long waits, service discontinuity, or forced reliance on private care.

Structural and Regional Disparities:

- Services available in Malta are often absent or severely limited in Gozo, including occupational therapy, fibromyalgia services, and accessible leisure opportunities.
- Families face financial, logistical, and practical barriers to accessing care.

Inadequate Therapy and Rehabilitation Services:

- Speech therapy, physiotherapy, and other essential supports are inconsistently provided and often delayed, especially in Gozo.
- Assistive devices may be unavailable, inadequately maintained, or unaffordable.

Mental Health Services:

- Services are outdated, inaccessible, and sometimes dehumanising.
- Patients report mistreatment, exclusion, and judgement, undermining trust in mental health institutions.

Lack of Continuity and Coordination:

- Institutional decisions sometimes contradict specialist guidance, eroding trust and safety.

INSTITUTIONS

Mixed Experiences with Services:

- Some participants reported positive experiences with CRPD and Agenzija Sapport, including timely responses, helpful staff, and functional programmes (e.g., personal assistants, sibling support groups).
- Participants raised concerns about the CRPD's effectiveness, with some participants stating that at times they expected more action.
- Positive initiatives are acknowledged but often seen as exceptions rather than reflective of systemic reliability.

Bureaucracy and Administrative Barriers:

- Simplified processes (e.g., a single application for multiple services) were praised as practical and user-friendly.

Fragmentation and Poor Coordination:

- Inter-agency and inter-ministerial coordination is weak, with overlapping responsibilities and inconsistent accountability. As such, interministerial boards were perceived as ineffective.

Autonomy and Political Influence:

- The CRPD and some NGOs were described as constrained by reporting lines to the Ministry for Inclusion, which undermines independence and impartial advocacy. Ministerial influence affects NGO support and can limit accountability across the sector.

Limited Strategic Planning and Leadership:

- Participants noted the absence of benchmarks, milestones, or long-term planning for the disability sector.
- Leadership gaps across education, health, and employment were seen as contributing to inconsistent service delivery.

Across all focus groups, the central message was clear:

Malta's disability landscape requires systemic, coordinated, and rights-based reform, placing the persons with disabilities at the centre of the discussion.

5.2 Recommendations

BASED ON THE FINDINGS, THE FOLLOWING RECOMMENDATIONS WERE PROPOSED FOR EACH SECTOR:

General Experience and Inclusion

- Embed a rights-based, person-centred approach across all policies and services.
- Ensure meaningful consultation of persons with disabilities and families through their NGOs at all stages of policy and programme development.
- Promote public awareness campaigns addressing stigma, particularly around invisible disabilities and mental health.
- Establish mechanisms for monitoring and accountability, ensuring that inclusion commitments translate into practice.

Accessibility and Independent Living

- Develop and implement comprehensive accessibility standards for physical, digital, and transport infrastructure.
- Ensure consistent accessibility in public spaces, buildings, pavements, and transportation networks.
- Subsidise assistive technologies and therapies, especially in regions outside main urban centres.
- Incorporate accessibility considerations from the outset in urban planning, service design, and policy development.
- Expand services and programmes that promote independent living, including accessible housing options, community-based support, and personal assistance tailored to individual needs. Policies should enable persons with disabilities to live autonomously, participate fully in their communities, and make choices about their daily lives.
- Develop inclusive community spaces and recreational opportunities that are physically, socially, and culturally accessible. Public planning should consider the diverse needs of individuals with both visible and invisible disabilities.
- Ensure that accessibility and independent living initiatives are consistently implemented across all regions, preventing geographic disparities in service availability and infrastructure.

Education and Employment

- Inclusive education should not only be accessible to all, but high-quality education must be available to everyone, including persons with disabilities, so that inclusivity truly ensures equitable learning opportunities.
- Strengthen multi-disciplinary support in schools.
- Train LSEs and teaching staff in inclusive education practices and disability awareness.
- Ensure sensory-adapted learning spaces, accessible curricula, and continuity of support across transitions (e.g., school to post-school pathways).
- Promote inclusive employment through workplace adaptations, employer incentives, and career development programmes.
- Integrate vocational and life skills training to support independence and employability.

Health and Social Services

- Improve coordination and integration across health and social service providers.
- Expand specialised services for complex and developmental disabilities, including mental health and therapy provision.
- Reduce waiting times through increased funding

and expansion of the workforce, giving established guidelines for and preference to persons with disabilities.

- Embed empathy, patient-centred care, and flexibility in service delivery to accommodate diverse needs.
- Ensure families and caregivers receive support, guidance, and financial assistance where necessary.

Institutions

- Strengthen institutional autonomy, inter-ministerial coordination, and accountability mechanisms.
- Facilitate collaboration between NGOs, public institutions, and private providers to ensure coherent service delivery.
- Promote representation of persons with disabilities in political and decision-making roles to enhance visibility, advocacy, and systemic change.
- Standardise professional training and continuous development for staff across agencies.
- Implement robust monitoring, evaluation, and feedback mechanisms to align policy and practice with lived experiences.

Implementing these recommendations is the key to transitioning Malta and Gozo from reactive, fragmented service provision to proactive, rights-based inclusion. Achieving this requires a coordinated effort across government, NGOs, educational institutions, and the private sector, ensuring that persons with disabilities are empowered, consulted, and central to all decision-making processes. Cultural, structural, and policy reforms must align to uphold dignity, autonomy, and equal opportunity for all.

Malta Federation of
Organisations Persons with Disability
(MFOPD)

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