

Research Study:

Obstacles and Challenges encountered by Persons with Disabilities in Malta

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Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
APA	Autism Parents' Association
CDAU	Child Development Assessment Unit
CEO	Chief Executive Officer
CRPD	Commission for the Rights of Persons with Disability
ENT	Ear, Nose and Throat
FITA	Foundation for Information Technology Accessibility
GDD	Global Developmental Delay
INCO	Inclusive Education Coordinator
KIDs	Kids in Development (at Richmond Foundation)
LSE	Learning Support Educator
MCAST	Malta College of Arts, Science and Technology
MCCF	Malta Community Chest Fund Foundation
NGO	Non-Governmental Organisation
OCD	Obsessive Compulsive Disorder
PNLD	Pallidonigroluysian Degeneration
SAV	Supervised Access Visit
SID	Special Identity Card (now the EU Disability Card)
SMS	Short Messaging Service
YPU	Young People's Unit (at Mount Carmel Hospital)

Introduction

This research study aimed at exploring the obstacles and challenges encountered by disabled people in Malta and Gozo in their everyday lives, with regards to the following areas: education, employment, healthcare, leisure and sport, goods and services, guardianship and planning for the future abuse and violence, hate crimes and access to justice. However, other issues, outside of these areas, that the interviewees raised during the interviews, are still discussed here.

Methodology

The research study employed a qualitative approach, and the interviewees were recruited via the snowballing method. Key organisations of people with disabilities and those working with people with disabilities were contacted via email and phone to invite people to participate in the research. Entities contacted included government agencies, commissions and departments, organisations providing residential and day services, NGOs (profit and not-for-profit) and advocacy groups. The organisations sent out an invitation to participate in the research to their members, which included information about the research project, as well as their rights as potential research participants.

Interviews were held with 25 persons with disabilities. In order to cast as wide a net as possible, it was deemed necessary to access both adults and children (see Figure 1)¹, so as to cover the challenges people with disabilities encounter both during childhood and during adulthood. Furthermore, care was taken to include people from both Malta and Gozo (see Figure 2), and to cover the major types of impairment², including people with physical, sensory (visual and auditory), intellectual, psychosocial and autism spectrum disorder³. A number of participants also have multiple disabilities. The original plan of having 2 adults and 2 children (up to 17 years of age) with each of these impairments, as well as 1 adult with multiple disabilities, was more or less adhered to (see Figure 3), with some minor changes due to project time frames, the availability of interviewees and response from the organisations contacted.

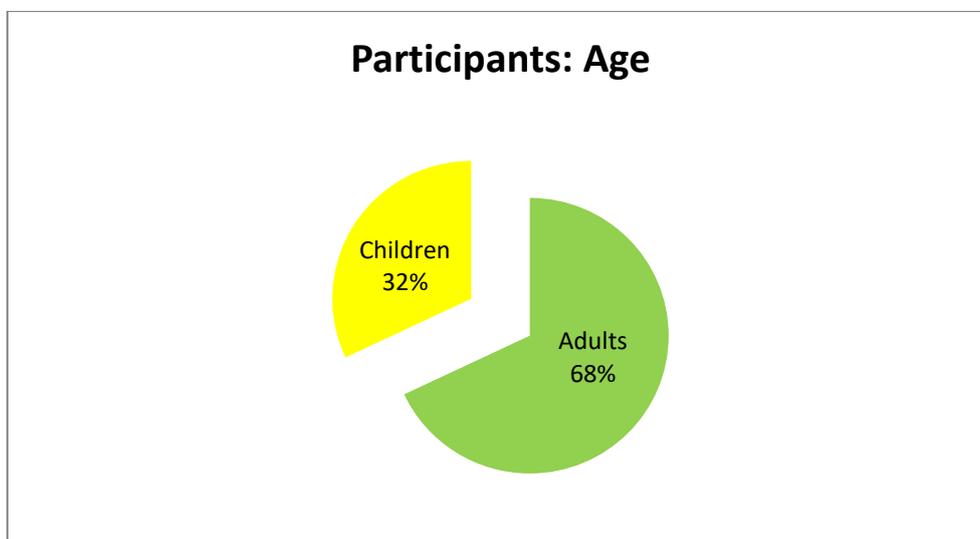


Figure 1: Participants' Ages

¹ While the emphasis of this research is on the emerging themes – rather than quantitative outputs – these figures are used here to present a clearer picture of the participants' characteristics.

² For definitions of each impairment, refer to Annexes.

³ People on the autism spectrum ranged from people who are verbal to others who do not have verbal skills.

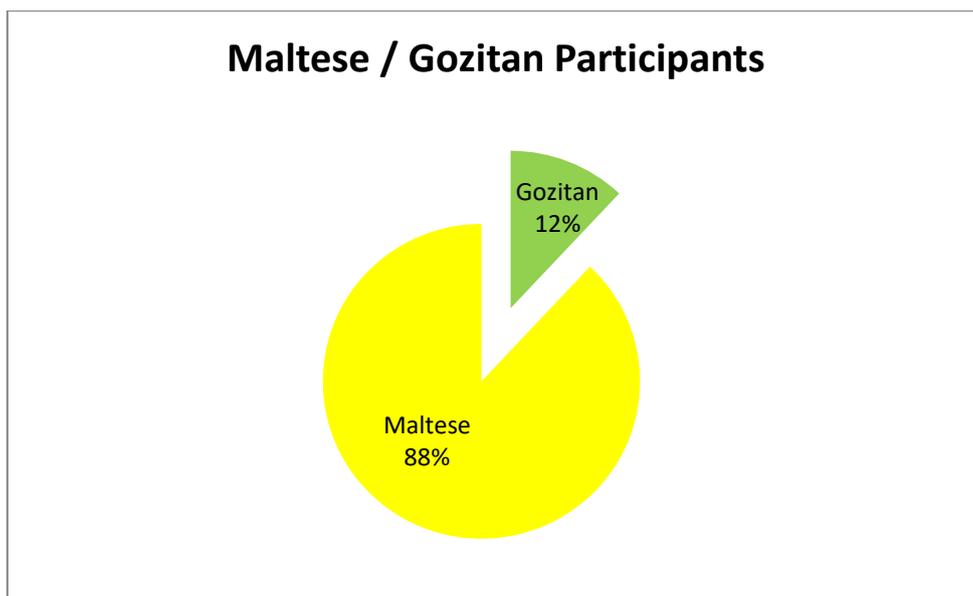


Figure 2: Maltese and Gozitan Participants

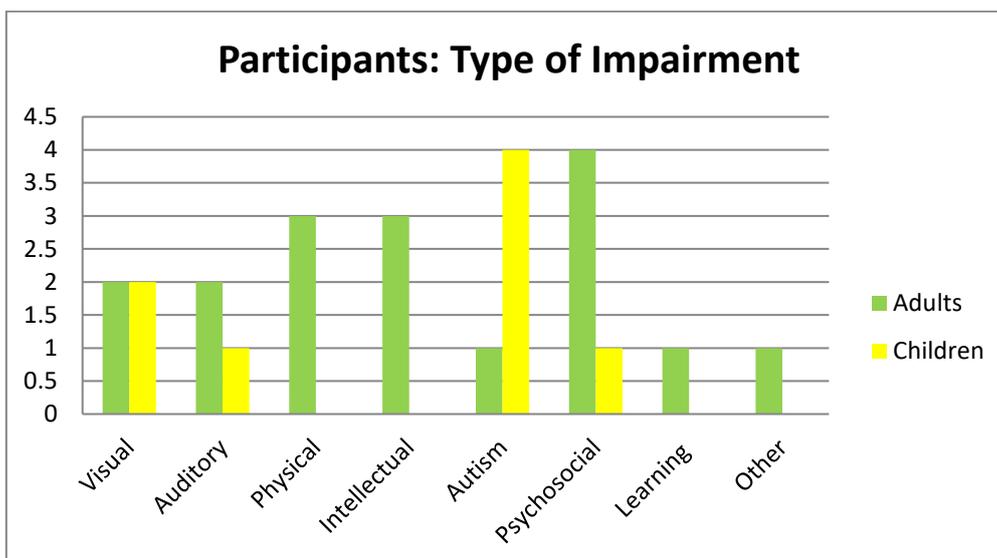


Figure 3: Number of participants classified by impairment

The research participants comprise male and female participants and the ages range from 4 to 63 years. Table 1 presents an overview of the interviewee characteristics.

Impairment Group	Name	Gender	Age	Specific Impairment	Malta / Gozo
Visual	Manuel ⁴	M	63	Blind	Malta
	Rita	F	63	Blind	Malta
	Matthew	M	16	Visual Impairment	Malta
	Dylan	M	8	Visual Impairment	Malta
	George	M	61	Deaf & Blind	Malta

⁴ Names have been changed to ensure the research participants' anonymity.

Auditory	Roberta	F	39	Deaf	Malta
	Amanda	M	14	Hearing Impairment (and Spina Bifida)	Malta
Physical	Josephine	F	57	Spina Bifida	Malta
	Claire	F	36	Wheelchair user	Malta
	Fabian	M	28	Physical Disability	Malta
Intellectual	Tania	F	49	Global Developmental Delay (GDD) (and Spina Bifida and microcephaly)	Malta
	Stefan	M	23	PNLD ⁵ (neurodegenerative disease)	Malta
	Christopher	M	25	Down Syndrome	Gozo
Autism Spectrum Disorder	Mark	M	29	Autism (and epilepsy and intellectual disability)	Malta
	Benjamin	M	13	Autism	Malta
	Patrick	M	13	Autism (and mental health difficulties)	Malta
	Julia	F	9	Autism	Malta
	Noah	M	4	Autism	Malta
Psychosocial	Joseph	M	52	Depression (and other mental health difficulties)	Malta
	Andrew	M	50s	Obsessive Compulsive Disorder (OCD) (and anxiety)	Malta
	Warren	M	41	Schizophrenia (and depression and mild learning difficulties)	Gozo
	Darren	M	19	Dyspraxia and OCD (and anxiety disorder)	Malta
	Rachel	F	13	Psychosocial	Malta
Learning Difficulties	Graziella	F	18	Mild learning disabilities (and behaviour difficulties)	Gozo
Other	Kristina	F	22	Joubert Syndrome	Malta

Table 1: Interviewee Characteristics

An information sheet and consent form⁶ were provided to each participant, informing participants of the scope of the research study as well as of their rights as interviewees. An Easy-to-Read version was provided for people with intellectual disabilities. In the case of children, the consent form was directed at parents, and the parents (or relative, carer or key worker) were allowed to be present in the interview and answer questions in the presence of the child, or adult where necessary (for example where the person does not communicate verbally). However, the person with disability was encouraged to answer as much as possible. When necessary, an interpreter was also present in the case of hearing impaired or Deaf participants.

The interviews were semi-structured in design: while a pre-set list of questions had been drawn up, targeting the areas pertinent to the research, it was also imperative to allow the interviewees to have the opportunity to “bring up their own ideas and thoughts” (Willis, 2006: 145). This ensured that the interviewees could elaborate on aspects which are important to them, which the interview might otherwise not have covered. In order to ensure that the interviewees felt at ease, they were given the choice of having the interview in a location of their choice; as well as to have the interview

⁵ Pallidoniroluysian Degeneration.

⁶ These can be found in the Annexes.

in either Maltese or English, with the majority preferring Maltese. The interview questions were grouped in the following manner: education, employment, housing, guardianship (including carer) and planning for the future, healthcare (physical and mental), leisure and sport, goods and services, justice, abuse and hate crimes (including violence). The interviewers, who were briefed by the key expert before the start of the interviews (including on specific definitions and the sensitivity of certain questions), are experienced in the fields of disability research. The interviewers took care to avoid situations in which psychological or emotional harm can be done to participants. Thus, if it was evident that the participant felt uncomfortable answering or elaborating upon certain questions, the interviewer would stop probing.

Following the interviews⁷ and their transcription, the analysis of the interviews was carried out. This was done through coding, where the key researcher employed coding methods used in Grounded Theory. Grounded Theory Methodology is used to “generate a theory from the collected data” (Stottok et al, 2011: n.p.): the researcher read the interview transcripts and identified concepts and links between various components of the text. The transcripts were then coded, that is, “segments of data” were named “with a label that simultaneously categorizes, summarizes, and accounts for each piece of data” (Charmaz, 2006: 43). Through coding the interviews, it was possible to identify trends and connections, and group the various codes “into larger, more meaningful categories” (Stottok et al, 2011: n.p.). Based on this analysis, the research report was then developed.

⁷ The interviews were carried out in July and August 2018.

Research Findings

Education

Attitudes and Accessibility⁸

School experiences differ for persons with disabilities, not only among those with different impairments, but also for persons of different age groups. While older (over 60 years of age) people with visual impairments did not finish more than primary school, children with visual impairments today have more opportunities available to them. A crucial aspect of the school experience for people with disabilities is the attitude of the school staff, which, from the interviews conducted, seems to have undergone quite a change over time, although some negative attitudes still persist. Josephine, a 57-year old woman with spina bifida, had not been accepted at a Church school she tried to attend:

“Qalulha [lil ommi]: ‘Din għax ma tibgħatiex Villa Monsinjur Gonzi – x’tambiha?’”⁹
“They told [my mum]: ‘Why don’t you send her to Villa Monsinjur Gonzi – what do you need her for?’”

When she finally entered a public school, the headmistress informed her mother that as soon as she has a seizure, she will be removed. However, she finished primary school and went on to secondary school (where another struggle due to physical accessibility was encountered) and managed to finish it. Claire’s experience with regards to attitudes, however, was quite different. Claire, a 36-year old woman using a wheelchair, was encouraged by a teacher to attend a mainstream school. While her mother was resistant to the idea of school in the beginning – she preferred to have Claire stay at home and do physiotherapy – Claire insisted. However, physical accessibility was also an obstacle in her case: since there was no lift at the time, her father and her LSE¹⁰ were obliged to take her up 3 flights of stairs for computer classes.

Others had mixed experiences but which eventually became positive. Fabian, a 28-year old man with physical disabilities had difficulties in primary school. His negative experience was mostly to teachers not wanting him there and him not being allowed to go to school when his LSE was sick (even though his parents offered to stay outside the school in case he needs help). However, he says, other staff had more positive attitudes. Mark, a 29-year old man who is on the autism spectrum and has epilepsy, had similar experiences to Fabian and Claire in primary school, where the headmaster did not want to accept him, but upon his mother’s insistence, did. Today, the headmaster still phones him to ask after him. At secondary school he had a lot of help, encouragement and support and had a positive experience. Meanwhile, Darren, a 19-year old man with dyspraxia and OCD, and the only interviewee who went to a private school, had a very positive experience at school, with staff being very helpful, and who, in his mother’s words, knew how to “handle him” and target his needs and capabilities. The only obstacles encountered in Darren’s education were his heavy tantrums; however the school interested themselves in his case and tried to help his family, speaking to them and trying to understand the issue. It was the mother herself who decided to withdraw her son from school for a time, so as not to expose the other children and teacher to any danger.

For children with sensory impairments, the school experience presents various obstacles. Amanda, a 14-year old girl with hearing impairment, puts the emphasis on getting along with her class mates, with whom she would like to speak sign language but cannot, since they do not know the language.

⁸ Abuse and bullying encountered at school are explored in the ‘Abuse and Hate Crimes’ section.

⁹ Where the interview was conducted in Maltese, the Maltese version is quoted first, followed by a translation in English.

¹⁰ At that time, LSEs were called ‘facilitators’ and later ‘LSAs’ (Learning Support Assistants).

She manages to get by, by continuously asking them to speak slowly; however she feels it is her right to be able to communicate in sign language. Dylan, an 8-year old boy with severe visual impairment, struggles to participate in certain school outings from which he cannot benefit fully like his schoolmates do, and thus prefers not to attend (or his mother prefers not to send him).

Meanwhile, for Deaf children, lack of awareness of Deaf issues renders the school experience more difficult. Amanda's mother has offered the (Church) school management to organise talks about Deaf issues to the staff and school in general; and she also gave books to the Head about the subject. However, this has not led anywhere. She insists that many teachers, in fact, are not aware of the needs of students with hearing impairment and cites the example of the teacher explaining something while writing on the whiteboard, rendering it more difficult for Amanda to understand what the teacher is saying.

Learning Support Educators

LSEs are a crucial part of the school experience for many disabled children. The two children interviewed, one of whom is in primary school and one in secondary school, both report that the LSE service is good, both in acquiring the LSE as well as in the service the LSE provides.

However, several parents of children with disabilities like Noah and Julia, a 4-year old boy and a 9-year old girl with autism, note that some LSEs are more dedicated than others. For example, Julia needs support to eat, but some LSEs do not realise that simply opening the lunchbox for Julia is not enough, and that she needs hand-on-hand support in eating. Others refuse to change her nappy, citing such reasons such as that they are only obliged to change her nappy once daily. When asked, Julia's mother says there is nothing much she feels she can do about this: she has to accept the LSE allocated to her child. However, she did once speak out when Julia's LSE, due to a skin condition, could not use the swimming pool, obliging Julia to miss out on her swimming therapy sessions. The mother had not known this beforehand, and for that year Julia could not go to the pool. For such reasons as this, Amanda's mother wants to ensure that the LSE allocated to her daughter with hearing impairment and spina bifida understands her daughter's difficulties. She has thus started to insist that she meets the LSE before the beginning of the scholastic year. In her opinion, the LSE (and the teacher) should meet and know the children they will be working with beforehand.

Meanwhile, for Deaf or hearing impaired children, rather than (or together with, depending on the impairment) an LSE, there is also a huge need for Maltese Sign Language interpreters. Roberta, a 39-year old woman who is Deaf, went to school at a time when there were no LSEs or interpreters provided for Deaf children. However, she emphasises that even today, there is a lack of interpreters – who could make life much easier for hearing impaired students – in schools. Amanda's mother concurs: sometimes Amanda is allocated an interpreter, but only for some lessons: for example, for three 1-hour sessions weekly. Confirming what was said by other parents about the varying dedication of LSEs, Amanda's mother also points out that not all LSEs know sign language and many do not want to learn it: in Year 1, Amanda, a 14-year old girl with hearing impairment, had to teach sign language to the LSE herself. The present LSE took interest and learnt some sign language, but she will be replaced by another LSE from the current scholastic year onwards.

LSEs are also in short supply. Noah's mother talks about how they experienced a delay when the Statementing Moderating Panel¹¹ was issuing an LSE for her son. They were informed that since their son was only 'borderline autistic', other students with more severe impairments were given priority. However, there was also a delay at the Child Development Assessment Unit (CDAU)¹² level: after Noah was assessed by the psychologist there, the psychologist report was delayed due to staff leave.

¹¹ https://education.gov.mt/en/education/student-services/Pages/Inclusive_Education/Statementing-Moderating-Panel.aspx

¹² <https://deputyprimeminister.gov.mt/en/ahcs/Pages/occupational-therapy-services/cdau.aspx>

Without this report, Noah's parents could not go to the Statementing Moderating Panel; and once they did, there was a delay to find an LSE due to the huge demand. Due to all this, Noah missed the first term of school. Relating this experience, Noah's mother emphasises the importance of increasing the staff at the CDAU and the Statementing Moderating Panel: due to understaffed and overworked entities, children like Noah might miss out on school.

Educational Resources

When it comes to educational resources, Matthew's and Dylan's (both children with visual impairments) mothers laboured extensively to obtain the equipment and services their children needed, such as doing exams orally and buying magnifying equipment. (Other resources, like material in large print, are provided against payment). While one mother obtained financial help from the Malta Community Chest Fund Foundation (MCCFF)¹³, the other mother chose to ask politicians for help until the necessary equipment was bought for the school. This notion of patrons – people asking for patrons' help when the system is too slow or does not work at all – emerges also with other interviewees in other situations (see 'Goods and Services' sections).

The availability of educational resources for disabled students does not depend solely on the availability of finances, however. Matthew's mother speaks about the lack of awareness of disabled children's needs (such as lack of knowledge of what Braille is), creating obstacles for her son's education. However, in Matthew's and Dylan's cases, who both attend public schools, they and their mothers mention that teachers and heads of schools were generally helpful (including planning ahead for the child and writing in large print), some more than others.

Meanwhile, for Julia, a girl with autism, the lack of necessary resources in schools is made up for by NGOs like Inspire Foundation¹⁴, which, in Julia's mother's opinion, is needed to help children become independent. Many other parents reiterate this, commenting that Inspire services are more holistic and also more frequent than government's services. This brings to light the importance of the role of NGOs in disabled people's lives (although it must also be mentioned that some Inspire services are subsidised by the government). Furthermore, however, as Noah's mother points out, some people cannot afford to access services privately like they (Noah's parents) do (see 'Goods and Services' section).

With regards to Resource Centres¹⁵, both Stefan's and Kristina's mothers speak positively overall. Both mothers comment that for their children (son with PNLD and daughter with Joubert Syndrome respectively), special schooling was better than the mainstream ones they used to attend, and some of them had the resources their children needed. Both children, according to their parents, flourished in special schools as against mainstream schools.

Examinations

Examinations can prove to be a stressful experience for many people with disabilities, especially for people with mental health difficulties such as anxiety disorders. Darren, a person with OCD, stopped attending school after secondary education, due to the stress caused by examinations. Andrew, also a man with OCD, recounts how, due to anxiety, examinations and deadlines made the school experience very challenging for him: they increased his anxiety to the point of not being able to sleep. This experience includes higher education, when he was doing his Master's degree: during this

¹³ <https://www.mccff.org.mt>

¹⁴ <https://inspire.org.mt>

¹⁵ These were previously known as 'special schools'. More information on the Resource Centres can be found here: https://education.gov.mt/en/education/student-services/Pages/Special_Education/Resource%20Centres/Resource-Centres.aspx

time, Andrew says, he did not receive any support. As discussed subsequently, similar experiences to Andrew are undergone by persons with other types of impairments.

Higher Education

Students with sensory impairments still face various barriers to higher education. Matthew, a 16-year old boy with visual impairment, is finding it difficult to go on to post-secondary education. While he has obtained four O-level examinations¹⁶, he needs at least five or six to attend the Higher Secondary School¹⁷. One of the reasons for his obtaining a low number of O-Levels, Matthew's mother insists, is that he was not able to sit for the O-levels orally (rather, the LSE writes his examination answers for him), as this is not currently an option. As his mother says:

"Allura dan it-tifel qatt ma jista' jidholli l-Universita'.... Matthew dejjem kien jghid: 'Ma, nixtieq insir avukat'."

"So this boy can never go to University...Matthew always used to say: 'Mum, I want to become a lawyer'."

Similarly, Roberta, a Deaf woman, had a great deal of support from her family and friends while in primary and secondary school. Although she still could not understand a lot of things that were being said, the biggest obstacle was encountered when she tried to go to Sixth Form. Her parents were unable to help her with her schoolwork at that level. Having to do everything alone proved to be too difficult for Roberta, and she was obliged to quit. The lack of higher education has repercussions on other areas of her life, such as Roberta's chances of obtaining a promotion at work as an adult (see 'Employment' section); and Roberta's husband, who is also Deaf and does not have a good level of education (he attended a special school where the services were very poor), gets paid minimum wage due to his lack of qualifications.

For people with physical disabilities, obstacles present themselves in a physical form. Fabian, supported by his parents, went to University and graduated as a teacher. Today he is also studying law. However, he notes that certain parts of the University are physically not accessible: he often has to go around all the premises to get to where he wants, whatever the weather, and wasting a lot of time. On the positive side, however, Fabian finds the ACCESS Disability Support Unit¹⁸ very helpful.

Employment

Physical Accessibility

While physical accessibility does not present an obstacle to all people with physical impairments regarding employment, some people still encounter problems in this aspect. Josephine, a 57-year old woman with spina bifida started working late in life: when she was young, disabled people did not usually work. However, she now works as an accounts clerk and seems happy. Fabian – a 28-year old man with physical disability – on the other hand, faced obstacles regarding physical accessibility when attending an interview for work as a teacher. Not only was the place of the interview inaccessible, but he was told:

"Għax inti missek avzajtna li inti persuna b'dizabilita'."
"You should have informed us that you are a person with a disability."

¹⁶ Ordinary level examinations

¹⁷ Giovanni Curmi Higher Secondary School: <https://gchss.edu.mt>

¹⁸ <https://www.um.edu.mt/access>

For others, it is the transport to and from work which presents a problem. Claire, a 36-year old woman who uses a wheelchair, also works as a clerk; and, while she does not seem to be completely happy with simply “typing on a laptop”, her major problem is the transport. She pays for disabled people’s transport (which is often more expensive than regular transport) to take her to and from work: however, she sometimes arrives late to work or she herself is not ready when the driver comes, and the driver refuses to wait for her. As Claire says, she dislikes the fact that she depends on someone else to go to work. The issue of dependency forms a significant aspect in many disabled people’s lives, as will be discussed in the ‘Guardianship’ section.

Promotions

The lack of education that people with disabilities like Roberta, a Deaf woman, possess, presents obstacles in advancing in employment. Roberta has been working at a bank for 20 years, where she recounts that her colleagues and management now understand her, making her working life easier than it used to be. However, she has problems with answering the phone, and thus has to ask her colleagues to do so (see also ‘Goods and Services’ section on this issue). Furthermore, it is also very difficult to get promoted due to the fact that she does not have ‘paper’ qualifications (see ‘Education’ section), even though she is capable in her work. Furthermore, since she does not have a broad knowledge of the work involved – due to communication problems – she does not do well in interviews leading to promotion.

Awareness

One of the greatest challenges encountered by people with disabilities in employment – and indeed, in other aspects of life, as is seen throughout this report – is lack of awareness on disability issues and on the capabilities of people with disabilities. Mark, a 29-year old man who has epilepsy, among other impairments, has been working in a hospital for a couple of years. After initial misunderstandings – his previous work with a private company had been negative (see ‘Abuse and Hate Crimes’ and ‘Justice’ sections) – including being accused of sexual harassment (he had not told the staff of his epilepsy), today he is happy working in logistics, and feels he has been given work that suits him. However, his father feels that Mark’s studies were in vain, since he studied to become an ECG technician (even going abroad to sit for examinations) and is not working in the area of his speciality. Mark also feels that sometimes, people with disabilities do not have the opportunities to work in the way they wish because of their disability, even though, as he emphasises, people with disabilities are capable like everyone else.

One aspect that comes out of Mark’s story, and is touched upon by Warren’s residential worker¹⁹, who points out that while Warren, a 41-year old man with schizophrenia, is involved in *Agenzija Sapport’s*²⁰ INK project²¹ - where people with disabilities are trained in order to support their inclusion in the labour market, as well as offering some training placements – the key is finding an employer who is truly willing to employ persons with disabilities. He observes that, while many employers accept to take on someone with a disability for a short period, they do not want to employ persons with disabilities on a long-term basis, despite the fact that someone like Warren is completely capable of working. It might be for this reason that Graziella, an 18-year old woman with learning disabilities who is also currently participating in the same project, says that she does not feel that this project is helping her much in terms of employment.

Evidently, not all employers have negative attitudes. Andrew, a man in his 50s who has OCD, says that his condition actually suits his job since, as a teacher of English, his boss likes the fact that he is a perfectionist and can be relied on. In fact, he is often used as a role model. At the same time, it is

¹⁹ Warren resides at one of Agenzija Sapport’s residences.

²⁰ <https://sapport.gov.mt>

²¹ <https://sapport.gov.mt/en/Pages/INK.aspx>

worth noting that Andrew's impairment suits his job and that his employer, rather than feeling it is a 'threat' to Andrew's output, feels that it is an advantage. Thus the work experience for people with disabilities seems to depend on employers' attitudes towards people with disabilities as well as attitudes towards specific impairments.

Healthcare

General

The views of healthcare emerging from the research participants vary according to their experiences. For example, both parents of children with visual impairments mentioned having to go abroad for healthcare, and in this case both the healthcare services received in England, as well as the support received from MCCF, Puttinu Cares Foundation²² and the government (in terms of flights and accommodation), are spoken well of.

However, Warren, a man with schizophrenia who stayed for a short period at the psychiatric ward in Gozo, did not have a good experience neither with regards comfort, nor therapy-wise, which he says did not prove to be much help (although his residential worker says there were some aspects which were more positive than Warren makes them out to be). Indeed, Warren notes: "*Imradt iktar hemmhekk*" – "*I got sicker there.*"

Accessibility²³

Healthcare proves to be inaccessible to people with different types of impairments. With regards to physical accessibility, Claire, who uses a wheelchair, mentions that while Mater Dei Hospital²⁴ is accessible, the health centre she goes to has stairs. Stefan's mother, whose son has PNLD, also talks about the Blue Badge²⁵ and the abuse of this parking permit by people who do not need it, especially when visiting Mater Dei Hospital, suggesting that security staff at the hospital might start checking if the patient does have a Blue Badge. She, together with Kristina's mother, whose daughter has Joubert Syndrome, also lament that sometimes there are not enough parking spaces reserved for disabled people (not only for hospital, but for other places as well).

Inaccessibility to healthcare, however, is not only physical. Roberta, a Deaf woman, recounts that she encounters many obstacles when she goes to hospital, and with healthcare in general. She is obliged to take her mother or her sister along with her when she has a hospital appointment: otherwise, she would sometimes spend hours waiting after she has been called to go in to see the doctor, even though she would have informed the staff that she is Deaf. Although she can make use of interpreter services for a hospital appointment, the interpreter cannot wait around forever. And, although with the interpreter she should be able to skip the queue, this does not happen:

"Bl-interpreter suppost ninqdew iktar malajr.... Imma din l-interpreter kemm se ddum tistenna? U jekk ikollha appuntament ieħor ma' klijenti oħra? Imma xi kultant ma jifhmuhiex in-nies: hemm bżonn ta' iktar awareness."

"With the interpreter we should be served sooner....But how long can the interpreter wait? And if she has another appointment with other clients? But sometimes people don't understand this: there needs to be more awareness."

²² <http://www.puttinucares.org>

²³ Transport to and from health centres and hospitals is discussed in the 'Goods and Services' section.

²⁴ <https://deputyprimeminister.gov.mt>

²⁵ The Blue Badge is a disabled person's parking permit. More information can be found here: <https://crpd.org.mt/services/blue-badge>

While the issue of awareness is tackled in the next sub-section, Amanda, a girl with hearing impairment and her mother, emphasise the lack of interpreters who have to be booked months in advance for a hospital appointment. Amanda can speech read but when doctors speak in English – and / or are not familiar to her – she has difficulty doing so, although sometimes nurses help with communication. While Amanda’s mother used to interpret for her, there were certain situations where it was preferable that the interpreter is present: for example, when Amanda had to undergo an operation, parents could not be present. Her mother says that while she could have made arrangements to be with her, she wanted her daughter to feel like an adult. This (and the fact that relatives might be emotionally involved and might not always support the disabled person in the most beneficial way) demonstrates the importance of interpreters in their role of enabling people with hearing impairments to live independently of their relatives and parents, a topic that will be dealt with more in depth in the ‘Guardianship’ section.

More importantly, Roberta points out another serious obstacle in healthcare services: Deaf people cannot call 112. Thus, in case of emergency, she either has to phone her mother or knock on her neighbour’s door.

The waiting time at hospital that Roberta alludes to above has more serious consequences for people with other types of impairments. Benjamin’s and Noah’s mothers point out that although their sons have autism, they have to wait behind other people, even with the Special Identity Card (SID)²⁶. Noah’s mother recounts how when she needs to take her son to the ENT²⁷ department at Mater Dei Hospital – an event that already takes her son out of his normal routine – they have to wait for hours in a noisy room, something that Noah cannot do. The first two times they went, the tests could not be finished due to Noah’s agitation. The last time, however, since the staff got used to them, they let them skip the queue.

Similar experiences are undergone by people with anxiety disorders. For Andrew, a person with OCD, the waiting time at the hospital – which sometimes amounts to four hours – brings on anxiety attacks:

“For those four hours waiting in the room with all those people, it is very difficult - it brings on anxiety attacks – [I] feel worse than I was before I went there. It’s really, really bad and when it’s time to see the doctor I’m all in a fluster, I’m not myself.... Every time I go.... It’s a killer and I tell them: ‘We are sick people here, you know?’ [And they reply:] ‘I’m very sorry, there’s nothing I can do, that’s the system.’ That’s the biggest problem with Psychiatric Out-Patients²⁸. I see others in the waiting room and they can’t handle it.... It’s not just me who is disadvantaged.... And it is a horrible experience each time I have to go there.”

On the other hand, both Stefan’s and Kristina’s mothers say that they are allowed to skip the queue in hospital, indicating the possibility that, rather than being based on the SID, the possibility to skip the queue is based on the willingness of the person in charge and their estimation of the need of the patient.

Meanwhile, Kristina’s mother speaks of the fact that when her daughter underwent an operation at hospital, there was no adequate room to put her in. Both because of her behaviour affecting others, and also because of her being affected by others’ behaviour, she would need a room of her own, which is not always possible. Furthermore, since Kristina was already considered an adult at the time, she was not admitted to the children’s ward. However, her mother feels the need to stay with

²⁶ This has now become the EU Disability Card: <http://crpd.org.mt/services/sid-eu-card>.

²⁷ Ear, Nose and Throat Out-Patients

²⁸ <https://deputyprimeminister.gov.mt/en/mch/Pages/Community-Services/psychiatric-outpatients.aspx>

her throughout the night, where, in adult wards this is not allowed (this is also linked to lack of awareness of the needs of people like Kristina by hospital staff, discussed subsequently). In Kristina's case, there was not even enough space for her mother and the wheelchair to fit in the cubicle she was allocated.

Lack of Awareness and Misinformation

Many of the participants of this research bring up healthcare staff's attitudes towards people with disabilities (and their families or carers) as something which affects their healthcare experience, whether positively or otherwise.

The healthcare experience starts from when the child is first diagnosed with a disability (see 'Goods and Services' section for more about this issue). As Darren's – a boy with dyspraxia – mother notes: "*Għall-bidu tieġu qatgħa*" – "*At first, you're shocked*". Her shock was not much eased by the staff at the CDAU, due to a doctor's lack of empathy. She kept attending the CDAU because the other services, such as those provided by speech therapists and occupational therapists were good. Darren's mother, however, emphasises the importance of doctors being understanding of the parents at that momentous time when they discover that their child has a disability. Similarly, Noah's mother talks about the difficult time she went through in coming to terms with her son's diagnosis: at first she was informed by childcare staff that her child was not integrating with the other children, but did not do anything about it. However when, at a doctor's, Noah once threw a tantrum, the doctor told her he might have ADHD (Attention Deficit Hyperactivity Disorder) and referred them to the CDAU. Even once diagnosed with autism, it was difficult for Noah's parents to come to terms with the diagnosis. After people also started pointing out Noah's behaviour, Noah's parents finally began to accept and adapt, and also make sense of why Noah behaves in a certain way. Such experiences also suggest the need for counselling for parents of children with disabilities in order to help them cope with the diagnosis (or birth) of a child with disability, both in order to support them as well as to enable to better care for their children.

The importance of doctors and other healthcare staff understanding disability issues continues throughout the disabled person's life. Joseph, a 52-year old person with mental health difficulties, also talks of doctors not knowing or understanding what his condition is, and his frustration with what he perceives to be lack of interest.

Lack of awareness is also touched upon by Amanda's – a 14-year old girl with hearing impairment – mother, who emphasises the need for professionals, not only to recognise the parents' knowledge of their child's difficulties, but also to 'destigmatise' sign language. She recounts how speech therapists, at the time when Amanda was young, did not look favourably upon sign language, and were of the opinion that sign language would prevent the child from learning verbal language. One speech therapist did eventually accept to work with Amanda in a different way than others; and once Amanda started being signed to, she started responding orally. Amanda's mother here emphasises the importance of medical professionals listening to the parents and what they have to say about their child. Parents are the ones who know their child best, since they spend 24 hours a day with them: in Amanda's case, her mother says that she had known her child was hearing impaired for 3 years before the doctors admitted that this was so.

Amanda's mother also brings up another significant point, that of information, or lack of it. While this will be dealt with extensively in the 'Goods and Services' section, it is also important to briefly mention it here with regards to health services. The same mother talks about how some crucial information is not given by doctors, such as parents of hearing impaired / Deaf children being given the impression that if their children have cochlear implants, they would not need sign language because they will hear normally, or that they will not encounter any difficulties in the future. These

instances underline the need for information: as Amanda's mother insists, parents need to be given information, starting from hospital, not just being told: *"Isma', it-tifla Deaf"* – *"Listen, your daughter is Deaf"*. Parents need to know what services are available to Deaf children. Amanda's mother obtained information on services from other parents of disabled children at a sports association. An initiative has already been started with regards to this: the Deaf People Association²⁹, together with interpreters, is working to put a leaflet in the ENT department.

Lack of awareness and understanding of disability issues sometimes leads to fear and stigma (issues which are dealt with more extensively in the 'Abuse and Hate Crimes' section). Warren's – a man with schizophrenia – residential worker insists that hospital staff *"let their fear overcome their responsibilities as a doctor or nurse"* when they deal with people with intellectual and mental disabilities. He cites the example of staff discussing the patient (a disabled person) with other staff where anyone can hear. Warren's residential worker insists that the stigma attached to people with disabilities interferes with their judgement and, rather than seeing the symptom of the patient, they see the disability. He also talks of the reluctance of treating the patients coming from the residence³⁰ he oversees:

"The red flag always goes up.... Because: 'Oh God, here [he] comes again... whatever!'... and it's like, they don't seem to be professional enough in their ethical standards."

Warren's and his residential worker's experience stands in stark contrast to Tania's – a woman with GDD – and her carer's experience at the private hospital they attend, where the staff refuse to charge the patients from the home³¹ Tania resides at (unless they see a specialist). These differences in experiences might be due to various reasons (such as difference between public and private hospitals). However it is worthwhile noting that in general, the residents of the home where Warren resides have mental health or intellectual difficulties, while the ones where Tania resides are not. Stigma towards and / or fear of mental health and intellectual disabilities stem from lack of information and awareness, and denotes the need for both awareness raising and training of healthcare staff.

Positive experiences are also noted by other interviewees. Andrew, a man with OCD, is happy with the healthcare services he receives, both with the psychologist at Mount Carmel Hospital³² and the Psychiatric Out-Patients service at Mater Dei Hospital. He also feels very well supported by Richmond Foundation³³ who also provide him with home support.

Goods and Services

Infrastructure

One issue that comes up with people with visual and physical impairments is the inaccessibility of roads. Matthew, a 16-year old boy with visual impairment, is learning to use the white cane, but, as he and his mother note, neither the pavements nor the roads are adapted for this (potholes being one of the problems). Indeed, they emphasise, lack of adaptations for persons with disabilities is found across the whole country, when considering that there is total chaos on the roads, including cars failing to stop at Stop signs or pedestrian crossings. Physical accessibility is an issue reiterated by Josephine, a woman with spina bifida, who also says that Valletta is not at all accessible.

²⁹ <http://www.deafmalta.com>

³⁰ An *Aġenzija Sapport* residence.

³¹ A Church home for children.

³² <https://deputyprimeminister.gov.mt/en/mch>

³³ <http://www.richmond.org.mt>

Josephine, who uses a wheelchair, also talks about how, in the town where she lives, she has to move in the middle of the road, making cars wait for her:

“Karożzi jdoqqu l-ħorn ...ma jistennewkx, għax ħadd ma jifhem li inti ma tistax titla’ din l-bankina. Nuqqas ta’ ħsieb, nuqqas ta’ ppjanar.”

“Cars honking...they don’t wait for you, because no one understands that you cannot go on the pavement. Lack of thought, lack of planning.”

Roads and pavements are not the only inaccessible (and sometimes unsafe) places, however. Josephine voices her frustration at the fact that she cannot withdraw money from the ATM of the bank of her choice:

“Jien għalfejn għandi ngħid lil ħaddiehor biex iġibli l-flus meta hemm metodu kif jiena nista’ ngibhom waħdi? Eżempju, xi ħadd jidħol ġewwa u jġibidli l-flus...għandi d-daddy tiegħi jkun jista’ ... prokuratur tiegħi: Imma għax għandi nagħmel dawn l-affarijiet?”

“Why do I have to ask someone else to get the money for me when there is a way for me to get them on my own? For example, that someone has to go inside and withdraw money for me? My daddy can be my attorney: But why do I have to do these things?”

When she spoke to the bank manager, Josephine was assured that the ATM is a standard one. However, since she cannot reach it because it is too high, she has to use the ATM of another bank which is accessible. Furthermore, many shops, as both Josephine and Fabian – a man with physical disability - note, are also physically inaccessible, forcing them to ask people to bring the items of interest outside for them to look at. Yet – as Josephine rightly asks – why should she? She laments that even those shop owners who can put a ramp outside their shop, fail to do so. Other places, such as government departments, are also physically inaccessible. Additionally, similarly to Josephine’s experience with the bank, some participants feel that no recourse is forthcoming. Matthew, for example, brings up the issue of traffic lights not beeping when it is safe to cross, an issue on which his mother struggled to get the authorities (including the local council and Transport Malta³⁴) to listen to her, some of whom even laughed at her. In such contexts, both Josephine and Matthew’s mother have turned to politicians: Josephine says that she is waiting for a particular disabled counsellor to be elected in her home town, so that he can solve the problem of the road and pavement not being accessible. This recalls what Matthew’s mother says: to buy equipment for her son’s school, she sought out politicians to help her.

Finally, three of the participants: Josephine, Stefan’s mother and Kristina’s mother, also spoke of the difficulties encountered when their wheelchair (or their children’s wheelchair) needs a part replaced, and the parts take very long to come, rendering their being mobile more complex.

Transport

Transport is another key area in disabled people’s lives. For example, what proves crucial to accessing healthcare services for the older people with visual impairments are the transport services provided by *Aġenzija Sapport* to go to Mater Dei Hospital or to a health centre. The older people with visual impairments both stress the importance of *Aġenzija Sapport* services in accessing goods and services. Rita, a 63-year old woman who is blind, goes as far as to say that it was the Agency’s services that enabled her to continue living in the community, rather than live in a residence (whether for elderly or for disabled people):

³⁴ <https://www.transport.gov.mt>

“Tas-Sapport jgħinuni ħafna.... Is-Sapport huwa importanti ħafna għalija... min ikun bħali ma jkollux min jieħdu tal-familja, veru nsibhom, għax li kieku hopeless: ma nistax ngħix waħdi. Ikolli nidħol f’home. Hekk bqajt mal-komunità.”

“Those at Sapport help me a lot.... Sapport is very important for me... those who are like me and do not have any family members to take them [on errands, etc.], they are really useful, otherwise it would be hopeless: I cannot live on my own. I would have to go into a home. Like this, I remain in the community.”

Besides access to health services, *Aġenzija Sapport* services also enable Rita to go out socially and shop for clothes and other similar items. For people like Manuel, a 63-year old man who is blind, however, the services *Aġenzija Sapport* provides are not enough, and he depends to a great extent on his children and his friends. He uses up all the hours provided by the Agency to access health services, thus needing friends and family to help him do his other errands, such as going to the bank. Shopping is a problem both for him and his wife (who is also unable to go out on her own due to impairments). As Manuel states, being dependent on others is a problem – there is a limit as to how much one can depend on a friend’s kindness (recalling the earlier discussion on dependence) – a sentiment which is echoed by Rita, who does not like the fact that she needs to be helped when before (when she still had her vision) she used to help others. Furthermore, while Rita feels comfortable with *Aġenzija Sapport* staff in helping her choose clothes, Manuel’s male friend feels uncomfortable going to shop for clothes and shoes with Manuel’s wife.

Meanwhile, Tania, a woman with GDD who resides at a Church home, finds it difficult to access Inspire services, where she goes for therapy and cooking sessions (among other activities). The nun who takes care of her at the home where she resides laments that sometimes the activities that Tania attends (provided by another NGO) are held in different places, and the staff from the home cannot take Tania everywhere: they do not have extra carers (and not all the carers drive), so transport is a big problem. Since Tania only has a small pension, they cannot order a taxi for her each time: they already pay for Inspire services and Tania’s other daily needs (including sometimes going abroad).

With regards public transport, both Fabian and Josephine, people with physical disabilities, comment that the service is good, now that the buses have ramps (unless they are broken). However, neither Fabian nor Josephine uses public transport for work. Josephine drives her own car and Fabian gets a lift with his father, which allows him to leave home an hour and a half later than if he had been obliged to use public transport (unlike Claire, also a person with physical disability who uses transport for disabled people – see ‘Employment’ section).

Housing

Physical accessibility in housing presents an issue to people with physical disabilities but also to those with visual impairments. Both mothers of children with visual impairments speak of the obstacles encountered due to living in housing which is not adapted to such impairments, such as lack of light and slippery floors. Dylan’s mother specifically expresses the wish to have more information on housing (see ‘Goods and Services’ section for the issue of lack of information).

Meanwhile, all three interviewees with physical disabilities, who currently live with their parents, cite issues with housing accessibility. Claire wishes to move out, should she be given the opportunity: she is tired of fighting with her parents – in her own words, she is young and wants to live in her own way – but she feels she has no choice but to stay with them. For one thing, she cannot afford to live on her own, and is not sure her parents would let her; for another, she would also have to find one or two persons willing to share accommodation with her. Josephine is not currently considering moving – she cites physical accessibility as a problem, where many

apartments, even ‘ground floor’ ones, have some steps leading up to them – although she would have to move once her parents pass away, since the house would be too big for her. Fabian, too, says that it is difficult for him to buy property, since, should his flat not be situated on the ground floor (which is also sometimes a problem, as Josephine points out), and the lift breaks down, he would be stuck. He feels that the government should help more in ensuring that buildings are accessible in alternative ways (that is, not only through having a lift).³⁵

Obstacles encountered by Deaf persons

Deaf persons encounter different types of accessibility obstacles to goods and services. Roberta, a Deaf woman, sums up Deaf people’s needs in one sentence:

“Kieku possibli jkollok full-time interpreter, imma mhux possibli l-ħin kollu.”
“Had it been possible to have a full-time interpreter, but it’s not possible all the time.”

While she herself acknowledges that it is not possible to have a full-time interpreter, her statement demonstrates the significance of interpreters in Deaf people’s lives, and perhaps the lack of recognition of this significance. While personal assistants are increasingly becoming common for people with other types of disabilities to live in the community, interpreters – whose services are also being increasingly provided – remain scarce. This also denotes the importance of reasonable accommodation³⁶ in goods and services. Roberta talks extensively about the obstacles she encounters with some shops (such as computer repair ones), where she asks them to contact her by SMS, while they insist on phoning her. One company even told her that it is their policy to phone, and that they cannot send her an SMS (or message her on WhatsApp / send her an email). Thus she cannot answer them: if she is on her own when they phone, she has to hang up:

“Misshom jagħmlu exception għal persuni Deaf: fejn nistgħu, nużaw il-mobile minflok telephone normali.”

“They should make an exception for Deaf persons: where we can, we should use the mobile phone instead of the normal telephone.”

While Roberta is right, what she calls ‘normal telephone’ today has almost become outdated and the mobile phone has become the major means of communication all around the world. It is thus quite inconceivable that certain shops and companies insist on not using them with Deaf people. While reasonable accommodation in employment is an obligation by law³⁷, it seems to be enforced less in goods and services³⁸. On another occasion, when Roberta had a problem with the water and

³⁵ As per email communication between the Commission for the Rights of Persons with Disability (CRPD) and the researchers during November 2018, the CRPD works in conjunction with the Housing Authority in order to render their buildings accessible (such as through installing lifts in government-owned buildings).

³⁶ Waddington and Hendricks (2002: 409) define a reasonable accommodation requirement as prohibiting “an employer from denying an individual with a disability or other relevant characteristic an employment opportunity by failing to take account of the characteristic, when taking account of it – in terms of changing the job or physical environment of the workplace – would enable the individual to do the work”.

³⁷ The Equal Opportunities (Persons with Disability) Act (2000) states that: “an employer shall be considered to discriminate on the grounds of disability against a person... if such employer unreasonably... fails to make reasonable accommodation for the disability of such a person, unless the employer can prove that the required accommodation would unduly prejudice the operation of the trade or business run by such employer.” The Act can be found here:

<http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=8879&l=1>.

³⁸ This is not to say that reasonable accommodation in employment is being fully implemented. Apart from legal obligations, political willingness is crucial to the implementation of such obligations, both in employment and in goods and services.

electricity bill and was told her meter needs to be changed, she was told she will be phoned to set an appointment:

“Għidtilhom: ‘Tuhuli issa.’ Kont hemmhekk quddiem il-Customer Care. Qaluli le. Għidtilhom: ‘Tuhuli issa għax ma nistax nirrispondi telefon, [jew ibgħatuli]... email jew SMS.’ Qaluli: ‘Ma nistgħux.’”

“I told them: ‘Give me [the appointment] now.’ I was there in front of Customer Care. They told me no. I told them: ‘Give me an appointment now because I cannot answer the phone, [or send me]... an email or an SMS.’ They told me they cannot.”

Other services, however, like the school where her son goes, are now aware of her needs, and they communicate to her by SMS.

Access to Information

Access to information is an area in which the majority of research participants encounter obstacles³⁹.

Visual Access and Information Technology. As Manuel aptly notes: *“It-teknoloġija kollox għalina”* – *“Technology is everything for us”* – emphasising the important role that technology plays in the lives of people with visual impairment. The importance of the internet and related technology also comes out in the interview with Joseph, a person with depression, who finds comfort in being able to book holidays or write a complaint to a company online, rather than having to go there personally.

In terms of visual access to information, three out of four interviewees with visual impairments (Manuel, Rita and Dylan’s mother) reiterate that the Foundation for Information Technology Accessibility (FITA)⁴⁰ has played a key role in their lives. The Foundation has helped them choose, use, install and repair technology such as the Voice Recognition Software. However, Manuel notes that there are elements of technology which are inaccessible, including the fact that the Voice Recognition Software in Maltese is lacking, and smart phones are not accessible due to touch screens (Rita says that she would like a talking mobile). Manuel suggests that Local Councils organise Voice Recognition Software courses.

Furthermore, certain information is not accessible: for example, filling in forms online is not always easy. While some government services (both by phone, such as the 153⁴¹, and online) are helpful, Manuel says he feels scared to fill in certain forms on his own. Furthermore, he points out that even when the service provider is obliging, they sometimes give him conflicting information. This brings out two salient issues: that of dependence (discussed further in the ‘Guardianship and Planning for the Future’ section), and of access to information.

³⁹ It is to be noted that a specific question was asked regarding this.

⁴⁰ <https://fitamalta.eu>

⁴¹ <https://servizz.gov.mt>

Lack of Information. When asked whether they think there is need of more information, almost all respondents answer in the affirmative, on one service or another. The issue of access to information (or lack of) in terms of obtaining information is voiced by Rita, a blind woman, who feels that she does not have enough information on her rights; and by the mothers of the two children with visual impairments. Both Matthew's and Dylan's mothers relate how they obtained much of the information about related services (such as adapted books and how to adapt the house) from parents of other children with disabilities, from organisations their children are members of (such as the Malta Guide Dogs Foundation⁴²), or even from England. Both mothers emphasise the need for more information, of which, while there is more than before, there is still not enough. While there is access to information, they do not receive the needed information: in a busy daily schedule (Dylan's mother has two children with visual impairment), it would be helpful to receive the information they need at home. She suggests that information should be distributed through such media as TV, radio and leaflets at home. Fabian, a man with physical disability, confirms this: if he wants to, he can look up the information needed but some service providers do not actively inform the public of their services. Similarly, Mark, a man with autism, comments:

*"Hawn servizzi, imma ġieli ma jgħidulekx kolloxx – trid tmur tiġri warajhom."
There are services, but sometimes they don't tell you everything – you have to chase them."*

Mass media do not provide information on services for disabled people: if a service is introduced, it is announced once in the news, but then it is not heard of anymore. This, Fabian reiterates, is a lacuna, since there are people who do not have the same means as him to access information. He suggests that available services should be advertised through adverts which can be seen by people at different times. The worth of suggestions to disseminate information about services through mass media is proven by Andrew, a man with OCD, who recounts how he got to know of Richmond Foundation when he saw their programme on TV, also advertising a helpline:

"Automatically I said: 'I need this', and I rang them. It was at night but they called me back the next day and I started to go."

Andrew continues to say how he then started to frequent health groups and counselling sessions, which made him feel much better, due to the fact that he then knew he was not alone and felt supported. This shows the importance of reaching out through media, and of advertising the existing services. In this area, as Andrew reiterates, they can change a person's life:

"I'm still not anxiety free. Of course not: unfortunately it's a thing for life, but my quality of life improved a lot because of Richmond Foundation."

Similarly, today, Joseph, a man with depression, is aware that there are many services available to him – such as *Aġenzija Appoġġ*⁴³ and Richmond Foundation, whose services he uses and is happy with – and he is still discovering other services. While he knew of Richmond Foundation before, he had not known what services they offer – it was after his psychologist recommended that he go there that he did. When, in the past, he had felt the need for someone to talk to, he did not know that he could access services to do this. He still had a negative image of when he was young and people used to laugh at him if he opened up to them regarding his problems.

This need for information about disability-specific services is felt by other research participants, especially the parents of disabled children. Amanda's mother relates how she was unaware that her daughter could apply for a SID for both spina bifida and for hearing impairment: she obtained this

⁴² <http://www.maltaguidedogs.org.mt>

⁴³ <https://fsws.gov.mt/en/appogg/Pages/welcome-appogg.aspx>

information from another parent, together with the information that she could obtain help from the Commission for the Rights of Persons with Disability (CRPD)⁴⁴ regarding hearing aids. Roberta, a Deaf woman, concurs, also pointing out that parents of Deaf children do not have information on such services provided by the Deaf People Association, the CRPD or other available services (see also 'Healthcare' section).

Parents of children with autism also come out strongly on this: Julia's mother feels that she has enough information now, but she wishes she knew of the necessary services before. Had she known of them, she would have accessed certain services for Julia, a child with autism, earlier. Otherwise, she says that she obtains a lot of information from TV, Facebook and word of mouth. Noah's mother also points out the important role played by NGOs: as she says, the handbook issued by the Autism Parents' Association (APA)⁴⁵ is "worth its weight in gold" (in her words, "mitq lu deheb"). While they (Noah's parents) had already gone through the process when the handbook was published, Noah's mother says she wished she had had this handbook – on what to expect when your child is diagnosed with autism – at that time. When they were new to it, they had no idea where to go for Noah's speech difficulties and other issues. Benjamin's mother also says that she finds information from some NGOs, and through looking up information herself. However, she does not know what she will be facing in the future, now that her son is a teenager: she has tried to look for more information but is not getting enough information on autism in teenagers.

It is apparent that NGOs – as well as government services – might need to publicise their services more. Noah's mother observes that before the Statementing Moderating Panel guided them to Inspire services – which was helpful for them, since, she notes, it would have been difficult to do the research themselves – they had no idea that Inspire worked with children with autism (they thought that the NGO only worked with children with Down Syndrome). This could be due to the 'higher visibility' of Down Syndrome than autism, but it also links to the need for awareness raising on disability, a point which was mentioned earlier, and which is discussed further in the 'Abuse and Hate Crimes' section.

Research participants also note how information on social benefits – such as when to apply and for which benefit – is often not forthcoming. Matthew's mother states that she learnt she could apply for social benefits – including the disability pension – for her child with visual impairment, from England. Meanwhile, Noah's mother notes that they got to know about social benefits for their child with autism through friends who had the same experiences (albeit their children having a physical disability), that is, word of mouth. Similarly, Darren's mother obtained information on the allowance that Darren, her son with dyspraxia, was entitled to when he was already 12, and she only got to know this by word of mouth. She insists that the government should give more information. Once again, the issue of having to ask, rather than information coming to you, emerges in these cases and also in others such as Tania's, a woman with GDD. Tania's carer (a nun at the Church home where she resides) also says she has no information on any benefits:

"Aħna mill-benefatturi. Nitolbu 'l hemm u 'l hawn. Għax hekk ngħixu. Il-bqija m'għandix informazzjoni u ma nafx fejn irrid insibha."

"We [depend on] benefactors. We ask here and there. Because that's how we live. Otherwise, I don't have any information and I don't know where I should find it."

Relatedly, even when they are registered with the CRPD and thus receive information from them (and sometimes call the CRPD for guidance), many research participants do not seem to refer to the

⁴⁴ <https://crpd.org.mt>

⁴⁵ <https://www.autismparentsassociation.com>

CRPD for information. When Noah's mother was asked about CRPD, she says she has heard of them but has never looked them up. This implies the need for the CRPD to publicise its existence. Benjamin's mother also notes that they had difficulty in obtaining the SID, the 'yellow card'⁴⁶ and disability allowance because each (medical) report they obtained did not say what conditions Benjamin has. Although the initial report was good, since it was outdated, it was not accepted later. Thus, each time, she was obliged to inform the relevant persons about Benjamin's difficulties from the very beginning. It thus took several years to acquire the SID (since the entities involved were not finding the necessary information in the reports).

Therapeutic Services

The important role that NGOs play in providing services, including different kinds of therapy, is evident. Noah's mother finds Inspire services very helpful for her child with autism, without whom they would have found it more difficult. Noah, for example, enjoys the horse riding therapy sessions very much. However, Noah's mother explains, they pay for speech therapy for their son at Inspire because there he has speech therapy sessions more or less once a week, rather than the once every 4 weeks he had with the government-offered speech therapy sessions. Similar to the point made on education-related services (See 'Education' section), Noah's mother once again makes a point about the shortage of staff such as occupational therapists provided by the government, of whom there are not enough to keep up with the demand. Although parents can work with their children at home, they still need someone to guide them: they might find a great deal of information on the internet, but it does not compare to having someone helping you. Thus the government needs to push to employ more therapists for these much-needed services. Furthermore, Noah's mother felt frustrated with the occupational therapy services provided by the government due to logistics: there were times when they would not have been informed of Noah's appointment, after which they would receive a phone call to say that they missed the appointment. Due to this – and the clashes (time-wise) that there were between the government-provided sessions and Inspire sessions, they finally chose Inspire services since, as noted before, they include everything the child needs. The provision of NGO services, however, is not without its share of obstacles.

Benjamin's mother notes that, since the government could only subsidise one service for Benjamin, her son with autism, they had to choose between different NGOs' services: they could only choose one, and if additional services had been used, no subsidies would have been forthcoming⁴⁷. They could not afford this second service, so they had to drop it. Julia's mother reiterates this, also saying that at one point Julia, her daughter with autism, used to attend two different services but then had to choose one. They chose Inspire because the programme offered by this NGO involves sessions three times a week and is holistic – the mother, indeed, would like it to be extended to five days a week. However, as Noah's mother notes, while they can afford to pay for extra services at Inspire such as her son's speech therapy, there are other parents who cannot afford to stop working and cannot afford – either time-wise (in terms of flexibility) or financially – to take their child to either

⁴⁶ The 'yellow card' refers to the Schedule V (Yellow Document), which entitles the holder to free medicinal treatment if the person has one of the listed chronic conditions. The consultant within the government health service can apply for a Schedule V card for the patient. More information can be found here: <https://deputyprimeminister.gov.mt/en/poyc/Pages/360%C2%B0-One-Stop-Shop-Service-Concept/Medicines-Approval/Schedule-V.aspx>

⁴⁷ Currently, the government in Malta (through such ministries as the Ministry for Education and Employment and the Ministry for the Family, Children's Rights and Social Solidarity) subsidises particular programmes and services provided by NGOs such as Inspire (rather than offering persons with disabilities financial support and allowing them to use it for whichever services they choose). Only a few schemes such as the Empowerment Scheme run by *Agenzija Sapport* (<https://sapport.gov.mt/en/Pages/Empowerment-Scheme.aspx>) offer persons with disabilities financial support for equipment needed for them to lead a more independent life. Some parents, like Benjamin's mother, think the fact that they have to choose one service is unfair.

free therapy or paying ones. Private therapy is expensive and if you cannot afford it, she states, you are “up against a wall” (“dahrek mal-ħajt”).

Leisure and Sport

Leisure: Transport

The discussion on services in the previous section is also linked to access to leisure. Indeed, both Manuel and Rita, the two older people who are blind, have very limited access to leisure activities. As Manuel notes:

*“Anqas tirranġa għal affarijiet tal-bżonn, ġieli, aħseb u ara għal tad-divertiment!”
“I don’t even have enough access to necessities, sometimes, let alone for leisure!”*

The major challenge in Manuel and Rita’s lives with regards to leisure is transport. Rita relates how she misses out on a lot of opportunities (in leisure as in other areas) because of this. In Manuel’s case he also needs to have an accompanying person:

“It-transport huwa problema għax importanti li mhux iwassluk u jitolqu hemm. Jien irrid bniedem li jibqa’ miegħi. Għax kieku ħlas inħallas hux: ma jstax ikun kolloxx b’xejn f’din id-dinja. Tas-Support b’xejn. Għandi sigħat, intitolat għal sigħat u kif naqbiżhom inħallas. Imma noqgħod attent li ma naqbiżhomx. Ma noqgħodx ngħidilhom ejjew ixtruli jew ħuduni hemm, nużah għas-saħħa biss dak.”

“Transport is a problem because it is important that not only someone takes you there – I want someone to stay with me. I have no problem with paying – you cannot have everything for free in this world. Support services are free: I have an amount of hours, and as soon as I go over, I pay. But I am careful that I don’t go over. I don’t ask them to accompany me for every little thing – I only use them for health.”

Rita, however, does use *Aġenzija Support* services once a week to go out for food or drink. She also participates in the social and cultural outings organised by Spero Training Centre for the blind⁴⁸ (which she attends) and the Malta Society of the Blind⁴⁹, as long as transport is provided. Mark, a man with autism, is involved in various sports and leisure organisations, both in those targeted at people with disabilities (such as Opening Doors⁵⁰, an arts organisation for adults with intellectual disabilities); as well as in mainstream ones. His major obstacle is also transport, however: since he does not drive, he uses public transport which renders it difficult to get to certain places on time.

Leisure: Access

Once again, physical accessibility presents itself as an obstacle to many persons with disabilities in accessing leisure services. Many leisure places that Claire, a woman who uses a wheelchair, would like to go to, are physically inaccessible to her:

“If I like discos, many discos are not accessible. Even the roads are bumpy. They are not good for the wheelchair. They are not physically accessible. Not even the houses: for example...I want to go and spend the day at my friend’s house... the house is not accessible and because I am in a wheelchair I cannot go up the stairs so they cannot take me in the house because of the wheelchair and the wheelchair, I cannot take it off. Sometimes I end up crying because I’ll want to go but they can’t take me... It’s difficult ...many cinemas have stairs so I can’t go... and many cinemas you have to stay in the front. You can’t go at the back... you have to stay in the front. With the wheelchair you find many obstacles.”

⁴⁸ <http://www.outlook.coop/News/Outlook-launches-SPERO-Centre/2711>

⁴⁹ <http://maltasocietyoftheblind.org>

⁵⁰ <http://openingdoors.org.mt>

Josephine, a woman with spina bifida, on the other hand, says that she finds no problems in going to the theatre or cinema: when she and her companions go, the manager prepares places for them. However, Stefan's mother talks about the inaccessibility of certain restaurants which do not have ramps, platform lifts or adequate lifts (lifts big enough for a wheelchair to go in without difficulties); and the lack of adequate toileting rooms for adults with disabilities who need help with changing, like her son with PNLN: while there are nappy changing rooms for children, leisure outlets do not provide adult changing rooms, for example by having a foldable couch (which are not provided in other places such as hospital either). Kristina's mother notes this lack of appropriate toilet changing facilities for adults with disabilities also in beaches, where, although noting many have become accessible, she cannot take Kristina, her daughter with Joubert Syndrome, to the beach because she refuses to change her daughter in full view of others.

For others, the obstacles take on a less physical shape, but still impede people with disabilities from enjoying social activities. Andrew, a person with OCD and anxiety, confesses that he does not "have much of a social life", because he does not feel comfortable socialising (for more about stigma and lack of awareness, see 'Abuse and Hate Crimes' section). Although Richmond staff encourage him to do so, he says:

"It's difficult because I get nervous that people won't accept me the way I am....It's easier just to have my dog and be at home...relaxed."

Cinema, Theatre and TV: Deaf People's Experiences

The cinema and theatre prove to be inaccessible for people with various disabilities, not only those with physical ones. While part of the inaccessibility is perhaps unavoidable – in the sense of them being visual kinds of entertainment, thus rendering it rather difficult to make them accessible for people with visual impairments⁵¹ – many other aspects are not. Cinema is a huge problem for Deaf and hearing impaired people. Roberta, a Deaf woman, talks of how a cinema hall used to show films with subtitles, but only at 4pm. As she rightly asks:

"Jekk inti ta'ndem, min ha jmur jara film fl-erbgha ta' wara nofsinhar matul il-gimgħa?"
"If you work, who's going to go watch a film at 4 o'clock in the afternoon on a weekday?"

Even when there was a film showing on Saturday (with subtitles), Roberta asks:

"Għaliex mhux fit-tmienja, bħal haddieħor?"
"Why not at 8pm, just like everyone else?"

This last question posed by Roberta captures the spirit of what inclusion truly means. Later in the interview, Roberta acknowledges the fact that some people might not like watching a film with subtitles. However, having a subtitled film at one single time where people cannot (or would not prefer to) go to the cinema, does not, in reality, signify accessibility. On the contrary, it is perpetuating segregation through 'forcing' Deaf people to watch films only at a certain hour, an hour which is not feasible to many. For this reason, Roberta, who has a son who is not Deaf, cannot take him to the cinema but has to send him with her mother or sister. The application which enables one to have subtitles does not enable one to enjoy the cinema experience either: as Amanda's mother relates, one has to look at the tablet all the time and thus cannot follow the film. She says that there was once an initiative by *ŽiguŽajg*⁵², where an interpreter was present for some films, but this event has not been repeated since.

⁵¹ Having said that, services of audio description can be provided.

⁵² <http://www.ziguzejg.org>

Furthermore, Roberta and Amanda point out, most of Maltese television broadcasts have no subtitles either, thus making them once again inaccessible to Deaf people.

Music

Music plays an important role in the life of Benjamin, a boy with autism. The fact that he plays drums and people appreciate his strengths – it makes him very proud of himself. Music has also proved to be accessible to Amanda, a girl with hearing impairment, who loves playing the piano. As her mother says, the teacher believes in her and has arranged for special treatment during piano examinations: for theory ones, she is placed in a room on her own; and for practice she has an interpreter. However, Amanda's mother says that she knows the public school of music also supports some students with disabilities, and it would be good if the school publicises this.

Sport

Matthew's mother talks favourably of sports organised for disabled people. Matthew, a boy with visual impairment, plays football with an organisation of sports for disabled people, who are very dedicated to Matthew and the other athletes, and Matthew is very happy there. Benjamin's mother, however talks about how since Benjamin, her son with autism, plays with Special Olympics⁵³, when she tried to get him to play in mainstream bowling (so that he does not only play with disabled youths but also with non-disabled ones), she was told that he cannot because "he's Special Olympics". She reported this to the head of Special Olympics who deemed this was discrimination, and so the situation was resolved. Other children like Dylan, a child with visual impairment, cannot exert himself too much, run or jump so he does not even do sports at school. He does however, enjoy swimming and going abroad.

As regards Deaf people, they can do most sports. However, attention needs to be paid to racing competitions: Deaf people cannot hear and thus they need other ways to know that the race has started. There are ways, Roberta, a Deaf woman, says, that Deaf people can be enabled to participate in such events. This is confirmed by Amanda, a girl with hearing impairment, who, although she participates in swimming, does not hear when the instructor calls 'Go' and has to look at other children to see when they jump. She also has difficulty in understanding her swimming instructor at Inspire. It is worthwhile noting that, while not mentioned by the interviewees, team sports such as football or volleyball provide similar obstacles to disabled people due to whistles used by referees.

Guardianship and Planning for the Future

Guardianship and planning for the person's with disability's future are often causes of worry for both the person with disability and their carers. Stefan's mother talks about the legal guardianship of her son who has PNLD: *Aġenzija Sapport* asked them to go to the Guardianship Board to obtain legal guardianship of their son with regards to their son's finances. However, Stefan's mother notes that she would have liked more information from *Aġenzija Sapport* on this, since they were given different information by the bank and by the Agency, and suggests that the two entities meet with some of the banks to discuss this issue. She would like more help to parents with regards to legal guardianship and how to manage someone's finances. This is a significant appeal, especially when taken in light of the following discussion, in the remainder of this section, regarding dependence on disabled people and their (and their carers') worry on what will become of them once their parents pass away.

⁵³ <http://specialolympicsmalta.org>

Role of Family Members

The role of family members comes out strongly in many of the interviews, as is also discussed in the 'Goods and Services' section. The importance of parents' involvement, for example, comes out clearly in Roberta's case, who, being a Deaf girl studying in a time when LSEs and interpreters at school were not present, depended heavily on her parents' support to keep up with school studies:

"Li konna nagħmlu l-iskola konna nagħmluh id-dar mal-mamà u l papà. Kieku ma kinux huma, ma kont nasal imkien."

"Everything we used to do at school, I used to do it at home with my mum and dad. If it hadn't been for them, I wouldn't have gotten anywhere."

As seen in the 'Education' section, the role of parents is key to their children's advancement. However, family members do not always help the person with disability, despite their best intentions. Joseph, a 52-year old man with depression and other mental health difficulties relates how:

"Tal-familja ma jifhmux... pjuttost itellfuk milli jgħinuk... Perezempju, anki l-fatt li jgħiduli: 'Int qed tirreċta?' Dik tweggħek."

"Family members tend to impede you instead of helping you, because they don't understand... For example, they tell me: 'Are you feigning it?' That hurts."

Rita, a 63-year old woman who is blind, emphasises that at times she finds it easier to deal with support staff with regards to aspects of independent living, rather than with family members:

"Dawn l-istaff tagħna... ikunu ittrenjati. Iktar ikunu jafu kif għandhom imorru miegħek milli tal-familja għax eżempju [dawn jgħidulek]: 'tgħaġġbiex;...u le għax miskina; ara ma tabbużax tmur hemm imbagħad; ara ma tabbużax toħroġ'... Jitfgħuk lura tal-familja ħafna...din tgħodd għad-disabled kollha mhux għaliya biss bħala blind. Għax tant ikunu jridu jiproteġuk...li iktar idejquk u jirrabjawk jiġifieri – iktar jagħmlulek ħażin."

"Our staff... are trained. They know how to behave with you, unlike family members, because for example [these tell you]: 'don't make a fuss;... no, you poor thing; don't think of going there then; don't go out (don't push it!)'... Family members keep you from moving forward... this applies to all disabled people not just to me as a blind person. Because they want to protect you so much... that they irritate you and make you even angrier – they do you more harm than good."

Rita's comments touch upon an issue which is a reality for many of the research participants: overprotection, which is the topic dealt with subsequently.

Overprotection

One element that comes out strongly in the interviews is the element of overprotection. As Fabian, a 28-year old man with physical disability notes:

"Il-genituri għandhom tendenza li jiproteġu lill-persuni b'dizabilità b'mod esaġerat."
Parents have a tendency to protect disabled people in an exaggerated manner."

But while Fabian feels he has addressed the issue and deals with it in his own way (sometimes by going behind his parents' back, because, as he says: *"huma mħumiex għal dejjem u jiena rrid naħseb għall-futur tiegħi"* – *"they are not [going to be here] forever and I have to think of my future"*), others do not find it so easy.

Amanda’s mother voices her concern regarding letting her daughter, a 14-year old girl with hearing impairment, go out with her friends, saying that she is afraid of strangers with bad intentions (for example on public transport) speaking to her daughter. Amanda, however, counteracts this with insisting she gets fed up at home and wants to go out with her friends. Matthew’s mother voices similar concerns: she is afraid of letting her 16-year old son who has visual impairment go out socially. She also accompanies him to the ATM because she is afraid that someone will steal the money he withdraws, or that he will not be able to retrieve the money before the machine takes it back. With regards to his education, the mother is also very much involved, and often makes Matthew’s decisions for him and speaks in the ‘we’ person when Matthew has to, for example, choose what subjects to study at school:

“Il-head tal-iskola riedu jieħu bilfors Biology: ma tarax ħa jmur jiftaħ xi heart! Għidtlu sciences insa - mhu ser intih xejn... u kellna nagħzlu bilfors Physics għax kellu jkun hemm one science [subject].”
“The head of school wanted him to take Biology: as if I’m going to let him open a heart! I told him forget sciences – I won’t give him even one science subject...and we had to choose Physics, because he had to have one science subject.”

As seen in the ‘Education’ section, the role of family members, especially in the child with disability’s life, is essential, regardless of the strength of support from the government. The parents play a key role in the child’s wellbeing and in his / her advancement and achievements. In this sense, the heavy involvement of a parent in a child’s life appears to be a double-edged sword, with one edge being crucial to a child’s flourishing, while the other potentially resulting in over-involvement. This is exemplified again by Matthew’s mother when she relates an incident where the Inclusive Education Coordinator (INCO) suggested that Matthew should not sit for O-Levels:

“Għidtilha: ‘It-tifel tiegħi u nikkmandah jien mhux tikkmandah inti. Fil-fatt għamel erbgħa O-Levels: għamel Malti, Inġliż, Taljan u Maths. Fit-Taljan ġab 5: mela dan it-tifel diġà hemm xi ħaġa li hu kapaċi.... X’jigifieri tiġi tgħidlek mhux kapaċi t-tifel?”
“I told her: ‘The boy is my son and it is I who will command him, not you.’ In fact he sat for four O-Levels: Maltese, English, Italian and Maths. He obtained a grade of 5 in Italian; so it shows that the boy is capable.... How dare she tell me the boy is not capable?”

Dependence

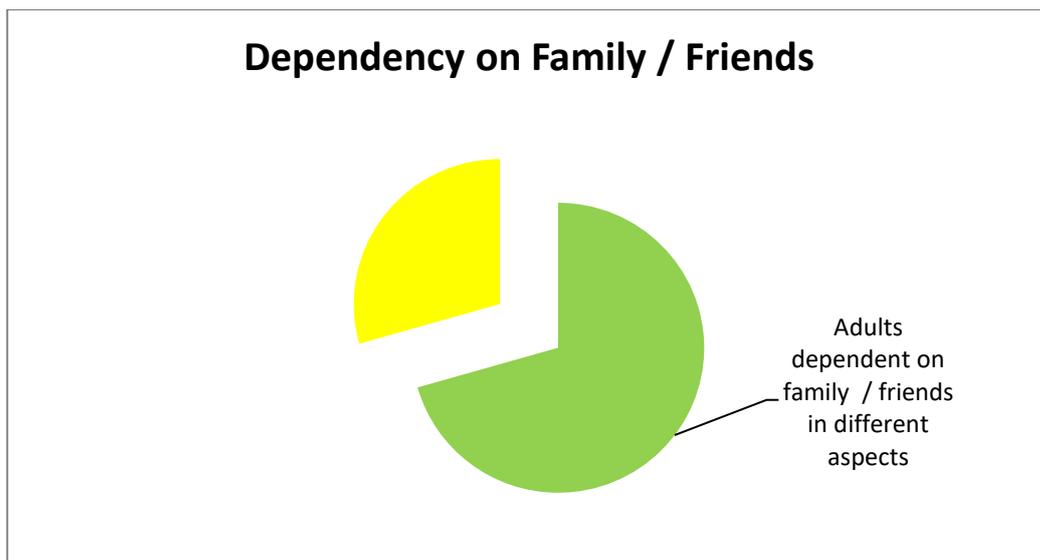


Figure 4: Participants saying they are dependent on family or friends

Overprotection may lead to dependence. However, even when the overprotection element is not apparent, dependence on family members is a reality for many disabled people, whether they choose it or not. Roberta, a 39-year old woman, is conscious that she cannot keep on depending on her parents: they will not be around forever. However, she sometimes has no choice, such as when accessing healthcare and other services. The reliance on relatives also comes out in George's – a 61 year old deaf (and blind) man whose siblings accompany him to the hospital and to the hairdresser when he needs. His siblings also sometimes come to sleep over – he lives on his own – and cook for him (see 'Healthcare' and 'Goods and Services' sections).

Josephine, a 57-year old woman with spina bifida, is taken care of by her mother, but sometimes she does not like the fact that she is of a certain age and her mother still takes care of her. However, she cannot help it. While not everyone is unhappy about being taken care of by their parents – Mark, a 29-year old man with autism, says he is happy that his parents take care of him – the problems with dependence come out strongly in the interview with Claire, a 36-year old woman using a wheelchair:

"Most times I say my life is not mine. My life is depending on what others do... I cannot do really what I want."

She does not have enough friends:

"I live with my mother but...I don't want my mother, I want my own friends."

Thus she is dependent on a limited number of friends for entertainment, which does not fulfil her leisure needs:

"I have only one friend...and she's not the type of person to go to Paceville...I have to adapt and have to say: 'Where do you want to go?' Because I know that she doesn't like Paceville so I am not going to take her to Paceville. I try to accomodate my friends."

Even the few friends that she has are mostly people she pays for their services, such as carers. Furthermore, besides the frustration of being dependent on others now, she is also afraid of the future:

"To tell you the truth I am scared that one day I will end up alone."

This is the same preoccupation that Darren's mother voices: the worry about the future that her son, a 19-year old man with dyspraxia, will have:

"Meta aħna ma nkunux hawnhekk... dik hija vaga ħafna. Imissu l-gvern iserħilna naqra rasna: għax aħna allavolja nistgħu naffordjaw finanzjarjament li t-tifel meta jkun kbir ikollu home, però ma nafx jekk teżistix din t-tip ta' home fejn ngħid hemmhekk se nibbukkjah u jekk jinqala' xi ħaga lili u r-raġel, ikun hemm dik il-home u jidhol hemmhekk.... Dik tbeżżani: Il-futur."

"When we are no longer here... that is very vague. The government should put our minds to rest: because we, although we can afford it financially that our child, when he is older, has a home, I don't know if this type of home exists: where I say I will book him there and if something happens to my husband and me, there will be this home and he will go there. That scares me: the future."

In the case of Claire, she experiences a big problem in finding carers, since there are not enough. Due to this, she usually has to find a carer from an Agency, which is more expensive (*Aġenzija Sapport* gives her funds and she has to find the carer herself). Stefan's mother notes the same thing with finding a paid carer to help her care for her son with PNLD. Meanwhile, she brings to light the perspective of a mother who, while happy to care for her son, talks also about the relief she and her husband find when they take their son to a respite centre, whose services are, in her own words, "excellent", and where they can rest for a few days.

Abuse and Hate Crimes

Bullying

Both children with visual impairments report that, whilst they have a good number of friends, they are or were bullied at school. In the case of Matthew, for example, a 16-year old student who was made fun of by other students due to his impairment, while the school administration was helpful, the problem was not fully resolved and Matthew ended up ‘dealing’ with the problem himself by hitting the boy who was bullying him. Warren, a 42 year-old man who has schizophrenia and mild learning difficulties, recounts how he used to go to trade school⁵⁴ where he was bullied. Following this he had mental health problems and had to go to Mount Carmel Hospital. He did not find much help from teachers (who were sometimes helpful and at others not) or family: his father thought he was imagining things.

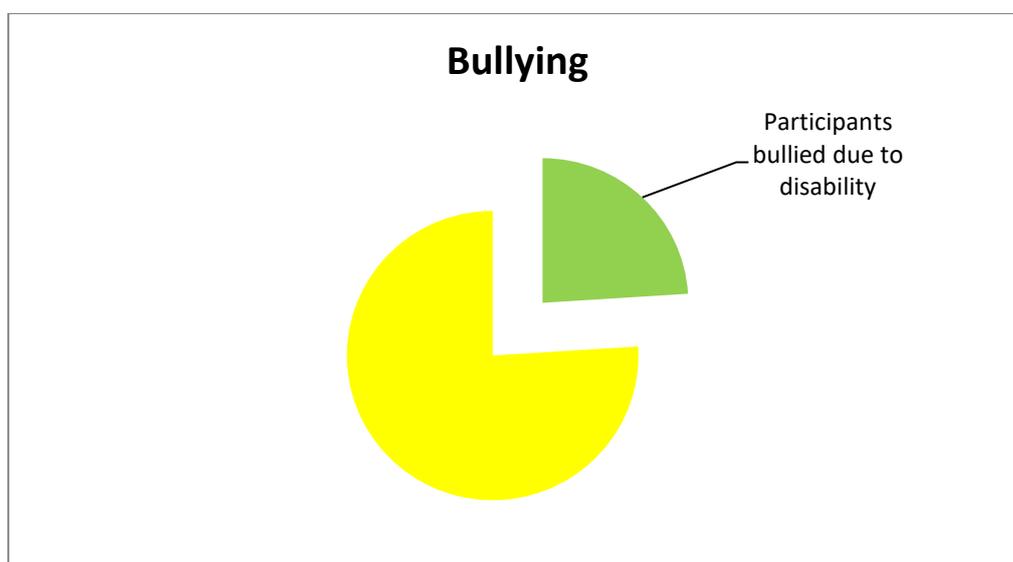


Figure 5: Participants saying they were bullied due to their disability or related circumstances

Negative attitudes towards students with disabilities also occur at post-secondary level. At MCAST, Mark, a man with autism, found some difficulties with lecturers, and also due to the fact that he was the only man among many women doing the course he was doing. However, Mark’s greatest problem at school were his schoolmates, both at secondary school and at MCAST, where, although he had friends, they did not invite him to social events “*għax kulhadd jibza*” – “*because everyone was afraid*”. Once, he even went out to a nightclub and his friends left him there. His LSE and the guidance teacher offered moral support. After that, he found refuge in drama (see ‘Leisure and Sport’ section).

This is not to say that all children with disabilities are bullied. Darren, a man with dyspraxia, had a very positive experience at school: other children not only never bullied him, but used to help him, both in primary and secondary school. It is once again important to note, however, that Darren went to a private school, whereas Matthew, Warren and Mark went to public ones.

Bullying also occurs in other settings. Patrick, a 13-year old boy with autism, is currently residing at KIDs (Kids in Development residential programme provided by Richmond Foundation) and is soon moving to a residence for minors run by *Aġenzija Sapport*. Patrick experienced bullying at KIDs, where, his key worker says, he used to be so afraid of them that he used to go in a room on his own

⁵⁴ This became MCAST in later years.

and cry. With the current cohort, however, Patrick feels safe. Furthermore, Patrick is currently under a care order⁵⁵: his Supervised Access Visits (SAVs) to his mother have currently been suspended since they were deemed detrimental to his wellbeing, although he would like to have them reinstated. However, when he used to live with his mother he used to throw a lot of tantrums and thus, Patrick relates, he used to be sent to the Young People’s Unit (YPU) at Mount Carmel Hospital, where he spent long periods of time and used to be bullied by the other children. He used to speak to the nurses about this and they used to put the bullies in solitary confinement to calm down.

Stigma and Lack of Awareness

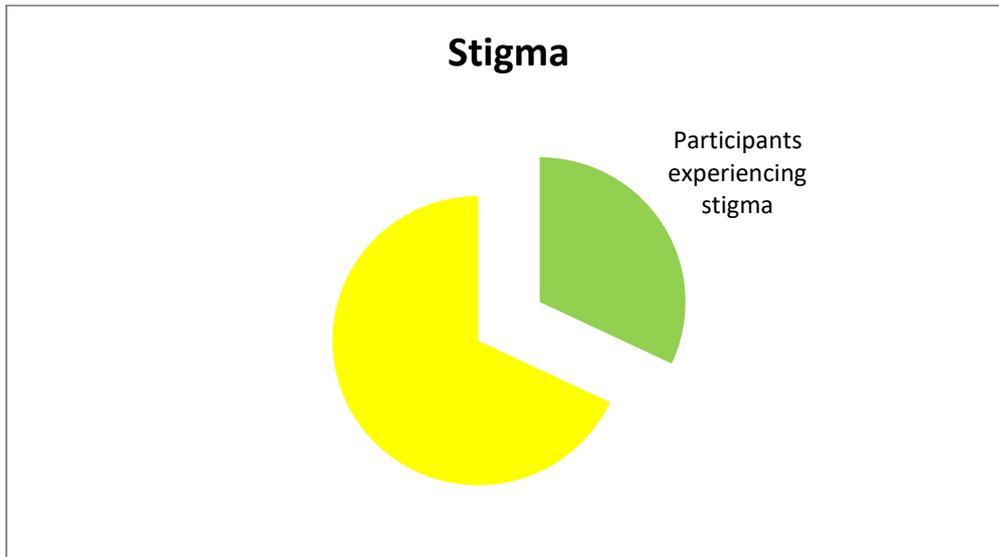


Figure 6: Participants experiencing stigma due to disability

Stigma and lack of awareness are themes which run throughout many participants’ observations, so much so that Rita, a blind woman, emphasises that there should be more education to children to teach them about disabled people, in order to reduce staring and stigma. Lack of awareness of disability issues has been mentioned in various sections of this report, but it merits a section on its own, due to various research participants relating related incidents.

Similar to Mark’s experience at work (see ‘Employment’ and ‘Justice’ sections), certain incidents arose with Benjamin, a child with autism, due to people’s ignorance of autism and its manifestations. An example was when Benjamin touched a woman’s necklace in a doctor’s waiting room and the woman, interpreting it as sexual harassment, threatened to go to the police. Another time, a neighbour told Benjamin’s mother that since he was 3 years old (at the time) and did not speak, she should put him in a corner and leave him without food or drink, an incident which still upsets Benjamin’s mother today:

“I’m trying my best to make him move forward so one day he will be accepted in society which unfortunately is not accepting him.”

Julia’s mother also used to experience people looking at her child with autism and asking her “*X’għandha?*” – “*What’s wrong with her?*”. Similarly, Stefan’s mother, while commending the accessibility of some of the beaches where boardwalks and equipment have been installed, notes that:

⁵⁵ Thus his care and his custody is under the current Ministry for the Family, Children’s Rights and Social Solidarity.

“Trid titbiddel il-mentalità tan-nies ukoll. Għax għandek l-affarijiet bżonnjużi, imma hemm nies li jibqgħu jħarsu lej. Jew jgħidulek: ‘Miskin, ara jaħasra’.... Ħallih, dak li jkun! Għandu l-libertà tiegħu: jista’ jiġi l-baħar ħa jgawdi l-baħar bħalek.”

“People’s mentality has to change as well. Because now there are the necessary things, but there are people who just stare at you. Or they say: ‘Poor thing’.... Why can’t people let him be? He has his own freedom and can come to the beach to enjoy it, like you.”

Noah’s mother also mentions this, in the sense that many people do not know, that, for example when her son is throwing a tantrum, it is not simply because he was denied something, but that he is on the autism spectrum.

The lack of awareness also comes out in interviews with people with mental health difficulties. Joseph, who has depression, talks about people (both at work and within the family) not understanding his difficulty and thus speaking in (perhaps unintentionally) hurtful ways:

“Eżempju, sifirt: ma ridtx insiefer, imma ħabba t-tifel kelli nsiefer. Issib min jgħidlek: ‘Biex issiefer kellek aptit: ma kellekx depression.’ Kummenti li jwegġgħu.”

“For example, I went abroad: I didn’t want to, but I had to because of my son⁵⁶. And there are some who tell you: ‘To go abroad, you felt like it: you didn’t have depression.’ Comments that hurt.”

Amanda’s mother feels that there is not a lot of awareness on children who are Deaf. When you are a parent with a Deaf child, she says:

“Qisha xi ħaġa ta’ barra minn hawn meta għandek it-tfal Deaf.”

“When you have children who are Deaf, it’s like it’s something out of this world.”

She also says this about using sign language in public, which is frowned upon by some: some parents do not want to speak to their children in sign language because they believe it is detrimental to the child. Partly due to these beliefs, Amanda’s mother insists, statistics show that not a lot of people use sign language and that there is therefore no great need for interpreters: authorities do not understand that even the few people who use it lack sign language interpreters. Thus, sometimes, awareness takes a step backwards due to parents themselves.

On a related note, Dylan’s mother, whose son is visually impaired, brings up the point of the cruciality of awareness by authorities, insisting that laws need to be discussed with disabled people and their relatives before they are passed, in order to see if they are adapted to people with disabilities.

Justice

As mentioned in the ‘Employment’ section, Mark, a man with autism, did not have it easy during previous work experiences, and went to court twice because of this. Mark had a negative experience at his previous place of work, saying some employees and his manager used to hit him. Once, he was suspended (with the CEO threatening him and his mother that he will get the police, which Mark took very badly. Mark explains that the staff had no idea what autism is.) because they mistook his epileptic seizure for masturbation. He was brought before a Board and his probation was prolonged to a year (instead of 6 months). He also went to court and since the accused did not appear, the lawyer told Mark and his family that he won the case. However, the case reopened and Mark started having more seizures due to his mental exhaustion. In both court cases, Mark and his family had a hard time due to lawyer not showing up, the process taking long (one case taking almost two years),

⁵⁶ His son is diabetic and is losing his sight. He thus needs to take him abroad for medical treatment.

and not being informed of what is happening. In one case, Mark and his family approached the Ombudsman who said he cannot help them since the case was decided in court.

The traumatic experience of going to court is brought up by other research participants. For people who have difficulties with anxiety, like Andrew, the court experience can be very stressful, especially when they are the victims:

"It's very difficult when you have this disorder when you have to confront legal issues... it's hard to describe. It's not comfortable at all."

Today he is afraid to take someone to court. Andrew lent a large sum of money to someone who has not paid it back (he feels he has been manipulated into doing so because of his disorder). He feels it is time to take action, and he is also encouraged by a friend to do so. However:

"I have fear and anxiety when it comes to legal things... I'm afraid of the stress: I don't want all that stress. I know I have a right and I know that I have to stand up for myself, but..."

He expresses the wish that there was an organisation that people with problems like his can go to:

"... where people like me with this problem, can go and speak to a lawyer who will understand that what happened to me was because of my OCD, that it wasn't that I was just being frivolous and throwing money away: it was manipulated out of me and I would like some legal help."

Andrew continues:

"I don't think I'm the only person. I think there must be others who would like legal representation for their rights and maybe they will stand up for themselves if they have help, but without help it's just easier to let go. It's too stressful to handle.... If we had legal representation – someone on our side who understands what we go through – maybe it would be a good step forward."

Rachel, a teenager with social and emotional difficulties, was abused by her elder brother. The court case regarding this has been dragging on for years, and she is still waiting for the sentence. During this time, she has been in foster care and for the last three years she has been living at KIDs at Richmond Foundation. As the residential worker who accompanied her to the interview says, it is the victim who had to leave home – Rachel is under care order and cannot live at home, while her brother still does:

*"U dik lil [Rachel] tkissirha ħafna."
"And this breaks Rachel down".*

Furthermore, she still has to go give testimony at court and she is scared every time she goes: she is scared of the police. Thus after her trauma, Rachel has to go through another trauma of a dragging court case and not being able to go home. All she wants is for the court case to be over as soon as possible and that she goes to live with her mother.

In the aspect of justice, the issue of service providers' attitudes and awareness of disability issues also emerges. Warren, a man with schizophrenia, and his residential worker, reiterate that some civil servants have no idea of disability issues, and have even laughed at them when they came into contact with persons with disabilities or disability issues (similar to a case mentioned in the 'Goods and Services' section). Furthermore, Warren was once hit and when he went to the police he was brushed off. Warren's residential worker insists that the police do not take people with intellectual and / or mental disabilities seriously and insists:

“It’s not professional. It’s unethical. It’s against human rights.”

As Warren’s residential worker acknowledges, when police officers come into contact with persons with intellectual or mental disabilities, they might be scared on how to proceed. For this reason, the police force needs more information and training regarding people with disabilities, and how to tackle such situations. As Warren’s residential worker points out, there is also the need to see how those people with disabilities who are unable to communicate verbally can be protected when they encounter abusive situations. Thus, training to the police needs to also include how to be sensitive and how to address people with disabilities who are more vulnerable than others.

Conclusions and Recommendations

Access to Information

From the above discussion of research findings, it is evident that one of the major issues that emerges is the lack of information: lack of information to disabled people and their carers about services, and lack of information to services providers on disability issues. As many research participants stress, information on different services, social benefits and human rights needs to be made available and widely advertised in ways that people can easily access. Many interviewees seem to be obtaining information by word of mouth. While this is not necessarily a negative factor, there needs to be a systematic dissemination of information in order to reach as wide an audience as possible. Timely information is crucial especially (although not only) to parents at the point where their child is born / diagnosed with a disability; and to those persons who become disabled at a later stage in life. As the research participants themselves suggest, information disseminated through mass media (such as TV and radio) is essential, but also through leaflets at key places such as hospitals and private homes. Evidently, the information needs to be accessible for people with different kinds of disabilities and target people through the media they use most. For example, as some participants with visual impairments mention, technology is everything for them, however there is as yet no good Voice Recognition Software in Maltese. This is important for older people with visual disabilities and others who might not have a good working knowledge of English.

From the research findings, it seems there is a need for the publicisation of the existence of the various entities working with and for persons with disabilities, as well as their role and the services they offer. This needs to occur not only among the disability community but also among the public in general. The latter is important since, as noted before, one of the most crucial times of a disabled person's life is when a person has newly acquired an impairment or when parents have just had a child born or diagnosed with a disability. The CRPD already organises awareness raising through such media as TV programmes. However, both the CRPD as well as other entities need to be supported with adequate funding in order to be able to expand these activities such as publishing regular publications to be disseminated in private homes. It is worthwhile noting that the CRPD is currently working with Mater Dei, physiotherapists and occupational therapists in order to design leaflets to provide such information. Work is also underway to set up a register of disabled people who can speak to people who have just acquired a similar impairment. Furthermore, *Aġenzija Support* plans to launch a One Stop Shop, bringing different disability services' information under one roof; thus some of the information needs mentioned here might be met through this initiative.

Secondly, there needs to be a comprehensive updated database of all entities working with people with disabilities and what services they offer. While a services booklet exists, this needs to be continually updated and made accessible to persons with various types of impairments. Once again, adequate funding needs to be provided to support such activities. This also applies to other information such as that published on related websites, which need to be provided in, for example, an Easy-To-Read version in order to be accessible to people with intellectual disabilities. Another possible way of reaching disabled people is having a helpline (which might depend on the possibility for independent mechanisms of having helplines) with view calls and sign language interpreting.

Awareness Raising and Training

Relatedly, the CRPD and the Disability Studies Department at the University of Malta raise awareness (including through commissioning and carrying out research) and provide training on disability issues. However, based on the research findings, there is evidently a huge lacuna still in existence with regards to, for example, government departments' staff. If people with disabilities are

being laughed at or shrugged off on issues of physical accessibility or justice by public service officials and private entities (even when it means that the latter might lose clients with disabilities, such as in the case of the ATM mentioned in the research findings), then there is evidently a need for awareness and training. Furthermore, if, for example, hospital staff is not trained with regards to disability issues, the SID is not fully effective in this case. While it is recognised that in cases of emergency, disabled people should not have priority over urgent cases; for regular appointments, it would make sense for people with disabilities such as anxiety-related disorders or behavioural disorders to get priority.

Accessibility

Another great obstacle that disabled people encounter in their lives is accessibility, and the CRPD has been key to promoting accessibility of public places in Malta and Gozo. Much progress has indeed been made in this area, but evidently more still needs to be done.

Leisure services, for instance, seem to be inaccessible for people with various disabilities, such as cinema for Deaf people and places in Paceville for people with physical disabilities. Furthermore, the fact that shops, roads, pavements, transport, housing and services (including health) still remain inaccessible for many people denotes the need for further investigation and problem solving. It might be beneficial for fora to be organised in which service providers, service users and authorities⁵⁷ could be brought together to discuss such issues as these, in order to identify what is still restraining full accessibility, and promote accessibility within reasonable limits.

Other aspects could have more straightforward solutions. For example, Mater Dei Hospital could install systems such as those which already exist in health centres, where patients are given a number which is then called through a PA system and screen, instead of being called by a nurse / health aide in a noisy room. This would be accessible to people with any kind of sensory impairment. Similar measures can be taken to render public transport more accessible to people with visual impairments. Bus stages could be equipped with an audio system which announces the number of the approaching bus and the length of time remaining for the bus to arrive. Simpler measures can include the bus driver announcing the number of the bus once the bus arrives on the stage.

Regarding the education system, examinations can be replaced by practical assignments in order to reduce anxiety for students with anxiety disorders and thus encouraging more students with disabilities to continue higher education.

Accessibility also emerges as an issue in housing. While people with physical disabilities have difficulties in having accessible housing, this is also an issue for those with visual disabilities, albeit for different reasons. While people with physical disabilities require ground floor apartments with no stairs leading up to them, the parent of one child with visual impairment states that she had no difficulty in giving up her ground floor apartment to move to a larger non-ground floor one. This suggests the need for better profiling of service users by the Housing Authority, with the possibility of enabling the swapping of housing where necessary and feasible.

Personal Assistance and Human Resources

Personal assistance, while meriting more in-depth study, needs to be mentioned here as an aspect which comes out in the interviews and is crucial to many disabled people. People with visual disabilities, for example, might benefit from personal assistance more than guide dogs that they would need to train and take care of, which might be a burden both financially and in other ways. Furthermore, as some participants with visual disabilities mention, they need accompaniment to

⁵⁷ Inter-departmental and inter-authority communication is also important.

access services, including leisure ones. While such services are provided by *Aġenzija Sapport*, there is evidently more need for them. It is evident that there is a shortage of the required staff needed by disabled people in order for them to be able to lead independent lives, such as interpreters for Deaf people. The issue of shortage of staff comes up with interviewees even in entities such as the CDAU and the Statementing Moderating Panel. One way of combating staff shortage is evidently the financial investment by the authorities in incentives encouraging young people to work in these areas. The government could launch campaigns to encourage young people to become speech and occupational therapists by enhancing work conditions if necessary; or for LSEs to study sign language (with a higher salary than a normal LSE's attached to the job).

Dependence and Guardianship

Dependence, on family members and other carers, a recurrent theme throughout this research, is partially linked to the lack of staff and lack of information mentioned above: if services are not available, disabled people have no choice but to depend on family, friends and carers. Another reason is also the overprotection of people with disabilities by family members, which a great number of research participants mention and has also been the subject of other research studies such as that conducted by Callus and Bonello (2017). The latter, although exploring issues encountered by people with intellectual disabilities specifically, reiterates that while many people with intellectual disabilities need support in their day-to-day lives, they do not necessarily need someone to make choices and decisions about their own lives, and confirms that there is a tendency to overprotection by parents in the case of people with intellectual disabilities in Malta. In this case, the importance of training for parents is also significant.

Dependence on family members however is also linked to the issue of guardianship, on which the research participants who need it state that they do not have enough information. Issues surrounding guardianship (such as its effectivity; and the remit and procedure of the Guardianship Board) need to be further delved into; and it would also be beneficial if the Guardianship Board publishes annual reports in order to render proceedings transparent. Such research would also need to cover issues of consent and other similar issues surrounding people with intellectual disabilities and mental health difficulties.

Future Research

While this research has spanned a vast span of disabled people's lives, it is evident that it only touches the tip of the iceberg and that more research is needed in order to have a more comprehensive and holistic view of the lived experiences of people with disabilities in Malta and Gozo. One important aspect in disabled people's lives that emerges from the interviews is the disability pensions and other social benefits that disabled people and their carers are entitled to. Other aspects which were only touched upon here and merit further research – possibly each topic merits a whole research project of its own – are physical accessibility, personal assistance, day centres and residential services.

Finally, as mentioned earlier, the importance of attitudes towards disabled people and the related stigma, awareness raising and training cannot be emphasised enough. Awareness of disability issues underlies all aspects of inclusion and the respect of disabled people's rights, both from the public and service providers, but also from the authorities. The greatest impediment to the flourishing of disabled people is the non-disabled society's lack of knowledge. Thus it is through the promotion of knowledge of disability and disabled people that the fear and stigma can be reduced and disabled people move forward.

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