

Enabling Technology in the Workplace:

Exploring the dis/ability-assemblage

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Submitted in accordance with the requirements for the degree of
Doctor of Philosophy

The University of Leeds
School of Sociology and Social Policy
Centre for Disability Studies

September, 2018

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Acknowledgements

To Dr Angharad Beckett, my principal supervisor. For sharing your extensive knowledge, for your insightful feedback, your precious time and your infinite kindness. Most of all for being there always, but especially during one of the most painful experiences of my life – the loss of my dear sister Terrie, two years ago. Thank you! I hope this is the beginning of a productive academic collaboration and a lifetime friendship.

A special thank you goes to Prof Alan Roulstone, my first principal supervisor, whose work on disability and technology inspired this research. Your expertise helped lay the foundations – I hope I did you justice.

To my other supervisors along different stages of this research journey, Prof Mark Priestley, Prof Anne Kerr, Dr Alison Sheldon. You taught me so much. Thank you!

To Matthew Wilkinson, Postgraduate Research Administrator. For your kind help.

To the Malta Government Scholarship Scheme for sponsoring the tuition fees.

To the participants of this study. For sharing your stories, your achievements and your struggles. Without you this project would not have been possible.

To my mother Maria and all my beautiful family. You generously helped and encouraged me in so many ways – I hope I will do you proud.

To my many friends. Thank you for your unfailing support. You are all so precious.

Special thanks to my colleagues and dear friends, Dr Anne-Marie Callus and Dr Sue Vella for your practical wisdom, your time and your genuine care. Thank you for keeping me going when I wanted to give up!

And most of all, to John, my dear husband. For your gentle presence, your infinite patience and your great love. Without you, I would not be where I am today.

To my father Angelo, my sister Terrie, my nieces Angèle and Elise, and to my friends and disability activists, Gordon, Kevin and Marcel: this thesis is dedicated to you – you are gone, but the beautiful memories of your lives continue to shine and brighten my life.

Thank you!

Abstract

This research explores Maltese disabled people's engagement with 'enabling technology' in the field of employment. Disabled people's right to work on an equal basis with others and to have access to relevant technologies to support them in this regard, is enshrined in the United Nations Convention on the Rights of Persons with Disabilities, a convention that Malta has signed and ratified. Accordingly, the study adopts a rights-based approach and is concerned with equity in disabled people's exercise of their rights. The study's starting point is a social model, UNCRPD-inspired approach, considering how barriers in the social environment hinder the participation of disabled people in the workplace. The research then builds upon this more traditional approach, to develop a mode of analysis informed by new materialist perspectives. In particular, the research deploys the concept of the 'network' and the 'assemblage' to analyse technologies that support Maltese disabled employees to engage in activities at the workplace, as components of complex 'entanglements' of human and non-human entities.

At the heart of the research is a qualitative empirical study informed by the aspirations of emancipatory research and new materialism. The 25 participants in this study had physical or sensory impairments. The research began with three focus groups, followed by 25 one-to-one interviews. Seven of the participants then consented to be observed whilst at work. The focus during the observations was on 'events', particular episodes of enactment of dis/ability within the workplace.

The research findings point to the persistence of multiple barriers and to 'dis/ability' as a shifting, relational concept, which is as material as it is social. A more sophisticated analysis of the relations within assemblages and networks that disabled people form part of at the workplace is thus called for. Stakeholders in the field are urged by the research findings to shape their policies and practices around the 'good' capacities that are produced within these relations, thus affecting new possibilities and 'becomings' for disabled people-technology-work assemblages.

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List of Abbreviations

ANT	Actor-Network Theory
AT	Assistive Technology
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DS	Disability Studies
ER	Emancipatory Research
ETC	Employment Training Corporation
FITA	Foundation for Information Technology Accessibility
HAAT	Human Activity Assistive Technology model
ICF	International Classification of Functioning, Disability and Health
KNPD	<i>Kummissjoni Nazzjonali Persuni b'Dizabilita'</i> (National Commission Persons with Disability)
NGO	Non-Governmental Organisation
NM	New Materialism
OT	Occupational Therapy
OTs	Occupational Therapists
SMD	Social Model of Disability
STS	Science and Technology Studies
UPIAS	Union of the Physically Impaired Against Segregation

Chapter 1

Introduction: The Research Contextual Framework

1.1 Introduction

This study is about technology, assistive and mainstream, and how it is, or might potentially be, enabling of the participation of Maltese disabled people in employment. It begins by exploring the topic from a social model approach (Union of the Physically Impaired Against Segregation [UPIAS], 1976; Oliver, 1990b), which proposes the binary impairment/disability. It considers the latter to be socially created and contrasts with the individual model of disability which views disability as a direct result of an individual's bodily impairment and which includes the 'medicalisation' of disability (Oliver, 1990a, no pagination). According to the social model of disability (SMD), the solution to the oppression of disabled people includes the removal of disabling barriers which exist beyond the mind/bodies of individuals, and the provision of supports that would enable people with impairments to be included in the community. SMD asks how, instead of disabling people who have impairments, society should think how disabled people might be enabled and supported to lead full lives. Employment and the labour market were a primary concern for the proponents of this approach and they suggested that disabled people's exclusion from this arena was key to disablement in society (UPIAS, 1976; Oliver, 1990b).

The SMD has been used ever since as a 'tool' for the identification of 'barriers' (Finkelstein, 2001; Oliver, 2004) and methodologically has led to various barrier-mapping studies (e.g. Roulstone, 1998; Shier *et al.*, 2009; Wilson-Kovacs *et al.*, 2008). This study therefore starts by mapping out the physical and social barriers (and enablers) that hinder (or facilitate) disabled employees from gaining access to, and using, technology such that they may carry out their jobs at the same level as their non-disabled colleagues. In disability studies (DS) there has been a tendency to view technology 'as principally occupying an assistive role' (Sapey, 2000, p.623). Research, however, shows that this is not always the case and demonstrates that multiple barriers still exist that hinder technology from being the enabling instrument that

it is designed to be (Roulstone, 1998; Robert and Harlan, 2006; Wilson-Kovacs *et al.*, 2008; Naraine and Lindsay, 2011; Critten, 2016).

A new way to understand the relationship between disabled people and technology and the disabling processes that can limit the potential of technology to be 'enabling' is needed. Barriers need to be analysed in a different way. In an effort, therefore, to build upon, but also move beyond, the social model approach, in the second stage, the research proceeds to consider the same issues from new materialist perspectives. New Materialism (NM) brings together the different standpoints on the recent 'turn to matter' (Fox and Alldred, 2017, p.3). Among the most noted new materialist thinkers are Bruno Latour, Gilles Deleuze, Rosi Braidotti and Karen Barad. They emphasise a relational, shifting ontology (not a fixed state) of the material world and its contents; a continuum of materiality between the physical and the social domains (not two distinct domains) and a capacity for affect/agency in both human and non-human actors. In this thesis it is proposed that NM may provide a useful perspective from which to analyse the relationship between technology, disabled persons and employment, offering fresh insights into *how* physical and social barriers operate within a workplace. The emphasis is therefore on the social production of disability rather than on its social construction (Priestley, 1998; Fox and Alldred, 2017). At this second stage of the research, therefore, the understanding of disability also shifts. It takes on a more relational interpretation. Technologies are analysed as components or parts of assemblages composed of human and non-human entities which form part of more complex, entangled networks in the workplace and beyond. The affective relations between the components are analysed in terms of the capacities that are generated within them through interaction. The study seeks to enhance DS perspectives on technology and disability in the workplace and to propose new ways of analysing/implementing policy and practice related to this vital aspect in the lives of disabled people. The goal is to provide actionable knowledge of use to relevant stakeholders, for example, disabled people and their organisations, policymakers, service providers, and healthcare professionals especially Occupational Therapists (OTs).

This chapter introduces the contextual foundations upon which this study rests. The motivations behind the research are stated, followed by the objectives and research questions that it seeks to address. Definitions of the main keywords, i.e. enabling technology, disability, employment and assemblages are then presented as they are to be understood for the purpose of this study. The chapter continues with a description of the Maltese context including demographics, a brief history of developments in the disability sector on the island, the disability policies and services related to employment and those related to assistive technology (AT). Finally, a structure of the thesis is presented so that the reader may know how the argument will unfold.

1.2 Study background and its motivations

As a disabled person myself, my own story has been the driving force behind my interest in AT. I obtained a diploma in Occupational Therapy (OT) in 1988 and, having worked in a variety of settings, I proceeded to do a Master's degree in Neurorehabilitation at Brunel University in London where I graduated in 1997. I worked for a year and a half at King's College Hospital in London and then returned to Malta in 1998, little thinking that five years later I would be returning to the United Kingdom (UK) as a patient myself. In fact, in March 2003 I had a road traffic accident in which I became paralysed from the waist down as a result of a complete spinal injury. Due to the limited resources in the rehabilitation of spinal injuries in Malta, I returned to the UK, this time to the National Spinal Injuries Centre in Stoke Mandeville Hospital in Aylesbury. During that time, I could appreciate the variety of assistive equipment and technology that exist to help disabled people like myself carry out activities ranging from the most basic of daily tasks to more complex work and leisure occupations. Although an OT myself, I had had little exposure to such technology in Malta and therefore I came back with a fervent wish to develop this area when back home.

Being disabled and an occupational therapist gave me an 'insider status' (Vernon, 1997, p.158). Griffith (1998) describes the 'insider' as having a feeling of sameness between her/him and the participants, which, however, cannot be solely due to having some of/the same characteristics as them (e.g. race,

ethnicity, gender or sexual preference). 'Rather, they [insider researcher claims] rest on biography, political activities, research practices, and the relation between the researcher and the community she studies' (*ibid.*, p.367). During this research process I felt that my biography and multiple social locations were shaping the research process in complex ways; I felt a tension between wanting to do things that are useful academically and wanting to do things that are useful politically and in practice; between having an intellectual agenda and a practice agenda. This was further incited by the fact that I am also an academic at the University of Malta and an activist in the Maltese disability sector. Inspired by the new materialist conceptual framework that will be introduced in further detail in Chapter 2, these four life roles, namely, being a disabled person, an OT, an academic and an activist, will be considered in this thesis as forming an assemblage – the researcher assemblage. This assemblage - my assemblage - will be part of the research process and the event being explored. It will therefore produce capacities not only for the research but also for myself as researcher. These may include, not only the capacity to produce new literature on the topic, but also to be reflexive and be able to propose new possibilities for OT practice and service provision as will be seen in the final chapter of the thesis. I am therefore positioning myself, firstly, as wanting to offer an important contribution to DS by enhancing DS perspectives around technology, employment and disability, and secondly, as desiring to speak to my professional field - OT - in a new way. This is not to say that the first position is more important to me than the second one. Both are equally important.

Apart from my personal story, the need for this study was felt by Maltese disabled people (*Kummissjoni Nazzjonali Persuni b'Dizabilita'*¹ [KNPD], 2010a) who are constantly faced with challenges accessing technology that may enhance their daily independence, especially in the field of employment. That this study was needed was also highlighted by the limited number of studies that have been carried out locally. These studies have shown that there are numerous barriers still existing in the AT field (e.g. Callus and Bezzina, 2004;

¹ KNPD has been renamed the Commission for the Rights of Persons with Disability as per Amendments to the Equal Opportunities Act (Bill 115) on 6th May 2016 (Fenech, 2018).

Foundation for Information Technology Accessibility [FITA], 2009; FITA, 2014; KNPD, 2014). Whilst until the age of 18, disabled people in Malta are generally being offered opportunities and support to develop to their full potential, they are encountering a huge lacuna when they come to enter the world of employment (KNPD, 2010a).

The employment rate of disabled people in Malta is very low. The last (2011) national Census statistics showed that only 16.5% of disabled people were employed when compared to the 51% of non-disabled people (National Statistics Office [NSO], 2014a). More recently, in 2014, 28.2% of disabled people in Malta were employed and although this indicates an increase in their employment rate, it is still very low when compared to the 48.7% of disabled people in the European Union (EU) member states who were employed in the same year (Grammenos, 2017). Although these statistics should be treated with caution because of the small sample, they place Malta amongst the EU countries with the lowest employment rates of disabled people (European Commission, 2017; Grammenos, 2018). Local research that offers explanations for these low statistics is limited and even more limited is the research that explores the relationship between participation in employment by Maltese disabled people and the availability and operations of supports required to enable their employment. One such potential support is technology. Although worldwide there are legislation and policies that affirm the importance placed on the role of technology to improve the lives of disabled people, and that ensures that the necessary mechanisms are in place (Equal Opportunities [Persons with Disability] Act, 2000; European Union Employment Equality Directive, 2000; United Nations Convention on the Rights of Persons with Disabilities [CRPD], 2007; Department for Work and Pensions, 2007; Equal Opportunities [Persons with Disability] [Amendment] Act, 2016), there is still a lot left to be done in practice to ensure that they are implemented effectively.

The CRPD, which is the latest international disability-related treaty (CRPD, 2007), positions access to AT as a human right:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all

persons with disabilities, and to promote respect for their inherent dignity.
(Article 1: Purpose)

States Parties are called upon to respect disabled people's right to AT in various Articles in the Convention (see Table 3.1: Articles relating to enabling technology), e.g. Article 4: General Obligations, points 1(g) and (h); Article 9: Accessibility, points 1 and 2(g) and (h); Article 20: Personal Mobility, points (b) and (d); Article 21: Freedom of expression and opinion, and access to information, point (a); Article 26: Habilitation and Rehabilitation, point 3; Article 29: Participation in political and public life, points (a)(ii); Article 32: International cooperation, point 1(d). Furthermore, in Article 27: Work and employment, point 1(i), States Parties are bound to 'ensure that reasonable accommodation is provided to persons with disabilities in the workplace', where AT is included in reasonable accommodation measures. All articles of the Convention are to be read as equally important and mutually reinforcing. For example, the right to personal mobility (Article 20) can be read alongside the right to work and employment (Article 27) in ways that suggest that people need to have access to transport to allow them to be active in the labour market and live independent lives. It is within this rights-based understanding that this research views access and use of enabling technology in the workplace and beyond.

Through this study, I would also like to build on the work of Prof Alan Roulstone, who was the first researcher in DS to apply a 'barriers-mapping approach' to the issue of technology use in the employment of disabled people (Roulstone, 1998). This work was used as an initial point of inspiration (Stage 1 of the research), and subsequently expanded upon, through the work of new materialist writers, in the second stage of the study.

This study, therefore, consists of a two-staged approach. Stage 1 is an exploration of social barriers in the field of disability, technology and employment in Malta. Extensive bibliographic searches have revealed no existing studies of this type in Malta. This approach was chosen because it provides Maltese disabled employees with a platform to voice their experiences and concerns around the subject. After identifying and documenting the persistent disabling barriers to the access and/or use of enabling technology in the Maltese workplace, Stage 2 considers how analysing the complex

relationship between disability, technology and employment, inspired by concepts from NM, may provide new and useful insights into human-technology 'assemblages' in the workplace. Unlike approaches that consider technology alone as the solution for the removal of disabling barriers in employment of disabled people, Stage 2 of the research would allow for solutions that are subtle and help avoid the pitfalls of the former approaches.

1.3 Research questions and aims

The study's aims are as follows:

1. To map the barriers and enablers, at the place of work and beyond, that limit or enhance the enabling potential of technology for Maltese disabled employees;
2. To explore, from a new materialist perspective, disabled employee-technology-workplace assemblages;
3. To identify the capacities that emerge from the relations between components within these assemblages;
4. To establish the place of these assemblages in their entanglement with other assemblages within and beyond the place of work, and the consequences thereof;
5. To explore how disabled people and their organisations might call for necessary change and improve the availability and operation of technologies that can support their participation in work;
6. To explore how stakeholders like employers, health professionals such as Occupational Therapists, policymakers and service providers might enhance their policy and practice to affect more effective participation of disabled people in work through the use of technology.

The research questions for this study are thus:

- a) From a social model perspective, what are the barriers and enablers, at the place of work and beyond, that limit/enhance the enabling potential of technology for Maltese disabled employees?

- b) How does working-age Maltese disabled people's engagement with technology translate into capacities (or incapacities) for their doing, being and becoming in the workplace?
- c) From a new materialist perspective, how do technologies form part of assemblages/networks/entanglements of human and non-human entities to produce consequences that are conducive to or limiting of dis/ability?
- d) How can disabled people and their organisations, employers, occupational therapists, technology service providers, and policymakers make use of NM as a tool to enhance their policies and practices in this field?

1.4 Clarification of terms

Classification of technology as related to disability can be found in various forms, such as: assistive versus rehabilitative or educational; low to high technology; hard and soft technologies; and commercial to custom technology (Cook and Polgar, 2008; Post *et al.*, 2008). The most commonly adopted definition for AT is the following:

Any item, piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities. (Assistive Technology Act of 1998, as amended [2004], 118 Stat. 1710)

This definition is limited in that it focuses only on the 'functional capabilities' of the person (doing) and does not include other consequences of the use of technology such as 'being', 'belonging' and 'becoming' as will be seen later in the findings chapters of this thesis.

Article 2 of the Maltese Equal Opportunities (Persons with Disability) Act: Cap. 413 (2000, p.1) defines AT as:

'assistive means' includes any palliative or therapeutic device, any prosthetic apparatus, or any other apparatus or means, including trained animals, that may be required by a person with a disability specifically because of that disability.

This definition is also insufficient in fully explaining what AT comprises. It solely focuses on AT as a compensatory tool for the individual's impairment. Abbott (2007) claims that although the term AT has a long history, its meaning is still rather vague. AT is defined differently in various studies (Roulstone, 2016). The term 'accessible technologies', for example, is recently being used in computer science to refer to technologies that are designed with in-built customisation features (Panchanathan and McDaniel, 2015). The many definitions and classifications indicate that the field of AT is broad and complex since it embraces not only a wide variety of aids and equipment but also numerous professionals from many different disciplines such as OTs, physiotherapists, communication therapists, engineers, educators, social workers, and medical doctors. Each have their own understandings and ideologies relating to AT and they signpost the multiple, heterogeneous networks that surround this field.

For the purpose of this study, therefore, the term 'enabling technology' (Roulstone, 1998) will be used to include both AT and other mainstream technology, for example, personal computers and mobile phones, that disabled people perceive as having been/being potentially helpful in their job. I will use the term 'mainstream' and not 'accessible' because, as shall be seen later, participants also mentioned furniture and DIY solutions as being 'enabling', and not only computer-related technologies. Since we are living in an age of integrated technology, 'the distinction between mainstream and AT has greatly blurred' (Mendelsohn and Fox, 2003, p.27). It is thus very difficult to separate the two categories. I am aware that there is no perfect term that includes both types of technology. It is worth noting that in this thesis, 'technology' is used to signal 'devices', actual, material devices and not practices (as in the sociological sense). Furthermore, medical technology, such as diagnostic and monitoring tools will not be discussed in this thesis.

The understanding of 'disability' in this research started from a SMD perspective, i.e. viewing disability not as a personal problem but as socially constructed/created through physical and social barriers (UPIAS, 1976; Oliver, 1990b). It will be seen that in the context of this study - Malta - barriers may arise from factors such as the geographical location and size of the island, the Church, and the family. Other factors include professionals such as OTs who

advise disabled people on technology that can enhance their independence in daily life activities including employment.

In the process of the research and following my encounter with NM, my understanding of disability then developed into a more relational understanding, as in the original UPIAS (1976) understanding and the description of disability in the CRPD (2007, Preamble, p.1):

- e) *Recognising* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others

Thus, the CRPD views disability as the consequence of an interaction between person and environment. This is why it is relational. In different contexts people may be more or less disabled (or 'abled'). Dis/ability will therefore be understood to emerge from the alliances, linkages, interactions and networks, human and non-human, that are enacted in daily life activities such as at the place of work. The word dis/ability is adopted from Goodley (2014, xiii) in which the forward slash (for want of a more appropriate symbol) indicates the relational existence (co-construction) of both states. I will therefore be focusing on how dis/ability is produced; on the relations and the capacities (to affect and be affected) that may come out of the interaction between bodies, things, ideas, feelings and so on. Both disability and ability can emerge from these interactions, at different times, places and contexts because neither is an inherent characteristic of any person.

For the purpose of this research, the term 'employment' will refer to paid work, both full and part-time, and therefore the study will include full and part-time employees, self-employed disabled people and ex-employees who were unemployed at the time of the study but who had a job in the past 10 years.

In this study 'health care professionals' include physiotherapists, communication therapists and OTs. It is mostly on the latter that I will be focusing, where OT is defined as:

a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of OT is to enable people to participate in the activities of everyday life. OTs achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement. (World Federation of Occupational Therapists (WFOT), 2012, no pagination)

The term 'assemblage' is difficult to define. Deleuze and Parnet (2002, p.69, cited in DeLanda, 2016, p.1) propose this definition:

What is an assemblage? It is a multiplicity which is made up of many heterogeneous terms and which establishes liaisons, relations between them, across ages, sexes and reigns - different natures. Thus, the assemblage's only unity is that of a co-functioning: it is a symbiosis, a 'sympathy'.

Another concept that will be adopted, regards what was otherwise known as 'agency' and which Deleuze (1988, p.101) calls 'affect', that is, the capacity to transform or be transformed and which holds assemblages together in a state of always 'becoming' (Deleuze and Guattari, 1988, p.256). Deleuze and Guattari (1988) explain 'becoming' as a movement of differing keeping opportunities open for change and new becomings, as against something that is fixed and unalterable. On the other hand, the 'something different' is not just a 'mere variation of existing formations' but 'being of another order, radically new in and of itself' (Currier, 2003, p.334). To summarise, assemblages are made up of multiple human and non-human components. Through their relations/interactions, components have the potential to affect (other components) and be affected. Capacities to transform and be transformed as thus produced. The nature of that 'affect' (how they are affected) is understood in terms of the 'capacities' produced. As a whole, an assemblage has 'properties' (the result of the affective relations between components and all capacities generated). In the context of this study, this property may be 'ability' (or 'disability') to do/be/feel/think/become. Chapters two and four delve deeper in the understanding of these concepts, but a brief explanation in this section was deemed important.

Certain words such as normal, client, abled or their other forms such as normalise, enable, will be presented in inverted commas when they first appear in the thesis because I am using these terms critically. I will then continue to write them without the inverted commas for ease of reading. Having clarified how the most important terms in this study will be understood and presented, the context in which the research took place will now be described.

1.5 The Maltese context

Malta is a small archipelago (316km²) with a population which, according to the 2011 National Census, stands at 417,432 (NSO, 2014a). Malta lies in the Mediterranean Sea, 93 km south of Sicily and 290 km north of Libya. It being a small island meant that, like any other island, its 'evolutionary clock ticked more slowly than on the [European] mainland' (Held, 1993, p.25). This also applies to the development of the welfare state and policies in favour of disabled people. Malta's welfare system is in fact a result of certain factors such as its colonial history, its geographical location, the importance of the Church and EU membership (Bugeja, 2010).

With regard to statistics related to disability in Malta, the situation is rather incomplete. This is comparable to the situation in many other countries and the CRPD committee has in fact highlighted the need for more data globally by dedicating Article 31 to this issue (CRPD, 2007, pp.23-24). The Maltese government is recently beginning to collect disability related data – for example, data from the 2011 National Census (NSO, 2014a). It is to be noted that, in this case, the definition and classification of impairments was formulated in accordance with the International Classification of Functioning, Disability and Health (ICF) although a free-text option was also included in the census questionnaire to facilitate the identification of specific impairments (Zammit, 2013). These results showed that the number of (self-identified) disabled people in Malta constituted 30,183 persons or 7.2 % of the total population (NSO, 2014a), when compared to the 5.9% recorded in the 2005 Census (NSO, 2007).

1.5.1 Disabled people in Malta: major influencing factors

With a history of colonisation by many different peoples, Malta has inherited a wealth of history and culture, but this fact has also shaped the personality of its people. The colonial impact on the islands also meant that its educational, legal and institutional set-up have been inspired by that of the people who occupied it (Formosa, 2009). The following sections will discuss these influencing factors, with a focus on the role of the Church, the first disability non-governmental organisations (NGOs) and the family. They will show that the oppression of disabled people can also result from paternalistic support and charity and the dominance of professionals (Shakespeare, 1993).

The majority of the Maltese population are Roman Catholic (Wright, 2010) and the Church has played a fundamental part in improving the lives of disabled people and their families in Malta. In the late 1940s, a priest, Dun Mikiel Azzopardi, was the first person to remove disabled people from the cellars or barns where they had been hidden for years, because they were considered to bring shame to the family (Camilleri and Callus, 2001). The high degree of social visibility resulting from the small size of the island meant that families with a disabled member used to want to protect the non-disabled siblings, especially the daughters, who would otherwise not have had any chance of getting married, the belief being that impairments were always genetically inherited (KNPD, 2012). Therefore, by opening the first institution for disabled people, *Id-Dar tal-Providenza* (the House of Providence) in 1965, Dun Mikiel helped reduce the stigma that was, until then, associated with disability. The above indicates a mix of religious and primitive scientific ideas about disability.

Dun Mikiel also used to hold a weekly appointment on the national radio station which he named the 'Call to the Sick and the Handicapped'. In his own way, he wanted to change the negative image of disability by calling the residents at *Dar tal-Providenza*, his 'angels' (Camilleri and Callus, 2001, p.82), a term now rejected by disabled people due to its paternalistic connotations (Oliver and Barnes, 1998; Drake, 1999). With his Catholic values of helping the needy and the marginalised, however, Dun Mikiel was transforming the existing

mentality of stigma and tragedy, to one of charity (Bonnici, 2005). He had paved the way from rejection and segregation to the charitable protection of Maltese disabled people.

The Church, however, was not the only institution that was working in favour of the disabled members of its society. In 1947, the post-second world war Polio epidemic in Malta brought about the setting up of the Physically Handicapped Rehabilitation Fund (PHRF). This was started by a small group of non-disabled Maltese people and British expatriates and was originally aimed at alleviating the effects of polio (PHRF, 2013a). It was based on the individual model of disability in which impairment is viewed as the main cause of disability (Oliver, 1990a); an approach which tends to result in a focus on rehabilitation above all else. It officially gained charitable status and started focusing on fundraising, projecting physical impairment as a personal tragedy and aiming at 'normalising' its members in order to re-integrate them into society (Wolfensberger, 1972, 1983; Stalker *et al.*, 1999). Its philosophy as stated in their website is still 'the promotion and the rehabilitation of the physically handicapped throughout the Maltese Islands' (PHRF, 2013b, no pagination). This is a classic case of an organisation 'for' disabled people (Campbell and Oliver, 1996), as are the greater number of disability NGOs in Malta. The majority of the committee members in these organisations are, in fact, non-disabled professionals or parents of disabled people, with only a few disabled people participating (Azzopardi, 2009). Despite this early provision, disabled people were still very much considered as objects of pity who depended on their families and non-disabled neighbours for care and cure (Callus, 2013). It was then that the influence of central government came into force.

In the 1970s, the Labour (Socialist) Government introduced a number of welfare incentives which were to help shift this mentality of charity to a sense of 'entitlement' to support as citizens, although not yet of rights (Bugeja, 2010; Azzopardi, 2011). In 1974, the Department of Social Security extended the non-contributory pension to more 'categories' of disabled people who counted as eligible for welfare, since up until that time only blind people were receiving a pension. This meant that all other disabled people depended on their families for a living.

These incentives helped disabled people and their families to maintain a decent quality of life (Harris and Roulstone, 2011), but on the other hand they gave rise to more classifications amongst disabled people - the more deserving and the less deserving - based on one's ability to earn a living (Social Security Act, 1987). At the same time it meant that more disabled people came out of their segregated status and were registered so that they could receive a pension. This allowed disabled people to become more visible in Maltese society.

During this same time a group of parents of disabled children formed what is now known as the National Parents' Society for Disabled Persons. Through the Society they provided parents of disabled children with support and guidance towards available services for families with disabled children, support that was so lacking in the Society's founders' experiences (Pisani, 2001). Through the same organisation they started demanding more services for their disabled children. It is interesting to note that whilst special schools for children with visual and hearing impairments were present in Malta since the 1950s, it was only much later that services for children with other impairments became available. Borsay (2005) comments that in the UK those who had visible impairments were considered to merit support more than those whose impairments were not as visible. These distinctions between different impairment groups also existed in Malta, and this fact urged parents of children with less visible impairments to demand more equal access to support from the state for all disabled children.

One outcome of this lobbying was the setting up of the Child Development and Assessment Unit within the Department of Health in 1995 and the opening of more Special Schools, until, in 1994 disabled children could start attending mainstream schools (Bartolo *et al.*, 2002). Another outcome was the setting up of the KNPD in 1987. KNPD is part of the portfolio governed by the Ministry for the Family, Children's Rights and Social Solidarity (MFSS)², and

² MFSS is responsible for family, child and social policy, social security and social housing, the rights of persons with disability and the care of the elderly and active ageing. It is also responsible for solidarity services, community care and pensions. (Department of Information, 2018)

works in collaboration with NGOs in Malta, coordinating efforts and voicing the Maltese government policies on disability matters (KNPD, 2012). It must be noted that by this time, the drive towards upholding the rights of disabled people was supported by both main political parties - the one in government and the one in opposition.

An important milestone occurred when in 1994, Mr. Joseph Camilleri, a disabled person, was appointed as first Chairperson of KNPD, in a bid to show Maltese society that disabled people could and should speak for themselves. KNPD in fact chose as its motto: 'Nothing about us, without us' which is a core idea of the Disabled People's Movement (Charlton, 2000; Ratzka, 2003). The climax of KNPD's work arrived in the year 2000 when the Maltese parliament enacted the Equal Opportunities (Persons with Disability) Act (EOA) 2000, which gave KNPD legal status and therefore the power to fight against discrimination (EOA, 2000).

In the voluntary sector, however, things moved at a much slower pace. Although in Malta there are about 46 disability NGOs (KNPD, 2009; Office of the Commissioner for Voluntary Organisations, 2017), the majority of them are still run by non-disabled people, such as parents and professionals (Azzopardi, 2000). As can be observed, parents and the family have always had a very influential role in the road that was travelled by disabled people in Malta. Although this means that the lack of community services is filled up by the dedicated work of the parents, usually the mother (Gauci, 2009), it most often means that disabled children are brought up to be very dependent, in that they are not expected to make their own choices and decisions, nor are they encouraged towards independent living (Cordina, 2003). It is however encouraging that the present generation of disabled youngsters that is finishing mainstream schooling is already making itself heard and demanding more opportunities in education, employment and independent living (Ayling, 2010; Calleja, 2009, 2012; Carabott, 2011; Cardona, 2012, 2013; Deguara *et al.*, 2012). These opportunities, here specifically for employment, could also come about with the establishment of inclusive policies and legislation which will now be discussed.

1.5.2 National employment-related disability policy and legislation

‘Malta is a democratic republic founded on work and on respect for the fundamental rights and freedoms of the individual.’ (Constitution of Malta, Article 1[1], 1964). In the Constitution of Malta, however, discrimination against disabled people is not alluded to explicitly, but only indirectly in Article 17 which affirms that disabled people who cannot work are entitled to education and vocational training. Legislation which provides a legal basis for the implementation of these rights was adopted in the year 2000 with a unanimous vote in favour of the Equal Opportunities (Persons with Disability) Act (Chapter 413). This Act was then amended by Act II of 2012 and Act XXIV of 2016. It establishes the principle of anti-discrimination on the basis of disability and prohibits both public and private sector entities from discriminating against disabled people in education, employment, goods and services, physical access, housing and insurance.

In 2014, the Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing within the Ministry for the Family and Social Solidarity together with the *Kumitat Azzjoni Soċjeta’ Gusta* (Action towards a Just Society Committee) launched a National Policy on the Rights of Disabled People. In 2016 a consultation was launched on a draft National Disability Strategy which is currently being developed (MFSS, 2016). Malta had, however, signed and ratified the CRPD on the 9th November 2012 (Commission for the Rights of Persons with Disability, 2016). According to Article 27 of the CRPD, Malta therefore has a commitment towards ‘the right of disabled people to work, on an equal basis with others’ (CRPD, 2007, p.19). Prior to the CRPD, Malta’s efforts with regard to employment can be summarised in the following timeline of policies and legislations.

In 1969, Parliament endorsed the Persons with Disability Employment Act, which emphasised the right of disabled people to work and to be integrated in society. This Act enforced an employment quota obligation of 2% which has been re-enforced in the National Budget 2015 by means of Act XXII of 2015. These quota systems are also found in many EU countries, but, as in Malta, their effectiveness is limited (Greve, 2009). The Employment and Industrial

Relations Act which was passed in 2002 (EIRA, 2002) further highlights that it is illegal to discriminate against disabled people at the place of work and in matters related to employment.

In 2010, KNPD launched an Employment Policy for Disabled People to promote efforts towards reasonable incentives aimed at ensuring the inclusion of disabled people in the employment sector (KNPD, 2010a). In a further bid to encourage employers to recruit more disabled people, the Workplace Accessibility Tax Deduction Scheme was launched (LN 428/2010) (KNPD, 2010b). This Scheme financially supports employers to provide any accommodations, including AT, required by a disabled employee to carry out her/his job. To date, there is no available data to support, or otherwise, the success of this Scheme and other financial and tax incentives offered to employers towards the employment of disabled people (Waddington and Priestley, 2018).

Following the CRPD ratification, KNPD published a report on the Implementation of the Convention (KNPD, 2013). In it KNPD refers to the importance of Article 9 regarding accessibility, including the use of technology to increase accessibility by addressing the specific difficulties encountered by people with different impairments. Furthermore, this Article states that this technology should be provided for disabled people at a minimum cost. With reference to Articles 19 and 20, KNPD recommends the adequate provision of AT through the re-structuring and strengthening of schemes which help disabled people purchase and maintain adequate assistive means.

Furthermore, the Equal Opportunities (Persons with Disability) (Amendment) Act XXIV of 2016 (p.877), introduced a new part to the original Act of 2000 under Part II: Rights of Persons with Disability, which specifically mentions the right of Maltese disabled people to enabling technology:

(12) A person with disability shall have access to a range of tools of support, community services and facilities including, but not limited to, personal assistants, technological equipment and mobility aid[s], to ensure an effective inclusion. Such services shall be available for a reasonable price and the freedom of choice shall pertain to the person with disability. The choice of

objects, services and facilities shall reflect the needs and preferences of the person with disability.

(13) The person with disability shall have access to mobility and orientation training, to the Maltese Sign Language, and the use of technological equipment.

In the Equal Opportunities (Persons with Disability) Act, Cap. 413 (2000, p.16) Part V: Test of Reasonableness, Article 20A specifies that there shall be a Board which determines what is 'reasonable' under this Act. "Reasonable accommodation" (*ibid.*, p.3) means,

necessary alterations not imposing a disproportionate or unjustifiable burden, where needed in a particular case, to ensure to persons with disability the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

In Part IV: Prohibition of Disability Discrimination, Title 1: Employment, Article 7(5) (*ibid.*, p.9), the phrase "make reasonable accommodation" includes,

- (a) making existing facilities used by employees readily accessible to and usable by persons with disabilities;
- (b) restructuring jobs, instituting part-time or modified work schedules, reassigning vacant positions, acquiring or modifying equipment or devices, appropriately adjusting or modifying examinations, training materials or policies, providing qualified readers or interpreters, and making any other similar alterations for a person with a disability; and
- (c) quality and vocational career guide, which guide shall be free for the person with disability.

The above Maltese legislations form the basis of the interpretation of what is 'reasonable accommodation' by employers and service providers with regard to Maltese disabled people's right to support for work and employment, including for enabling technology.

Schemes that help disabled people purchase the necessary technology are in place and include KNPD's Assistive Apparatus Fund³ and the subsidies given by the major national Charity called the Malta Community Chest Fund. These schemes however, need to be developed further in order to adequately support disabled people's employment-related accommodation needs.

Maltese disabled people are underrepresented in employment, which may be due to the fact that they find lack of support and barriers in pursuing an education (Cordina, 2003). In employment, other barriers include low levels of access to information and negative attitudes of employers (Callus and Bezzina, 2004). Another barrier occurs when searching for a job is perceived as a risk to the individual's level of social welfare benefit thus leading disabled people to prefer to remain inactive⁴.

The Employment Training Corporation (ETC)⁵ is the national agency that is responsible for all programmes and services related to employment. Services offered by the ETC include guidance to disabled job seekers, support at the place of work and financial assistance to employers who recruit disabled employees (ETC, 2013). Despite these services, figures still indicate a low presence of disabled people in employment as discussed previously. Among the most recent initiatives to increase the number of disabled people in the world of employment are fiscal incentives for employers who employ disabled people, the enforcement of the Employment (Persons with Disability) Act of 1969, and the disability pension being granted to disabled employees who are earning more than the National Minimum Wage (Ministry for Finance, 2014). The funds that are collected from companies which do not respect the 2% quota are utilised by the Lino Spiteri Foundation which was set up purposely to

³ Since 2016 this service moved to *Agenzija Sapport* and is now called the Empowerment Scheme. This Scheme forms part of a larger unit called the People Assistance Scheme, which, since 2017, also includes tax exemption services and grants on adapted vehicles and AT that is personally funded by the disabled person/carers.

⁴ The 2015 national budget introduced a measure which entitles disabled people who are in employment to their full disability pension (ACT, 2018).

⁵ In 2016 ETC was renamed Jobsplus (Jobsplus, 2017, p.9).

train/inform both employers and disabled employees. It also introduces disabled people to employment opportunities with the support of job coaches (Malta Employers Association, 2015b). According to the Jobsplus 2017 Annual Report, over 400 employers were made to pay the fine because they did not conform to the law in 2015/2016, while another 150 employers refused to pay the fine and will be facing legal action (Jobsplus, 2018).

Along the years, ETC also worked hand in hand with KNPD to provide disabled people in Malta with training and opportunities that would allow them to enter the field of work (KNPD, 2010a). A Supported Employment Unit was set up in 1995 within ETC for this purpose (Cassar, cited in Formosa, 2009, p.43)⁶. Disabled job seekers who register with this Division, are seen by a medical doctor who decides whether the person is fit for work. This decision is based on the ICF (WHO, 2001). Those who are, are then seen by an OT who assesses the person's functional abilities through an interview and a home-made assessment schedule. The OT assessment findings then help the employment advisors at ETC and Lino Spiteri Foundation to match the 'client' with the available vacancies (ETC, 2014). This process is therefore based on the individual model of disability, which includes the 'medicalisation' of disability (Oliver, 1990a, no pagination), and is not sufficient to fairly assess the person's skills since disability is solely viewed as a 'medically assessable impairment and functional limitation' (Shakespeare, 1993, p.253).

In the absence of Vocational Rehabilitation Centres in Malta, OTs have to work with very limited resources which in turn produce very limited results. In these Centres OTs evaluate the work tolerance of clients, help to develop work-related skills and recommend modifications of job demands and environments (Griswold *et al.*, 2009). In order to make up for this need, the first full-time OT was recruited at Jobsplus in 2015, such that a more comprehensive service could be provided to the disabled people who approach it for support to find and retain employment. In a personal communication, this OT reported that there are plans for the development of a Vocational Assessment Centre which will

⁶ This Unit was more recently renamed Inclusive Employment Services Division (ETC, 2013).

include a multi-disciplinary team of professionals, thus ensuring a more holistic service (Sciberras, 2017).

The FITA also provides support and training through ICT to disabled people to help them overcome barriers to education and employment. Nevertheless, in 2009, 197 companies participated in a survey carried out by FITA, out of which 88% declared that they did not employ disabled people and 81% said they had never done so. The main reasons given were that disabled people had never applied for jobs with them (31.5%); their company was too small (27%) or lacked full physical access (16.8%); and also due to job requirements and qualifications needed (16%) (FITA, 2009). In a more recent survey with 234 private sector businesses, it was found that only 23% had some form of policy towards disabled people and only 12% employed disabled people. When asked whether the disabled people they employed use any AT, 56% of the participants replied that they do not use any, whilst those 19 respondents that did, gave varied replies such as arm rests, touch screens, tracker balls, scanners with optical character readers, portable tape-recorders and wrist supports. The need for more awareness among employers was indicated, such that 47% of the employers showed that they would like to receive assistance in this field, with the majority (16%) requesting information campaigns and 13% requesting training sessions for both employees and managers (FITA, 2014). This is comparable to recommendations that emerged from a study carried out by ETC in 2005 and those found in an Academic Network of European Disability Experts (ANED) report, which indicated that raising awareness among employers in Malta was a priority (ETC, 2005; Greve, 2009). Similar findings also emerged from a study carried out on behalf of the Malta Employers Association in 2015, entitled 'Equipping employers for a more equal and inclusive labour market' (Malta Employers Association, 2015a). 100 employers participated in this survey with the majority (55%) claiming that they required more practical information about the employment of disabled people and that they did not agree with the National Budget 2015 measures regarding quotas and related fines if they did not abide by them. Interestingly though, 59% of the employers agreed that it was society that was disabling people with impairments through the existing barriers. This indicates a wish on the part of

these employers for the removal of barriers but also a need to be better informed prior to the imposition of quotas and similar measures.

To date, very few studies have looked in depth at the way disabled people are being included in Maltese society and especially in employment. In 2004, 599 disabled people registered with KNPD participated in a study, entitled 'Major Concerns of Disabled people and their Families' (Callus and Bezzina, 2004). Among the major concerns in this survey, disabled people indicated their concern about employment. Most of those interviewed did not work, and most of those who did, were engaged in elementary or clerical work. Moreover, disabled people asserted that they had few opportunities for on-the-job training and promotions. Disabled people also expressed the need for more flexible hours when it comes to working times. A similar study carried out in 2014 by KNPD among 600 disabled people showed that only 10 have AT at their place of work and only 7 reported the need for AT for work purposes (KNPD, 2014). These findings and other outcomes from the limited local research discussed above, indicate obvious gaps in the field of enabling technology and current employment policies and services for disabled people in Malta. This highlights the importance and urgent need for research such as the current one.

1.5.4 Assistive technology provision in Malta

The field of AT is new on the island and there is, up to now, no known research that brings together disability, technology and employment locally. AT service provision is very fragmented and based on a 'charity/welfare' model. The major funding for AT, including that for employment purposes, comes partly from the People Assistance Scheme which is state funded, and partly from the Malta Community Chest Fund. This, in spite the fact that the adoption of a rights-based approach to disability issues has been a core element which disabled people and those who represent them have fought for all over the world (European Social Charter, 1996; Scotch, 2001; Hurst, 2003; CRPD, 2007; Heap *et al.*, 2009). In this context, rights-approaches mean the adoption and use of human rights, legal (equality) rights and civil rights principles as laid out in the country legislation, guidance and codes of practice. This is not to claim that rights-based countries always succeed in matching formal rights with

substantive rights, but that the explicit state recognition of rights underpins the operation of disability policy.

Disabled people who require assessment and advice regarding AT in Malta, are normally referred to healthcare professionals such as OTs and, to a lesser extent, to physiotherapists for mobility aids and to speech and language therapists for communication aids. These professionals are mainly hospital-based and receive only basic training in AT during their undergraduate courses, supplementing this knowledge with whatever experience they obtain during their clinical practice. This has created the promulgation of what is called the deficit model (Roulstone, 1998). Although this model, when related to AT use, has helped highlight the potential of technology in 'enabling' disabled people in their daily life activities, it does this by focusing mainly on the impairment of the individual. Conversely, the social model focuses on those barriers that disabled people face, in this case in employment, namely, attitudinal, environmental and technical. This divergence in the understanding of disability by healthcare professionals (Hammell, 2003) and that promoted by disabled people (UPIAS, 1976; Oliver, 1990b) is in itself a barrier that hinders the relationship between these two groups, as shall be seen in the findings from this study.

Another barrier ensues from the fact that local AT suppliers do not stock a wide variety of equipment since the market is small, and therefore up to a few years ago, before the developments outlined further below, disabled people would order equipment from a catalogue or over the internet without trying it out first. This often resulted in a trial and error approach with inappropriate expensive equipment being discarded after only a short period following its delivery. Moreover, disabled people who required more specialised assessment in any aspect regarding AT, had to go abroad (due to historical ties, usually to the UK), at their own expense, to be assessed and trained in Mobility Centres and Centres for Integrated or Inclusive Living that were until recently non-existent in Malta. Consequently, over the years, both disabled people and professionals started feeling the need for a more specialised Centre where disabled people could receive more in-depth assessment, professional advice, and have the opportunity to trial out different assistive equipment before deciding which AT to purchase.

In 2008, KNPD embarked on two EU-funded projects, through which the first Independent Living Centre was constructed and equipped, and a number of professionals working in the rehabilitation field were trained both locally and abroad in AT. The Independent Living Centre was named after Sonia Tanti, a disabled activist who had struggled hard to achieve her independence and who was a role model for other disabled people locally. The Sonia Tanti Independent Living Centre was officially opened in June 2011. The trained therapists are now giving their services at the Independent Living Centre and disabled people who require advice on AT and the actual trialling of assistive equipment. This ranges from wheelchairs and seating solutions to adapted vehicles and transport solutions and other assistive daily living equipment. In this way, this project is starting to help eliminate the inconveniences, and the lack of professional support and resources of the past, in the field of AT.

More recently, the Malta Communications Authority announced that it is planning to open three Assistive Technology Centres in Malta and Gozo to facilitate disabled people's use of Information Communication Technology (ICT) in their daily lives (Malta Communications Authority, 2017). Through these initiatives it is anticipated that with the right support, disabled people would become more independent, and ultimately more employable in various sectors. For those already in employment, this may result in the possibility of progressing in their place of work to posts that match their level of education and skills.

Apart from the establishment of the above-mentioned policies and services, it was also fundamental to work on raising more awareness among the Maltese population with regard to disability issues. This started mostly with the setting up of KNPD in 1987. Since then, there has been an increased awareness in Maltese society that disability issues have to move from a charity to a rights-based model. As in the UK, where the social model has played a key role in shaping current policies pursued by major Charities, Government departments, and official agencies (Thomas, 2007), KNPD bases all of its endeavours on the SMD (Camilleri, 2017). Although policies and programmes based on the social model have achieved a great deal, such as in the inclusive education sector, disabling barriers remain, especially in employment. The

stubborn nature of these barriers made me think: what additional approaches might be helpful, allowing us to build on the achievements of the SMD in Malta? This led me to new materialist perspectives which, in the second stage of this study, was used as a tool to analyse how the complex relations between disabled employees-technology-workplace assemblages are enacted and what in/capacities are produced as a result.

1.6 Structure of thesis

The introductory chapter of the thesis has paved the way to the research by describing the background against which the study was undertaken (contextual foundation), clarifying the main terms and giving an overview of the history of the disability sector in Malta. In the second chapter, the conceptual framework that served as a basis for the research process will be presented (conceptual foundation), namely the social model of disability from DS and concepts from science and technology studies (STS) and NM. Two literature review chapters follow. The relevant research from rehabilitation studies and DS is discussed in the third chapter, whilst the fourth chapter reviews literature from STS and new materialist research. Both chapters, although from different perspectives, appraise how this research has exposed the complex reality of technology and disabled people in general and with a particular focus on employment. The fifth chapter then presents the methodology and methods that were used in this study. It is followed by Chapters six and seven in which the findings are laid out, analysed and discussed. Chapter six maps out the barriers and enablers that the participants related in stage one of the study, and chapter seven analyses dis/abled employees-technology assemblages at work via a series of vignettes. Chapter eight will then knit together the conclusions, theoretical and methodological reflections and recommendations for future research that emerged from this study. Implications for activism, policy and practice are then highlighted. An Epilogue including my personal reflections on this exciting 'journey' will conclude the thesis.

1.7 Conclusion

This chapter has provided an overview of the background against which this study has taken place. It has shown that various factors have shaped the journey that disabled people in Malta and Gozo have experienced from exclusion, segregation, and charitable protection to a more rights-based reality. These factors included the family, the Church, political agendas, and health and social care professionals. In this study it shall be seen that these 'macro' factors are also present in the micropolitics of disabled people's lives, with a focus on the access and use of enabling technology in disabled people's lives at the workplace. Barriers that hinder this aspect of disabled employees' working lives will be seen to persist and a new approach to analysing this topic will be proposed. I am fully aware that the research outcomes in themselves will not bring about a major political and social revolution, but, it is hoped, they will highlight and stimulate the demand for change (Barnes, 2004) in an area where there is an ever-increasing risk of exclusion for disabled people (Roulstone and Barnes, 2005; Waddington and Priestley, 2018).

The next chapter will discuss the conceptual framework that guided the research process and it will be followed by two chapters on literature that has thrown a light on the entangled relationship between disability, technology and employment.

Chapter 2

Conceptual Framework: Journeying into Uncharted Territory

2.1 Introduction

In this chapter, the theoretical journey that led to the choice of the theoretical framework for this study will be described. A wide spectrum of literature on the relationship between humans and technology from a variety of perspectives has been consulted. For the purpose of the present chapter, I will be focusing upon DS, science and technology studies (STS), and the contribution of NM, since they have the most relevant bearing upon the research focus and questions. In most of the theories/literature there were elements that could be applied to what I wanted to achieve in my study, so rather than one single theory, concepts from a variety of theories will be taken. Although the terms and language used in these theories vary, I noted that they all point to the same concept: the complex networks and entanglements within which the disabled person engages with technology and the rest of society, including the workplace.

2.2 The social model of disability

This research will commence with the SMD as the conceptual basis for the study, i.e. the oppression of disabled people will be considered to be a consequence of the physical, economic, social, cultural, technological and other disabling barriers that exist in society. Therefore, it rests on the initial premise that disabled people face various barriers related to the access to, and use of, technology in their employment, that do not directly derive from their impairments, for example, inadequate provision of technology and stigma attached to the use of assistive technology. These barriers constitute some of the causes that hinder disabled people from fully participating in this aspect of daily living. I will subsequently build on this premise by applying concepts from NM in an attempt to broaden the notions proposed by the SMD.

This model originated in the UK from disabled people who formed part of UPIAS which came together following a letter that Paul Hunt, a disabled

resident at a Cheshire Home, sent to The Guardian in 1972. In the letter, Hunt proposes:

the formation of a consumer group to put forward nationally the views of actual and potential residents (...) to formulate and publicise plans for alternative kinds of care. (Hunt, 1972, no pagination).

UPIAS was fundamental in highlighting the difference between impairment (biological) and disability (social) (UPIAS, 1976); it lobbied against segregation in institutions, and worked towards more opportunities for participation in community life. It proposed a social interpretation of disability, for which, Mike Oliver, a disabled academic, later coined the term SMD (Oliver, 1990b). SMD views disability as a social phenomenon and 'blames' society and the environment as the main determinants of disability. Whilst not denying the negative dimensions of certain impairments, disability is seen as something imposed on people with impairments by society:

the social model is about nothing more complicated than a clear focus on economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, sensory or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media. (Oliver, 2004, p.21)

The proponents of the SMD, contrary to the position of the individual model of disability, challenge the suggestion that any problems experienced by those deemed different should be blamed on their differences (Pfeiffer, 1998), as in the so-called 'medical model of disability' used by medical and rehabilitation professionals. Oliver (1990a, no pagination), however, suggests that:

there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component.

The so-called 'medical model' may imply that it is medicine and its professionals that perpetuate this 'medicalisation' of disability, but they are not the only culprits. The term 'medical model', however, will still be used in this thesis since it is found in most of the technology and rehabilitation studies literature, and its use will ensure some consistency throughout the discussion. The medical model presumes that an individual whose body structure or function is perceived as deviating from socially recognised norms requires the 'expert' help of professionals who will assess, diagnose and legitimate the person's impairment (Hammell, 2006). The impairment is deemed to be the inevitable and tragic cause of any restriction in function or social disadvantage (Thomas, 2002). The power of this model is perceived in its very implicit nature, as for example, there are no proponents or literature on the medical model (Kelly and Field, 1994). French and Swain (2008) claim that the medical model is the main professional version of the individual model and that it is not easily defined: 'It is a way of thinking that reverberates through the dominant ways of conceptualising disability within our society' (p.24). And yet, it is the model that has traditionally underpinned the rehabilitation professions and was considered to be a medical speciality (Turk and Mudrick, 2013). It places disability as the problem of the person, created by disease or trauma and requiring the services of a health care profession such as medication, surgery or rehabilitation (Cole and Tufano, 2008). The power is in the hands of the professionals.

On the other hand, the SMD focuses on the structures in society that cause the oppression of disabled people (Oliver, 1990b). The SMD has for the first time in history shaped a 'we', an identified group, a disabled people's movement that could speak out to bring about change (Beckett and Campbell, 2015). In order to bring about change, the causes of oppression need to be identified. Although the SMD is not in itself a theory, but a tool (Finkelstein, 2001; Oliver, 2004), it has informed many of the policies concerning disabled people in the past 30 years (Oliver, 2013) by shedding light on the barriers that have impeded disabled people from exercising their affect/agency in the various spheres of their daily lives. For this reason, the SMD and the barriers-mapping approach are at times used interchangeably. I am aware that proponents of the SMD may claim it is 'more' than barrier-mapping and is about identifying larger systems of oppression (e.g. capitalism). In the hands of many researchers and

disabled people's organisations, however, it has become about barrier-mapping with some useful effect and some limitations. In this light, however, society may be seen as static, to be fought and overcome, with disabled people as passive objects, 'victims of society rather than victims of the body' (Watson, 2012, p.100).

The notion above was not the only criticism of the writings of the primary proponents of SMD and its usage/operation. Mallett and Runswick-Cole (2014, pp.11-16) summarise the various debates that arose in the years following the birth of the SMD. Oliver (2004, p.18) himself shows his disappointment regarding the fact that the SMD had not brought about the fundamental changes in society that had initially been thought it would bring because there had been more 'talking' than 'implementation'. Shakespeare (2006) accuses the SMD exponents of being unsympathetic to medical interventions in claiming that they were of limited value in the lives of disabled people. Tregaskis (2002) argues that the SMD focuses too exclusively on the material characteristics of disability and leaves out the influence of culture and prejudice in creating the exclusion of disabled people in society. Similarly, French (1993) claims that barrier removal on its own will not end discrimination against disabled people because the model leaves out from its debate the bodily impairments which disable some people more than social barriers do. Thomas (1999, p.42; 2007, p.120) calls these 'impairment effects' and argues that bodies are both biological and social and these two aspects cannot be separated. Hughes and Paterson (1997) have highlighted the need for a social theory of impairment and, like Thomas above, assert that impairment and disability are experienced together rather than separately. This challenges one of the central tenets of the SMD, i.e. the impairment/disability binary. Feminists such as Thomas (1999) and Morris (1992, 1993) have also argued that the SMD does not take into account multiple discrimination experiences, for example, that which might result from being a disabled woman. They also claim that there should not be a separation between that which is public and that which is private. Other authors criticise the SMD for not including all groups such as people with learning disabilities (Chappell *et al.*, 2001), people with mental health issues (Beresford *et al.*, 2010) and disabled children (Stalker and Connors, 2007). The last criticism comes from Global South writers such as Ghai (2002) and Grech

(2009) who claim that, since the model emerged in the UK, it is mostly based on Western ideologies and cannot be applied as it is to Global South countries. Impairment effects in these countries can mean life or death to disabled people and, therefore, cannot be left out of the debate. Notwithstanding these criticisms, the SMD cannot be denied its importance in placing disabled people's struggles on the political agenda.

Up to now, therefore, models of disability have tried to find the causal agent for the oppression of disabled people with, for example, the individual/medical model attributing the problem to the individual and the social model attributing it to society; but the effect of the constant interaction between the individual and society/environment cannot be ignored. For example, the relational model of disability (Tøssebro, 2002, 2004) that originated from academia in the Nordic countries, stemmed from a difficulty in translating the binary 'impairment/disability' into Nordic languages. It proposes that disability is a relational mismatch between the person and the environment. Like the CRPD (2007), therefore, it is an ecological model. The proponents of the model also suggest that disability is contextual and relative. The focus of the model is on the relational interaction between person and environment. Likewise, Thomas (2004a; 2004b) suggested that the original SMD, as proposed by UPIAS in 1976, had a social relational focus that by time was lost in the ensuing debates. She asserted that this social relational construction of disability needed to be re-discovered and developed. This involves an understanding of:

disability as a quality and product of the social relationships between those with and those without impairment in society, or more accurately, between those socially constructed as problematically different because of a significant bodily and/or cognitive variation from the norm and those who meet the cultural criteria of embodied normality. (Thomas, 2004b, p.28)

In this way, the body is brought back into the definition of disability. For the purpose of this study, the interaction between the body and society also includes the relationship of these two entities with technology.

This relational concept prompted me to turn to STS literature to try and find insights into alternative perspectives which, together with the SMD, could

shed light on the answers to my research questions. Prof Alan Roulstone, in his 2016 book, *'Disability and Technology'*, highlighted the need for DS to engage more with STS and signposted the Actor-Network Theory (ANT) as a good place to set off from. This meeting with STS literature led me to Latour, Callon and Law, the main proponents of ANT. These researchers' work was the first to be applied to the phenomenon of disability in different contexts and therefore I started exploring the work of, among others, Ingunn Moser, Annemarie Mol and Jeannette Pols. More recently, the work of Deleuze (and Guattari) was adopted by DS scholars such as Shildrick and Goodley and although I did not engage as deeply with these researchers' works, concepts from them that were relevant to the current study were adopted. Braidotti and Barad's works, although not focused directly on disability, were also referred to because of their contributions on the concepts of the 'post-human', and 'entanglements' respectively. The sections below will follow the above 'history' of my engagement with STS and NM literature, in which all researchers are drawing from each other, are ontologically similar, and all share the concepts of, for example, assemblages, networks, and entanglements.

2.3 Theories of technology

Several scholars have proposed various theories of technology that started to emerge from STS and the communication studies of the 1980s/1990s. These theories have been categorised into three types: the social theories (Pinch and Bijker, 1992; Latour, 1997; MacKenzie and Wajcman, 1999; Luhmann, 2000); the group theories (Short *et al.*, 1976; Daft and Lengel, 1986; McGrath, 1991; Postmes *et al.*, 1999; Kock, 2001) and the analytic theories (Markus and Robey, 1988; Orlikowski, 1992; DeSanctis and Poole, 1994; Bimber, 1998). Feenberg (1991) suggests the existence of two major theories of technology, instrumental and substantive theories. He then proposes a third, the critical theory of technology, which can also be grouped under the social theories mentioned above. Among the main proponents of this theory, apart from Feenberg, there are Marcuse (1964) and Nissenbaum (2001). The critical theory of technology does not try to control technological advancement so that it does not get out of hand but suggests that it needs to be reformed from the inside. This theory asks how values such as privacy, autonomy, democracy,

and social justice can become integral to conception, design and development, not merely retrofitted after completion (Nissenbaum, 2001).

Various debates have, therefore, attempted to throw light on the relationship between technology and society. On the one hand there are those who claim that technology has taken complete control of the world we live in (substantive theory) and, on the other, there are those who believe that technology controls us in as much as we let it do so, that is, that technology is neutral (instrumental theory). The former is technological determinism (Heidegger, 1954; Ellul, 1964), while the latter, where technology is neutral (Tiles and Oberdiek, 1995) affirms that it is society that shapes technology. Both perspectives see technology as destiny. Proponents such as Latour (1997), however, in the ANT have suggested that it is difficult to separate the social from the technological. Instead they propose that both are continuously interacting to form assemblages and networks that produce capacities to affect and be affected. This will be discussed further in Section 2.3.4 below.

To summarise, Roulstone (2016, p.60) reports that the key theories of technology include Technological Determinism, Economic and Social Determinism, Social Shaping of Technology theories, Social Constructivist theories and ANT. It is not the aim of this chapter to go into detail about these various theories, but they will be briefly discussed below to introduce the NM perspectives that are at the core of the second stage of this research.

2.3.1 Technological determinism and neutrality

Technological determinism emerged in the late 19th/early 20th century to counter the consequences of industrialisation and capitalism and attributed all historical and social change to the advancement of technology (e.g. Ellul, 1964; Smith and Marx, 1994). It considered technology as having a pre-determined, and therefore fixed, path that human actions could not influence. In short, technology is autonomous. This gave rise to technological optimism (e.g. Gates, 1995) that raises expectations regarding the benefits of technology. The World Report on Disability (WHO, 2011) in fact, reports on research carried out all over the world depicting the benefits reaped by disabled people from the use of AT. On the other hand, technological neutrality (e.g. Kranzberg and Pursell,

1967; Florman, 1994) claims that, in itself, technology is neutral. It depends on what the end-user does with that technology that will make it beneficial or otherwise.

2.3.2 Social determinism: the social construction of technology

During the 1980s/1990s, various theories of technology started to emerge in the field of STS as a criticism of technological determinism. The social theories of technology were proposed to suggest that technology is a dimension of society and that humans do have a role in the shaping of technology. The Social Shaping of Technology theory (Williams and Edge, 1996), one of the social theories of technology, is based on the Social Construction of Technology theory (SCOT) (Pinch and Bijker, 1992; McKenzie and Wajcman, 1999). SCOT proposed that human action and social factors shape technology (social determinism) and the Social Shaping of Technology theory took this further to suggest that the relationship between technology and society is one of mutual shaping and, therefore, is open to change.

2.3.3 Complex interplay of technology, self and society: the actor-network theory and after

ANT (Callon, 1986; Latour, 1987; Law, 1987) suggests that there is a complex network of equal and interrelated human and non-human actors in the relationship between humans, technology and society. It focuses on ontology rather than epistemology:

What is of interest is what people and things become as a result of their position in a network ('relational ontology'), and the power that emerges from dynamic configurations of human and non-human actors. (Greenhalgh and Stones, 2010, p.1287).

It also focuses on the processes that occur in these networks and lead to the 'ordering of things' (Harris, 2005, p.169).

Before I came across ANT, I had been considering technology as part of the 'structure' (i.e. outside the 'agent') but, according to Latour, this separation of agent and structure cannot really happen. What Latour emphasises is the complex network in which the agent, whom he calls actant (rather than actor),

and the structure are embedded. They need to be understood as one hybrid composite. Rather than focusing on the agent and the structure as separate entities, ANT therefore focuses on the networks that exist between the human and non-human world such that they become a 'composite entity' (Harris, 2005, p.166) making the separation between the two difficult. ANT is therefore neither for social determinism nor for technological determinism.

Various STS scholars, however, have criticised ANT for various reasons. Sismondo (2009) classifies these into four major criticisms. The first regards practices and cultures. ANT is accused of being 'culturally flat' (*ibid.*, p.89). Because of its focus on agency, ANT has also been criticised for the possible marginalisation of certain groups who have difficulty exercising it and making their voices heard. There was also an admission on Latour's part about this criticism (Latour, 1988, p.302) where he claims that ANT leaves out, for example, elderly and disabled people. Later, STS scholars such as Galis (2011) have proposed ways how ANT can be used in DS. A third criticism involves problems of realism. ANT is claimed to be a 'blunt version of constructivism' (Sismondo, 2009, p.90) in which everything is constructed by networks of actants. The pros and cons of this problem have been discussed but, in STS, it remains an open question (*ibid.* 2010). The last criticism involves problems of the stability of objects and actions. This centres around the question of whether non-human actors can have feelings and intentionality that bring about actions. This was rebutted by Callon and Law (1995) who explained that non-humans do not in themselves have intentionality but that, in the interaction with humans, they act and function.

Notwithstanding these criticisms, ANT has been identified as the most important proposal in recent STS (Roulstone, 2016) and 'as the best known of STS's theoretical achievements so far' (Sismondo, 2009, p.92). Fox and Alldred (2017) consider ANT as the best known of the new materialistic perspectives. As Roulstone (2016, p.75) suggests, 'ANT is here to stay and forms a key weapon in the theoretical armoury of researchers and writers on technology'.

ANT, therefore, raises questions rather than offer solutions. This is the position that I am adopting, since it (ANT) asks questions and opens up

possibilities for both DS and professional practice. Ingunn Moser (2006a, p.376) describes this well:

There is no clear dividing line, at least in principle, between the technological, the social and indeed the human. This also means that ability and disability are located neither within people nor society, but in the particular sociomaterial arrangement of relations and ordering of practices that simultaneously produce the social, the technological, the embodied, the subjective and the human. Any of these entities as well as their character, composition and boundaries are thus understood as relational effects, and as effects of ordering work.

Mol (2010) states that the aim of ANT is not to define reality as it is but to help us raise questions, 'It seeks to shift our understanding and to attune to reality differently' (p.255). It makes otherwise silent, invisible events and situations, audible and visible. In this current study, ANT helps us to question, for example, what are the networks present for disabled people at work? How are work and disabled workers being produced through the relationships and arrangements of bodies, technologies, affect in the workplace?

Law (2007, p.2) himself describes ANT as a tool with which to analyse the natural and the social worlds:

as a continuously generated effect of the webs of relations within which they are located. It assumes that nothing has reality or form outside the enactment of those relations.

Moser and Law (1999, p.204) indicate that barriers are the result of 'bad passages' between the components of an assemblage and between assemblages themselves. So, if the disabled person is so 'entangled' in the assemblages/networks that are around her/him, it is difficult to remove structural/societal barriers without also changing the disabled person her/himself in the process. The 'changed' disabled person in turn changes the networks around her/him. Disabled people, however, have to get into those networks first to be able to enact such changes! As Mol (2010, p.255) asserts, 'An actor acts (...) if an actor were eliminated from its setting, it would take others a lot of work to replace these actions'. If this is applied to the context of

the current study, then it can be said that workplace networks are very different without/with disabled people in them.

It is not only the networks present at the place of work, however, that may influence disabled technology users-work assemblages, but also what they bring with them from the outside, for example cultural and family influences, as well as what they bring with them in terms of their impaired body, such as pain and fatigue. Since all these assemblages/networks are so inextricably woven together, it is difficult to remove all the barriers, as the strong SMD suggests. We must see how, by getting into those very same networks, disabled people can change them from the inside. As stated above, these theories of entanglements often imply a flat ontology. This means that no distinction is made between the material and non-material. Also, bodies are part of these assemblages. Nonetheless, what is produced by the interaction of various components is not determined by just one component, for example the body. This allows us to get past the problem of the strong SMD, which in effect appears to neglect the body, while in no way reverting to the older individual/medical model. It offers a new way of bringing the body back into the disability debate as suggested in Moser (2009, p.83):

My aim here is therefore to contribute to a recent move towards reclaiming the body and engaging with medical practices and technologies in ways that neither deny the body and experiences of pain and suffering nor fall back upon the individual, impaired body of the medical model.

Theories and debates continue to develop both in STS and in DS. In fact, following the initial presentation of ANT, its proponents continued to adapt this tool and some of their original thinking. More recently, the discussion has moved on to materialities, entanglements, and affect, a new stream in STS called NM.

2.4 New materialisms

New materialisms (Coole and Frost, 2010; Fox and Alldred, 2017) include a collection of standpoints that together have been described as a 'turn to matter' (e.g. Latour, 2007). The major propositions that NM puts forward include:

1. the material world and its contents are not fixed, stable entities, but relational, uneven, and in constant flux
2. 'nature' and 'culture' should not be treated as distinct realms, but as parts of a continuum of materiality. The physical and the social both have material effects in an ever-changing world
3. A capacity for 'agency' – the actions that produce the social world – extends beyond human actors to the non-human and inanimate (Fox and Alldred, 2017, p.4)

Without abandoning social constructionism, new materialists focus on social production and 'give materiality its due while recognising its plural dimensions and its complex, contingent modes of appearing'. (Coole and Frost, 2010, p.27)

Together with others, Latour and Deleuze are considered in Fox and Alldred (2017) to be two of the most prominent new materialist scholars. Latour's contribution involves his bringing together, on a more level playing field, human and non-human 'actants'/assemblages thus defying dualisms such as mind/matter and agency/structure. Deleuze and Guattari are also consonant with Latour 'in their ontological emphasis upon relationality and in their model of power as potential capacity to affect' (Massumi, 1988, xvii).

For these last two reasons I decided to adopt concepts from both Latour and Deleuze because their proposals are very much in line with wanting to view disability in a relational manner (relational with both the biological and the social worlds). They also agree in asserting the potential for transformation of environments and institutions, for example, disabled people together with their technologies, transforming their communities through the complex networks and

processes they are involved in, in this case at their place of work. Similarly, I will follow the Deleuzian proposal that:

regards human bodies and all other material, social and abstract entities as relational, having no ontological status or integrity other than that produced through their relationship to other similarly contingent and ephemeral bodies, things and ideas. (Deleuze, 1988, p.123).

This is also in agreement with the description of disability found in the CRPD (2007, Preamble, p.1).

As discussed in Section 1.4: Clarification of terms, another concept that will be adopted regards 'affect' (Deleuze, 1988, p.101) or what was otherwise known as 'agency', that is, the capacity to transform or be transformed. Affect holds assemblages together in a state of always 'becoming' (Deleuze and Guattari, 1988, p.256). Assemblages are not fixed, they are about dynamic processes and relationships. As in ANT, what is being proposed is that all entities, both human and non-human assemblages, have agency or the possibility to affect or be affected. This also places thoughts, emotions, feelings on the same plane as physical things, and, therefore, they also have material effects on/from the assemblage. DeLanda (2006) explained Deleuze's assemblage theory in simpler terms. Among other concepts, DeLanda confirms that this theory is against essentialism (*ibid.*, p.26ff.). He also suggests that the relations between components of an assemblage are provisional/contingent, such that they can 'unplug' themselves from one assemblage to 'plug' themselves into another. Another relevant concept to this study concerns the 'macro' and 'micro' levels in society. Neither is more important, nor is one privileged more than the other. There may be more than one explanation for a single process, that is, it may be due to 'micro' factors as much as it can be due to 'macro' factors acting at the same time in the assemblage (*ibid.*, p.37).

Although they are not the main writings that have shaped the second stage of the study, the concepts of the cyborg (Haraway, 1991) and the posthuman (Braidotti, 2013) will also be briefly considered. These researchers have challenged the thinking about the boundaries of the body/the self and about the central focus given to the human (anthropocentricity). They have

proposed a more collectivist view of the self as opposed to an individualistic one. Collectivist in the sense that human and non-human entities are considered an assemblage of interdependent components, in which none is distinct or more important than the other. In this perspective, the technological (and other supports) are viewed as an assemblage with the body and not as a supplement to it. Haraway (1991) calls this 'a cyborg (...) a hybrid of machine and organism' (p.149). Technology and the body are thus interdependent, and the latter becomes dis/abled depending on the interactions produced between the two (and the other components of the assemblage). Therefore the body does not become automatically enabled if technology is added to it (as per rehabilitation studies thinking). Such concepts are compatible with those proposed by ANT and by Deleuze and Guattari as discussed above, in that they focus on the capacities that may emerge from the affects among the components of an assemblage and among assemblages themselves.

I am therefore interested in following and advancing this new strand of work in DS that looks at dis/ability in a relational, messy, complex way. As Galis (2011) claims, STS can bridge the body/society divide by offering conceptual tools that can combine the experience of dis/ability with socio-material arrangements. Very few disability scholars have tried to put together the relational debate with STS (Näslund and Gardelli, 2013). This can therefore attest to the new contribution that this study offers. Another original dimension of this research is that most of the studies on disability, technology and employment come from North America, the UK and Scandinavia (Roulstone, 2016). This study adds a new perspective to the above since it is enacted within a Mediterranean context.

Whilst this chapter discussed the conceptual/theoretical framework that this study rests on, the next two chapters will provide a review of empirical research and other literature on the topic.

Chapter 3

Enabling Technology in Rehabilitation Studies and Disability Studies

3.1 Introduction

The literature review for this study consists of two chapters. The first (Chapter 3) appraises research coming from Rehabilitation Studies and DS, whilst the second (Chapter 4) draws upon empirical work from STS and new materialist perspectives that theorises a relational ontology of disability and technology.

In this chapter a range of research is considered which provides useful insights into the complex relationship between technology, disability and social opportunities, with a particular focus on technologies in the workplace. This is a critical review of relevant literature in which the strengths (and otherwise) of particular disciplinary perspectives and methodological approaches are considered and knowledge-gaps are mapped. The chapter begins with a brief history of AT and its development over the years. This will serve as a background to the diverse empirical work that will subsequently be described and analysed. Literature from rehabilitation studies will be considered first in order to understand how the role of technology in disabled people's lives has been perceived by healthcare/rehabilitation professionals and especially by OTs. The latter have long been considered to be the main mediators between disabled people, AT and the (work) environment. This section will also include a critical discussion of various AT models that have been developed in the rehabilitation field, in a bid to help these professionals measure outcomes in this area of practice.

An analysis of how technology has been theorised by researchers in DS will follow. The chapter then explores the disability literature relating to disabled technology users at their place of work. Research on disabled people's use of technology at work, and especially that mediated by OTs, has not been as extensive as might be desirable and therefore literature considering the

application of AT in a range of different contexts - not only at the place of work – will be considered.

3.2 History of the relationship between disabled people and assistive technology

Cook and Polgar (2008) assert that AT has existed since the Stone Age when humans started using tools to help them adapt to their functional limitations. This section will highlight the significance of the historical periods and events that acted as a backdrop to the invention of assistive technologies and services, and how they have helped to shape the field of AT as it is today. Although the presence of AT has been documented in various countries, the following summarised history of inventions of AT and related legislations mostly covers developments in North America, the UK and Northern Europe. This is an acknowledged limitation in the research evidence in this field (Roulstone, 2016). Although not extensive, some empirical work from other countries, such as Australia, Turkey and Oman, will also be discussed later on, in order to portray different emerging perspectives from different contexts.

Bryant and Bryant (2003) identified three periods related to the history of AT: (1) the Foundation Period, prior to 1900; (2) the Establishment Period, between 1900 and 1972; and (3) the Empowerment Period, from 1973 to the present. The Foundation Period includes recorded evidence of people with speech impairments as far back as 1000 BC, people with intellectual impairments in AD 33 and people with spinal injuries in AD 600. It also includes stories of sailors and pirates with hooks for hands and wooden legs to compensate for the loss of limbs. In 1817, Gallaudet opened the first school for deaf students in the USA and in 1829 Louis Braille adapted a code used by the French military so that blind people could access the printed word. In about 1834, Blomer set up an institute for people with physical impairments which included a workshop for the manufacturing of artificial limbs and early AT devices. In 1869, the first patent for the design of the manual wheelchair was filed, although, during the Civil War, injured soldiers were already making use of wooden wheelchairs with wooden wheels for mobility. With his invention of the phonograph in 1877, Edison opened the way for blind persons to listen to

material on recordings and in 1892, Hall invented the first Braille typewriter. Hearing aids were also first patented in the 1890s (Cook and Polgar, 2008).

The Establishment Period saw the rehabilitation disciplines established as specific entities and this brought with it policies and laws that enabled disabled people to advance their fight for rights. In the USA, World War I led to the first Soldier Rehabilitation Act in 1918 which included the first vocational rehabilitation services to assist injured soldiers in their re-integration in society. This was followed in 1920 by the Smith-Fess Citizens Vocational Rehabilitation Act which allowed vocational rehabilitation services to be extended to other disabled people who were not veterans of the war. Guide dogs were introduced in Austria in 1819 and then in Germany in 1916. They were introduced in the USA in the late 1920s and by 1931, in Italy and England. The Social Security Act of 1935 was the first such Act in the USA and it provided grants to blind people and disabled children. 1937 was the year in which the X-frame folding wheelchair was manufactured. The first talking books were developed between 1939 and 1945 in the USA and the UK.

World War II brought with it the development of the Hoover cane for blind people and the first battery-operated hearing aids for hearing impaired people. 1951 saw the birth of the Perkins Brailier, and the first communication device, the Tellatouch, appeared in 1952. 1955 was the year in which computerised Braille first appeared. The 1950s brought with them the introduction of numerous legislations which included the use of captioning in films for deaf people and education Acts that catered for bilingual students and those with learning disabilities. 1963 saw the birth of the first architectural access code in South Carolina, USA. Thus, this period included wars that produced a new generation of disabled people and advances in medicine that allowed children who were born with an impairment to live longer. It also included a proliferation of new technologies and equipment that would help disabled people enhance their 'independence' and quality of life.

The Empowerment Period is marked by the birth of the Disabled People's Movement in the USA and around the world. This gave a great impetus to the growth of the field of AT. The legacy of these years was that disability was turned from an absolute to a relative phenomenon (Mendelsohn

and Fox, 2003). This is in keeping with the SMD, in that disability was considered to become functionally greater or lesser depending on the decisions that society took with regard to the design of buildings and products, transportation and so on, as opposed to it being an absolute characteristic of people with impairments.

In the UK, the Chronically Sick and Disabled Persons Act of 1970 is regarded as the first legislation in the world to introduce policies to ensure equal opportunities for disabled people (Mercer and Barnes, 2004). In 1973 the revision of the Rehabilitation Act in the USA (Section 504) established that it was illegal to discriminate against disabled people, but it was not until 1977 that this civil rights legislation was put into practice following intense activism from disabled people themselves. This Section included the provision of assistive aids so that disabled people could have equal opportunities to access publicly funded programmes and services in their communities.

The first special education law was passed in the USA in 1975 and this was modified in 1985 to include the first provisions for AT in educational settings. This period went on to see the development of such technology as, for example, the closed-circuit television for electronic magnification of printed material in 1974; the Kurzweil Reading Machine for blind people in 1976 and the Braille embosser in the late 1970s.

In 1979, the Rehabilitation Engineering Society of North America (RESNA) was set up in order that, together with the National Institute of Disability and Rehabilitation Research (NIDRR) founded in 1978, it would promote the transfer of science, engineering and technology for the advancement of the quality of life of disabled people (Seelman, 2001). RESNA was fundamental in the development of standards in the field of AT. The Tech Act (Technology-Related Assistance for Individuals with Disabilities Act) was passed into law in the USA in 1988 and has been reauthorised in 1994, 1998, 2004 and 2010. This Act provided financial assistance to states to develop technology-related assistance programmes, thus acknowledging the potential of AT to help disabled people to be on a 'level playing field' with their non-disabled counterparts. In the 1980s there were also numerous initiatives in the technology field especially in biotechnology, microelectronics and new industrial

materials (Seelman, 2001) which supported new developments in the field of AT. The Americans with Disabilities Act (ADA, 1990) was fundamental in extending the principles of Section 504 of the Rehabilitation Act to all public and private sectors of the USA. In 1994 the Tech Act was revised to include those projects whose main purpose was not only to raise awareness regarding the potential of AT in the lives of disabled people, but also of those that help to identify and remove the barriers related to the access of AT devices and services for all disabled people in the USA.

The establishment of these AT legislations demonstrates that disabled people in North America have been much more active regarding their rights for AT than, for example, disabled people in the UK where the AT debate remained somewhat marginal to other issues in the disability rights movement of the same period (Blume, 2012; Roulstone, 2016). Priorities here were primarily focused on identifying and challenging physical and social barriers, as instigated by the SMD that had just been proposed in the UK.

In the European Union, the increase in the ageing population was a major factor in bringing AT on the agenda, such that in 1991, a programme called Technology for the Integration of Disabled and Elderly People (TIDE) was initiated through funds allocated by the European Parliament for further research and development in AT (Ballabio and Whitehouse, 1999). It was also during this period that the European Union set up a research and development framework that boosted European member states' cooperation in the field of science and technology (Commission of the European Communities, 1992). In 1995 the Association for the Advancement of Assistive Technology (AAATE) was set up to promote the development of AT for disabled people and elderly persons in Europe.

The birth of the SMD in the UK (UPIAS, 1976; Oliver, 1990b) was another important milestone for disability activism (Morris, 1991). Inspired by this model and by the 'Center for Independent Living' in Berkeley, USA, the Derbyshire Centre for Integrated Living (DCIL) identified 7 needs for independent living amongst which the need for technical aids and equipment (Davis, 1990, p.7). From the 1980s, public policy worldwide became subject to free market-based thinking that stressed consumer choice. This development

also affected the disability movement and especially the AT market. With their quest for wider choice and control in this market, disabled people were fighting for more empowerment (Blume, 2012).

Although not mentioned directly, disabled people's right to AT in Great Britain was further consolidated with the passing of the Disability Discrimination Act (DDA) in 1995. In Part II: Employment, Section 6: Duty of employer to make adjustments, Sub-section 3 provides examples of steps that an employer would need to take to comply with the Act and these include '(h) acquiring or modifying equipment' (DDA, 1995, Cap.50, p.5). Other areas of discrimination covered by this Act and which include Goods, Facilities and Services (Part III, Section 21); Education (Part IV); Public Transport (Part V) also mention 'access and use of auxiliary aids' (*ibid.*, p.19) as fundamental supports for disabled people to be able to participate in these aspects of daily life. Furthermore, Part II, Section 8 and Part III, Section 25 describe Enforcement procedures that may be taken in order to further safeguard the right to these supports. In order to promote research on innovative technologies and their development in the UK, the Foundation for Assistive Technology (FAST) was set up in 1998. This led to the formation of the AT Forum in 2003 in which service users, service providers, professional bodies and manufacturers of AT collaborated to set up the standards for AT service provision, among other initiatives.

But, on an international level, perhaps the most important piece of legislation that has been instrumental in recognising AT access as a human right, was the CRPD (2007). This Convention was adopted in 2006 and entered into force in 2008. It was written with the involvement of disabled people from all over the world. The Convention understands disability as 'an evolving concept' and has played an important role in helping to change disabling attitudes, albeit there is still progress to be made in this regard. It consists of 50 Articles, dedicating two of its General Obligations in Article 4 specifically to enabling technology:

(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies,

suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities; (CRPD, 2007, Article 4: General Obligations, p.6)

Furthermore, six other articles in the Convention refer to the right for support including AT (refer to Table 3.1).

Apart from the development of landmark legislations, in the last 30 years or so, the electronics revolution and the advancements in computer technology have left their impact on the development of AT applications. AT, such as screen readers and adapted keyboards, which, up to a few years ago, would be purchased separately and installed on the computer, are today being integrated within mainstream tablets and computers, thus making them more financially accessible and available to a greater number of disabled people. Other factors underlying the ever-increasing use of AT are the ageing population, resistance to hindrances to independent living, and changes in legislations (e.g. anti-discrimination laws that bind employers to provide AT for disabled employees) (AT Forum, 2004).

In the UK it was reported that the demand for AT is increasing and surpassing supply (Winchcombe, 2006), whilst in the USA, it was found that 32-45% of disabled people use AT (Litvak and Enders, 2001). Not all disabled people, however, who need AT have access to it. The World Health Organisation (WHO, 2018) reports that globally, more than 1 billion people need 1 or more assistive products, but only 1 in 10 of them have access to such products. For example, only 5–15% of those who require a wheelchair have one and the production of hearing aids at present only meets 10% of the demand. Back in 1995, Roulstone (1995, p.6) had already reported that ‘research is beginning to make clear that many disabled people would want more new technology to enable them, whilst provision is inadequate or inappropriate’. It is indeed disconcerting that the WHO is reporting the same situation today, more than 20 years later. With disabled people being amongst the poorest across

Table 3.1 Articles Relating to Enabling Technology - This table shows the CRPD articles which consolidate disabled people's right to enabling technology

CRPD ARTICLES RELATING TO ENABLING TECHNOLOGY
<p>Article 9: Accessibility; 2. States Parties shall also take appropriate measures (g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet; (h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost. (CRPD, 2007, p.10)</p>
<p>Article 20: Personal mobility (b) Facilitating access by persons with disability to quality mobility aids, devices, assistive technology and forms of live assistance and intermediaries, including by making them available at affordable cost; (<i>ibid.</i>, p.14)</p>
<p>Article 21: Freedom of expression and opinion, and access to information (a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost; (<i>ibid.</i>, p.14)</p>
<p>Article 26: Habilitation and rehabilitation 3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation. (<i>ibid.</i>, p.19)</p>
<p>Article 29: Participation in political and public life a) (ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate; (<i>ibid.</i>, p.21)</p>
<p>Article 32: Article 32 International cooperation: 1(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies. (<i>ibid.</i>, p.24)</p>

Global North and South (Shakespeare, 2012), ATs are often unaffordable – whether that be a pair of spectacles in a developing country, or an exoskeleton in a wealthier country. Without these supports, many disabled people remain at a disadvantage when trying to access education, employment and leisure activities.

The history of AT recounted above illustrates the complex dynamics that have existed (and still exist) between the phenomenon of disability and the development of technology. Both have undergone significant changes along the years and their history has raised important questions for disability academics and activists alike. With the emergence of disability rights, for example, the expectations of disabled people have been raised. But are all countries sufficiently committed, or economically able, to provide for these increasing needs? Are the benefits of these technologies outweighing the shortcomings? Is the advent of new technologies fostering more participation of disabled people in all aspects of daily life? It was against this background of historical events and the increasing numbers of disabled and elderly people globally, that a number of researchers set out to examine the various facets of the relationship between disability and technology and provide an evidence-base in this important field.

3.3 Research on disability and enabling technology: An overview

Existing research on disability and technology originates predominantly from the health sciences/rehabilitation field, computer science, DS and STS. This research is based mainly on small-scale studies with small samples and short timescales. In reality, however, AT interventions may take a long time, because the whole process starts with identifying the need for AT, through to the follow-up stages that may take place months (and sometimes continue for years) after the technology starts being used. Therefore, in order to accurately reflect the AT user's experience with the technology, AT research should include more longitudinal studies (Ivanoff *et al.*, 2006). There are another three major limitations with regard to this research. First, research emerging from outside North America and Northern Europe is limited. This is problematic in

that such literature does not take into account the different socio-economic contexts of countries in the South. Second, insufficient research has been taken from a DS perspective into the intersection of disability with technology. What is available mainly focuses on AT use in the educational sector (Florian, 2004; Seale, 2014; Quek *et al.*, 2015) or in the field of gerontology (Hoenig *et al.*, 2003; McCreadie and Tinker, 2005; Roulstone, 2016). Whilst this is useful, its limitation is that there is a lacuna in the evidence base for AT use by disabled adults at the workplace. A review of existing AT models and taxonomies showed that out of 22 AT specific models, 6 were specific to the education setting, 2 to the field of gerontology, 1 to wheelchair evaluation and the rest were of a general nature and not specific to a particular setting (Smith *et al.*, 2006). The absence of the workplace in this review that spanned almost 50 years of research is to be noted and indicates an urgent need for more research in this area. Third, research that has emerged from outside DS shows evidence that it does not fully understand or embrace disability politics (Layton, 2014). Whilst on the one hand, such research has helped to identify the dis/abling patterns in different social contexts, it has fallen short of offering a causal explanation for them. Consequently, outcomes from this research do not necessarily leave any significant impact on AT users' lives.

A field of AT research that has been regarded with scepticism by DS scholars, but which is also being questioned by academics from the healthcare disciplines themselves, is that which stemmed from rehabilitation studies. In this chapter, it will be considered before research coming from the disability field because, historically, AT was dominated by healthcare professionals who 'often framed new technology benefits as inhering in their compensation of disabled people's deficits' (Roulstone, 2016, p.93). This led disabled activists and academics to react and propose that, in line with social model thinking that was emerging at the time, such technology should be used for the 'rehabilitation' of environments rather than impairments. The following section, therefore, will give an overview of rehabilitation research that focuses on AT and disabled people, first in general and then specifically within the employment setting. DS research on the topic will then follow.

3.4 Disability and enabling technology in rehabilitation studies

Rehabilitation research has explored the field of AT from a wide range of perspectives. A broad body of rehabilitation literature has, for example, considered the use/non-use/abandonment of AT and the factors that influence these (Gitlin *et al.*, 1993; Sonn *et al.*, 1996; Wessels *et al.*, 2003; Verza *et al.*, 2006; Federici *et al.*, 2016). There is a variety of such literature about the interface between technologies and the human body, but only limited research that looks at how technology impacts the lives of disabled people (Lupton and Seymour, 2000; Layton, 2014). Few rehabilitation studies have looked at the lived experience of use/non-use of technology among disabled people and what meaning is given to the experience of using technology (McMillen and Söderberg, 2002; Lund and Nygard, 2003; Seymour, 2005). Even less has been written about the potential use of AT as a preventative measure for secondary impairment and further potential disability, for example, the use of a walking aid or the installation of grab rails to prevent injury from falls by elderly people with emerging mobility problems or people with progressive/degenerative conditions (Gitlin, 2002).

Rehabilitation literature has suggested that the purpose of assistive devices is to enable and enhance an individual's engagement in activities and participation in society through bridging the discrepancy between the individual's abilities and the demands of the environment in which s/he exists (Baum, 1998; Lund and Nygard, 2003). Others spoke of technology in a deterministic manner:

In a world where human beings and the machines they command have the power to control the quality of life, handicapping can only be the result of failure to properly apply technology or the neglect of its development (Rahimi, 1981, p.22).

Traditionally, in fact, rehabilitation professionals have regarded AT as tools to 'augment or replace functional limitations' (Cook and Polgar, 2008, p.56) and as 'fixing-the-deficit' tools (Roulstone, 1998; Foley and Ferri, 2012; Gibson, 2012). The limitation/deficit, therefore, is seen to be in the body. This

perspective is in contrast with the posthuman view (Braidotti, 2013) of the relation between the body and technology and other supports. According to this view, it is in this relational process that both body and technology (and not only the body) are transformed to produce capacities (or incapacities) for new possibilities of doing, being and becoming.

Even though rehabilitation studies claim that healthcare professionals have moved away from fixing the body towards enabling social participation (Gibson, 2012), there is an uncritical ideology of 'normality' (Oliver, 1993) that permeates rehabilitation. Bodies that cannot be fixed through surgery, therapy and/or medications risk bearing the stigma of pathology since they fall outside the limits set for 'normal' bodies (McCormack and Collins, 2010). Rehabilitation studies have in fact been criticised as having an under-appreciation of the social and political dimensions of disability (Magasi, 2008; Nicholls and Gibson, 2010). 'As in the case of research on medical services, research on assistive devices has focused on clinical issues' (Batavia and DeJong, 1990, p.54). This quote from 1990 and more recent literature (*e.g.* Roulstone, 2016), demonstrates that little has changed in this field of research. In fact, this remains one of the major barriers related to technology in the rehabilitation field, since it considers impairments rather than the person's choices and goals within a particular disabling context.

Other barriers that have been mentioned in the rehabilitation literature with regard to AT services are the cost of such devices and funding difficulties, the issue of access to AT, the complexity of the problems involved in matching the person with the device, the availability or lack of training related to both users and providers, the rapid development of new technology making AT devices become quickly obsolete, and the problem of non-use or abandonment of AT (Scherer, 2005b; Castellina, 2010; Encarnação and Cook, 2017). A particular barrier to AT access is that it is limited to what is available or known (Brown-Triolo, 2002). This may be due to the fact that AT companies tend to be small with domestic, rather than global, marketing strategies such as those used in large information technology systems (Seelman, 2001). The barriers mentioned in this section are similar to those described later in DS literature and to what the WHO (2018) reports as barriers related to AT and disabled people

around the world. Among others, WHO mentions the lack of affordability, lack of AT policies in many countries, the AT industry being very specialised, limited and supplying mainly high-income markets, fragmented AT provision services with little or no follow-up programmes, and lack of specialised AT professionals (WHO, 2018, no pagination). Although both DS and rehabilitation studies recognise the same barriers, research shows that they are falling short from providing solutions for the removal of these barriers.

Whereas many a time clinical research has focused on the usability of AT in the performance of daily activities and therefore on how this technology enables a person's independence in doing things, AT users may place more importance on how they perceive the devices they use. Findings in a study by Lund and Nygard (2003, p.67) indicate that, 'the participants' experiences of using assistive devices reveal meanings about their use that go beyond the traditional medical perspective that focuses on the role of technology as compensation for impairment', such as self-image and identity issues. The participants in this study revealed that for them, self-image was more important than whether the assistive devices compensated for their impairment or not. Similarly, Ravneberg (2009) reports that for the participants in her study, who were either wheelchair users or had a hearing impairment, the assistive devices had to be as invisible as possible so that they would look as normal as possible. For example, some preferred flesh-coloured hearing aids rather than fancy colourful ones and others wanted their wheelchairs to match their clothes and to be the least bulky possible. On the other hand, this might be changing because other literature has reported that, for example, specially coloured and styled hearing aids are being manufactured for children and adolescents as fashion statements (Norman, 2013, p.245). Other authors have written about disabled people who consciously choose, for example, prostheses whose 'abstract elegance challenges the duality that has existed for so long between aesthetics and functionality' (Pullin, 2009, p.31). Aimee Mullins, athlete, actress and model with bilateral leg amputations, in a personal communication with Pullin, in fact declared, 'Discreet? I want off-the-chart glamorous!' (Mullins, cited in Pullin, 2009, p.31). The above not only show that these technologies affect disabled people's identities and self-image, but that they do so in different ways with different individuals. This signposts to designers that they have to weave this

factor into their designs, apart from merely considering functionality issues. Otherwise, users may choose not to use the devices after all. It also shows how an interaction takes place between human and technology, with the human transforming the technology into something more than a functional device, for example, into a fashion accessory. A case in point is the relation between Mullins and her prosthetic, which shows how she affects her prosthetic, which in turn is affected by her use of it and vice versa. The prosthetic becomes a fashion item; Mullins becomes a style-icon.

A review of the literature on the satisfaction with AT devices from a user perspective (Wessels *et al.*, 2004) showed that there is very little literature on the topic since 1996. Other research showed that disabled people are rarely involved in the design of AT devices, except for some involvement in wheelchair design (Roulstone, 2016). Recently, however, designers and people involved in the marketing of these products are giving particular importance to participatory design, that is, the involvement of users in the design of AT devices. This is fundamental since, on their part, designers attach particular meanings and lifestyles to the products they create. Users though may see technology from another perspective, in that they do not only focus on what the technology/device helps them do but what it helps them be:

While accessibility and enhanced functioning are important goals, many disabled people believe that more crucial are the individual's basic needs for security, autonomy, affiliation, accomplishment, intimacy, and identity. (Scherer, 2005b, p.77)

In other words, these are quality of life issues. In a bid to counteract this problem, participatory design is becoming progressively more important (Wu *et al.*, 2004, 2005; Pullin, 2009; Norman, 2013). It consists of designers involving AT users in the whole of the design process of a technology, from research to development stage, so that they understand how that technology will be used and pre-empt any challenges that will hinder its use (Robinson *et al.*, 2009). It is about co-creating and co-producing; designing *with* rather than *for* disabled people, because, as Pullin (2009) puts it, 'When design meets disability, this meeting will change design itself' (p.307).

Another way forward that has been suggested for better inclusion of disabled people in this field, is that new technology is developed in such a way that it would not need adaptation (Emiliani, 2006; Harris, 2010). In fact, the boundary between assistive technologies and mainstream technologies is becoming ever more blurred because technology has become so much a part of our daily lives. In computer science, for example, the term 'accessible technologies' is recently being used to describe those technologies that are designed with a wide range of users in mind. Users can then customise the device for their individual needs because of in-built customisation features (Panchanathan and McDaniel, 2015; Weible, 2018). Accessible technologies therefore embrace the concept of universal design which does not so much accommodate disabled people through special features in the design of things, places and information, but seeks to accommodate the widest possible spectrum of users (whatever their age, size and ability) in society, without the need for adaptation (Mace, 1985; 1997). As has already been stated, many mainstream technology designers are starting to adopt this concept, for example in ICT, for the benefit of those disabled people who can afford/access such technology.

Furthermore, mainstream technology proponents and researchers are not only looking at which technology is available and whether it is useful, but also which of the variety of technologies available is the most efficient for the person's goals and how s/he can be further facilitated to make the best use of it. This applies also to AT. De Jonge *et al.*, (2007) propose that there are two approaches in mainstream technology that have the potential to influence AT service provision, i.e. the human-centred design (Maguire, 2001) and attributional theory (Martinko *et al.*, 1996). Human-centred design focuses on the usability of technology, that is, not only focusing on the task that the technology is created to facilitate but also on the user and the physical, technical and organisational context/environment. Attributional theory on the other hand suggests that the emotional and behavioural reactions that the user has towards the technology are influenced by previous experiences. This is a dynamic, interactive view of the variables involved in such an ongoing, and constantly evolving relationship. If this is applied to AT/user relationship, then it

can be assumed that the user's attributions of the technology are formed and evolve before, during, and after the AT selection/delivery/use process and this in turn will influence whether/how the user will interact with the technology. This has implications for the professionals who are working in the sector and highlights the importance of their being aware of the complex dynamics and the multiple influencing variables (later seen as assemblages and networks) that are involved in the AT process.

In this regard, Scherer (2005b), a rehabilitation psychologist, suggested that AT providers need to be more user-centred than technology-centred. The model she proposed in 1998, the Matching Person and Technology model (MPT), was in fact an attempt to apply a user-centred perspective in this important area of rehabilitation. The next section will discuss this model, and others that have been proposed, in an attempt to describe the relationship between disabled people, AT, activity/function and the environment.

3.4.1 Assistive technology models

There are a number of models that bring together the human, her/his activities and the environment, but many of these have failed to include AT (Haynes *et al.*, 2009). Research in AT flourished considerably in the early 1990s (Weiss-Lambrou, 2002) in parallel with the development of a number of technology theories that were discussed in Chapter 2. Various models for the understanding of the relationship between AT and disabled people were thus proposed. Amongst the leading conceptual models were: The MPT (Scherer, 1991,1996); the Human Activity Assistive Technology model (HAAT) (Cook and Hussey, 1995) and the human-environment/technology model (Smith, 1991). These models attempted to provide a basis upon which AT assessment, selection, service provision and use can be based. Although all emerge from the psychology or the rehabilitation fields, these models demonstrate an attempt to bring together disability and rehabilitation. They helped to steer rehabilitation studies to also consider psychological and social influences in the AT process, from assessment to follow-up, rather than solely centring it on technical or impairment-related issues. These models will be discussed in further detail below.

Scherer (1998) proposed the MPT, based on the person, the technology and the environment. In this model, the 'person' refers to the user, supporters and providers of AT; the 'technology' includes AT services and products; and the 'environment' includes the physical, architectural, attitudinal and cultural context in which the person lives. The model is specific to the selection of AT devices. Both the model and the process are user-driven and person-centred. The model was the result of a grounded theory study (Scherer, 1998) and there is evidence of its good reliability in various countries. The Assistive Technology Device Predisposition Assessment (ATDPA) (Scherer *et al.*, 2005; Scherer, 2005a) was proposed as a tool based on the MPT model. In a literature review carried out by Alves and Matsukura (2016), 14 conceptual models that are specific to AT were identified. Out of these, the MPT was recognised as the model most frequently used in this field. In 2007, Scherer *et al.*, developed the Framework for Modelling the Selection of Assistive Technology Devices which builds on the Framework for Modelling the Outcomes of Assistive Technology Devices (Fuhrer *et al.*, 2003). Together with the user, the 2007 framework also considers the service provider. However, there are no assessment tools based on this framework.

Apart from the two above, other models related to the AT field have been developed. The HAAT model was proposed by Cook and Hussey (1995, 2002). This is a holistic model that is made up of 4 components: human, activity, AT and context. It focuses on the AT user (someone), with the activity to be carried out (doing something) and the AT device forming part of the AT system, that in turn is placed in a specific context (somewhere). The setting (e.g. the workplace), and physical, social and cultural factors are considered part of the context. Driscoll *et al.*, (2001), for example, used the HAAT model to explore the barriers and enablers that workers with spinal cord injury, their employers and colleagues meet while trying to integrate their AT in the workplace. They found that the model was helpful for them to understand the factors related to the disabled employees, their AT and the workplace, both individually and as they interacted together. Other authors agreed that the model acknowledges the dynamic relationships between the AT device, the person and the activity, and the impact that the context has on them, individually and collectively (Giesbrecht, 2013). The novelty here is that functional outcomes are seen to be

the result of the human-AT system interaction rather than the result of human performance on its own. However, in HAAT and all other models, the human is still placed at the centre of the system and therefore given superior status to the other components of the model (anthropocentric).

Haynes *et al.*, (2009) acknowledge that the HAAT model has highlighted the importance of the environmental factors on the performance of activities by the human, but they suggest that it has not proposed ways in which these factors can be intervened upon to facilitate human performance. The model places much emphasis on the importance of the AT selection process but has neither been validated nor has it proposed any AT assessment tools (Bernd *et al.*, 2009). The model is in fact still being revised and developed. New materialist thinking such as the concept of the posthuman, mentioned further above, could be taken into consideration in these developments and consider the human-activity-AT-context system as an assemblage where each component inter-dependes (equally) on the others.

Bernd *et al.*, (2009) carried out a systematic literature review on models for the selection and advisory process of AT in the rehabilitation field and identified the three models above as AT specific and suitable for the AT selection process. Lenker and Paquet (2003) also reviewed six models that are related to AT, namely, Cook and Hussey's HAAT model, Scherer's MPT model, Social-cognition decision making theories, Rogers' Perceived Attributes Theory, WHO's ICFDH, and Gitlin's Model of AT User's Career. This review was based on claims that 'there is no dominant conceptual model that describes and predicts AT outcomes' (Lenker and Paquet, 2003, p.1). Of the models reviewed, the MPT and the HAAT were identified as being the most important, in that they place the user at the centre of their framework. According to Lenker and Paquet (2003), however, they still do not explain how AT and the various components (proposed in the models) work together to enable AT users to do what they want to do, how they wish to and where they want to.

More recently, Lenker *et al.* (2010, p.131) have again confirmed the above lacuna in AT theoretical frameworks and added that, consequently, clinicians in the field have to 'rely on case studies and anecdotal appeals' to justify their requests for the funding of AT-related services and devices. It is also

difficult to justify the latter because AT is generally used with other supports, such as the support of a personal assistant. It is therefore difficult to 'measure' the outcome of an AT intervention and to say that the outcome is solely due to that particular intervention. The variables involved in reality are multiple and intersect in a complex way that is difficult to demonstrate with the use of the available models/assessment methods. This could explain why the AT field is so lacking in a sound theoretical basis. This difficulty in identifying appropriate theoretical frameworks and the many diverse models that exist highlight the complexity of the multiple factors involved in the process of selection, acquisition, use and follow-up of AT systems. Among the factors that make this field very complex is the multi-disciplinarity of professionals involved along the entire process. Very often health and social care professionals are the ones who assess disabled people's impairments and decide whether and what for they are eligible with regard to AT. They are often the gatekeepers of AT resources (Roulstone, 2016; Layton, 2014). Apart from raising questions of power and resource distribution, this gives rise to another important issue as Hasler suggests:

The disability movement does not reject the idea of gadgets. One of the basic requirements for independent living is appropriate technological equipment. But even here, appropriate can be defined differently by a non-disabled person and a disabled one (Hasler, 1993, p.15).

Although they do not hold expertise in all existing categories of AT, OTs have claimed that:

the use of AT as a means of intervention to support a client to participate in a desired occupation has always been an integral component of occupational therapy practice. (American Occupational Therapy Association (AOTA), 2016, p.5).

Interestingly though, OT literature is limited in critical discussions of technology that is being recommended by OTs as an intervention on their service users' occupational performance. Because of this, OTs do not have much evidence to base their AT interventions on (Letts *et al.*, 2003). Therefore, referring to Hasler's and the AOTA quotations above, how are OTs defining disabled people's needs in AT service provision? How do they define what is

'appropriate' for the disabled person? How do they support disabled people to participate in their desired occupations? Do they perceive the value/purpose of technology in the same way as disabled people do? What is the relationship between OTs, technology and disabled people, especially in the workplace?

These questions will now be examined in an attempt to find out whether the core belief underlying OT practice that:

All people need to be able or enabled to engage in the occupations of their need and choice, to grow through what they do, and to experience independence or interdependence, equality, participation, security, health and well-being (Wilcock and Townsend, 2008, p.198)

is meeting the need of disabled people to be provided with opportunities that enable them 'to take part in the normal life of the community on an equal level with others' (Barnes, 1991, p.2). A brief description of the development of the OT profession and the philosophy underlying its practice will first be delineated. This will set the foundations for the following section which will discuss the OT role in AT access and provision in general and then with a special focus on OT-AT research in the field of employment of disabled people.

3.4.2 Occupational therapy perspectives

OT emerged as a profession in the USA in 1917 (Schwartz, 2003) and in the UK in 1925 (Kielhofner, 2004) delineated three important paradigms that have appeared in the OT profession since its foundation: the paradigm of occupation from 1900 to 1940s, the mechanistic paradigm in the 1960s/1970s and the contemporary paradigm from the 1980s onwards.

The beginnings of OT are set in the mental health field and were inspired by Moral Treatment following the birth of the asylum (Kielhofner and Burke, 1977; Bing, 1981). It was Philippe Pinel, a French physician who is said to have removed the chains from inmates in mental health hospitals in Paris and contemporarily, William Tuke of York, UK, who set up 'The Retreat', a hospital for people with mental illness run by the Quakers, whose beliefs in humane treatment gave rise to what became known as Moral Treatment (Digby, 1985; Foucault, 2006).

Moral Treatment claimed that 'participation in the various tasks and events of everyday life could restore persons to more healthy and satisfying functioning' (Kielhofner, 2004, p.30). Browne summed up Moral Treatment in two words, 'kindness and occupation' (Browne, 1837 as cited in Shorter, 1997, p.43) as opposed to the cruelty that people with mental health conditions had been subjected to, up to that point. By the beginning of the 20th century, it was widely accepted that people with mental health conditions were best treated through the use of occupation. European physicians in asylums were also introducing work programmes for inmates since they had noted that lower-class patients who performed work tasks while incarcerated, recovered more quickly than did 'idle' upper-class patients (Roberts *et al.*, 2008).

From the early 1900s through to the 1940s, OT was in fact based on the paradigm of occupation and acknowledged that participation in everyday meaningful activities influenced mental and physical well-being (Paterson, 2002). Meaningful occupations were described as activities with a purpose, and it was believed that, 'An activity entered into without a purpose is not occupational therapy' (Willard and Spackman, 1947, cited in Turner, 2002, p.11). The type of activities used were those representative of that era, such as arts and crafts like woodwork, leatherwork, weaving, and canework (Kielhofner, 2004).

Following the outbreak of the First World War, important developments took place in the practice of OT especially in the treatment of people with physical impairments. For example, Sir Robert Jones, Inspector of Military Orthopaedics during the First World War, persuaded the War Office to allow him to open Curative Workshops in Military Hospitals all over the UK, which then became models for OT departments for the treatment of people with physical impairments. These workshops were modelled on similar ones in the USA and included activities such as carpentry, window cleaning, and painting (Turner, 2002). During the Second World War, rehabilitation became recognised as a medical specialty in its own right (Roberts *et al.*, 2008). OT was considered to have 'an extremely important role in the modern concept of total rehabilitation' and OTs were seen as 'an important adjunct in the treatment and early recovery in injury and disease' (Samberg, 1947, cited in Roberts *et al.*, 2008, p.290).

This resulted, however, in OTs aligning themselves with rehabilitation medicine and abandoning their commitment to the value of occupation, in favour of reductionistic goals of increasing joint range of motion and muscle strength (Friedland, 1998). With this arrival of Reductionism, OT was pressured by the medical profession to find a scientific basis for its philosophy (Kielhofner, 1977) and it sought professional recognition through the adoption of biomedical explanations and approaches to impairments. The need to measure therapeutic outcomes, including independence (Tamaru *et al.*, 2007) indicated a change in the values of the profession. The OT practice of the time could not be explained in terms of measurable outcomes of cause and effect and, therefore, it developed various scales that could 'measure', for example, the ability of a person to carry out activities of daily living thus interpreting the meaning of 'independence' as being able to function without help. It also changed its paradigm to a more medically oriented one, that is, curing the parts of the body that were affected by the disease or trauma.

The problem was seen to lie within the individual. The body was separated from the person. To this effect, a variety of sensori-motor approaches to treatment of the physically impaired person were developed in the 1950-60s (Kielhofner, 2004). These approaches were intended to influence the inner mechanisms that determined everyday functioning through therapeutic exercise, splinting and positioning, prescription of adaptive devices and the teaching of compensatory techniques of everyday life activities. For example, in the treatment of persons with neurological conditions, OTs would identify the abnormal movement patterns and inhibit them to facilitate normal movement patterns. The Mechanistic paradigm of OT was thus established (Kielhofner, 2004).

By the late 1960s-1970s, however, many OTs were realising that they had lost sight of the meaning that the activities they were using had for their clients; they had ceased to consider the client's experience within the therapeutic occupation.

Occupations are more than movements strung together, more than simply doing something. They are opportunities to express the self, to create an identity. (Christiansen, 1999, p.552)

There were claims that the reductionistic medical model was especially failing to address disabled people's problems since these extended beyond deficits of internal mechanisms (Safilios-Rotschild, 1970). By this time, disabled people were struggling towards achieving meaningful lives and the OT philosophy of the time was not helping them to fulfil these expectations. This was because, as Vic Finkelstein, a disability activist and academic, describes it, professionals in rehabilitation services were trying to fit disabled people into the able-bodied and non-accessible society that was excluding them and were thus developing a new medicalised approach to social issues:

Under the term 'rehabilitation' they made a medical interpretation of the social problems facing disabled people and then tried to make this the dominant framework for the interventions of a whole team of multi-disciplinary workers. (Finkelstein, 1984, p.3)

An emphasis on the 'therapeutic' value of activity was placed especially when OTs had to start justifying what they were doing, through measurable outcomes, to insurance companies and funding agencies which paid for their services.

With the arrival in 1967 of the systems theory proposed by Bernstein, a Russian scientist who claimed that no system can be fully explained by examining the component parts that it is made of (Shumway-Cook and Woollacott, 1995), OTs started reflecting again on their practice; they started focusing on the 'whole' person rather than on its component parts (Mathiowetz and Bass-Haugen, 1994). Whilst the underlying anatomical, physiological and psychological systems are important to occupational performance they are not sufficient for occupational performance. It was recognised that the context and the environment within which the person is performing must be taken into consideration since these too affect the dynamics of that person's behaviour. The contemporary paradigm of occupational behaviour was therefore proposed (Kielhofner, 2004) and this returned OT practice to the more holistic viewpoint in which the person, the environment and the occupations in her/his life are considered together (Law, 1991). Whilst this was an important step away from viewing the body in a positivist mechanistic manner, the idea of viewing the person as a whole (with her/his physical, cultural, and social environment), has

today become problematic because of the difficulty in defining a body's boundaries. This argument will be further explored later on.

Following the OT paradigm shift towards human occupation, various theoretical models that form the basis of current OT practice have been documented but the ones most relevant for this study are categorised as Occupation-based Models and have been described in Cole and Tufano (2008, pp.89-134) as the Occupational Behaviour Model (Reilly, 1958, 1966), the Model of Human Occupation (Kielhofner and Burke, 1980), the Occupational Adaptation Model (Schkade and Schultz, 1992), the Ecology of Human Performance Model (Dunn *et al.*, 1994), and the Person-Environment-Occupational-Performance Model (Christiansen and Baum, 1991). Whilst a detailed analysis of these models is not within the scope of this thesis, it is important to note that they were mostly influenced by theories of holism and humanism, systems theory and developmental and social psychology. They were all proposed by OTs and all attempt to theorise on the fit between the person, the task/occupation and the environment.

But how is the term 'occupation' understood by OTs? Along the years there have been many different interpretations of the term (Yerxa *et al.*, 1989; Law, 2002; Larson and Zemke, 2003). As discussed in the above historical account, in its early years, the aim of OT was more focused on diversionary activities. It was believed that occupying the mind on some form of activity was beneficial for the wellbeing of the person. Occupation has been defined by Wilcock (1998, p.248) as:

all the things that people do, the relationships of what they do, with who they are, as human beings, and that through occupation they are in a constant state of becoming different.

Based on Wilcock's work, the concepts of 'doing', 'being', 'becoming' and 'belonging' are regarded as central to the understanding of 'occupation' for OTs (Hitch *et al.*, 2014a; 2014b). The definition proposed by Wilcock stresses a dynamic, shifting, relational relationship between the four concepts that makes up the complex experience of occupation. Wilcock (1998, p.253) also reminds OTs that their primary role is not geared solely towards people's personal

independence (self-sufficiency) but towards enabling participation in 'occupation as an agent of health and well-being'. Occupational participation has subsequently been defined as 'the ability to choose and move freely in one's environment and do what one wants and needs to do' (Ward *et al.*, 2007, p.150).

It can therefore be said that, apart from the time when it shifted to more positivistic practice, OT was always the profession that understood the value of the role of the environment/context on the in/ability of the person to be able to do what s/he wanted/needed to do. From the above-mentioned models, the Person-Environment-Occupation Model (PEO) (Law *et al.*, 1996; CAOT, 1997) has been identified as being potentially useful to illustrate an OT perspective to research AT and physical environmental issues. O'Brien *et al.* (2002), however, suggested that this and similar models are still not taking into account the complexity of the relations between, in this case, the person, the environment and the occupation. In this regard, Sellar (2009), proposed that occupational science, which is the academic discipline that supports occupational therapy practice, should adopt assemblage theory to transform its theoretical frameworks (including models) to be more focused on complex processes rather than dualistic thinking. This was the only paper I found in the OT literature that engaged with NM concepts, but which makes way for further exploration and application of these concepts to the OT-AT field.

Another framework that is fundamental for OT practice is the Occupational Therapy Practice Framework (OTPF) (AOTA, 2014) which is based on the ICF (WHO, 2001). Disabled activists and academics, however, have criticised the WHO classifications proposed in the ICF (Pfeiffer, 2000). Claims that assessments of ability and categories of functioning require a value judgement of what is assumed to be normal have also been made by rehabilitation theorists (Law, 1992) and indicate that these assessments are creating further marginalisation of the people who are being classified. Furthermore, the proponents of, for example, the SMD, challenge the suggestion that any problems experienced by those deemed 'different' should be blamed on their differences (Pfeiffer, 1998).

The ICF (WHO, 2001), however, claims to integrate the medical and social model by using a bio-psychosocial approach. This claim has been criticised as being 'theoretically naive' (Michailakis, 2003, p.219) since there is no super system that embraces all these aspects. The ICF perceives a person's functioning as a 'dynamic interaction' between a health condition and contextual factors. Contextual factors are defined as 'features of the physical, social and attitudinal world' which facilitate or hinder participation (WHO, 2001, p.8). This is similar to what OT proposes, in that it identifies activities and contexts as the main determinants of disability. OTs therefore help to identify the actual performance of a client and her/his potential capacity, and subsequently alter the environmental/task conditions of the client in order to improve her/his occupational performance or participation. OTs are said to enable individuals to learn to meet the demands of the environment to participate in desired occupations in home and community life (AOTA, 2014). This they do by using therapeutic interventions, teaching compensatory strategies, advising about environmental modifications or recommending AT. But by basing the OT Practice Framework on the ICF, OT interventions are dependent upon an assessment of the individual abilities and needs seen to be associated with personal functioning. Additionally, the 'personal factors' element in the 'Contextual Factors' section of the ICF, which includes 'behaviour pattern and character style, and individual psychological assets' (WHO, 2001, p.17), is also questionable, implying as it does that some people are more resilient (better at coping with illness or disability) than others. It also implies that some people are inherently more prone to becoming autonomous/independent (following an illness or disability) than others. This is a very individualistic approach in that it is not, and should not be, the individual's sole responsibility to be resilient and autonomous/independent. This is in conflict with what disabled people propose in the SMD in that the problem does not lie solely in the person's impairment but in society's discriminatory policies and practices that continue to exclude disabled people from fully participating in community life.

The OT model that shifted and brought a balance, although still not symmetry, in the power-game between the client and the professionals was the Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists (CAOT), 1997). It proposed client-centred practice

to OTs and urged them to focus more on the person's goals and wishes than on solving her/his problems. This is comparable to what Finkelstein (1981, p.4) proposes:

that the role of the professional worker in rehabilitation needs to change from management of the patient to that of being a resource for the patient to use in reaching his or her own goals.

The Canadian Model of Occupational Performance emphasises that it is pointless to have interventions that are focused solely upon the individual, arguing that OTs must seek to improve the circumstances of disabled people by working for environmental changes (CAOT, 1997). It defines the environment as including cultural, physical, social and institutional elements (CAOT, 1997). By using activities/occupation to increase function and participation in their clients, OTs are said to be helping to break down the barriers between the person, the task to be carried out and the environment in which it is being carried out (Law *et al.*, 1996). They are, however, remaining too close to the individual's immediate environment and are not striving to remove the bigger societal barriers that hinder disabled people from living a full life in the community (Hubbard, 2004). It has in fact been argued that while OTs work constantly to adapt physical environments by removing physical barriers, the same cannot be said for the removal of social and institutional barriers (Jongbloed and Crichton, 1990; Ivanoff *et al.*, 2006).

A literature review of 75 articles published in 9 international peer-reviewed OT journals was undertaken to investigate how AT and physical environmental issues have been studied in the field of OT (Ivanoff *et al.*, 2006). A major flaw that was highlighted in this literature was the lack of a theoretical underpinning for the AT research. Few authors provided theoretical definitions of their main concepts and only 1 article was classified as theoretical. This indicates a critical gap in this type of research and also that OT is more of a practice-oriented profession. Another important conclusion in this review was that most articles dealt with the outcomes of specific AT products by users from specific impairment groups. These studies generally considered how AT influenced body functions and structures rather than how AT impacted on the person-environment-occupation relationship. There was also a general

tendency amongst OTs to treat AT as a separate intervention from the user's rehabilitation programme. The majority of studies indicated that interventions were still provided on an individual level, an 'as the need arises' service, which was usually based on the medical model. A societal level perspective (rather than an individual one) was claimed to be taken by a significant number of the studies but it was not always clear how/whether this was achieved. Only few of the studies involved users. Therefore, since OTs claim that they carry out client-centred practice, it is necessary for their research to also take into account the user's perspective. Clear connections between the society/environment and the individual are also missing from this research.

On a methodological level, most of these studies claimed limitations which implied validity and generalisation issues. The latter was further exacerbated by the fact that the studies were carried out in different countries and were therefore accountable to different legislations such as anti-discrimination and entitlement ones. Notwithstanding the gaps and limitations described, this literature review served to highlight the potential impact that OT research in the AT field can have if it further develops its theoretical foundations and if it strives to include AT users' perspectives in both intervention and research processes.

Other OT literature also invites OTs to have an appreciation of the concept of disability from the viewpoints of disabled people (McCormack and Collins, 2010). Linton *et al.* (1994, p.480) further propose that the shift of emphasis from a prevention/treatment/remediation paradigm to a social/cultural/political paradigm both emanates from, and supports, the Disabled People's Movement. This is where the SMD and OT/professional practice may meet. By taking a broader societal approach to enablement and social inclusion, by being more sensitive to disabled people's viewpoints and to their actual lived experiences of disability, OTs may 'translate client-centred rhetoric into client-centred practice' (Hammell, 2006, p.157). Although this focus on client-centredness will later be questioned, it was an important shift from reductionistic practices to ones that attempt to consider the person as a whole and not merely her/his biology.

One strategy for making this happen was proposed by Sinclair (2005) who recommended that OT professional education should incorporate 'a strong component on enablement, advocacy and social reform' (xiv), if the profession is to develop OT as an agency for social change.

One domain in which this shift is particularly urgent is the field of employment of disabled people. OTs have been involved in the rehabilitation of disabled people in the world of work ever since the early days of the profession (Harvey-Krefting, 1985). The next section will review the role of OTs in this field, the literature that brings together OTs, disabled people and employment, and the lacunas that still exist therein.

3.4.3 Occupational therapy, enabling technology and employment of disabled people

The belief that active engagement in meaningful occupations supports the health and well-being of an individual is central to OT philosophy (McHugh Pendleton and Schultz-Krohn, 2006). Some individuals with impairments may need support, more than others, to participate in daily life occupations. The assistance necessary for a person who has a physical, sensory or mental impairment to engage in occupations does not necessarily require the restoration of such impairments. Assistance may include the use of aids and assistive equipment for that person to be able to perform those tasks that s/he would otherwise find difficult to do. It is in this niche that OTs have found their specialism, i.e. in guiding the people they work with, to the optimal strategy or equipment that would help them carry out a particular task/life role (e.g. Winchcombe, 2006). One particular life occupation is work, and work/vocational rehabilitation involves interventions from various professionals including OTs. What makes OTs particularly suited to assess the person as a whole is their knowledge of performance skills, i.e. physical, sensory, psychological, and social skills. However, as Sandqvist and Henriksson (2004) claim, a person's ability to work cannot solely be determined through the assessment of body functions and impairments. The AOTA in fact explains that:

Occupational therapy practitioners, through their education and training, have the skills to evaluate worker capacities, task performance, and the work

environment, and to provide interventions related to these areas. (AOTA, 2018, no pagination)

Using a client-centred perspective, OTs evaluate the impact of wellness, cognition, physical impairments, psychosocial factors, and medical conditions on work performance. In particular, OTs possess the distinct ability to evaluate the intersection of an individual's work demands and the work environment through task analysis. The OT evaluation can identify supports and barriers to success in the work environment, including work culture, that can be addressed in the intervention plan to enhance work performance. The occupational therapist also considers other contexts and environments that may support or hinder the ability to fulfill the worker role, such as access to transportation and the ability to dress oneself in a timely manner for the work day. These specialised evaluation skills allow the occupational therapist to understand and deliver results in the complex psychosocial and physical work environment (AOTA, 2017). But, as has been said above, this practice at times restricts its focus on to the individual, her/his immediate environment and the task at hand, rather than on the wider networks around the individual. Furthermore, although client-centred practice has helped to delegate some professional power from OTs to their service users (CAOT, 2002), as Finkelstein (1981) had augured above, the person is still in a privileged position at the centre of the system. Given the messy nature of today's societies in which bodies, technologies and communication systems have become entangled in complex networks, it is perhaps opportune for OT to re-think its philosophy and practice towards a more new materialist, post-anthropocentric perspective, as shall be discussed further ahead.

The empirical research located in OT vocational rehabilitation literature attests to this claim. The research was found to focus mainly on workers with specific medical conditions such as people with mental health conditions (Arbesman and Logsdon, 2011), neurological diseases (Townsend, 2008), and musculoskeletal conditions (Bevan *et al.*, 2007) indicating a more impairment-based approach to intervention. There is also evidence of more OT vocational rehabilitation research coming from the mental health area than from any other field (Waghorn, 2016a; Waghorn, 2016b). A particular lacuna was noted

regarding literature covering OT and employees with sensory impairments (Wittich *et al.*, 2017). Primarily, the available literature describes the type of services being offered by OTs in vocational rehabilitation. A literature review of 22 empirical studies carried out between 1980 and 2008 on various OT interventions related to productive work (Law and Gewurtz, 2010) indicated the services that OTs are offering in this area. These mainly included education and provision of information to clients, modification of work tasks and activities, and programmes to improve work skills and participation in both simulated and real work environments. The authors claim that this review does not sufficiently provide evidence of the challenges and outcomes of the OT interventions, and the need for more research in the area was highlighted (Law and Gewurtz, 2010). The specific role of AT and other technologies as potential enablers to workers with impairments is therefore lacking in this type of literature.

The modalities used by OTs in their vocational rehabilitation interventions and the philosophies behind them also lack a strong evidence-base. For example, early OTs used craft activities to rehabilitate their clients with the assumption that there would be transfer of training to the work tasks that the person would want to perform. More recently, simulation of particular work tasks is carried out with the clients in the belief that the closer the task and context is to the worker's demands at her/his job, the better the occupational performance. Rice and Luster (2008) however claim that there is a lack of outcome research that prefers one method over the other and therefore OTs generally base their practice on previous experience or individual 'good practice' examples that are also rare in the OT literature.

Another limitation is that the specific interventions used by OTs in empirical research on the topic are usually not documented in detail and so they cannot be replicated in other studies or contexts by other OTs. Furthermore, in a study among OTs and physical therapists who practise in worker rehabilitation in the USA, Lysaght and Wright (2005) found a high degree of overlap between the interventions offered by different professionals. OTs, however, were found to be more involved in job analysis and job/environment modification as well as in the analysis and treatment of the arm/hand, given that it is directly related to the performance of skilled tasks. It is to be noted that this study was not

measuring intervention outcomes, but only exploring the nature of the services provided in this field. Given the overlap found between the two professions, further research is required to examine how OTs could better exploit their specific knowledge and training in occupational/environmental analysis and performance.

OT literature has also indicated that OTs often lack awareness on the latest developments in AT and are not sufficiently trained in this area. A study among OTs in the UK demonstrated that this was one of the major factors that determined the lack of uptake of these technologies by OTs (McGrath *et al.*, 2017). They suggested that various AT 'experts' should be appointed to update their OT colleagues on the most recent devices on the AT market and to be available as a resource/reference point on such issues. The increased training/use of online AT platforms was also recommended. Another study that was carried out among OT students in Australia (Hills *et al.*, 2016) explored their skills and confidence in issues related to technology as relevant to OT practice. The assumption underlying the study was that the younger generation of OTs would be naturally skilled and more inclined to use these technologies. Findings showed that, although the participants were competent in using mainstream technological devices, they lacked confidence in using AT and other specialist software and devices. Although findings were not considered generalisable to other countries, the recommendation in favour of more technology-related subjects to be included in OT undergraduate courses is valid for the whole OT profession. This is considered fundamental if upcoming OTs are to be adequately prepared for future OT practice that needs to be in synch with the rapid technological advancement that permeates it.

The sections above have considered the research and literature emanating from rehabilitation studies which signposted the gaps that still exist between theory and practice in the field of AT (and especially in vocational rehabilitation), and between professionals, such as OTs, and disabled people who approach them for advice on their AT needs. The next part of the chapter will review technology-related empirical research and literature that emerged from DS, in order to gain an understanding of the topic from the perspectives of the people whom rehabilitation professionals are/should be of service to.

3.5 Enabling technology and disability studies

‘A review of the literature of the disability movement provides little evidence of a serious analysis of the implications of telematics and other new technologies’ (Johnson and Moxon, 1998, p.243). Similarly, Lupton and Seymour (2000) claim that little has been written about disability and technology from within the disability movement. Although these two references are rather dated, the literature below will show that their observations remain largely true today.

Roulstone (2016) indicated that research in the field of disability and technology has mainly consisted of reviews and assessments of specific impairment-related aids and equipment such as wheelchairs, orthotics and prosthetics. This type of research, as was made evident in the previous sections, still viewed disability as the problem of the individual, who required this equipment to compensate for her/his deficits in order to be normalised. Additionally, Johnson and Moxon (1998, p.243) suggested that, since technology and disability literature has mainly come from service providers or professionals, there is the danger that issues of choice and control, usually coming from the disability movement to challenge professional control, are missing perspectives in this debate. This is because disabled people have traditionally lacked professional or market power. Moreover, the experiential knowledge of disabled people still plays an insignificant role in the development of technologies that are intended to help them (Mallin and Gomes de Carvalho, 2015). Consequently, a need for research in this field to become more user-driven was felt not only by academics but also by AT service providers and service users (Layton, 2014).

Traditionally, AT has been claimed as being beneficial in disabled people’s lives (Scherer and Glueckauf, 2005; Abbott, 2010). Definitions of AT indicate this. Thus, AT is ‘any product or service designed to enable independence for disabled and older people’ (King’s Fund Consultation, 2001, p.2). The promise of technology in fact, is that it can transcend barriers of mobility, communication, time and space (Seymour, 2005). Roulstone’s (1998) research, for example, was fundamental in demonstrating technology as an

enabling source of barrier-removal in disabled people's lives at work. It also highlighted the complexity of the relationship between technology, environments and the presence of impairment. With the growth of information and communication technologies and the advent of the internet in the late eighties, there has been a shift from the industrial to the digital era, which brought with it new hopes for disabled people (Sheldon, 2001). It is therefore generally taken for granted that technology is beneficial for disabled people. Paul Cornes (1991, p.98) claims that:

the products of modern science-based industries and the new technologies which underpin their operation are now too much in evidence for their potential to improve the independence and quality of life of people with disabilities to be overlooked.

More recently, the World Report on Disability (World Health Organisation [WHO], 2011) also reports on research carried out all over the world depicting the benefits reaped from the use of AT.

DS authors and activists, most of them disabled themselves, had also started to present their views on the role of technology in their lives. The UPIAS' (1976) *Fundamental Principles of Disability* are profoundly based on technology and employment, for example:

In the last fifty years of so developments in modern technology have made it increasingly possible to employ even the most severely physically impaired people and to integrate us into the mainstream of social and economic activity. (p.15)

Since society already has the technology that could integrate severely impaired people into social life it would be the task of the panels to ensure that adequate assistance, human and technological, is provided for the working person at his or her place of work. This would help ensure that nobody is refused work on the grounds of physical impairment. (p.19)

Later, Finkelstein (1980) proposed three historical phases in his analysis of society's technical, industrial and social change. In phase one, which is the period prior to capitalist industrialisation, disabled people worked in agriculture and handmade craft production usually on their family farms. He described

phase two as the period in which the industrial revolution occurred. With its development of new technologies for industrial production and later of 'electronic technology for automating the production-line' (*ibid.*, p.8) this phase offered new opportunities for disabled people. Finkelstein claimed that:

This technology enables the most severely physically impaired people to operate environmental controls which can enable them to live relatively independently in the community. (*ibid.*, p.8)

He then indicated phase three as the emerging period in which there would be more development and equal provision of these new technologies. He optimistically suggested that:

In industrialised societies, phase two can be seen as the period in which cripples disappeared and disability was created. Phase three heralds the elimination of disability. (*ibid.*, p.8)

Finkelstein also suggested, however, that technology did not necessarily guarantee a disabled person's independence, because disabling attitudes towards disabled people continue to dominate society. In short, social barriers tend to stand in the way for disabled people to fully benefit from this technological advancement. Other DS writers were also doubtful as to the promise that technology held for disabled people (Illich, 1973; Zola, 1982; French, 1993). French (*e.g.* 1993, 2008) proffered a sceptical view of the perceived benefits of new technologies. She claimed that the main issue is not whether or not she has access to these technologies, but whether she feels that they have been thrust upon her by professionals. She challenged the idea that technical aids are necessarily helpful, claiming that personal assistance, rather than technology, would give her more time to do other things. Similarly, DeJong (1979, cited in Zola, 1982, no pagination) warned that care cannot be reduced to a technical task: 'it is not the quality of tasks we can perform without assistance, but the quality of life we can live with help'.

Zola (1982) and Oliver (1978) stressed the fact that technologies can be disempowering rather than empowering and isolating instead of integrating. Just as the phenomenon of disablement, defined as the 'process of marginalisation, oppression, discrimination, exclusion(...) that affects people with impairments'

(Sapey, 2004, p.273), was intensified by the Industrial Revolution, so it can be worsened by the modern Technological Era (Sapey, 2000). Goggin and Newell (2003) further claimed that society, consciously and unconsciously, has built in disability into digital technologies. This is because such technologies are not available to all disabled people, either because they cannot afford to buy and maintain them or because they do not have the necessary information and training on them. This exclusion might also exist because governments and commerce are increasingly relying on the internet, thus leaving the groups of people who are unable to access it even more excluded (Newell, 2011). Others claimed that technologically driven emancipation for disabled people is social science fiction (Williams, 1999). All this implies that technology can worsen inequalities just as much as it can improve them.

Sheldon (2001) and, more recently, others such as Goggin (2012) have also warned against the possibility of inequality of access to this technology (especially ICT) and other authors suggested that it might even broaden the digital divide (Seelman, 1993; Goggin and Newell, 2007; Seale, 2011; Macdonald and Clayton, 2013). The digital divide refers to the disparity that exists between different groups in society, such as disabled and non-disabled people, in their access to modern technologies like computers, telephones and the internet. Apart from affordability and availability issues, this gap can be widened further because the advancement of such technologies is growing at an exponential rate and this makes it even more difficult for disabled people to keep up with it, economically, technically and information-wise. The more sophisticated technology becomes, the more it may become inaccessible to certain sectors of society also because of age, gender, education and work factors (Sheldon, 2001; Seymour, 2005; Kaye *et al.*, 2008). For example, a survey in 15 EU member states found that, usage of information technology was higher among men, professionals, university graduates and the employed (Ortega Egea *et al.*, 2007). Similarly, a profile of internet users in Malta showed that there were 66.9% of women as against 70.9% of men who used the internet; in the 16-24 age group, 96.4% used the internet as against 22.8% in the 65-74 age group; and that only 11.7% of the population with no/primary level schooling used the internet as against the 97% of the population with tertiary level education (NSO, 2014b). These statistics clearly indicate that

gender, age and education levels are factors that strongly influence the uptake and use of technology.

Seale (2011), when writing about digital inclusion, claims that the assumption that disabled people can become economically productive members of society through the provision of digital technology is not wholly true. This assumption highlights the remediation of individuals and ignores the remediation of society. It assumes that by providing the disabled person with technology, s/he will automatically become employable, whereas it does not also seek to transform (work) environments and practices to make them more inclusive of disabled people. The assumption also creates increased expectations, for example, of employers from their disabled employees, because, once they provide the technology, it is expected that the employee will be able to 'produce' as much as her/his non-disabled peers. This of course does not consider the unpredictability and fluctuating nature of impairment consequences such as pain and fatigue for which workplace technological devices can do very little, unless supported also with enabling work practices such as flexible working hours and the possibility of teleworking.

Furthermore, AT provision, including for the world of work, is still dominated by the individual/medical model, with mainstream standards and clinical design in many countries (Stewart *et al.*, 2005). It is being increasingly acknowledged that assessments for AT should be more person-centred and focus more on 'the person's abilities and aspirations rather than the traditional medical model that emphasises impairments' (Hoppestad, 2007, p.197). The user-technology relationship is not static but fluid, at times even leading to non-use or complete abandonment of the device (Seymour, 2005). Access to technology is therefore not sufficient; there have to be follow-up services and an efficient infrastructure in place (*e.g.* for maintenance and repair) so that disabled people continue to do/be/become through their technology. Otherwise, it will create more problems than solutions for them.

Other research has shown that AT has a double-edged nature in that it can be used as a tool but can also inadvertently highlight disabled people's impairments (Tate *et al.*, 2002). Participants in Seymour's (2005) study, for example, claimed that it was humiliating for them to have to continuously ask for

help from their colleagues at work regarding problems with their technology. This brings out the concept of stigma and the effects of stigmatising technologies, even if this is not intentionally incorporated in their design. In this regard, Garland-Thomson (2011) proposed the concept of 'misfits', where the concept of 'fitting in' is re-imagined in a socio-technical manner. The discrepancy between certain bodies, a certain way of being, and certain environments produces misfits. Misfitting is therefore relational. 'Misfitting focuses on the disjunctures that occur in the interactive dynamism of becoming' (Garland-Thomson, 2011, p.594). Fitting in makes one invisible, anonymous. Misfits are considered to be different than what is expected and therefore are looked at and treated in a different way than the norm. They become visible and therefore prone to stigmatisation. For example, in their study of 15 people with a physical impairment in Adelaide Australia, Lupton and Seymour (2000) found that while the participants considered most of the technology they used as highly beneficial, they also felt that sometimes these devices marked them out as 'different' or 'lacking', thus acting as a barrier to presenting themselves and their bodies as they would prefer.

For disabled people, therefore, the use of technology is not only about overcoming barriers, but it is also about their identity and self-representation (Woods and Watson, 2004; Ravneberg, 2009). Technologies have a culturally symbolic value. As Hocking (2000, p.25) puts it, 'using objects in modern times holds and expresses personal and social meanings, including one's sense of self and one's identity'. Unlike the participants in Lupton and Seymour (2000) above, the interviewees in a study by Scherer (2005b, p.153) emphasise that the devices they use have become very important parts of their body, 'My two legs and two motorcycle wheels have turned into a four-wheel motorised chair' which 'is now my freedom and independence' and enabling them to live 'life to its fullest.' Such disparate effects of these technologies, as perceived by different disabled people, are testimony to the ambiguities that are integral to the nature of AT.

Because of this double-edged nature of technology, disabled people 'must work out an appropriate political strategy' (Oliver, 1990b, no pagination) to ensure that the debate on technology is placed high on the agenda of the

Disabled People's Movement. From a social justice point of view, until technology is accessible to all, only the potential (rather than the actual) benefits of technology can be studied/written about. 'The question is to know whether all this new technology will lead to greater integration or further exclusion' (Roe, 1991, p.61). It depends on the disability movement to ensure that new technologies help include and not confine: 'The disability movement is central to ensuring that technology is used to liberate rather than further oppress disabled people' (Oliver, 1990b, no pagination).

The literature cited above has clearly exposed the existing divide between DS writers who view technology as essential for disabled people's increased participation in society and others who call for caution in viewing technology as a panacea for all disabled people's predicaments. Various barriers have been documented that hinder technology from being the enabling support it is intended to be. One domain in which technology was predicted to become a potential solution for the removal of these barriers is employment (Cohen and Zeitzer, 2004). The following section will explore the DS literature that considers disabled people and their experiences regarding the access/use of technology at the place of work.

3.5.1 Enabling technology and employment of disabled people

A number of key writers have indicated that employment of disabled people is crucial for their independent living (Abberley, 1999; Evans, 2003; Zarb, 2003b). However, employment rates for disabled people remain low in the European Union with more than 70% of non-disabled people and less than 50% of the disabled population being employed in most of the EU member states. Malta's employment rate for disabled people (16.5%) according to the last national census (NSO, 2014a) is reported to be among the lowest together with Greece, Ireland and Croatia (Priestley, 2012; Waddington and Priestley, 2018).

Langton and Ramseur (2001, p.27) suggest that:

keys to achieving more successful employment outcomes are timely considerations of AT and accommodation options and the availability of technology specialists to provide the technology services that are needed.

Use of AT is also about levelling the playing field for disabled people so that they can compete on an equal basis in finding and maintaining employment (Stumbo *et al.*, 2009; Sayce, 2011). Technology for workers and work environments may in fact enhance mobility within the environment, manipulation of materials or objects, communication and connection to others, organisation of the workspace and activities that occur during the workday (Mueller, 1990). For example, in a study with 30 people with different impairments in the UK, Roulstone (1998) found that new technologies served in numerous ways to enhance these disabled people's opportunities for employment by removing barriers of physical access and demands, facilitating communication and allowing their work to be judged on a more equal basis with other workers. Strobel and McDonough (2003) gave case examples from North America that showed that AT can enhance and reinforce the current skills and abilities of a disabled employee and can complement other accommodations, such as personal assistants, in the workplace.

On the other hand, Yazıcı *et al.* (2011) carried out a survey in Eskisehir, Turkey, with disabled people from all impairment groups who were employed in both public and private companies using a policy-based quota scheme. 16.9% of the respondents claimed that lack of access to technology was one of the obstacles that they meet with in their daily life at work. Driscoll *et al.* (2001) interviewed 5 people with spinal cord injury, 3 of their employers and 2 co-workers in Brisbane, Australia and identified various facilitators and barriers to the successful integration of their ATs in their workplace. Among the factors that influenced this integration, they mentioned attitudes on both the users' and employers'/coworkers' part; knowledge and education regarding AT and AT services; involvement of the user throughout the whole process; the importance of trialling the devices at the place of work prior to installation and use; training in their use; consideration of future needs and options; the work environment and accommodations such as accessibility issues and flexibility in the workplace. In addition to these, in her editorial to an issue of the Journal of Vocational Rehabilitation that looked at AT as a workplace support, Inge (2006) referred to the importance of coordination across services, as well as access to funding for these technologies.

Other studies demonstrated that legislation has also helped to bring the issue of employment of disabled people to the forefront, and AT features prominently in disability employment legislation (Mendelsohn *et al.*, 2008). It supports AT as reasonable accommodation (ADA, 1990; DDA, 1995; Equal Opportunities [Persons with Disability] Act, 2000; EU Equality Directive [2000/78/EC]; CRPD, 2007; Equality Act, 2010). An accommodation is considered to be reasonable when it 'provides equal employment access to a person with a disability so that he or she can perform the essential functions of the job' (de Jonge *et al.*, 2007, p.10). A literature review by Butterfield and Ramseur (2004) showed that the most common accommodations for disabled people at the workplace include environmental access, computer technologies, tool operation and seating/positioning adaptations. It also found that employees with physical impairments were the largest group to receive accommodations followed by employees with visual impairment.

Legislation can contribute to reduce discrimination through the provision of these accommodations. There are however loopholes in the interpretation of what is 'reasonable'. Because the accommodations must not impose 'undue hardships' to the employers, many of them resort to this clause so as not to provide these accommodations to the disabled employees (Russell, 2002). Additionally, legislation cannot legislate against the misconceptions that exist in this aspect of disabled people's lives (Schall, 1998; Wilson-Kovacs *et al.*, 2008). De Jonge *et al.* (2007) claim that more research is needed to explore the barriers that disabled people find in this area and the facilitators that have helped them, if legislation is to be effective. An example of supportive practice is the 'Access to Work Scheme' in the UK. This scheme supports disabled people to take up and retain paid employment by helping with practical advice and payments for assistive aids, adaptations and support so that they can work effectively (Sayce, 2011). The same support is offered to employers. Thornton and Corden (2002) published a report regarding the impact that this scheme has had and claim that 45% of customers would be out of work but for the support they receive through Access to Work. Similar findings were reported by Roulstone *et al.* (2003) in which 55% of the interviewees reported that Access to Work was the main source of support in their work. However, the authors also note that this scheme is not widely advertised and that it focuses on

retainment in jobs rather than access to employment. Burchardt (2005) also suggests that this Scheme should be accompanied by work placements and that its availability should be further extended, especially for the benefit of the younger generation of disabled people.

In an evaluation of a programme that was aimed at improving employment prospects for disabled people by providing ICT-based adaptations of workplaces in Sweden, Michailakis (2001) found that these adaptations can be very beneficial. They need to be accompanied by schemes, however, such as wage subsidies that motivate employers to recruit disabled people. He also admits that 'there are many serious problems' and that the outcome of the evaluation is 'hard to judge' (*ibid.* p.496) due to its diverse implications for people with different impairments. In fact, a study by Dutta *et al.* (2008) carried out in the USA with 5000 clients of vocational rehabilitation services, who had either sensory/communicative, physical or mental impairments, found that technology related accommodations contributed mainly to positive employment outcomes for the people with sensory/communicative or physical impairments but not for people with mental health issues. The authors claimed that at the time of the study there had been legislative reforms that promoted provision of services to the disabled people who had the greatest needs. This could have impacted on people with mental health issues, seeing that they were considered as those with the least need for technology related accommodations when compared to the other impairment groups.

Various writers, especially in the vocational rehabilitation literature, have mentioned the fact that there is no one outcome measure regarding AT assessment for employment purposes that fits all situations, and this makes service provision in this field even more complicated and lengthy (Mendelsohn *et al.*, 2008). Other factors that have been identified as facilitators/barriers in this aspect of disabled people's lives are whether the user has been involved in the device selection, the user's motivation to use the device, whether training is available, presence of follow-up/repair/after-sales service and the user's perception of the device such as aesthetics, reliability, comfort and ease of use (Driscoll *et al.*, 2001; Langton and Ramseur, 2001; Roulstone *et al.*, 2003; Strobel and McDonough, 2003; Gamble *et al.*, 2006; Stumbo *et al.*, 2009; Price

et al., 2011). Therefore, it can be concluded that, although technology is found in virtually every workplace today, and although its many features may help disabled employees and potential ones, there are persisting obstacles such as the ones discussed above that hinder this. There may also be other obstacles that are directly related to social factors.

A major social barrier that is mentioned in the literature is that of employer attitudes/misconceptions, for example regarding the cost of AT/accommodations. The investment mentality, that is, when employers expect more from disabled employees because they have provided them with accommodations, may be subtly (or not so subtly) present (Roulstone, 1998). The de Jonge *et al.* (2007) study found that, although in principle most employers felt a responsibility to be fair with disabled employees, in practice they often felt they were not sufficiently knowledgeable about practical technological solutions and therefore any decisions related to AT provision were left to the discretion of the employees themselves. This, however, often resulted in the employers not bringing up AT issues with the employees, thinking that the latter would request the technology if necessary. On the other hand, the employees were often reluctant to raise the issue with the employer either because they themselves did not know about resources (financial and informational) or because they felt embarrassed to make extra demands on their employers. In her study conducted with employers of two companies in Norway, Kuznetsova (2016) corroborated this finding. Her respondents indicated that their understanding of inclusion was put into practice by providing work training to unemployed people, but this did not include the provision of supports such as technological accommodations. Whilst publicly (on their website and annual reports) the companies showed their commitment to the inclusion of disabled employees, interviews with the employers indicated that the work training programmes that were offered to people seeking work as an expression of this commitment, had not even included any disabled people.

Similarly, a study by Shier *et al.* (2009) and another by Jakobsen (2009) provided evidence that discrimination and attitude barriers, including from employers, were more disabling to the disabled employees than lack of

accommodations. This indicates that it is still difficult for employers to recognise the value that disabled people bring to their workforce.

Social isolation could be another barrier since, although technologies may enable disabled workers to work from home, this fact may further exclude disabled people from mainstream employment (Lloyd, 1992; Annable *et al.*, 2002). Similarly, Scherer (2005b) claims that technology helps to break down barriers to social participation and relationships, but also, that it can itself be a barrier to interpersonal contact. Social barriers are especially real for blind and visually impaired employees (Naraine and Lindsay, 2011) and, because generally employers tend to comply only with the minimum requirements expected of them by legislation, social barriers because of stereotypes remain a problem in many workplaces (Ruggeri Stevens, 2002; Robert and Harlan, 2006).

It is interesting to note that both older and newer studies from different countries still indicate the presence of more or less the same barriers that disabled people encounter at the place of work. These studies have shown that it is difficult to generalise about the appropriate technologies for particular impairment groups since needs are specific to every individual employee. This factor makes it even more challenging for large-scale research to take place and slower for solutions to be found. In his article written thirty years from the introduction of the SMD, Oliver (2013, p.1025) claims that the SMD has not yet managed to make its mark on some 'much more intractable' barriers such as in the field of employment. This raises the question: do we need to find a new way to consider this problem – one that builds upon, but also goes beyond the barriers-mapping approach, which has yet to provide effective change in the lives of many disabled employees?

3.6 Conclusion

This chapter has explored existing research in the field of disability, technology and employment. Studies have uncovered the different facets of technology, its double-edged nature, its unplanned consequences, its role and potential within disabled people's lives, and specifically within employment. Various barriers and enablers, both structural and social, that shape disabled

people's experiences with enabling technology in the workplace have been discussed. Among these barriers and enablers, professionals such as OTs have been identified as possible mediators between the person, the technology and the environment. It has been, however, seen that, in order for them to take on the role of mediators, professionals need to shift their practices (and research) from a biomedical/functional mode of viewing disability, and mediate together with disabled people for a more choices/rights-based agenda as in the case of technology access and use. The literature reviewed in this chapter has also indicated a lack of theoretical foundation and evidence-base to the use of technology in general and especially with regard to OT interventions in the workplace.

As disability understandings and technologies continue to evolve, Roulstone (2016) indicates that further research needs to be undertaken, based on the more recent developments in technology and disability research from the STS field, for example, ANT. In the next chapter, literature from this field (among others) will be reviewed. This literature is inspiring researchers to look at the 'messy' character of everyday life and technology usage, and then try to understand that 'messiness'. STS literature is encouraging researchers to examine disablement within the weave of networks and assemblages in which it is located. Technology is not the only factor that determines, for example, whether disabled people gain and maintain a job (Michailakis, 2001). Technology is part of that mix where people, environments, policies, legislations and attitudes come together. This is what NM's critical gaze is suggesting. Furthermore, the 'enablement' discourse could be understood in the same way. Technology can therefore be part of an assemblage that enacts dis/ability. This can comfortably run alongside the SMD from where this study commenced. The current study is moving away from the fundamental idea that disablement is just about the body (individual/medical model) or just about society (strong Social Model). It is adopting a more socio-material, relational understanding which is not however incompatible with the barriers-mapping approach.

As a concluding remark, it has been noted that the field of technology and disability is complex and entangled within many different influencing factors. Technology will continue to be important in bringing together issues

such as design, identity, independence, impairment-related consequences such as pain and fatigue, mediators such as professionals, technology suppliers, and users. This further indicates that dis/ability can be enacted in any of these assemblages and networks and that it is difficult to place it neatly either within the individual or within the environment/society around her/him.

This chapter has established the persistent presence of barriers and identified them. It has acknowledged that the available supports have not been effective in the removal of these barriers. Furthermore, it has recognised the messy nature of the phenomenon of technology and disability. This first chapter of the literature review for this project has, therefore, left me with the following questions: how can we move from knowing what the barriers are, to understanding how they work to dis/able people with impairments at the place of work? How can the topic under study be analysed in such a way as to identify the components involved in the worker-technology-workplace assemblage, trace the relations between the components and evaluate the capacities (or otherwise) that emerge from these complex relations? The next chapter therefore will be reviewing the literature, mainly from NM perspectives, that lays a foundation for the above claims and may provide a reply to the latter questions. Although the majority of these studies did not have the workplace as context, the insights gained from them will be applied to the assemblage/networks of disabled employees-technologies-workplace (and beyond) as is the context of this research.

Chapter 4

Dis/ability in Science and Technology Studies and New Materialist Research

4.1 Introduction

The previous chapter explored how the literature from DS and rehabilitation studies has identified a series of barriers and enablers in disabled people's access to, and use of, enabling technology, especially in relation to employment. The SMD has been important and necessary – part of a process of re-defining disability from being a personal problem to being a problem in society and the environment (a public issue). The barriers-mapping approach (which stemmed from the SMD) has also been a valuable tool/methodology for challenging exclusion in the field of employment. However, as the literature has indicated, barriers remain stubborn in this field. The SMD, whilst politically powerful in many ways (Beckett and Campbell, 2015), does not appear to have been sufficient as a mechanism/tool to understand these barriers and their operation in ways that allow for their complete removal, arguably because it was never designed to have such an 'explanatory' function (Finkelstein, 2001). A new way of looking at the 'problem' of disabling barriers and technology is therefore required. This is a new way that pushes beyond identifying that disability does not equate to impairment and is a form of social oppression, vital step though this was, to one which attempts to understand the processes and relationships that take place at the workplace and beyond, to dis/able employees with impairments. A number of new materialist researchers have in fact attempted to move away from the either/or materialist/idealist perspectives in DS.

Among the first researchers to propose this kind of re-definition of disability were John Law and Ingunn Moser. They use ANT, one of the most important theories in NM, to explain disability. They suggest (*e.g.* Moser and Law, 1999) that disability is made and unmade as a result of the heterogeneous networks that surround disabled people and that they engage in. These networks are made up of humans, technological devices, service animals, and

policies and practices in which they are embedded. Therefore, according to these researchers, one is not disabled *a priori* but is made or unmade disabled in the interactions, in the relationships s/he has with the material and non-material environment around her/him. Furthermore, Galis (2011, p.835) proposes ANT as a tool with which DS researchers could 'follow disability as it is enacted in everyday life, in policy spaces, in infrastructure, and among disabled people, academics, experts and politicians'.

Others, such as Feely (2014), have used Deleuze and Guattari's (1988) concept of assemblages to analyse how multiple, heterogeneous entities work together to produce/hinder capacities to affect or be affected. According to Feely, 'DeleuzoGuattarian assemblage analysis refuses to privilege and grant final causality to a particular order' (Feely, 2014, p.47), where an order is, for example, the material, the biological, the technological, the social, the economic. Research based on this type of analysis, therefore, moves on from, for example, the SMD which places the main cause of disability within society. It aligns itself with the view of disability as a shifting relational concept, as also indicated by researchers such as Moser and Law above.

Amongst other insights, these studies have also shed new light on the way the body is viewed, its boundaries and its functions. Because of the ubiquitous nature of technology in today's daily life, it has become possible to view the body as an assemblage. The ability of bodies to perform tasks (doing) has thus come under investigation: doing and being are not pre-set (conditions) in some bodies and are lacking in others, but one is able to do and to be depending on the relationships one enacts/engages in. What does it mean then, in today's reality, to be autonomous? How is a person being un/made autonomous? In these studies, autonomy is considered to be of the relational type, that is the result of the heterogeneous relationships that the actors (both human and non-human) engage in and not an inherent characteristic of any one actor. In the current study, we shall see how disabled employees find their autonomy as it is enacted in the multiple relationships they have at the place of work. We shall also see how the various assemblages are viewed by colleagues, managers and employers and how the employees manage any arising stigma because of their use of assistive devices at the place of work.

These studies have also shown that the various assemblages are in themselves entangled in messy networks and that it is currently difficult to consider bodies and technologies as separate from their environment and contexts. This was also proposed by OT models such as the Canadian Model of Occupational Performance (CAOT, 1997), but in this model the person is placed at the centre of OT intervention (client-centred practice), whereas materialist perspectives are post-anthropocentric, in that the person, technology, supports and the context/environment are all 'equal' components in the assemblage they form part of and, therefore, all can potentially dis/able the assemblage/network around them. Consequently, this throws a light on the need to reimagine the understanding of barriers and, in this case, how disability is un/made at the place of work. Studies also propose the presence of mediators (human and non-human) that can help navigate these barriers and enact alternative links to more enabling ones in the assemblage/network. DeLanda (2006) elaborates on Deleuzian thinking on this matter and recommends this kind of creative unplugging of components from one assemblage in order to plug them into another and enable new capacities to emerge.

As will be seen in the following sections, these studies were embedded in various contexts, such as hospitals, with none, to my knowledge, focusing on the world of work. As noted in the DS and rehabilitation studies literature in the previous chapter, very few have been carried out with disabled people from the southern European countries. The current study may therefore provide evidence for this new theoretical perspective in new contexts where it is currently lacking.

4.2 Assemblages

In the following literature it will be seen that technologies are part of an assemblage together with the disabled person and her/his environment. For example, in her study with people with neuro-muscular disorders, Winance (2006) describes how, during the trialling of a new wheelchair, these people not only act by delegating their affect/agency to the supports (both human and non-human) they use, but, in turn, actants are transformed as a result of the hard

work that is done through the various relations involved in the process. Both abilities and disabilities are created which shape the user's being and identity.

For example, 'David' (*ibid.*, p.61), is a 20-year-old manual wheelchair user, who has paraplegia following a road traffic accident. He goes to the wheelchair clinic to be assessed by therapists, tries out different wheelchairs and eventually acquires his own first wheelchair. Because of his paraplegia and the consequent use of the wheelchair, David feels that his world has been closed up, for example, he cannot enter places that have stairs. The therapists assess the David-in-the-wheelchair assemblage (which consists of David's body parts and the parts of the wheelchair) but they also assess his world (which consists of, for example, his car, his home lift, the social worker who is responsible for procuring funding for the new wheelchair). At the beginning of the session, David is quiet and hesitant. He says he wants a not very expensive folding manual wheelchair with a removable footrest. During the course of the session, however, David gets to know that he does not have to rely solely on the funds from social security, but that his social worker will be able to get some more funding from other associations. This opened up a possibility for David to get to try out different high-performance and sports wheelchairs. He is told that this type of wheelchair will enable him to go up curbs and, because it is extra-light, he would be able to easily transfer it into his vehicle. This also means that the wheelchair would have a rigid frame (not a folding one) and therefore be more robust. It would look nicer too, he is told, since, with its very low back, the wheelchair is less visible, and people would focus more on him than his wheelchair. The components of the David-in-sports wheelchair assemblage are not all enabling however. The therapists point out that he might not be able to access very small spaces because of the fixed footrest. In this process of adjustment therefore, David and his world (made up of human and non-human components), are transformed. This transformation is not only physical, in that he acquires a different wheelchair than the one he originally thought he would get, but also emotional, in that by the end of the session David is smiling, talking and actively moving around.

In this same study, devices are seen to be mediators of action, in that any engagement of the person with the device enables an enactment of an

activity. An example of this is when 'Theo', a 2 year old boy, receives his first powered wheelchair and realises that the push of a joystick makes possible the movement of the 'Theo-wheelchair assemblage', enabling him to go 'to the park and look at the ducks' (*ibid.*, p.59). This is also, however, where an action does not only remain a 'doing' but enables a 'being' to emerge, a fun-loving Theo-in-his-wheelchair who can now chase after the ducks, laughing. Similarly, Schillmeier (2008) reports how people with visual impairment become 'sighted' through the mediation of devices such as a plastic template to recognise money bills or the white cane to navigate through different spaces. The assemblage Mary-white cane (*ibid.*, p.226) means that she can go outdoors, to/around the supermarket independently. Through the use of mediation strategies/devices she becomes a courteous shopper who can keep the right distance from others, she becomes a consumer, she becomes 'abled'.

This mediation of action does not happen automatically though. Through a study with 29 users of AT, Hoogsteyns and van der Horst (2013), indicate that, by deciding to wear or not wear their devices, it is the users themselves who are constantly negotiating and renegotiating whether they are perceived as 'normal' or 'different', and whether they become 'abled' or 'disabled'. For example, for prosthesis users, the person-with-arm assemblage enters into situations and becomes a particular embodied experience of either inclusion or exclusion which is different from that which the person-without-arm assemblage would become. So the prosthesis does not just compensate for the loss of the person's limb, but it transforms the user's affect/agency and experience (*ibid.*, p.64). Similarly, Gibson *et al.* (2017) carried out research with adolescents who have communication and mobility impairments and demonstrated how assemblages of bodies, technologies and social meanings enable or constrain specific activities in specific settings.

For example, the assemblage Grandma-Jessica-dining room-computer = playing cards (*ibid.*, p.8) enabled 'Jessica' to be actively engaged in the game she was playing with her grandmother even though she was not physically controlling the computer herself. On the other hand, another participant, 'Andrew', who spent a lot of time working on his computer (Andrew-computer assemblage), at times wished to get away from it, but this meant he had to rely

more on his mother (Andrew-mother assemblage). For his mother, Andrew being on his computer meant more free time for her to do other chores, her chores. As we shall see later on, this has important implications for rehabilitation professionals in their understanding of the concept of independence. The assemblage Andrew-mother might be considered 'dependence' by professionals whilst the assemblage Andrew-computer might be seen as 'independence'; however, according to Andrew himself, at times, depending on his mother is actually 'freeing' him from the computer. Therefore, independence/autonomy depends on the specific time, place and person/s involved in the specific activity. This cannot be decided *a priori*. Autonomy emerges as a result of the relationships among the components of the assemblage, in this case, Andrew-computer-mother, and a process of adjustment.

The components of assemblages are however not always visible on the outside. Dalibert (2016) shows that implanted technologies, such as spinal cord stimulation devices, are hidden from view and have certain expectations of the body's behaviour. They are still, however, 'embodied' and 'incorporated' in a highly relational manner, through the person's gestures, the materiality of the body and the relations that one is embedded in. Even if they are invisible on the outside, these technologies still matter; they enable the body to be 're-worlded', to be part of the world, to be in-the-world again. Therefore, as Winance (2006) suggests, body shaping is also world shaping. The implantation of devices in the body, such as spinal stimulation devices and cochlear implants, are a good example of this. In a study with users of cochlear implants, Mauldin (2014) suggests that the body-cochlear implant-brain assemblage is reinforcing the social category of being a normal hearing person as more culturally acceptable. It relegates sign language users to the deaf world as 'failures' (*ibid.*, p.147). Therefore, these very same devices, that are implanted to make non-hearing children 'equal' to hearing children, are themselves reinforcing social categories that they were meant to remove in the first place.

Other researchers have questioned where the body starts and where it ends and what they called its 'leaky boundaries' (Shildrick, 1997). Mol and Law (2004), for example, interviewed patients with diabetes and examined how they

use their glucose measurement devices to control their hypoglycaemic episodes. The authors concluded that their participants have (outside) and are (inside) their bodies. For example, Miriam (one of the participants) said she never goes out without food, insulin and dextrose in her bag and she says, 'That has become ordinary, it belongs to me. That is me.' (*ibid.*, p.53) This can be identified as 'Miriam-bag-food-insulin-dextrose' assemblage. But it does not function on its own. Miriam has also involved her colleagues in the management of her condition – she has warned them about what to do if she got a hypoglycaemic episode. So Miriam's body boundaries have 'widened' to include her colleagues. These are not neatly defined assemblages. These are also messy assemblages because a decision that the diabetic person might take, may affect one body part in one way and another body part in another way. For example, strict regulation of blood sugar levels prevents damage to the arteries, the eyes and the neurons but jeopardises brain function with its risk of hypoglycaemia. The diabetic person has to make choices to try and balance out what is the 'best-worst' at any given time. Similarly, in Hoogsteyns and van der Horst (2013), two women who make use of arm prostheses comment that these have become part of their lives. They have to constantly decide, however, whether to wear the arm or not since, as they said, it can be a nuisance at times (such as when it is very hot outside) and can offer a sense of freedom at other times (like when one of the women could ride a bicycle with two arms and therefore look normal).

Pols and Limburg (2016) also noted that the assemblage patient-feeding tube in patients with amyotrophic lateral sclerosis (ALS) becomes a different one as the condition progresses. This is because of the emotional attachments that patients have in its regard, making the decision about whether to put it in, or not, a very complex one. It can be at the same time, a 'symbol of deterioration' (*ibid.*, p.369) and/or an 'eraser of complaints and concerns' (*ibid.*, p.370) and therefore a 'facilitator of happy events' (*ibid.*, p.371). These examples show that it is not automatic that giving assistive devices will necessarily make people independent, as assumed in rehabilitation literature. There is a continuous making and remaking of their bodies which, in turn, shapes people's surroundings and actions. 'Each assemblage leads to specific, embodied experiences of inclusion and exclusion' (Hoogsteyns and van der

Horst, 2013, p.64). Being included or excluded, and autonomous or not, depended also on the different contexts and decisions that participants had to take in order to function/participate in that particular activity, and not just on whether they had their devices or not. When the assemblage changed, so did the experience of the activity/occupation. This shows that dis/ability is never either entirely due to the impaired body or entirely due to the disabling environment/society, but it is a fluid relationship that is constantly changing; it is constantly being negotiated:

The actor-network discourse places ability and disability on an equal footing, as the result of how our surroundings, or the set of relations of which we are part, is arranged and organised. (Moser, 2000, p.222)

The story about Olav, one of the participants in the Moser (2000) research project, demonstrates how technology is not simply an extension to one's body. It affects new possibilities, new capacities for that body which might be physical, emotional, and so on. To be able to communicate verbally and connect with other people, Olav uses his computer and various writing and speaking devices. He says he cannot make do without technology; his body seams/boundaries are made fluid through a materiality of cables, keyboards, and internet/networks. He is a 'hybrid collective' (*ibid.*, p.225). Moser (2009) continues with this discourse in the autobiographies of people who survived road traffic accidents. She speaks of the 'continuous recomposition of the embodied subject' (*ibid.*, p.84) which calls on Latour's 'reassembling' notion (Latour, 2005). Building upon Latour, she proposes that bodies are not only 'matters of fact' but 'matters of concern' (Moser, 2009, p.85). Human embodiment therefore does not start and stop with the body, but it is also made up of feelings, thoughts and emotions. It is open, able to affect and be affected, continually shifting, depending on the setting, on the relations and practices going on therein. It is therefore 'much more open and widely distributed and delegated than is commonly imagined' (*ibid.*, p.96).

Participants speak of how their bodies were invisible before the accident (taken-for-granted) and how, after the accident, they became visible again in the 'de-composed' bodies. With the devices, because they could again participate in activities of their choice (re-composed), the body-devices-environment-

practices assemblage became invisible again as long as the components and interactions between them worked well. All elements in the assemblage are brought together through practices, but practices also emerge during the process of these interactions. They are collective and relational at the same time. New possibilities and new subjectivities are opened up for the participants.

These possibilities and subjectivities, however, are enabled (or not) depending on other 'entanglements' that Callon and Rabeharisoa (2004, p.17) explain as follows:

A and B, whatever they are, are entangled if at any stage any action by B affects A, and vice versa. The event 'being affected' defines A and B as distinct and entangled entities. It also defines the action (B affects A) and the passion (A is affected by B). This definition opens onto a research programme in its own right, focused on all the mechanisms and material mediations that make these affections, and the entanglements they reveal, visible and perceptible by the actors themselves.

For example, building upon/inspired by Deleuze and Guattari's (1988) concept of assemblages, Michael Feely (2014) analysed a community-based service for people with intellectual impairments to understand how sexuality issues emerged and were dealt with within this service. He reports on how, for example, the hierarchies created by professionals with regard to psychiatric deficits get entangled with assumptions and discourses around the sexuality of these people to create a disabling service/assemblage. Feely offers recommendations that do not attempt to remove these barriers, but that offer alternatives to make the assemblage function differently, notwithstanding the entanglements.

4.3 Messy entanglements

As we have seen above, we cannot speak of assemblages as though they have a definite boundary (DeLanda, 2006). It is difficult to say what is 'in' or 'out' (Gibson *et al.*, 2017). Assemblages are in fact entangled with many other elements or 'heterogeneous but interacting components' (Feely, 2014, p 49). Karen Barad, another new materialist scholar, describes entanglements as follows:

To be entangled is not simply to be intertwined with another, as in the joining of separate entities, but to lack an independent, self-contained existence.

Existence is not an individual affair. Individuals do not pre-exist their interactions; rather, individuals emerge through and as part of their entangled intra-relating. (Barad, 2007, ix)

The provision of prosthetic limbs (Kwek and Choi, 2016), for example, is entangled with factors such as high design and manufacturing costs, suitability and safety, costly maintenance and repair and specialised professionals. The assemblage body-prosthesis is entangled with these other very important components which may ultimately mean acquiring the prosthesis, and using it, or not. Likewise, Lopez Gomez (2015) refers to the use of telecare systems for older persons and their autonomy-enabling possibilities for the older persons to remain in their homes for as long as possible. But it is not enough to have the telecare system. The older persons must wear it around their necks, some need people to remind them to wear it because they do not like to have things hanging around their necks. As their conditions worsen, some of them add to the telecare a few hours of personal assistance, some use other do-it-yourself arrangements to remind them to press the green button on before they sleep and when they wake up. So it is not only about having the telecare in the home, it is also about the 'creation of technical, social and legal entanglements with arrangements that already operate in the day-to-day routine' (*ibid.*, p.96) of the older persons. Since there are often access or expense issues when it comes to acquiring these devices/systems, it might make more sense to analyse the arrangements that are already in place and see how these can be maintained and made to fit better with these arrangements, rather than replacing them completely.

As with the above study, Näslund and Qais al Said (2017) show that the ordering of disability is also entangled with the availability and quality of societal support. They interview a group of 6 adult students with visual impairments in Oman. In this country, like Malta, close-family ties and the influence of religion, limited services and people's attitudes are some of the major factors which make dis/ability emerge to determine these students' participation in education and community life.

These studies open up a reflection on the concept of barriers. Social model research through its barriers-mapping approaches has, up to now, presented barriers that are 'out there', fixed in society and that are prohibiting disabled people's participation in daily occupations. New materialist research (as discussed in the conceptual framework of this study) presents barriers as the result of fluid and entangled interactions/'bad passages' (Moser and Law, 1999, p.204) between the components of an assemblage and between assemblages themselves. For example, through a study with Norwegian disabled people, Moser (2006a) explains that barriers are 'produced in the clash between non-standardised bodies with standardised practices and environments' (Star 1991, cited in Moser, 2006a, p.387); and that affect/agency always has to be mediated across these barriers. These are barriers that the author (Moser 2006b) calls upon to be analysed as patterns of interferences, interferences that emerge from the relational effects between society and the body and that produce or unmake disability. This ordering of disability (Moser 2005) gives the idea of an ongoing, recursive motion and is therefore not a fixed feature of a body or of society. It is all the time happening/becoming. If disability research continues to focus only/predominantly upon identifying the barriers between abled and disabled people, it will continue to reinforce the concept of normativity/asymmetry.

Furthermore, if it continues to regard technologies as being able to bridge this gap between dis/ability by compensating for the impairment consequences, it will only be reinforcing this very same concept it is trying to re-define. This is because this type of research would still be focusing on the individual and how technology might help to 'fix' her/him thus making her/him more normal. On the other hand, what these new materialist studies are showing is that it would be more truthful for disability research to analyse the entanglement of components/assemblages within a particular context, time, and place, in particular practices and relations. It is in this complex scenario that affect/agency/autonomy is enabled (or not). Many a time this does occur through the support of technology, but it also occurs through the support of other, human or non-human, mediators in the network.

4.4 Mediators for autonomy

The studies reviewed above have questioned what the normal body is; what the 'autonomous'/'independent' body is. Categorising bodies *a priori* (as often happens in the rehabilitation sector) is the result of positivist/medical thinking about the body. New materialist literature has, however, shown that there are no *a priori* disabled beings as there are no *a priori* autonomous beings. We are what we are because of networks made up of human and non-human supports and practices. Autonomy, like disability, is therefore a relational process and not a fixed characteristic. In the study with older persons mentioned above, Lopez Gomez (2015) suggests that autonomy emerges from the multiple, heterogeneous arrangements that older people live in and enact every day. Struhkamp *et al.* (2009) refer to rehabilitation programmes for people with physical impairments and indicate that what is actually measured as independence by scales and outcome measures (degree of independence) is not the same as the independence that disabled people experience in their daily lives (kind of independence). Whereas in the lab independence is linear, predictable and consistent, in real life this is not so. This questions the understanding of independence and what it means to professionals and disabled people. If this understanding is different, then, which independence is being referred to when literature claims that technologies enable independence in disabled people?

Independence, for example, can be enacted not only when disabled people do things without assistance (independence as understood by professionals), but also when they resist conforming to current practices, environments, and discourses. Winance (2016, p.17) calls this understanding of independence 'recalcitrant' autonomy. Because disabled people, however, have a harder time to show their autonomy (due to the barriers they meet with), they at times need mediators to facilitate this enactment of autonomy. These mediators can be human, as in professionals and professional practices and non-human, as in the technology/service animals/AT devices.

In their research with people who have visual and hearing impairments, Måseide and Grøttland (2010) demonstrate that the assistive devices used by

their participants with visual and hearing impairments act as mediators between the impaired body and its material and socio-cultural surroundings/environments. They also show, however, that while devices can help their users gain autonomy by not needing help from others, they can also in this way produce social isolation. This is an important implication for the work of healthcare professionals such as OTs. OTs' interventions aim to help enable autonomy/independence in their clients and as such they may be considered as mediators between their clients' 'doing' and 'being'. They must however be aware that in enabling 'doing' and self-sufficiency, they do not relinquish their clients' 'being' social members of their community. Moser (2009 p.96) speaks of practices as 'productive' (p.91), productive not only of bodies but also of subjectivities, agencies and collectives. Professional practices therefore must ensure they are not themselves adding to the decomposition that people go through after an accident or an illness, but that they help in the recomposition of new collectives, of new autonomous agents by helping them experience new possibilities of being.

By continuing to measure disabled people against a norm (Moser, 2000, p.210), professional practices will continue to treat their clients as the 'Other', and as long as they continue to treat them as others they will continue to try and fix them (either through therapy or through providing them with technology) to make them like 'us'. But neither therapy nor technology on their own can enable a person; only in relation to other people, devices and practices can a person become autonomous through a particular arrangement, time and place. Instead, rehabilitation professionals should strive to help people 'articulate alternatives' (Moser 2005, p.669) towards *reordering* their lives after what was previously seen as *disorder* or *disability*.

An important implication for OT/professional practice emerges from Moser and Law's (1999) example of Liv, a woman with a physical impairment who uses a powered wheelchair. Liv is able to act, to control the environment around her, because she delegates some of this action to the devices and people in her life. In this way, new capacities emerge for Liv. Part of the work of professionals would therefore be to enable the 'good' passages between these actions thus making them possible. The implication from this study is that

professionals need to see *how* these passages can take place and not only whether they are there or not. Furthermore, if these 'good' passages are considered as opportunities, then, in the case of the employment of disabled people, the need to demonstrate to employers the opportunities/capacities that these employees bring to the workplace instead of only looking at the challenges they may create in order to be accommodated, may be considered. This may be done, for example, if professionals (as allies to disabled people and therefore themselves enacting these 'good passages') revisit their methods of assessing disabled employees at the place of work. They can do this by focusing not solely on the fit between the person's impairment and her/his immediate environment, but by analysing how through their technologies, practices and relations at the workplace, disabled employees may contribute to a more enabling environment for *all* employees. From this perspective, employers may be able to view the opportunities, rather than the constraints, brought about by employing people with impairments.

Another important implication for professional practice emerged from a study by Pols (2014) of people with chronic obstructive airways disease. It was found that, when they had problems with their technologies, patients in this study turned to their peers for assistance and not to professionals. Peers therefore also came to form part of the patient-technology assemblage. This is because the former would have developed what Pols called 'a practical *knowing in action*' (*ibid.*, p.75), Fox *et al.* (2005, p.1301) as 'expertise', Fox and Alldred (2013, p.769) as 'knowledgeabilities' and Rabeharisoa and Callon (2002, p.62) as 'research in the wild', and which is a significant resource in disabled people's lives. This is not to say that peers should replace professionals, because they each have different types of knowledge that may act as mediators when technology fails. But it implies that disabled people may choose whom to turn to for mediation and that they may, at times, prefer a more collaborative/social alliance rather than an individual/professional one (Pols, 2017). These findings highlight the importance of the relational aspects of living with a chronic disease/impairment and the related technologies. They also highlight the place of healthcare professionals and peers as 'equal' components of the same assemblage, as well as their role as mediators in the resulting networks.

4.5 Conclusion

This chapter has generated a number of important questions that have helped shape my research questions and subsequently the conceptual framework for the study. The literature reviewed has offered new perspectives on how the body is viewed, where it starts and where it ends. It has shown that, in a world where technology and communication are ubiquitous, bodies can now be considered as assemblages, as one component interacting with other human and non-human components. These studies have also questioned the concepts of barriers, autonomy/independence and mediators.

In the absence of new materialist research with disabled people at the workplace, these studies have explored the concept of assemblage in different contexts. They have shown that there is an inter-relationship, an entanglement between human and non-human components in assemblages and between assemblages themselves. This literature suggests that events/phenomena in the social world emerge within these entanglements while the reviewed studies suggest that these events are better analysed in this messy manner, in order to understand the processes within which they operate. Applied to the context of the current study, this is a push beyond merely identifying the barriers that hinder disabled people in their access to, and use of, technologies in order to be able to participate in the world of work. I wished to be informed by this approach as suggested in Fox and Alldred (2017) in Stage 2 of the study, but, in Stage 1, I also wanted to capture disabled employees' experiences so as to understand how their entanglements with technology at the workplace made them feel.

The next chapter will describe the methodology and methods used in this study and the research process that ensued in order to find an answer to the research questions proposed at the start of this journey.

Chapter 5

Methodology and Methods

5.1 Introduction

This chapter will outline the methodology and methods chosen for this research study, which aimed to explore how employment of disabled people in Malta is/could be enabled via the realised and potential capacities of both assistive and mainstream technologies. A qualitative research method was chosen to address research questions that require explanation or understanding of social phenomena and their contexts (Snape and Spencer, 2003) and, because it was concerned with interpretation, to give research participants 'a right of voice' (French and Swain, 2000, p.40). It is a mixed methods study consisting of three stages with the use of focus group discussions in the first stage, individual interviews in the second stage and observations in the third stage.

The study then developed a methodology inspired by a new materialist approach to social enquiry (Fox and Alldred, 2017). This chapter starts with a discussion about the choice of the research methodology and methods. This is then followed by sections on the sample of participants, the data generation strategies and how the analysis of the data generated was carried out. The ethical issues taken into consideration in this study will then be explained, followed by a final section on the dissemination of the findings that emerged from the research.

5.2 Methodological framework: ontological and epistemological considerations

Ontology relates to the nature of reality and its characteristics (Creswell, 2013). As a qualitative researcher, the idea of multiple realities will be assumed, i.e. that there is not one fixed reality out there. This study will show that the assemblages of disabled employees-technology are not pre-determined but are constantly shifting because of the ways in which relationships and interactions are produced around disabled employees, assistive and mainstream technologies, colleagues, and practices and systems at the place of work.

Therefore a relational materialist ontological stance was taken in this study, in which human and non-human entities are regarded as not having inherent properties and characteristics, but they *become* as they *do* interactions with other entities/assemblages (DeLanda, 2006). Their capacities emerge as they interact; they do not exist outside of these relations. Assemblages are considered as fluid, unstable and continually fluctuating according to the relations that join and leave the assemblage (Fox and Alldred, 2017, p 57). Ontological positions such as the ones proposed by Latour (ANT) and Deleuze and Guattari will be adopted for the purpose of this study.

ANT is an anti-essentialist tool and may be considered one of the first new materialist approaches to research.

Latour (2008) suggested that we should follow the actors, reveal their actions, and show how the social structure is created, thus clearly indicating that the ANT approach also focuses on societal issues and how society is produced. (Skjølsvold, 2015⁷, cited in Ravneberg and Söderström, 2017, p.4)

The DeleuzoGuattarian materialism is similar to ANT in that it also adopts a relational ontology of entities, human and non, which are produced through their inter-relationships (Deleuze and Guattari, 1988; Deleuze, 1988). It is also similar to ANT because it rejects the idea of hierarchies; all relations have the capacity to affect, to transform the 'world' around them. Bodies, material, social and abstract entities thus take their form and essence as they become part of an assemblage.

According to my ontological position, the employee with an impairment will become dis/abled as s/he relates to, as s/he enters into/detaches from an alliance with technology, the work environment, her/his colleagues, her/his managers, her/his family, professionals, systems and practices at the place of work/beyond, and how these on their part affect the employee with an impairment to un/make her/him dis/abled.

⁷ original article in Norwegian language.

Therefore if this is the way the social world of the participants will be viewed (ontology), how will this world be studied (epistemology)? It will be studied by finding out what the component parts of the assemblage/s are and how they interrelate. The study will then seek to understand the results of these entanglements, i.e. what capacities (the abilities to do, to be, to feel, to become) are produced through these interrelations? It will also seek to understand whether in the end the participants feel excluded/valued in the workplace as a result of these processes.

In this study I will be following disabled employees and their use of technology at the place of work. The assemblages that will be studied are the following and any combination thereof:

Disabled employee-technology-work environment-colleagues-managers-professionals-peers-workplace policies-workplace practices and so on.

As the present study aimed at gleaning depth insights into the relationship between assemblages of technology and disabled people at work, it took an interpretivist rather than a positivist epistemological orientation (Bryman, 2008). Epistemology consists of 'philosophical ideas about knowledge' and tries to 'answer questions about how we know what we know and whether this knowledge is reliable or not' (Seale, 2012, p.567). I believe that as human beings we cannot be fully objective, value free, because we are all the time influenced by what is going on around us and inside us. Therefore, I will be taking the position that the topic under study cannot be measured as a fixed reality (positivist) but will be studied from the lens of the people who are living the phenomenon, how they perceive it, how it is interpreted by them, through their subjective experiences (interpretivist) (Bryman, 2008; Creswell, 2013). Since, however, the study is moving from a social model approach to a new materialist type of research, I would like to highlight that the participants' accounts during the focus groups and the interviews will be taken not only 'as a means to collect subjective representations of the world but as evidence of how respondents are situated within assemblages' (Juelskjaer, 2013, p.759).

5.3 New materialist research

In new materialist research, the ontological focus is on the relationality of assemblages (human-non-human or any combination of both) rather than on their essence. It asks not what the assemblage *is* but what it *does*. It therefore focuses on the *processes* and not on the *essences*; and on the *becoming* rather than on the *being* (Fox and Alldred, 2017).

When writing about feminist new materialists such as Barad and Grosz (cited further below), Frost (2011, p.71) asserts that they:

push feminists to relinquish the unidirectional model of causation in which *either* culture *or* biology is determinative and instead to adopt a model in which causation is conceived as complex, recursive, and multi-linear.

In order to do this, she continues, feminists will have to 'rethink how to apportion responsibility for injustice and assess the possibilities for and paths toward social and political transformation' (*ibid.*, p.71). The same can be said for DS researchers, who want to push beyond the impairment/disability binary to a view of dis/ability as the result of the complex reciprocal interactions of bodies (human and non) and society as per new materialist thinking.

None of the research studies reviewed in the previous chapter have outlined *how* new materialist research should be carried out. Although, in DS, researchers like Shildrick, Goodley and a few others have adopted Deleuzian concepts in their research, none offer specific ways of carrying out, for example, assemblage analysis (Feely, 2014). On the other hand, Fox and Alldred (2017) have presented a practical procedure of how a new materialist methodology could be done. I will be following these researchers' procedure because they not only propose a theoretical basis for carrying out new materialist research, but they elucidate *how* this type of research can also engage with policy and activism in social issues, which is what the current study would also like to achieve. What Grosz asserts with regard to feminism, I would like to apply to disabled people:

The problem is not how to give women more adequate recognition (who is it that women require recognition from?), more rights, or more of a voice but how

to enable more action, more making and doing, more difference. That is, the challenge facing feminism today is no longer only how to give women a more equal place within existing social networks and relations but how to enable women to partake in the creation of a future unlike the present. (Grosz, 2010, p.154)

This affirmation, when directed at disabled people, could be taken as a justification for the conceptual journey that this research undertook as the process took shape, i.e. from social model framing to a new materialist methodology.

So how can this happen? Fox and Alldred (2017) came up with 6 principles for a materialist methodology (pp.22-28; p.153):

1. That it should have a focus upon matter (not on text, as in post-structuralism, or structure, as in historical materialism);
2. That it should explore what matter does not what it is;
3. In which human agency is not privileged (post-anthropocentric). It bestows affective capacity to both human and non-human relations;
4. In which thoughts, memories, desires and emotions have material effects;
5. In which material forces (power and resistance to power) act locally, not in a top-down manner;
6. In which sociology is itself part of the materiality of the social world.

According to them, the materialist data collecting 'machine' in this study will therefore strive to:

- identify assemblages of human and non-human, material and abstract, cutting across what are usually termed the micro and macro (e.g. person-technology-colleague attitude-employer policy-employment legislation);
- explore how each element in the assemblage affects and is affected;
- assess what bodies and other things in these assemblages 'do' and their impact on other 'components';
- explore how the respondents describe these affects and the capacities produced, i.e. how technologies allow them to do/think/feel/be in certain ways; or how, for example, the attitudes of a co-worker might affect a

technology, producing a capacity in that technology to affect the user in a different way.

5.4 Choice of methodology

The initial choice of methodology was primarily made to give disabled people a voice on the topic and to provide evidence from disabled people themselves. My assumption here was that since enabling technology policy and practice is supposed to be for disabled people, it has to come from them if it is to be credible and if it is to make a difference in their lives. Oliver (1992) criticised research carried out 'on' disabled people for having failed them because it had not involved them, had produced information of little or no use for policy-making and because it had tended to consider disability from a medical or welfare, rather than a political, perspective. The result, as Barnes (1992, p.118) concluded, is that 'most social policy initiatives, compound dependence rather than alleviate it'. It was research 'on' disabled people and not 'with' them (Reason and Heron, 1986). Disabled people have therefore come to mistrust research because it was not making any difference in their daily struggles (Abberley, 1992; Oliver, 1992; Barnes, 1997; Beresford, 2003). As Stone and Priestley (1996, p.711) suggest, on the other hand:

taking the initial decision to adopt a social model of disablement as the theory which drives our research is in itself taking an important step in establishing our political commitment to the disability movement and transferring a degree of control to disabled people.

It is to be noted, however, that in this claim, the authors refer to the social model as a theory. With reference to Finkelstein (2001), the social model cannot be referred to as a theory because theories explain, and the social model was never designed to explain disability, but rather to describe it. He therefore clarifies that the social model is more of a 'tool', a device, rather than a theory of disability. In stage 1 of the study, I was informed by the social model in that, through disabled employees' subjective experiences of dis/ability, I could describe 'disablement' and map out the barriers (and enablers) they meet with in their access to, and use of, technology at their workplace.

As the research process progressed, and in the light of insights gained from new materialist concepts, whilst not leaving the above behind, I was compelled:

to think of causation [in this case, of disability] in far more complex terms; to recognise that phenomena are caught in a multitude of interlocking systems and forces and to consider anew the location and nature of capacities for agency. (Coole and Frost, 2010, p.9)

The particular ontology proposed by NM therefore was considered to be the most useful way of understanding the processes involved in dis/abling employees with impairments in their interactions with technologies at the place of work.

5.5 Study Design

In 1992, Oliver laid down the foundations of what was to become the ER paradigm. He suggested three main fundamentals for ER, i.e. reciprocity, gain and empowerment. Stone and Priestley (1996, p.706) further elaborated that ER should include the adoption of the SMD; the surrendering of objectivity and challenging oppression; being of benefit to the empowerment of disabled people; being accountable to the participants; giving voice to the participants; and being ready to use a variety of methods that may reflect the changing needs of disabled people.

Initially, I had only adopted principles from the ER paradigm in my study. ER served as a 'moral horizon' for this research. This means that as much as I could, I remained faithful to ER goals, knowing full well that it would not be possible to fully achieve them. Since this study aspired to propose policy and practice recommendations that have emerged from disabled people's experiences, the ER principles were deemed to be useful at that stage. The study then shaped itself into/adopted a new materialist approach as explained below.

This work began from an SMD perspective but, after carrying out the focus groups and the interviews, I felt that a theoretical framework to sit alongside SMD, was needed. This was because I realised that the participants

were uncovering a much more complex reality than originally thought, and that is when I started to explore NM. SMD was not left behind; it was built upon. SMD was considered as a tool rather than as a theory. The original title of the study and the research questions developed over time (and were changed) as it became clear during fieldwork that the participants were talking about their experience of dis/ability in complex, entangled ways that were not simply the result of a unidirectional cause (i.e. society versus impaired bodies). This prompted the search for theoretical concepts/ideas that look at phenomena like dis/ability in this more relational manner, which in turn brought about revisions to the research questions. It was thus a cyclical process: from an inductive approach it slowly changed into an abductive approach to research (Blaikie, 2007). The abductive research strategy consists of entering the field with an initial conceptual framework (premonition) which the researcher is willing to go beyond/improve on.

‘Abduction involves analysing data that fall outside of an initial theoretical frame or premise’ (Meyer and Lunnay, 2013, p.1). This allows the researcher to identify links and relations that would not have otherwise been noted and to generate new notions from a different perspective. Blaikie (2007) recommends that ‘a series of in-depth interviews, and/or periods of participant observation is a useful way of doing this’ (*ibid.*, p.103).

In the current study, as the research proceeded, I realised that I did not only need to analyse the bigger picture as I had been doing through the use of the barriers-mapping approach with focus groups and interviews, but that I had to zoom in on the micropolitics that were going on between the various components of the disabled employee-technology-work assemblage. This was done by going back to the participants to observe them while they worked. A more detailed discussion on the methods used and their advantages and disadvantages will be presented later on.

The choice of the methodologies in this research was also not bereft of difficulties. These will be discussed below, first those challenges related to ER and then those related to NM research.

Various difficulties have been outlined in the implementation of ER studies. Oliver (1997) himself questioned the possibility of implementing ER in full, and Barnes (2003) argued that there have been a number of research studies that have come close to meeting the requirements of the ER approach even if they contained only implicit reference to it. Therefore, I was aware that, although the theme chosen for this study was one of the topics that emerged from the needs of Maltese disabled people themselves as identified in the consultation process preceding the publication of the National Policy on Disabled People and Employment (KNPD, 2010a), and just because I am a disabled person, it cannot be affirmed that the control of the research agenda was in the hands of the participants.

Zarb (1992) proposed that for a study to be truly emancipatory, disabled people themselves should control the research process and decide who should be involved and how. The fact that an advisory group was not involved from the start is a limitation of this study. In fact the use of focus groups as a tool for data collection is an attempt to make up for this limitation as suggested by Stone and Priestley (1996).

Stone (1997) refers to the difficulties encountered while applying the social/emancipatory model in China, indicating that it might not be accepted in all contexts and cultures. This was a factor to look out for in this study, i.e. how ER can be applied in a Maltese culture, with Maltese disabled people. As explained in the introductory chapter, Malta has particular characteristics of a formerly colonised island, which, together with the influences from religion, politics and the overprotecting family, may make implementation of an ER study in Malta challenging. This is because, due to these long-term influences, and due to the fact that Maltese disabled people were always represented by non-disabled parents and professionals, they may not yet have reached the level of self-advocacy that would make them want to participate in ER. As Barnes (2004) said, people will have to want to be empowered; empowerment cannot be given simply by involving disabled people in a research project. If well facilitated, however, the research process itself can be empowering.

Various limitations have also been outlined with regard to the implementation of NM research. One of the limitations is that it is only recently

that studies based on NM approaches are being explored for their contribution towards activism and political action (e.g. Fox and Alldred, 2017). Another difficulty regarding these studies is that, because they use a variety of methods to gather the complex data, the time needed to carry them out is much longer than for other studies. Also, because it is a risky, non-linear, adventurous kind of research which starts from the middle of entangled assemblages and processes, it might elicit surprises that researchers would not have been expecting and which would have to be resolved as they come up. This is also because there are not many previous studies which are likely to be similar to theirs and, therefore, solutions would have to be thought of on an *ad hoc* basis.

Another limitation was pointed out by Feely (2014, p.54) when referring to the assemblage analysis used in his study. He claimed that:

While such an approach can open up new ways of thinking about a problem, and these ways of thinking might be of use to a wide range of people, the maps I produce will be open-ended and incomplete. This approach will not, and cannot, lead to closure and does not hope to solve, or tell others how to solve, the problem.

The same can be applied to the current study, in that it will be offering new ways of looking at dis/abled employees which might lead to actionable outcomes at the workplace, but it cannot offer ready-made solutions for every scenario because each one will have to be analysed on its own merit.

5.6 Choice of research methods

Data generation for this research was carried out through the use of three methods, namely, focus group discussions in the first stage to capture the breadth of the subject, individual interviews in the second stage to delve deeper into the issues raised by the participants during the focus groups, and observations in the third stage to zoom in on the interactions between employees, technologies and related assemblages. New materialist researchers have also used multiple methods in their research, such as ethnography, interviews, documentary sources or a mix of these. Indeed, this is also encouraged by Fox and Alldred (2017, p.171).

5.6.1 Stage One: Focus group discussions

With regard to the first stage of the study, Stone and Priestley (1996, p.711) suggested that organising a focus group 'can substantially enhance the collective and participatory content of the research', since this would possibly lead to more 'empowerment' of the participants (as per ER principles).

Focus groups have been defined as group discussions in which the researcher makes use of a group interview that capitalises on communication between researcher participants in order to generate data (Kitzinger, 1995). Focus group researchers aim at bringing to light how the group participants regard the issues under discussion in a setting that is as unstructured as possible, balanced with a clear research focus, for the extraction of their experiences and perspectives on the subject (Kroll *et al.*, 2007; Bryman, 2008) 'on their own terms, in their own vocabulary' (Barbour and Kitzinger, 1999, p.5).

By using focus groups or rather the analysis of the data generated through them, the method gleaned 'collective accounts of collective experience' (Oliver, 2002, p.4), rather than individual accounts as in interviews. But it is not enough to 'faithfully capture the experience of the group being researched' (Oliver, 2002, p.11), research must also be 'available and accessible' to disabled people as an instrument towards improvement of their daily existence. This is also why I am adopting Fox and Alldred's methodology which suggests that policy-relevant and event activist-style research can be conducted from a new materialist perspective.

The use of focus groups facilitated the implementation of the three fundamentals of gain, reciprocity and empowerment, in that participants were able to share opinions and experiences and were able to learn from each other. My aim was to capture their experiences and look for the 'general' within the 'particular'. In other words, I listened to their discussions and from this tried to establish how technologies 'operate' within the workplace, as part of assemblages. I was also beginning to look for shared experiences of certain types of assemblages (human and non-human) and the interactions between them.

5.6.2 Stage Two: Individual interviews

The second stage of the study consisted of individual interviews with the participants of the focus groups, in order to delve deeper into the topics raised during the discussions. The use of interviews for such a purpose was recommended in various texts (Oppenheim, 2005; Bryman, 2008; Byrne, 2012). This is called triangulation, where multiple and different sources and methods are used to substantiate evidence (Lincoln and Guba, 1985; Miles and Huberman, 1994). The use of data and methods triangulation, with interviews following the focus group discussions, also helped to compensate for the disadvantages in both methods thus attempting to increase the trustworthiness of the findings (Creswell, 2013). As will be seen later, however, the issue of trustworthiness in new materialist research is particularly debatable.

The major disadvantage of focus groups is that information is gathered about a topic generally and therefore the researcher gets the breadth of the subject; whilst interviews generate data from individual persons and therefore it is difficult to collectivise experience in this way (Stone and Priestley, 1996). In focus groups some participants may find it difficult to be open whilst they may feel more comfortable discussing the same topic in a one-to-one context. Tonkiss (2012) however argued that the difference between focus groups and interviews is not only in the characteristics of generality versus detail and openness versus confidentiality. He claimed that the two methods are based on 'separate models of social action and meaning' (*ibid.*, p.233). Using the two methods together, it was hoped that the widest possible range of perspectives, constructs and meanings would be generated on the topic under study. In new materialist research, interviews are used to produce accounts of events supplied by the participants, which are relevant to the research questions and which privilege the researcher's interpretations of the affects produced in the event (Fox and Alldred, 2017, p.161). This might have provoked certain dilemmas for me as researcher in that, with my interpretations, I would no longer have been solely privileging the participants' narratives. The latter authors however suggest that the research process be considered as an assemblage itself.

As part of the assemblage, it was not possible to extract myself from it. As soon as I became involved in the research and the analysis of the data, my own interpretations became part of the research assemblage and it was therefore impossible to claim that the participants' voices were being privileged. This point also applies to my position during the observation sessions which followed the interviews.

5.6.3 Stage Three: Observations

Observations were carried out since, following the individual interviews, I felt I needed to go back into the field to gather more detail about the event-assemblage first-hand, that is, to see the disabled people actually working with their technologies at the place of work. Unstructured observation was used, which is:

when the observer observes but does not use an observation schedule for the recording of behaviour. Instead, the aim is to record in as much detail as possible the behaviour of participants with the aim of developing a narrative account of that behaviour. (Bryman, 2008, p.257)

So, what was the observation going to give me that the interviews did not? By observing participants working with their technologies in the 'here and now', I was in close contact and 'looking through their eyes' for a longer period of time (Bryman, 2008).

Furthermore, interviewing did not necessarily take place on the place of work and when it did, it involved only momentary contacts with their technologies, such as when they showed me a device or referred to a piece of equipment they used, but were not actually working with, at the time of the interview. During the interview I relied on the participants' information about the devices, whereas during the observation I observed their behaviour whilst using the technology for their work. In such instances, I was able to see those taken-for-granted actions that the participants would not necessarily have told me about during the interview, but which I could observe because I was present for quite a while during their engagement with the device, in the context in which it is normally used. The new materialist approach that was used in this part of the study gave a new meaning also to the method of observation. This was

because devices, technologies, and materialities were seen to become participants, not as passive tools in the hands of human participants, but as active participants themselves (Law, 2004). Thus, these observations brought me closer to the participants' everyday lives because they were observed in their natural setting/arrangements, during their everyday interactions, whilst carrying out their everyday practices.

The data generation strategies section further below will go into detail as to what was being observed and how it was done. In the meantime, the following reflection communicates a practical dilemma that I found myself entangled with, before going for the observation sessions.

I had initially felt hesitant about doing these observations, thinking that I would end up analysing the activities that the participants were doing as an OT would. But then I realised that it would be beneficial to reflect on what I would be observing in the light of the new literature I had met with and in conjunction with the data that had emerged from the focus groups and interviews. I had carried out most of the interviews at the place of work and these proved to be more enlightening than the ones that were carried out at the participants' homes. For example, I had noticed pieces of equipment, certain set-ups, that the participants had not referred to whilst talking and which I would not have known about had I not gone to their workplace. This prompted me to think about how I might expand on this approach by using observations at the place of work with some of the participants.

5.7 The sample

As this study aimed to explore perceptions that disabled ex/workers have of technology and was largely about illustrative depth rather than representative breadth, a purposive sampling method was chosen. Purposive sampling (Seale, 2012) is a non-probability sampling strategy which is adopted when the sample has not been chosen using a random sampling method but implies that some groups in the population are more likely to be selected than others (Bryman, 2008, p.696). I selected participants 'because they can purposefully inform an understanding of the research problem and central phenomenon in the study' (Creswell, 2013, p.156). This is consonant with new materialist research

thinking, where this type of sampling 'provides sufficient events to be studied, sets a cut-off point for recruiting events and justifies how many events are included in the research process-event assemblage' (Fox and Alldred, 2017, p.161).

In this study, the sample was accessed through two sources. The first source was through Maltese DPOs since members would have joined the organisation because they want to raise their voices and do not wish other people to speak on their behalf (Oliver, 1984). This was thought to be better than accessing participants through the disability NGOs which, in Malta, are run mostly by non-disabled people (Azzopardi, 2009). This was also thought to be more compatible with ER principles (Oliver, 1992). The DPOs were therefore gatekeepers, i.e. they helped me access the sample.

I, however, also wanted to give a chance to other participants who do not necessarily belong to a DPO but may have experience with technology at work. There were some disabled people in fact who have invaluable experience in using technology in their work who are not part of a DPO. In order to give an opportunity to these disabled people to voice their opinions, an invitation for participation in the study was also sent through the database of the KNPD. Invitees were people between the ages of 18-60 years and beneficiaries of the Assistive Apparatus Fund. The two DPOs of people with intellectual impairments in Malta were not included in this study due to the different research approach that would have had to be used as explained in the inclusion criteria below.

Participants in this study had to have a physical and/or sensory impairment; be between the ages of 18 and 60 years; be either currently employed or have had some work experience within the last 10 years; and be using/have used enabling technology in their work. These characteristics were considered to be the most likely to provide me with the answers to the research questions. Statistics in fact indicate that the category of working age disabled people who most make use of enabling technology in Malta are people with physical and sensory impairments (KNPD, 2015). More recent statistics from *Agenzija Sapport* regarding this indication were not available (Spiteri, 2018).

Some of the participants were accessed via DPOs as identified by Callus (2014) where 7 such Maltese DPOs were named. These are DPOs with at least half of the committee consisting of disabled people. 3 of these DPOs are composed of people with mobility impairments; another DPO is composed of Deaf people who use Maltese Sign Language; and another organisation whose committee is made up of a majority of blind people. There are two other DPOs, but these are of people with intellectual impairments and therefore were not included in the study. This decision was taken since research with people with intellectual disabilities needs to take a different approach and method (Stalker, 1998; Walmsley and Johnson, 2003) and this would have made this study less doable in the time and with the resources available. Other participants were accessed via the KNPD as described above. I propose that this study begins a longer programme of research (*e.g.* post-doc) in which I would broaden this approach and become more inclusive of people with a range of different impairments.

As a first step, the Presidents of the DPOs and the Chairperson of KNPD were approached via an email including an information/consent letter (Appendices A and C respectively) in which the aims of the study were explained. It also asked whether they would accept to send out an invitation to the members on their database to take part in the study and whether they would accept to hold the focus group at their premises. Members who did not have access to email were sent the same letter with a self-addressed envelope. This was done through the respective DPOs and through KNPD, to safeguard the potential participants' anonymity. The respondents who accepted to participate in the focus groups were then invited via an information letter and consent form (Appendices B and D respectively) to attend for a focus group session at a public place of their choice, *e.g.* the DPO's premises. A donation was forwarded to the DPOs for their participation in the study and for the use of the premises. Following the focus group, participants were invited to sit for an individual interview which served to probe deeper into the issues mentioned during the focus group discussions. An information letter and a consent form (Appendices B and F respectively) was sent to the focus group members who accepted to be interviewed and to the respondents from KNPD. As mentioned earlier, following the individual interviews, seven observation sessions were carried out.

Participants for these sessions were recruited from those who took part in the focus groups and interviews. They were sent an information letter (Appendix I) outlining the aims of the session and what it would involve, together with a consent form (Appendix J).

The sampling procedure, however, encountered a number of barriers. For example, there was insufficient response from Deaf/hearing impaired DPO members such that follow-up strategies had to be used. When recruited, there was an imbalance between the characteristics of the participants. There was an unequal representation of groups i.e. only 5 deaf participants in comparison to 9 blind/visually impaired employees and 11 employees with physical impairments. These factors might have influenced the content and flow of the group discussions and, consequently, the quantity and quality of the data generated. When there were not enough participants for the focus groups, such as with the Deaf participants, snowballing (Seale, 2012) was used to recruit other participants whom they knew and who fit into the inclusion criteria.

There were also some barriers to recruitment for the observation sessions. The time required to carry out the observation sessions was substantial, and this proved to be a challenge for both researcher and participants. Although the issue of being observed while they work could have made the participants feel uncomfortable, this did not transpire, and I made sure to send them the data following the sessions so that they could check that it faithfully represented what had happened during that time. Another barrier which I felt could have influenced the type of data gathered during the sessions was due to the fact that the participants chose the time most convenient for them, which was not always the busiest time or the time when they would normally be using their technologies. In one instance for example, the participants were told by their manager not to carry out observations during the time when they had clients, even though I had assured them that the confidentiality/anonymity of all present would be respected. This might have somewhat reduced the insights gained, when compared to observing other participants during busier times at work. This might have given me a better understanding of their everyday work practices.

Another barrier was that of language. I was aware that the presence of a sign language interpreter for the Deaf participants could have changed the dynamics of the group and the individual interviews, but the fact that all the Deaf participants knew the sign language interpreter would have prevented this from happening. At the time of the fieldwork, in Malta, there were only 4 sign language interpreters and so, the participants knew them from their school days. In a small community like Malta, where trust is a value that matters, this fact would have attenuated the potential barrier. Similarly, one of the participants had a very weak voice because of his impairment and his wife had to act as 'interpreter' for him. This husband (with weak voice)-wife assemblage produced the capacity for the participant to express himself and for me to understand what was being said, but it might also have affected the content and meaning being presented. Since I did not receive any comments or amendments to the transcripts that were sent to him following the interview, I assumed that he was content with the way his wife had voiced his replies and how they had been understood by myself.

5.8 Participant demographics

The main participant demographics are presented in Table 5.1 below. 25 participants participated in total. 11 have a physical impairment, 9 have either a visual impairment or are blind and 5 either have a hearing impairment or are Deaf. 16 participants are male and 9 are female. 21 participants are currently employed and 4 are not currently employed but had been employed during the past 10 years.

With regard to the level of employment, according to the hierarchy presented in the Labour Force Survey (NSO, 2017) Occupational Groups: 4 participants are managers, 3 are professionals, 7 are clerical support workers, 7 are service and sales workers, 2 are technicians and associated professionals and 2 are in elementary occupations. The length of time they have been working, spans from 1 month to 42 years, with 6 participants working between 0 - 5 years, 7 working from 5+ - 10 years, 3 from 10+ - 15, 3 from 15+ - 20 years and 6 have been working for more than 20 years. It is interesting to note here that the impairment group who have been working the longest are those with

visual impairment or who are blind, and those who have been working the least are those with hearing impairment or who are Deaf.

5.9 Data Generation Strategies

Prior to starting the fieldwork, the participants were given a pseudonym and their jobs were described in a general way (not per job title) to protect their identity. This is especially important for research with disabled people in Malta, where people know each other and are easily identifiable. The focus groups were organised by entity (i.e. DPO or KNPD), and this also meant they were organised by impairment, such that a total of 3 focus groups were held at the DPO/KNPD/University of Malta premises.

One of the focus groups was held at my university office since their DPO premises were not accessible for wheelchair users. One group consisted of people with hearing impairment/Deaf; one focus group consisted of people with visual impairment/blind and one focus group consisted of people with physical impairment. In organising the focus groups per type of impairment, I intended to bring together people who had some level of shared experience of impairment and of the types of technologies likely to have been provided to them/used by that particular impairment group. Organising the groups per impairment, therefore, possibly meant increased homogeneity (Krueger and Casey, 2009). This was also done for practical reasons (financial and logistical) such as recruiting one sign-language interpreter for a whole group of sign-language users.

Each group consisted of 4 to 8 participants as suggested by Kitzinger (1995) and did not take longer than two hours as suggested by Bloor *et al.* (2001). The sessions took place in a quiet room free from distractions at a time that had been previously agreed upon by the participants. Any expenses involved, including adapted transport such as Wheelchair Accessible taxis and sign language interpretation, was paid for by myself. Funding for these accommodations was possible owing to the Maltese government's partial sponsorship of the study.

Table 5.1 Participant Demographics - This table shows the main demographics of the participants in this study

PARTICIPANT IMPAIRMENT GROUP	PSEUDONYM	GENDER	AGE (YEARS)	OCCUPATION
VISUAL IMPAIRMENT / BLIND	Elton	Male	30-39	Manager
	Carl	Male	30-39	Professional
	Ann	Female	50-60	Manager
	Cecilia	Female	50-60	Clerical Support Worker
	Elias	Male	50-60	Elementary Occupation
	Philip	Male	40-49	Service/Sales Worker
	Gertrude	Female	40-49	Clerical Support Worker
	Lionel	Male	40-49	Service/Sales Worker
	Duncan	Male	50-59	Professional
HEARING IMPAIRMENT / DEAF	William	Male	18-29	Service/Sales Worker
	Anthony	Male	18-29	Technician/Asst. Professional
	Terence	Male	18-29	Technician/Asst. Professional
	Lino	Male	18-29	Clerical Support Worker
	Beatrix	Female	18-29	Clerical Support Worker
PHYSICAL IMPAIRMENT	Etienne	Male	30-39	Manager
	Miriam	Female	30-39	Manager
	Norman	Male	30-39	Clerical Support Worker
	Yanica	Female	30-39	Service/Sales Worker
	Daphne	Female	40-49	Manager
	Avril	Female	40-49	Clerical Support Worker
	Ray	Male	30-39	Service/Sales Worker
	Vincent	Male	30-39	Elementary Occupation
	Harold	Male	18-29	Service/Sales Worker
	Tonia	Female	18-29	Service/Sales Worker
	Robert	Male	30-39	Professional

At the start of the session, I explained to the participants the main aims of the study. The theme of the discussion, i.e. enabling technology and employment of disabled people in Malta, and the research questions were also read out. The main topics that were to be discussed included Maltese disabled people's experiences of enabling technology in employment; the factors, such as workplace practices and supports, which aid or reduce the value of enabling technology; and the extent to which professionals/stakeholders/wider organisational influences shape disabled people's access to, and use of, workplace technologies. These topics were also distributed electronically to the participants prior to the group so that they would have had time to reflect on them (Appendix E).

Those participants who had not yet returned the consent form via email, were presented with one (Appendix D) which they signed as evidence that they agreed to participate in the study. Alternative formats were available as necessary. Participants who are blind or visually impaired were presented with the consent form, theme and research questions electronically or in Braille prior to the session according to their preferences. Those who preferred, had it read to them by myself prior to the session. Participants who are Deaf had a sign language interpreter present as requested by themselves. Participants who have dexterity and mobility difficulties were also offered assistance as necessary.

The session was recorded with prior permission from the participants. During the introductory part of the session, the participants were reassured that only I would be listening to the recordings for the extraction of the data and that every contribution will be treated as confidential. They were also told that the recordings would be deleted as soon as the study is completed, to avoid ethical issues rising from the fact that recording was used during the focus group discussions as a primary means of data collection.

My role as moderator of the discussion was also explained to the group at the start of the session. This was done for both practical and ethical reasons (Tonkiss, 2012). Practical issues included explaining the use of the tape recorder, the importance of turn-taking during the discussion, and encouraging every participant to voice their opinions. Ethical issues, as further elaborated

below, included obtaining consent for the use of the tape-recorder and maintaining confidentiality when the discussion was over. I also tried to adopt as balanced a role as possible and not impose my own sense of what was interesting or important on the group participants. During the discussion, however, I encouraged the participants to discuss any disagreements among themselves on the topic, clarify why they thought as they did and elucidate their points of view when necessary.

As an incentive, the participants were offered refreshments after the session. This also allowed the participants to informally discuss what they felt during the discussion and how the session had evolved in general.

Of the 15 participants in the focus groups, only one participant did not reply to my invitation to take part in an interview, such that there were 14 participants recruited for the interviews from this source. Another 9 participants were recruited for the interviews from KNPD and another (1) participant from the DPOs.

Following the focus group sessions, the data was transcribed and sent to the participants for validation. The transcripts were then amended according to the feedback received. The transcripts were read and re-read, and the audio recordings were re-listened to. I thus familiarised myself with the content and prepared for the questions that I would ask during the interview. In this way, the gaps that I felt had been left out from the focus group discussions or needed clarification were filled. A total of 24 individual interviews were carried out, each no longer than 2 hours, with breaks when fatigue became an issue. The same interview schedule (Appendix G) was used for all interviewees but for the participants who had taken part in the focus group more in-depth questions were used as described above, in order to clarify and expand on any issues that had arisen during the focus group discussions. The amount of 24 interviews was decided upon, due to the volume of data that was generated; when I felt that the subject had been saturated and no new surprising data was emerging. The interviews took place in a public venue and at a time that was convenient for the participants. These interviews were semi-structured in such a way that the interviewee was guided to the specific points that needed more clarification.

Interviewees, however, were free to expand on the issues as they framed and understood them (Bryman, 2008).

In semi-structured interviews the researcher 'knows the questions that need to be asked but not all the possible responses' (Morse, 2012, p.195). In this study therefore, I planned how to introduce the interview and the range of topics that needed to be covered. Interview questions revolved around the types of technologies the participants used at work, the effect these technologies had on their performance at work, and which enablers and barriers supported (or not) the access to, and use of, these technologies. They were also asked about wider factors (outside the workplace) that they thought had influenced their access to, and use of, such technologies. During the interview I listened and guided the order or sequence of the topics to be discussed without putting undue pressure on the participant to reply in a certain manner (Oppenheim, 2005). The data generated during the interviews was transcribed and sent back to the participants for validation. Amendments were made to the transcripts following the respondents' feedback.

The observation sessions were also preceded by re-listening to the audio recordings of the interviews of the specific participants and the re-reading of the transcripts. The sessions consisted of an average of three hours per participant. They took place at the participant's place of work at a time chosen by themselves. When I arrived, I re-read the information letter (Appendix I) and the consent form (Appendix J) to the participants, which they then signed (if they had not already done so). Each participant was then invited to carry on with their work. I also requested their permission to take photos, for example, of their office layout. During the photo shooting, care was taken to leave out the participants' faces and anything that might risk their being identified. When it was impossible to leave out their face, I later edited them in a way that they could not be identified (see Chapter 7).

I positioned myself next to the participants, at a distance that would not make them feel uncomfortable and took notes on what was happening and what I was observing. I did not use a particular protocol or schedule but when I did not understand something, I would ask the participants, at an appropriate time when it was not disturbing the employee from her/his work, to clarify the action

or explain how a device worked, for example. Having listened to the interviews before the session, I had also listed the particular comments or events mentioned by the participant during the interview which I wanted to specifically take note of during my observations. Since the observation sessions were shaped by my understanding of assemblages, I looked out for (and noted) the various components, relations and capacities that were being generated in the interactions between the participant, the technologies and other human and non-human entities at that particular place and time. These included, for example, assemblages of employee-technology/devices, furniture set-up-technology; work colleague attitude/behaviour-disabled employee; technology function-employee/colleagues utterances/gestures/expressions; work policy/practice-employer-workplace accommodations. Therefore I observed not the individual components' function/behaviour on their own but when they were interacting and the outcomes thereof. These will be illustrated in further detail in the vignettes in Chapter 7.

When I left the workplace, I sat in my car and reviewed the field notes while they were still fresh in my memory. I also added other thoughts that were relevant to the adopted methodology and methods, such as the accessibility features of the latter.

Given that I wanted to be faithful to emancipatory principles during the research process, accessibility of the research methods/venues was given particular importance. Literature on the subject has indicated practical tips that a researcher conducting research with disabled people should take into consideration (Barrett and Kirk, 2000; Seymour *et al.*, 2003; Cooper *et al.*, 2004; Kroll *et al.*, 2007). These suggestions included the setting of the venue and its characteristics, for example, the quality of lighting, the noise levels present, and the positioning of the sign language interpreter. Not only were the venue and transport accessible for me (as a wheelchair user) and for the participants with physical impairments, but any printed material was available in alternative formats such as in soft copy, Braille or large print for the participants with visual impairment or who were blind. For the focus group involving Deaf participants, a flip chart was present so that the aims of the group discussion were written down. A sign language interpreter was available during the focus group and

interviews that involved the Deaf participants and care was taken so that she positioned herself to face the light source in the room. Quiet rooms with good lighting were chosen for focus groups and interviews with all participants whenever possible.

5.10 Analysis of the Data Generated

Analysis of the data generated throughout the research process took place at different levels. A first-level analysis was carried out using a more traditional manner as Braun and Clarke (2013) suggest in order to map out the main themes as narrated by the participants during the focus group discussions and the interviews. A second-level analysis was then carried out as suggested by Fox and Alldred (2017) for the data generated during the interviews and observation sessions.

I chose to do the analysis of the data manually, with the help of the Microsoft Word editing features through the use of comment bubbles at the side of the text. The reason for the decision not to use a qualitative data analysis computer software package was that I felt I had the amount of data that I could handle effectively with manual analysis. Another reason for this choice was because I wanted to avoid 'fracturing the text', which is a known risk using such software (MacMillan, 2005). The manual technique was chosen since this also allowed me to remain very close to the data generated during the fieldwork.

The main points/topics from the focus group discussions and from the interviews were extracted and the common themes formed and grouped together. This is called Thematic Analysis, which is a qualitative data analysis approach that extracts key themes from the data generated (Bryman, 2008). Although thematic analysis lacks a clearly specified series of procedures, it is one of the most popular means of conducting qualitative data analysis (Bryman, 2008). The method suggested by Braun and Clarke (2013) was used to code the transcripts from the two sets of data, whilst looking for relevant and emerging themes. Table 5.2, adapted from Braun and Clarke (2006, p.87), summarises the process undertaken to come up with the topics and themes from the data generated.

One topic that I had expected would have arisen during the focus group discussions was the participants' experiences with professionals who had recommended the technology to them. This, however, did not emerge as amply as I had expected, in that most of them had not had any interventions by professionals, so I probed about this further in the interviews. Table 5.3 shows the themes and sub-themes that emerged from the focus group and interview data.

At a certain point in the transcription of both focus group and interview data, I realised that participants were talking in bits and pieces, jumping from one topic to another especially when describing their journeys to access technologies. While drawing the Route Map of how access to technology happens in Malta and the services that are involved (Appendix K), I realised that the way participants were talking reflected the way things happen in reality. The system is very hard to navigate, and it is very difficult to get it to 'join up'. This explained why participants talked the way they did in the focus groups and interviews: they could not speak of a smooth journey because it does not exist; they got their information and eventually access, from here, there and everywhere. The participants' accounts reflected the fragmentation of the AT services in Malta.

The second-level analysis consisted of 'dredging' the empirical data sources, i.e. the interviews and the observation sessions fieldnotes and photos, in order to 'identify the relations and affects that comprise assemblages of bodies, things and social formations' (Fox and Alldred, 2017, p.172) within the disabled employee-working-with-technology event. The data was read and re-read to identify the components of assemblages; human, non-human or abstract relations within and among the assemblages; and how these affect or are affected by each other. As Chapter 7 will show, this level of data analysis gave me an understanding of what the assemblages can do and what capacities, limits and opportunities for action are produced in the relational processes going on in the particular events narrated/observed. This analysis will be reported 'in terms of pre-selected themes' imposed on the data by myself (Fox and Alldred, 2017, p.162). The themes/sub-themes used will be the ones that were extracted from the first-level analysis explained above.

Table 5.2 Phases of thematic analysis (adapted from Braun and Clarke, 2006, p.87)

PHASES OF THEMATIC ANALYSIS	
1.	Familiarising yourself with your data: Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2.	Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3.	Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme.
4.	Reviewing themes: Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5.	Defining and naming themes: Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6.	Producing the report: The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table 5.3 Themes and sub-themes from focus group and interview data

THEMES	SUB-THEMES	
Meaning of technology	<ul style="list-style-type: none"> • Independence • Equality • Self-esteem • Extension of the body 	<ul style="list-style-type: none"> • Identity • Investment • Worsening of Condition
How technology enables them	<ul style="list-style-type: none"> • Function/Doing • Adjustment 	<ul style="list-style-type: none"> • Control • Access
Characteristics they look for in technology	<ul style="list-style-type: none"> • Flexibility • User-friendly • Reliability • Aesthetics 	<ul style="list-style-type: none"> • Portability • Affordability • Availability • Efficiency
Barriers	<ul style="list-style-type: none"> • Structural e.g. lack of access; transport • Institutional e.g. education; professionals; service provision; training; policies and practices 	<ul style="list-style-type: none"> • Attitudinal e.g. employers • Impairment-related issues
Enablers/facilitators	<ul style="list-style-type: none"> • Human support e.g. colleagues; peer support • Financial support • Technological support • Other: Animal support 	<ul style="list-style-type: none"> • Strategies • Self-determination • Legislation/Policy • Media
Pathways to technology	<ul style="list-style-type: none"> • Research • Resourcefulness 	<ul style="list-style-type: none"> • Peer Support Networks
Specific to Malta	<ul style="list-style-type: none"> • Family e.g. overprotectiveness • Size/isolation • Language 	<ul style="list-style-type: none"> • Charity • Limited services • Religion/culture
Participants' Recommendations	<ul style="list-style-type: none"> • Vocational rehabilitation services • Enabling technology information hub/website; service-user involvement e.g. Deaf Office 	

Figure 7.1 shows the disabled technology user-work assemblages and networks that emerged from the second-level analysis and that will be discussed further in Chapter 7.

5.11 Issues of Trustworthiness and Authenticity

The terms 'trustworthiness' and 'authenticity' as proposed by Lincoln and Guba (1985) will be adopted here, instead of the terms 'validity' and 'reliability' since these are used with reference to measurement in quantitative research (Bryman, 2008). Lincoln and Guba (1985) propose four factors that need to be taken into consideration when carrying out a qualitative research study, thus giving it trustworthiness, i.e. credibility, transferability, dependability and confirmability. On the other hand, Blaikie (1993) claimed that when a study is based on the subjective experiences of the participants, as in the major part of the present study, it cannot be replicated and therefore issues of objectivity, bias and validity are irrelevant. This is consonant with new materialist research where it is taken for granted that both researchers (e.g. in their subjective interpretation of the data) and participants (e.g. in their choice of what to in/exclude in their stories) are not fully trustworthy. Latour (2005) calls an actor-network (or in Deleuzian terms, assemblage) account, 'a *risky* account meaning that it can easily fail (...) since it *can put aside neither the complete artificiality of the enterprise nor its claim to accuracy and truthfulness.*' (p.133, italics in original). Feely (2014), for example, claims that he was taking an ontological position when he treated his unreliable narrators, his unreliable readers and his own unreliability, as part of the reality he was studying.

With respect to ER principles, however, I made every attempt to render the findings from this study as trustworthy as possible. During the observation sessions, for example, the use of photos helped in 'connecting research audiences directly to the events' (Fox and Alldred, 2017, p.173). This compensated for the fact that it was difficult for me to narrate the events observed in a way that they represented comprehensively the complex events occurring during the session.

To increase the credibility of the findings, I validated all data collected with the participants by sending the transcriptions of the focus group

discussions and the interviews, and the narratives of the observation sessions to the participants so that they could re-read, confirm, amend, any information that they deemed incorrect or that did not faithfully represent their contributions. This is in line with ER principles since it gives disabled people control over what is published as findings of this study. Furthermore, it shows whether I had understood the social reality as narrated by the participants (Barnes, 1992; Zarb, 1992). Such a strategy is also congruent with new materialist thinking, where 'power, in new materialist ontology, is a transient, fluctuating phenomenon - a momentary exercise of affectivity by one relation over another' (Fox and Alldred, 2017, p.179). Since I am considering the research as an assemblage, through this step I was placing the two components researcher-participant in a relational position of exchange and collaboration in which both had the capacity to transform the research process.

Instead of reliability, the term dependability was suggested by Lincoln and Guba (1985) to refer to the auditing of the documentation produced throughout the research process to assess the clarity of the account of the same process including the researcher's thinking and conclusions. Confirmability is used instead of objectivity to establish the value of the data and this is also done through auditing (Creswell, 2013). In the current study, although I did my best to have my documentation checked, this proved to be challenging, since a large amount of data was collected and it was difficult and expensive to find peers to audit all the paperwork, transcripts and documents produced during the research process.

5.12 Ethical Issues

The major ethical issues in this study arose from the fact that I was working with human research participants; that I was carrying out the study in Malta (lone working); and that I had to take into consideration locality issues, including data protection and approval processes pertaining to Malta. In fact, this study was not only approved by the Research Ethics Committee of the University of Leeds, but, because I am an academic member of staff at the University of Malta, carrying out my fieldwork in Malta, I had to submit my

proposal to the University of Malta Research Ethics Committee. This Committee also gave me its ethical clearance to proceed with the study.

This study was considered as not including vulnerable participants. According to the SMD (UPIAS, 1976; Oliver, 1990b), the concept of vulnerability and disabled people is a socially constructed issue. I am taking the position that all human-beings are 'vulnerable' (Fineman, 2008, 2010), but society tends to categorise particular groups as such and it is often a paternalistic and disempowering category. Since historically disabled people were socially stigmatised and marginalised, they are labelled 'vulnerable' simply by virtue of the group to which they belong. The use of the word 'vulnerable' with respect to disabled people has a disabling effect on the affect/autonomy of these people. This is the reason why the participation of disabled people in this study was not considered to include vulnerable people.

Since this study did not involve any vulnerable people, the risks of abuse were reduced. Apart from the potential risks, there were also some benefits for the research participants. Validation of data from the focus groups, the interviews and the observation sessions were carried out so as to make this study 'of' and not 'on' disabled people. This study has given the participating disabled people a voice, it did not violate their experiences but will be 'used' to form the basis of recommendations for future policies and practices regarding enabling technology and employment in Malta, which at present are very limited. During the focus group discussions, participants also exchanged helpful information with each other and were of support to each other in issues of importance to them. In this way the research was not only beneficial to me as the researcher but also to the participants.

In the event of disclosure or distress by participants, I was prepared to reassure and calm them down and ask whether they would like to terminate the interview. I would have reminded the participant/s that s/he has the right not to reply to particular questions or to withdraw from the study at any time if s/he so wishes. This statement was also included in the consent forms (see Appendices D, F and J). The participant would also have been referred for further support from relevant professionals/service providers if the participant so consented. I implemented all measures to prevent disclosure of information that could be

used to identify participants as shall be seen below. However, had identification occurred, the data generated by the participant in question would not have been included in the study.

The nature of the subject being studied was not envisaged to create difficult situations when I interviewed the participants on their own. However, since I was interviewing on my own, I always carried my mobile with me so that I could easily access help if necessary. It is to be noted also that this research did not involve any element of deception for the participants.

In order to ensure the confidentiality and security of the participants' data, factors such as anonymising data, storage and coding of data were taken into account and will now be described.

Given the small amount of DPOs and the small community of disabled people in Malta, this issue was of great importance. The names of the organisations and the participants that accepted to take part in this study remained anonymous. Every participant was given a pseudonym which was only known to me. Personal data such as mobile phone numbers was only requested to make arrangements for the interviews in the second stage of the study and for the observation sessions in the third stage. Only the general description of the nature of the jobs pertaining to the participants was revealed in the writing of the study to protect the identity of the participants. Each consent form had the relevant pseudonym on it to ensure anonymity (see Appendices D, F and J).

The recorded sessions and the eventual transcriptions were kept in a locked cupboard and the key was kept in a safe place. Any information stored on USBs was also kept locked in the same cupboard. Any data that was recorded on the computer was kept in files that could only be accessed with the use of a password that was known only to me. Any personal data, such as participants' telephone numbers that were needed to approach the participants for an interview or for the observation sessions, was locked away in a separate cupboard from the other research data, e.g. transcriptions, to ensure that the anonymity of participants was protected.

Every piece of data was given the same pseudonym as pertaining to the particular participant as explained above. The raw data from the study will be stored for 3 years after the end of data collection. Since the wider dissemination of the study findings (publication of digested data) may take place within those three years, this option was chosen. Any data on paper will then be shredded and software destroyed. Data on the hard-drive will also be deleted.

5.13 Dissemination of Findings

The dissemination of the findings upon completion of the study is one of the important initiatives in ER (Stone and Priestley, 1996). One of the practical aims/outcomes of this study will be that findings will serve as recommendations for enabling technology policy and practice in Malta. They will 'speak to' both disabled people and stakeholders involved in the area of employment. The findings will therefore be sent to all participants when the study is completed and to their DPOs when they so consented. In addition they will be sent to the Inclusive Employment Services Division of Jobsplus, and the Lino Spiteri Foundation which are the national government organisations responsible for all issues related to employment and training of disabled potential/employees. The fact that I already have a good working relationship with the managers and staff of both organisations, will be a good platform from which to launch the findings as a basis for future enabling technology-related initiatives at the place of work. The Ministry for Education and Employment will also be approached in order to discuss the findings from the study and to propose the recommendations that emerged from them. Since this project was part funded by the government, it should be easier to make a case for the findings to be included in future employment policies and practices.

There is evidence of research making an impact on disabled people's lives (Beresford, 2000; Barnes *et al.*, 2002; Bethell and Harrison, 2003; Jade, 2003; Goodley and Lawthom, 2005) and, although these studies cannot be described as full ER, the researchers have used particular aspects of it well for the benefit of disabled people (Barnes, 2002; Zarb, 2003a). In this case, I was not simply interested in identifying the barriers that existed but, through the

dissemination of the findings, also to politicise, mobilise, and improve the area of enabling technology in the employment of disabled people in Malta.

Another aim/outcome of this study involved the healthcare professions with a special focus on OT. The dissemination of the research findings through participation in conferences and continuing professional development events will impact on these professions both at a professional practice level and also at a pedagogical level. I am already involved in the planning and implementation of OT curricula and therefore in a privileged position to make a change in the preparation of future OTs. I have also contacted the present OT working at Jobsplus and staff at the Lino Spiteri Foundation, to discuss how the findings of this study can be put to fruition in their services.

Viewing the research process as Fox and Alldred (2017) proposed, it can be said that the dissemination phase is when the research assemblage interacts with other assemblages in the networks around it such that transformations and new becomings are made possible. It is in this manner that NM research can contribute not only on a theoretical level but also on a political level (see also Galis, 2011).

5.14 Issues of Reflexivity in this Study

This section includes reflections that emerged along the research process on the relations between ER and NM. This kind of research complements well the principles of ER mentioned earlier in the thesis, because, where traditionally the researcher was the one who controlled the research process, in both new materialist research and ER, the researcher and the researchee are on a more level playing field; the approach is not top-down. In new materialist methodology, the researcher and the researchee are treated as an assemblage, the union of which produces a multiplicity of capacities in its human and non-human relations. ER principles also promote the importance of research as being of benefit to the research participants. ER and NM however differ in other aspects. ER is based on the SMD which rests upon the duality impairment/disability whilst new materialist research is against dualisms. SMD is about structure versus agency and NM is for assemblages of both. In SMD power is in the structure, whilst in NM power is 'a transient, fluctuating

phenomenon - a momentary exercise of affectivity by one relation over another' (Fox and Alldred, 2017, p.179). In NM a repeated categorisation of bodies as abled and disabled establishes the basis for ableist power which 'has continuity only as long as it is replicated in the next event, and the one after that, and may quickly evaporate as and when an assemblage's affect economy changes' (*ibid.*, p.180). It exists as it is at any one moment in space and time. This is why I am taking SMD as my point of departure, using it as an initial tool, then moving on to NM. As Coole and Frost (2010, p.26) claim, NM 'can hardly ignore the role of social construction'. In this study I have accepted the social constructionist position whilst 'giving materiality its due and recognising its plural dimensions and its complex, contingent modes of appearing' (*ibid.*, p.27).

Other reflections revolved around my position as researcher. The ontological stance I took, was affected by the fact that I am a disabled person-OT-academic-activist assemblage. I am aware that my research was not independent of my own values and perspectives (French and Swain, 2000). Indeed, being a disabled researcher:

can provide an 'insider' status when interviewing other disabled people and as such the presence of a visibly disabled body in the research process can be beneficial. (Brown and Boardman, 2011, p.29)

This is because the participants can identify better with the researcher and may be more open during the data generation process. These concepts of subjectivity and reflexivity have also been experienced by other researchers in, for example, gender studies (Oakley, 1981; Ribbens, 1990; Cotterill, 1992) and in the disability field (Vernon, 1997; Andrews, 2005; Seymour, 2007; Brown and Boardman, 2011; O'Toole, 2013; Rinaldi, 2013). Therefore the components of my assemblage may have contributed to the richness of the research process because of the relations and interactions that were ongoing during the study. In other words, as part of the research assemblage, I too affected (and was affected by) the research process. This will be developed further in Chapter 8 and in the epilogue of this thesis.

5.15 Conclusion

This chapter has outlined the methodology and methods that have been used to carry out this study. Advantages and disadvantages of the various methods were discussed, together with the ethical issues that the study might have raised. This chapter has also shown that the research process itself can be regarded as an assemblage. It discussed the components that form the research assemblage (*e.g.* the researcher, the participants, the events that are being studied, the methods, and the emerging data) and the entanglements they enact among themselves. It is hoped that, as a result of these interactions and the capacities it produced, this study will prove to be research 'with' disabled people and not 'on' them, such that it may leave practical and positive effects on their daily lives at work.

The next two chapters have been assembled according to the conceptual process that this study went through. The first (Chapter 6) will discuss the first-level analysis and the thematic priorities that emerged from the data, *i.e.* it will present the barriers and enablers, including a section on Professional Interferences. The second one (Chapter 7) then presents the second-level analysis of the data generated during the observation sessions and interviews via a series of vignettes. Chapter 8 subsequently advances the Recommendations on both the findings and the research methodology that are a direct result of the previous chapters. This chapter will then conclude the thesis with implications for future policy and practice in this field.

Chapter 6

Disabled Technology Users at Work: Barriers and Enablers

6.1 Introduction

This chapter will present the Stage 1 findings, i.e. a first level analysis of the data that emerged from the focus group discussions and the interviews, in which the participants voiced their experiences of accessing and using technology at work. It will provide a thematic analysis of how participants spoke about their engagement with technology in the workplace and what helps or hinders them in this engagement (see Table 5.3).

A presentation of the types of technologies that participants use to carry out their work will start off the chapter. The participants will then share what this technology means to them, followed by the main section of this chapter, which will present the main barriers that the participants indicated as interfering with the potential benefits of technology use in their jobs. It was difficult to unpick the barriers from the participants' accounts without also identifying the enabling factors that were mentioned, and therefore these will also be presented. By using a more traditional thematic approach with the stage 1 findings that map out a list of individual barriers/enablers as identified by disabled technology users at work, this chapter aims to set the scene for a more detailed discussion in the next chapter of how these 'components' inter-relate and interact as part of 'assemblages' (the Stage 2 findings).

6.2 Types of enabling technologies used by participants

The technology used by the participants ranged from low to hi-tech equipment, custom made devices, mainstream and AT. The distinction between assistive and mainstream technologies was not easy to make, because as noted in the clarification of terms section in Chapter 1, and as the participants themselves noted, most mainstream technology, especially communication and information technology, is now designed and manufactured with integrated accessibility features. Participants also indicated that there is a perceived hierarchy of importance amongst the different devices and that technology permeates most aspects of their lives. As they asserted, they carry it with them

wherever they go. The technology that is used at work is generally the same as that which is used elsewhere, for example, at home. It was therefore difficult to neatly categorise enabling technologies for work and enabling technologies for other activities of daily living.

Participants in this study mentioned a variety of technologies that they use at work; these included both hardware and software and spanned from very basic low-tech devices such as hand-held magnifiers to very high-tech equipment such as speech-recognition software. Some devices mentioned were off-the-shelf types such as walking sticks and talking devices and others were custom-made for the individual needs of the participants, such as specialised seating devices. Others consisted of home-made, do-it-yourself solutions such as wooden foot-stools or elevated tables for computer screens or keyboards. Technologies did not only consist of what would be categorised as AT (Cook and Polgar, 2008) but also mainstream technology such as personal computers and mobile phones.

Lionel (interview): I use a lot of different types of technologies, the most common one is the computer, which I use together with a screen reader technology like Window Eyes. Then other technologies that I use every day are the talking watch, talking calculator, talking mobile, radio, TV (...) those are the technologies that I use.

Researcher: then I can see your headphones.

Lionel: yes, those are important because in an open office environment you wouldn't want to disturb your colleagues if you can help it. Apart from that, the headphones help me concentrate on whatever I am doing, but I don't only use the headphones here at work, I also use them at home.

Researcher: and you are also using a hearing aid (...)

Lionel: ah yes, yes, yes, for a moment I forgot it because it is such a part of me that I almost forgot it.

Lionel and other participants have mentioned that they actually prefer to take the technology they have at home with them to work and vice versa. This is supposed to guarantee an easier transition from home to work life, with the technology being the link that facilitates the passage. Furthermore, Lionel said, 'I forgot it because it is such a part of me', indicating a taken-for-granted symbiotic relationship between his body and the technology (hearing aid). This

is related to the concept of the posthuman condition, in which the body that is enhanced by technology becomes a body-machine or as Haraway puts it, 'a hybrid of machine and organism' (Haraway, 1991, p.149). Apart from the devices that could be seen on the outside, participants in fact also mentioned technologies that are implanted within their bodies, and that, for example, enable smoother mobility of the user:

Robert (interview): With the rollator, now, I get around more easily, also because of another piece of technology that I have: the baclofen pump. I can walk better in the last 18 months but before that, I couldn't walk so well.

This discourse will be taken up again and developed further in the next chapter since, as the Stage 1 analysis developed, it became obvious that I was dealing with descriptions of complex entanglements of human-non-human assemblages and could not continue to view technology as separate from bodies. For example, in the above quote, Robert cannot be considered separate from the device and vice versa. It is the 'Robert-baclofen pump assemblage' that is producing an 'ability' ('I can'); an 'enabling' capacity to 'walk better'.

Appendix L shows the types of technologies used by the participants. In line with the SMD, which was the main conceptual tool at this stage of the analysis, I categorised the devices according to the tasks that they support the participant in doing, rather than according to the impairment that the participants have. In very broad categories, the participants mentioned technologies that help them in their mobility and transport; others that help them access and use IT equipment; and technologies that help them communicate. Participants also mentioned workplace furniture and infrastructure such as desks, chairs, doors, lifts and sanitary facilities that facilitate or hinder their participation at the place of work.

6.3 Meaning of enabling technology for the participants

When asked what the technology that they use means to them, most participants came up with very strong statements:

Avril (who does temporary work from home) (interview): eh, God knows what I would do without it, imagine, when the internet goes off, it's like the end of the

world. For us it is very important. If we do not go out for a whole week, it is not a problem, I have everything around me, I have the computer, I have the internet, the iPad, the mobile and the TV remote control. (...) What else do I need?

And from Philip's interview:

Er, from the moment I wake up until I go to sleep (laughs) (...) it is my life, it's my life; technology has changed my life (...) at work, if it weren't for the computer, I would not be here (...) I would not even have a job (...) the role of the computer in my case was to pull me out of poverty, because when you work, you are making your life better, you know what I mean? And not only yours but also that of the persons who are dependent on you to a certain extent because since she [his wife] doesn't work, you are making her life better too; that is why the role of the computer and all this technology is important.

The following is an excerpt from the first focus group (visually impaired/blind participants) in which, as in the study by Scherer (2005b, p.32), participants describe technologies as 'world openers':

Ann: For me, technology plays an important part in my life, not only for work (...) at work I cannot do without it (...) to research, to browse, to communicate, to write a letter (...)

Cecilia: if it weren't for the laptop I would not have been able to work; I could work because I could use the laptop.

Carl: For me technology is everything. If it weren't for technology, had it not advanced as much as it has done till today, I think I wouldn't have succeeded (...) it would have been much more difficult to arrive where I have arrived because it [technology] gives me great support (...) the internet has opened the world for us.

There is, therefore, an overall agreement among the participants in this study that technology has led to a major improvement in their quality of life especially in terms of employment. However, some other studies, for example Macdonald and Clayton (2013) have shown that this is not always so. 73% of the participants in their study in fact 'reported that they felt technology had not improved their life-chances in relation to employment and income' (*ibid.*, p.714). But it is difficult to determine what exactly had hindered their life-chances since disabled people function within the complex social, cultural and economic

networks that pervade them (see also for example Michailakis, 2001), with technology being only one component in the assemblages that form part of those complex networks, as shall be seen in the next chapter.

6.4 Barriers and enablers related to technology and disability at work

Various studies have highlighted the enablers and barriers that disabled people meet with to get into, or when they are at, the place of work (Roulstone, 1998; Robert and Harlan, 2006; Shier *et al.*, 2009; Jakovljevic and Buckley, 2011; Critten, 2016; Ravneberg and Söderström, 2017). The main barriers that disabled people meet with in the world of employment according to Roulstone (1998, p.12) are 'environmental, attitudinal and technical'. By recounting these individual experiences of disabled people in their relations with technology at work, I will be shining a light on the barriers because:

When people identify disability as 'our problem' they will respond to us as victims in need of 'special' treatment and requiring 'special' services. When people identify disability as a problem with the way society is organised, they will work to remove the barriers by which we have been prevented from taking part in society. (Oliver, 1990b, no pagination)

To my knowledge, this type of research that maps out barriers and enablers regarding disabled people and technology in the employment field has not been carried out in Malta to date, and thus the importance of the first stage of the current study. This chapter is also fundamental because it will be exposing the individual barriers/enablers as individual components in preparation for the next chapter in which they will be seen working together in assemblages and networks.

In the following sections, therefore, I will be delineating the major structural and attitudinal factors (barriers and enablers) that the participants indicated as impacting on their working lives on an everyday basis. The structural factors have been re-categorised under four themes: Getting in, Getting there, Staying in, and Getting on, to reflect the stages of the employment process as suggested in Sayce (2011). Sub-themes for each

category were also identified and will be presented below. These include, in the first stage (Getting in), the role of healthcare professionals with a special focus on OTs in the AT assessment and training of disabled employees, employers and service providers. The second stage (Getting there) includes transport as an important sub-theme. The third stage (Staying in) sub-themes comprise peer support networks, access in the workplace, colleagues, and workplace practices; whilst the fourth stage (Getting on) includes sub-themes revolving round issues of maintenance and repair of technology due to lack of specialised personnel, and the gradual self-determination of disabled employees as they move from one job to another. The following section will then discuss attitudes as an overall dis/abling factor that the participants indicated as being present in every stage of the employment process.

The section will therefore describe the participants' views and experiences with OTs', employers', colleagues', and their own attitudes and how these operate to help or hinder them as technology users (real or potential) in the workplace. The final section of this chapter will present other context-specific factors that (although not directly related to technology) the participants mentioned as having shaped who they are today, including who they are as Maltese disabled employees. These factors include the level of education attained; the influence of culture through the family, religion, and the small size of the island; and policy and legislation.

6.5 Theme 1: Getting In

6.5.1 The role of health and social care professionals

As discussed in the literature review chapters, health and social care professionals, and especially OTs, are the first port of call for disabled people to get into the world of employment. They are fundamental in assessing, advising and training disabled people in the area of enabling technology for work purposes (AOTA, 2017). In this sub-theme participants described their experiences with these professionals. Findings showed that participants may have had any of four types of experiences. There were those who had negative experiences, others had positive experiences whilst others had a mixture of positive and negative encounters. Others (the majority), had never had any

encounter whatsoever with OTs. These findings have important implications for health and social care policies and practices in the relationship of disabled employees with technology. As a disabled OT, I have mainly focused on this profession, because through this study I hope to also contribute towards the transformation of current practices in this/my professional field.

6.5.1.1 Left to their own devices

The majority of participants claimed that they had never met with any professional who told them which technologies would be beneficial for their needs, especially those regarding the work setting. This notwithstanding the fact that 'Occupational Therapists occupy an important position in facilitating the appropriate and sensitive specification and implementation of assistive technology' (Lansley, 2006, p.97). This also notwithstanding the fact that OTs have historically been involved in work-rehabilitation (Lysaght and Wright, 2005) and that work/productivity is considered to be one of the key domains of OT (AOTA, 2014).

Miriam (FG 3): Whereas abroad for example there is an entity that comes to see, comes to assess you (at work) (...) In Malta this is not yet available; up to now, in none of the jobs that I had, (...) none were open for me to say, 'Listen, I need this and I need that' but this ideally should be done in every place of work. I mean my first job was in a government department, and nothing (...) you can imagine how much it is to be found in the private sector! I think it is important that you have an OT who comes and assesses and sees that the environment is suitable, who makes a list of the things you need; because, if it is the OT who recommends them you are not going to feel as if you need to beg so that they give you a laptop or a telephone system with a headset for example. It is structured, you know you are going to sit down properly, you know you are going to be given these things and they're listed there and you don't have to stay asking for them (...) begging, cos that's the word.

Other participants mentioned that professionals' intervention in their lives had only included the domestic sphere:

Daphne (interview): No, the only time that I ever met with an OT was when I had had a hip replacement and he came to my house and he measured the

height of the toilet [chuckle] and he measured the height of the stair treads and the heights of the bed and things like that (...) but I haven't really ever had anybody advise me about assistive technology at the place of work. No [with emphasis], no, no.

This is also corroborated by OT literature. For example, in a review of research regarding OT interventions addressing the physical environment for a variety of populations (Stark *et al.*, 2015, pp.414-417), the vast majority of the studies involved home modifications with none involving the worksite. Finkelstein (1999) proposed that health and social care professionals should make a radical shift which does not only involve a change in name but also a stand of allegiance with the people they 'care' for. He recommended that these professionals should change from being 'Professionals Allied to Medicine' to 'Professionals Allied to the Community' (pp.1-2). When applying this to Malta, it is immediately clear that one of the main reasons why professionals are so 'absent' in this field is that they continue to deliver their services from hospitals or clinics rather than in workplaces. They are not yet sufficiently present in the community. The networks of professional practice need to expand to reach the environments where disabled people are enacting their daily lives and not just their homes.

Another evidence that this is needed is that professionals continue to focus their intervention strictly on the person's impairment:

Tonia (interview): I used to go to OT because of the condition of my arm (...) they move it for you and they give you suggestions on how you can do training and exercises to improve it, and so on.

Others commented on the fact that doctors, and medical consultants especially, had only spoken to them about their medical condition, as this excerpt from the first focus group shows:

Carl: the only professionals I encountered were the ophthalmic consultants (...) who, from a medical point of view are ok, but from the social assistance perspective they make you despair because they depict a world that has ended for you forever.

Ann: It is as if our professionals are not informed about this technology because they never tell you (...) never (...) not even that talking watches exist, which is the smallest thing that exists (...) nothing.

Researcher: so you had to discover this equipment by yourselves?

Elias: Yes, but the thing is, if you go to hospital with a fractured leg, they give you a walking stick; if your back hurts, they give you a wheelchair (...) but have they ever given anyone a white stick because he is blind?

Carl: Even worse, they threw me into a sea of despair (...)

Cecilia: Because it is not his line (...) he [consultant] only tells you what is in his line of work.

These responses recall Oliver's (1990a) claims when describing the medical model, that the medical and all other professions have failed to involve disabled people in a meaningful way except as passive objects of intervention, treatment and rehabilitation. Similarly, a review of international peer-reviewed OT journals (Ivanoff *et al.*, 2006, p.115) indicated that especially in AT research, therapists are still mainly 'focusing on the individual rehabilitation perspective, generally characterised by the medical paradigm'. The authors, in fact, recommend the need for more research that adopts a societal level perspective rather than an individual level one. These findings are also consistent with research carried out by Jakobsen (2004) in which three Norwegian, (now unemployed), disabled women were interviewed about the barriers and enablers they met with when they were employed. They criticised healthcare professionals for focusing their interventions on their impairments rather than advising and supporting them on a practical level in their daily life management as disabled employees.

So how did participants react in the absence of this type of professional support? Findings showed that participants turned either to technology itself through the internet, or to their peers:

Researcher: have you ever had contact with OTs for this technology, to get information about it I mean?

Gertrude: no, the information I got was through the internet or through Lionel.

Is there therefore still a role for professionals in this field? Professional intervention in the form of assessment or provision of AT and other

accommodations is still considered necessary, including in the world of work (Roulstone, 2016). The role of these professionals is to 'teach people to choose and use their tools and technology, manage the assistance received from a person or service animal, and foster problem-solving skills' (Litvak and Enders, 2001, p. 726). Participants in the current study however reported a lack of such professional interventions. But even when professionals were present, participants identified important barriers such as their lack of training in issues related to disability, and lack of training in issues related to AT. This results in lack of information both for the service providers and for the service users.

6.5.1.2 Lack of disability equality training

Philip (interview): they are not informed about disability, so then, with all due respect to the people we call professionals [laughing], they have that area missing.

Miriam (interview): (...) there are also particular influences when it comes to professionals (...) there is the medical model that we cannot escape from (...) I'm sure it is popular also during their training and from my experience it is very very difficult that certain professionals get prised off from it (...) it's going to be very difficult for one session of disability equality training to turn them away from it [the medical model].

Miriam is referring to the one hour of disability equality training that medical students receive in the final year of their course, and which, according to her, is insufficient to change their mindsets to viewing disability in a more socially relational manner. In a local study, deBono (2015) also suggested that healthcare professionals need to learn about the real world that disabled persons live in, to realise how different this is from the experience they go through during the rehabilitation process. This lack of awareness among professionals is especially prevalent with regard to disabled people with sensory impairments. Recent OT literature is in fact calling for this topic to be included in OT curricula (Wittich *et al.*, 2017).

As health professionals are only being traditionally trained according to the medical model, DS scholars recommend that they receive disability equality training as an essential part of their academic training (French and Swain,

2008). Disability equality training enables trainees to identify and address discriminatory forms of practice towards disabled people which prevent disabled people from gaining equality and achieving full participation in society (Gillespie-Sells and Campbell, 1991). It would also be commendable that education and training be based on the principles enshrined in the CRPD (2007) including 'empowerment', participation and full enjoyment of human rights. Kielhofner (2005), an OT scholar, suggests that professionals should reflect on the messages coming from DS especially with regard to their deeply embedded attitudes towards disabled people and that the best place to start with this reflection is in the OT educational programmes (Block *et al.*, 2005; Gitlow and Flecky, 2005). Block *et al.* (2005) further recommend that OT students be encouraged to carry out volunteer work with disability NGOs/activists and other entities in the community so that they become aware of the value of the relationship between disabled people and healthcare professionals.

Gitlow and Flecky (2005) report on the positive outcomes of a service-learning course/experience of OT students with disabled people in the community. The authors found that the students understood the concept of disability beyond common stereotypes that are solely impairment-based and valued the experience of being mentored by disabled people themselves. They also started to appreciate the role of the occupational therapist as an advocate with disabled people on issues such as accessibility in the community. Such experiences are recommendable and should be included in OT undergraduate programmes in order to nurture future therapists in the awareness of socially constructed barriers and their role in disabling people's lives.

6.5.1.3 Lack of training in AT

Other participants were specific about professionals' lack of training and knowledge of AT:

Researcher: now who did that for you [a voice amplifier attached to participant's wheelchair]? Was it a specialised technician? Or had you spoken to an Occupational Therapist who told you what you could do?

Norman (interview): no, I tried with them [OTs] but they did not come up with any solutions. I almost knew what I had to do. I knew it was possible, and then I

spoke to someone and he spoke to someone else who works in these things and then he came to see the wheelchair and what I needed and, although he took a long time, he finally came up with a solution.

Avril (interview): whether we are speaking about social workers, or about OTs, I feel it is as if you are telling them what they have to do rather than them coming up with a solution (...) like last time I went to see if they [at the Independent Living Centre] had a wheelchair that can be controlled with my chin, you know I ended up telling her [the therapist] myself how it works? (...) it shouldn't be like that (...) they don't know how to work the equipment they have there, they are not trained. (...) OTs do not have a lot of exposure to different equipment (...) what bugs me the most is that you have to discover everything by yourself (...) that really hurts; it really bugs me (...) eh, I think, in Malta, the number of people they [OTs] see is too small (...) they don't have enough experience.

Scherer (2005b) suggests that since the AT field is relatively new and the credentialing of AT practitioners is even more recent, training and continuing professional development in the area is imperative. Furthermore, Gamble *et al.* (2006) propose that increased training for professionals in the field of AT is likely to lead to increased opportunities for employment for service users.

But if they are not present on the field, how are OTs 'enabling' disabled people in this area? Petty (2003, p.282) asserts that:

technology is not widely discussed in occupational therapy literature as a treatment modality to improve occupational performance, yet it is evolving into an obvious option of environmental accommodation in today's increasingly technological world. (...) Occupational Therapists do not want to feel incompetent or unable to properly support clients, thus many may avoid the area all together.

Long *et al.*, (2007) and Orton (2008) claim that lack of awareness on the part of health care professionals often creates barriers to clients getting the technology they need to facilitate their participation in meaningful occupations. Similarly, Herz (cited in AOTA, 2013, no pagination) believes that OTs are not using technology to its full potential. 'Don't be afraid of technology' he says,

'understand that there is so much it has to offer, and we haven't really touched the surface yet'.

While 84% of the respondents in a questionnaire among Irish community OTs said that it is the role of the OT to assess for and prescribe AT, only 34% claimed that they are able to do so (Verdonck *et al.*, 2011). But given that 'the level of knowledge of the person facilitating the provision and matching of AT is potentially one of the most facilitating access factors' (Michaels *et al.*, 2002, p.13), OTs and all professionals involved need to keep up to date all the time not only regarding the prevalence of such technology but also about the complexity of any new technologies (AOTA, 2016; Gamble *et al.*, 2006). The fact that technology is always changing, and at a fast pace too, has implications for OT practice. OTs working in this field will need to find new ways how to use new technologies in their practice because technology can assist and enhance what OT practitioners are already doing (Herz, 2013). Already in 1998, Kanny and Anson were claiming that OTs have moved from prescribing adaptive equipment to including high technologies to help people with disabilities achieve functional performance in all daily life activities. And yet, 20 years later, disabled people are claiming they do not find much support from these professionals.

During both the focus groups and the individual interviews, participants in the current study showed their frustration and disappointment as they felt cheated and let down by the very same people and services that should have been there to support them. This, they pointed out, could also be due to the lack of material or human resources.

6.5.1.4 Lack of resources

The resources that participants mentioned included lack of choice of different devices, lack of funds to purchase equipment for trialling purposes, and lack of personnel:

Miriam (FG3): It's a pity because sometimes they are things that do not cost much; because the argument is always, you know, that 'we [OTs] need more funds for that [AT]', that 'the budget is not enough'; but sometimes you do not need huge sums of money.

Harold (interview): at the moment I am waiting for a reply from a [Mobility] Centre in England; er the OT who works here suggested it (...) because it seems they have a lot of adaptations that we do not have in Malta, so I wish to go and try there.

With regard to lack of personnel, it is to be noted that at the time of the fieldwork for this study there were only two part-time OTs working with ETC to assess disabled people who were looking for a job, with OTs based in hospitals (acute and rehabilitation) giving recommendations regarding workplace accommodations (including AT-related advice) as the need arises. Since that time, in 2015, a full-time OT has been employed with Jobsplus to oversee the assessment/advice of disabled job-seekers.

Although this set-up is not sufficient to cover the needs of the whole of the island, it is a step in the right direction. This (global) lack of professionals working in the field of AT was reported also in other literature. For example, Gupta *et al.* (2011) report that there are huge shortages of human resources in the AT field, for example, over 75% of low-income countries have no prosthetic and orthotics training programmes. Countries with the highest incidence of disability-related health conditions tend to be those with the lowest supply of health professionals skilled in the provision of AT. According to the World Report on Disability (WHO, 2011) there are 2 OTs per 10,000 population in Malta, which when compared to other countries is relatively low, with 11 for Denmark (being the highest).

Therefore, the Maltese scenario is comparable to what is happening in many countries which report 'inadequate, unstable or non-existent supplies of rehabilitation professionals' (WHO, 2011, p.108). Another reason for professionals' insufficient services may be the increasing demands on them from the institutional delivery systems in which their practices are embedded and on which they depend (Wilson, 2000).

Some of the participants, however, did have more positive experiences with OTs, such as when Harold needed a new wheelchair and when Tonia changed jobs and found the OT's recommendations on the accommodations she needed at work 'very helpful'.

6.5.2 Employers

Following their encounter (or not) with professionals, disabled people in search of a job would then meet with prospective employers. Several participants mentioned how in principle all employers agree about having disabled people working with them, but then, in practice, they find it difficult to implement what is necessary to support them so that they can work on a level playing field with their colleagues and retain their job.

One reason for this difficulty given by the participants was the lack of information on the part of employers as to how best they could support their disabled employees. At times employers would rely on their goodwill but this, more often than not, did not include consulting the disabled employee.

Daphne's experience below (the first one) is a classic example:

Researcher: In your various jobs, did you ever get employers asking you if you needed any equipment (...) in the focus group you mentioned one experience about the small laptop (...)

Daphne (interview): yes [laughing] that's right, that was very funny because it [small laptop] was useless, it was so small (...) it showed that in spite of my having been there 6 weeks, successfully carrying around a full-size laptop, my boss was still thinking that this must be a problem for me and he never asked but simply presented me with this ridiculous little tiny laptop and said, 'I found this in head office and I thought of you straight away because it will be so much easier (...)'. In one company, the first company that I worked in in Malta, they actually had somebody come in who measured me and told the boss what sort of chair would be best for me. (**Researcher:** a private company?) yes, and then he went round every other member of staff within the office telling them what sort of amendments they should make to their chairs and the boss was very receptive to this; he actually bought a whole office full of new chairs so that people would be sitting in something that was appropriate for their body shape and size which made me feel great because it wasn't just me that I had been made to feel like he's coming in to deal with me because I am an issue. (...) He was very good.

This positive experience with the employer providing reasonable accommodation for all, not just for the disabled employee, is a good-practice

experience which should be the norm and not the exception. It seems however, that until now, it still depends on the benevolence of the individual employer. In this case the presence of a disabled person at the place of work brought about positive change for the whole team at work, again indicating an interdependent relationship between co-workers, whether they are disabled or not.

Unfortunately, though, some participants reported very negative experiences with their employers, such as Tonia's below:

Tonia (FG 3): I think there needs to be more information for employers, because as soon as they see you (...) I used to work at [name of place] but as soon as they realised that I could not use one of my arms, that's it, they found some excuse to fire me (...) They just decided without consulting with me whether I needed any support; they just made a decision based on what they saw.

Participants indicated that some employers are generally reactive rather than proactive and do not go beyond their stereotypes and misconceptions in order to accommodate and include disabled employees. Daphne explained this well:

Daphne (FG 3): There is this reluctance in employing people with disabilities because they think, 'I am going to have to buy half a ton of specialised software so that this person can do the job properly. Do I really want that sort of hassle?' (...) there's a perception that you are going to cost more to an employer.

6.5.3 Enabling technology service provision

So from where did participants obtain the technologies they needed for work? In Malta, AT provision services depend partly on the national budget and partly on charities. This brings with it its very own set of barriers which are largely due to the fragmentation of these services, so much so that many a time disabled people end up buying the technologies themselves. Additional major problems that the participants found with regard to service providers, such as technology suppliers, varied from lack of expertise in specific technologies, to the small size of the market. This latter issue means that suppliers do not invest in a wide array of devices so that one can try out the devices before they are bought. This results in lack of AT choice for the users.

This problem is even more real for service users in Gozo, Malta's smaller sister island. The biggest problem is however the expense of such devices (see also Harris, 2010) and the fact that prices are inflated because the suppliers know that clients will be getting subsidies from charities. Another barrier is the length of time it takes to obtain the final product with a common attitude on the clients' part being, 'What can you do? We only have these shops to buy from (...)' (Avril). Participants also mentioned the fact that suppliers are only available until they sell the product to the user, then they are not as available when it comes to maintenance and repair of the technologies purchased. Difficulties related to lack of specialised support were also experienced by participants in other studies as in Driscoll *et al.* (2001), Seymour (2005) and Hodge (2007). These studies inferred that many a time this scarcity of support was leading to the abandonment of the technology and to difficulties in retaining a job.

With some participants buying technology over the internet, there is an added difficulty. Lionel, for example, mentioned the purchasing of audiology devices over the internet, even though the users know that they would probably have to throw them away if they develop some fault because they would be more expensive to send back for repair.

Ann (FG 1): (...) and another thing, you buy without having ever tried it (...). What you buy is not always accurate, especially when it is still a new product (...)

Carl (FG 1): (...) yes, and the advert shows one thing, then when you buy it, it's another thing.

And from Miriam's interview:

Many a time, and unfortunately this really exists, there is a monopoly on these things, er, like there is on medicines probably and other things. They know they will make a difference to someone's life and yet they still do it because of the money (...) and the same thing happens with the suppliers in Malta when they get to know that you have applied with KNPD or with Malta Community Chest Fund. In fact they ask you, 'have you applied for funding?' And I am sure they do it to mark up the price.

The frustration of the participants was felt in their 'It's not fair!' comments, mainly because they know about the abuse of the system of funding by the technology suppliers. Therefore, even if service users can revert to Technology Funding Agencies such as KNPD, *Agenzija Sapport* and Malta Community Chest Fund, they are still being faced with various dilemmas. Although many of them are aware of where to get funds from, they still complain about the amount of paperwork involved (as in Harris and Bamford, 2001), the length of time it takes, the invasion of privacy regarding one's earnings, and the small amount of funds given when compared to other countries. These findings are exposing a network of factors (policies, practices, feelings), that complicate the act of an individual accessing a piece of technology. These complex 'entanglements' will be analysed in further detail in the next chapter.

Another factor that participants mentioned, and that further complicates AT provision, was that not all technology is considered in the same way by funding agencies. There are different criteria for the funding of medical devices or equipment that is given out from hospital and that which falls under the social welfare entities' responsibility. Some pointed out that the quality of, for example, hearing aids that are given out for free from the health services, is inferior and therefore they prefer to buy their own privately. Others said (rather indignantly) that the state is willing to pay for very expensive interventions, such as the cochlear implant surgery, but then it imposes restrictions on the funding of appropriate hearing aids. There are also different criteria for assistance regarding technology that has to do with education and that which has to do with employment. This results in a great deal of fragmentation, with disabled people having to shop around for different services that only partially see to their needs. Additionally, there is no financial assistance for equipment which is considered to be mainstream but which is still necessary for the user because of impairment-related consequences, e.g. air conditioning for a user with multiple sclerosis (Robert).

Due to the restrictions above, some of the participants think that the funds available would be better used for those disabled people who do not work. Those who cannot afford to buy the needed technology, however, have no choice but to apply for assistance. Many resign themselves and wait,

however long it takes, to receive the funds, otherwise they would end up without the very much needed equipment:

Researcher: and we spoke, Elias, about how in order to buy these things we need to go and ask for funds from Malta Community Chest Fund. What do you think about this?

Elias (interview): you have to apply to tell them what you are going to buy; then a month or two passes whilst they process your request; in the meantime the prices change, because you need to give a quotation and you have to tell them about your earnings and all these things that are so embarrassing!

Researcher: so you get discouraged about applying?

Elias: yes, you would get discouraged if you can afford it, but then if you can afford it, you wouldn't apply in the first place.

Although 'grateful' for the partial funding of the AT they need, participants clearly emphasised the 'charity' mentality that this type of service provision brings with it:

Cecilia (interview): it's not because of pride, but yes, the fact that you have to stay asking, for everything you have to beg, that really hurts.

Gertrude (interview): no, no, no, they [the funding agencies] do not treat everyone equally; so I decided that if I need to buy something, I will buy it myself and not ask anyone for help basically (...) If I can afford to buy it, I buy it, if not, I save up for it and then buy it, but this thing - as if you are begging for charity [shudders] - I hate it!

Miriam (interview): but that comes from the medical model, because if something is medical ok (...) for example I have a lot of scars and they had told me, 'after two years, if you want, you can come and we will sort them out for you, obviously for free at hospital', so for those it's ok and then for a pair of legs [prostheses] - which, had I not had them I would not be working here, I would not be doing this interview with you, I would not have continued my studies - then for something like that, I have to go and beg.

The quotes above indicate that access to this technology is not only about its enabling function but, because it is often tied to financial donations, it is producing consequences on the users' emotions. Feelings/words like 'embarrassing', 'hate', 'beg', become live components of the disabled person-

technology-charity assemblage, as shall be further elaborated in the next chapter.

Some participants also felt betrayed on account of the discourse around independent living and the present services (see for example Solstad Vedeler and Mossige, 2010); betrayed by the mismatch between the rhetoric that goes around and what is done in practice:

Researcher: so do you think there is sufficient financial aid?

Harold (interview): Help there is, but listen; I think rather than there is not enough financial assistance we should be doing more effort to include disabled people into the world of work. (...) It is useless that you tell me that I have a right to choose. True, but how limited is that choice when I don't have sufficient finances?

6.5.4 Technology training agencies

Another important barrier mentioned was that regarding the lack of specialised AT training agencies. Some participants mentioned that these agencies offered them what they had, rather than what they needed. This is further complicated by the fact that, because in Malta the market is small, the local trainers do not have constant experience in a wide variety of technology and therefore they tend to forget the training they had initially received. Many participants in fact mentioned that they make use of a whole network of people such as family members and their peers and not just professional technicians.

Carl (FG 1): I don't know what training they [service providers] receive (...)

Elias (FG 1): In Gozo there is lack of training and support (...) in Malta there is a bit but in Gozo it does not exist (...)

Cecilia (FG 1): First and foremost you have to know about them, these devices; then you have to know how to use them; there have to be people who train us in using them; and then you have to have the money to buy them.

Ann (FG 1): Another comment on training: (...) it was I who found Zoom Text, they [service providers] did not even suggest it to me. And this did not only happen to me, there were other disabled people who shared this same experience and they told me the same thing (...) They tell everyone the same thing, whether you need it or not. It isn't easy for them to cater for all types of impairment.

From these comments it can be affirmed that technological training and support which could lead towards accessing and retaining a job is still fraught with challenges. As has been seen throughout this first theme, these challenges do not only have an influence on the individual with an impairment but because s/he has to relate to many others in the employment process, such as professionals and employers, these too become affected and in turn the whole network is disabled.

6.6 Theme 2: Getting There

6.6.1 Transport

Although transportation technology was not part of the enabling technology that the participants use to carry out their job (since none are delivery persons or have similar jobs where transportation/driving is the primary tool for the job), the transport sub-theme was raised by the majority of the respondents and considered to be a fundamental dis/abling factor in the access to the workplace. This indicates that there are different layers in the network surrounding the workplace. With public transport not considered to be very accessible and reliable, most participants rely on their parents/relatives or the subsidised transport available for disabled people to take them to work. However, they complained about some of the latter drivers' attitudes towards them. On the other hand, other participants feel lucky that they can drive themselves to work and blame this inability in others on parents' overprotective upbringing of their disabled children:

Daphne (interview): I think in Malta where you have parents who won't let disabled children get on buses even when they are in their thirties (...) it limits a disabled person's ability to be independent because your independence I think stems from the ability to be autonomous and able to do whatever you like, whenever you like, because you want to. And I think transport is absolutely fundamental to that.

And the following barrier, concerns participants who go to work by public transport:

Carl (FG 1): In Malta the biggest problem is mobility. (...) I have a huge problem (...) with technology today there are a lot of solutions, but in Malta the biggest problem is mobility and transport. That is my biggest problem as a disabled person (...) and another thing, I think none of the bus drivers know that if they see a person with a white stick on the bus stop, that is a blind person and they have to stop, I don't think any bus driver knows, I don't know what training they receive (...) I put my white stick right in front of me so that they [bus drivers] can see it (...) because otherwise they don't know eh?

But even when the infrastructure is in place:

Philip (interview): For example, with regard to transport, there we need to work too. One of the drawbacks that I find, I go to Valletta to the bus terminus and from Bay 1 the bus has moved to bay 4 and from bay 4 (...) they do not keep the same position; if there is something in place, for blind people you have to stick to it, otherwise we are left stranded. When they arrive, they do not announce that bus number 24 has arrived so I am left there on the bus stop staring and I have to ask all the time. What can I do? At least now, once you're on the bus, they announce the next bus stop, but even that is not reliable, sometimes they do it sometimes they don't (...) Now I don't use public transport to come to work anymore, now I use the subsidised transport. Yes, obviously transport is very very important for me because to keep a job you have to be always on time.

This transport barrier is common to many other countries, as in Charlton (2000, p.105), 'In the US and Europe, transportation has been a long-standing problem.' As one of the participants in that study claimed:

There has been nothing in the way of transportation options here. It's dreadful. People are stuck or dependent on others to take them around. Indeed, I think transportation is the key link to all other aspects of life. It's crucial. (*ibid.*, p.105).

Other studies such as Naraine and Lindsay (2011) and Ystmark Bjerkan *et al.* (2013) also mention transportation as being a major barrier to disabled people's access to work and work-related activities. Participants in these studies claimed that many a time it shaped the quality of their working days and at times even determined whether they kept their job or not.

Participants in the current study also implied that physical and sensory access on buses is not sufficient or reliable. They indicated that there are different layers regarding what constitutes barriers, for example, bus drivers are further out in the chain of linkages but they are very important for a network to work or not. These outer layers of the network also need to be knowledgeable regarding disability issues, for the workplace to be fully inclusive. The enabling links and supporting network are seen to extend much further than the actual place of work. It is not sufficient to have the infrastructure in place; practices also need to be reliable. It was indicated that even if the technology/non-human support is there, it has to be used well, otherwise the whole system falls apart. Findings in this stage 1 analysis therefore strongly signpost that individual components, such as the disabled employee or the technology that s/he uses at work, do not exist in a vacuum. Since they are clearly linked to other components in the assemblage and then in turn with other assemblages in the network, in a state of relationality and interdependence, the need to re-think how barriers are viewed is being highlighted.

6.7 Theme 3: Staying in

6.7.1 Peer support network

Lack of information about AT and other accommodations has been reported as a major barrier in various studies, such as, Strobel *et al.* (2006), Ravneberg (2009), and Näslund and Qais al Said (2017). For participants in these studies, this lack was often a source of frustration because they had to look for the information themselves. The majority of the participants in the current study also spoke of this barrier. They reported that they bridged the existing gap that is created by lack of information about enabling technology, through their peers and 'grapevine knowledge' (Harris and Bamford, 2001, p.973).

Carl (FG 1): The greatest help I found (...) the most effective system in Malta (...) is to share information amongst ourselves. That is what I found, 'I am using this, see whether you can use it too' (...) that is the greatest help I found (...) one way or another we have built this network to help each other.

Elias (FG 1): (...) there are a lot of services (...) in Malta they are in one centre; in Gozo we do not have anything, you have to go to Malta. But then we help each other. We share and help each other [others in group all nodding in agreement]. For example, I had a problem with my mobile so I gave it to Ann [FG 1] to see what she could do about it; my laptop yesterday was at Carl's for another problem (...) they [at the NGO] gave me all the information I know about the guide dog. With regard to the laptop, I use Carl's system, I did not buy it because it cost a lot, he gave me his.

Researcher: How did you learn to use this technology?

Terence (FG 2): Standard things like the mobile, email and internet, we learnt from each other, we help each other, we understand each other, how to use a video call for example. And we help each other. Even the people around us who can hear, sometimes they help us, and even we Deaf amongst ourselves we help each other.

Robert (interview): er I had asked people who already use it [technology] for advice, like when I wanted to buy the wheelchair, I went to another wheelchair user who uses a powered chair; because you have to see these things in practice, so it is very important to get the experience from someone who already uses it.

Researcher: so who introduced you to this technology?

Philip (interview): Lionel, Lionel. He gave me the key and then as I said earlier I love technology, but he gave me the key and then I carried on. I searched, I experimented on the internet and I asked other blind people what they use and what they do, then I did my thinking and took my decisions.

Similarly, participants in, for example, de Jonge and Rodger (2006, p.85) stressed the importance of the peer networks, and considered them indispensable supports, 'Well, I have a couple of very computer-literate friends who I can call on occasionally to give me a hand, other than that it's sink'. Pols (2011, 2014), through her studies with patients with chronic obstructive pulmonary disease signposts these peer support initiatives as a road that 'opens up for a new politics of social inclusion' (Pols, 2011, p.189).

However, as Miriam and others pointed out in the current study, this peer support is still on an informal basis in Malta and they recommended that

something is done to place it on a more formal level. One way of doing this is to bring together disabled people's knowledgeabilities with health and social care professionals' knowledge in what Callon (2003, p.59) called 'hybrid forums'. Here, disabled people and professionals collectively form assemblages of knowledge that are founded on both 'scientific' and 'experiential expertise'. In this way, as Galis (2011, p.834) suggested, they would be able to 'collectively modify the enactment of disability', and, in the context of this study I would add, the modification of the enactment of dis/ability in technology-work assemblages.

6.7.2 Physical/sensory access at place of work

Environmental accessibility at the workplace was acknowledged by most participants as an essential element for them to be able to retain a job. They alleged that accessibility can be enhanced (or hindered) by the presence (or absence) of assistive technologies, as these quotes show:

Anthony (FG 2): I told them [his managers], 'I cannot hear the alarm. You should put up something visual so that I can see it (...) it is not clearly signed where you have to exit from if there is a fire; and then if there are clear signs, this is not only for myself but for everybody, so that it is clear where we have to exit if there is a fire.'

William (FG 2): I don't know why but many places of work put up a ramp, they have braille signs in the lift, but you never find anything for the deaf; I don't think that is fair! (...) I do not use the lift anyway, because I don't like to use it on my own because if there is a problem and I have to use the emergency call, I cannot communicate.

William here is in consonance with Imrie (2002, p.1) when he claims:

Most designers (...) conceive of disabled bodies as mobility or ambulant-impaired, with little perception of the wider range of physical and/or mental impairments which need to be catered for in producing inclusive design. Where designers do produce design for disabled people's needs it tends to be for wheelchair users.

These experiences can also be summarised by the feeling expressed by a participant in the study by McMillen and Söderberg (2002, p.180) when she

said, 'The lack of access (...) feels like being very thirsty but having your hands bound and therefore not being able to reach the cold glass of water that is put in front of you'. Accessibility in the workplace, however, can be made possible not only through the provision of technology for the individual disabled employee, but also through the adaptation/arrangement of the wider surroundings, as some of the participants recounted:

Harold (FG 3): For me, a door with sensors would be ideal, but obviously these cost a lot of money. (...) if you are using a powered wheelchair, in one hand you have the joystick and in the other you have other things like files for example and it is not easy to open the door; if it opens automatically then all you have to do is approach it and then it opens and in you go.

And from Miriam's interview:

Miriam: obviously the set-up is important because if you want to give your maximum then I think it is very important, for example, that you have everything close to you; sometimes personally even to get up to get the photocopies from the photocopier, if it is a day when I have a sore in my leg because of the prosthesis and my leg is hurting I find it a bit hard; so ideally even these machines should be as close as possible; and the chair obviously helps because if it is a short distance, you can do it with a wheeled office chair, so yes, I do think it is important to have everything within easy reach in your working space.

The 'sore' and the 'hurting' are not in themselves the 'disabling' barriers, but, will be viewed in the next chapter, as components of the Miriam-work assemblage that could be 'abled' or 'disabled' depending on the specific arrangement of machines and furniture in her office. Participants' stories are thus pointing towards a more transient, interdependent nature of the relation of bodies (including impairment effects), technologies and spaces than the fixed, immovable picture that 'barriers' portray.

6.7.3 Colleagues

Participants also referred to colleagues as helping or hindering their lives at work. Roulstone (1998) reports similar findings regarding his participants' work colleagues, for example, being suspicious, jealous or curious about their

disabled colleagues who used AT. Others pre-empt possible negative reactions from their colleagues by involving them, as with Ann below:

Ann (interview): yes, yes, I always do that. (...) I show them and I tell them how I do everything for many reasons, why? Because when people know you have a disability they almost don't let you do anything; so when they see you are doing something they say, 'let me do it for you', so I show them I can do this, I can do that, so that they know my capacities and my limitations because that is important. How do they take it? Most of them are amazed because for the first time they are hearing a computer talk, or a speaking mobile; they are impressed because they do not know that these things even exist, so normally with new colleagues I spend a lot of time discussing things to show them also the importance of me having to have everything organised and knowing where everything is. So it is important that if someone takes something, from somewhere, a pair of scissors, a pen whatever, it is important to put it back from where they took it.

Talking about his colleagues' frustrations when he cannot do something at work, Carl (FG 1) said:

You don't only have pressure due to accessibility problems, you also have the pressure of work, of deadlines, the important thing is that you reach your deadlines. The fact that I have this document that I cannot read is not their [colleagues'] business (...) if I don't do it, someone else has to do it, because work has to be done (...) they [colleagues] also feel the pressure that I am indirectly putting on them because I am not reaching my deadlines.

This feeling of being a burden on others was also reported in Jakobsen (2009, p.123) where disabled employees would wait for as long as possible before requesting accommodations (such as doing slower paced work tasks), in order not to 'strain your comrades at work'.

But colleagues could also prove to be an enabling factor at work. In fact, at another point of the conversation, Carl (FG 1) commented,

In my office there are three of us in the same office which is open plan. We are three and we work without absolutely any problems (...) sometimes they are interested, they are curious about how my technology works (...) Especially our secretary, poor girl, she is very patient with me (...) I am lucky because my

secretary has managed to understand the way I work (...) I give her credit for this, because this is not a secretary's work.

In Focus Group 2, Deaf participants explained how they use their resourcefulness to propose strategies to their colleagues so that they can all work better together:

Terence (FG 2): At work we have a lift and it has stopped quite a number of times, then I had an idea (...) we agreed that when I who am Deaf press the alarm button three times then they know it is me inside (...) we agreed about this with my colleagues, but other employees who are not deaf press once and it rings only once, or they can phone of course we agreed and I told them all and they said, 'yes, that is a good idea'.

Anthony (FG 2): [at work] there are a lot of people who know how to communicate with me in sign language, which is great, it is good for me (...) there is a girl who works with me who had done the same course at [name of college] and she is working there and she knows a lot of sign language and she really helps me (...) sometimes it is impossible for me to book a sign language interpreter in such a short time so she comes with me for the meeting and then I can understand.

At other times, though, participants felt they would be judged negatively by their colleagues when requesting accommodations and AT:

Researcher: but how did you feel with your colleagues because of having to ask for accommodations?

Miriam (interview): yes, when I had to ask for accommodations (...) So for the others they gave them a computer because that is what they needed; but when you are on the same level as your colleagues and you need to ask for something different; my colleagues may think, 'Who does she think she is asking for a laptop?' because laptops are only given to managers you know. You know there might be that perception. Or, for example, having to ask for an executive chair because it is more comfortable for me, I am embarrassed to ask for one because they say, 'she has just started, who does she think she is?' But my colleagues did not make a problem of this; I think the major problem is the employer or whoever is representing the employer, like the HR manager.

From the data above, and data from other studies, for example, Wilson-Kovacs *et al.* (2008) and Jakobsen (2009), one gets the feeling of a mixture of

relationships varying from moments of diffidence, animosity, curiosity and at times frustration, to moments of friendship, solidarity and camaraderie. At other times, colleagues are filling in the gaps where the services or the practices are not sufficiently efficient. In these situations, it is not technology but the disabled employee-colleague relationship that is a potential/real capacities-producing alliance that would help (or otherwise) the worker with impairment to stay in the job.

6.7.4 Workplace practices

Workplace practices were also considered by the participants to mediate the functionality of disabled employees:

In Focus Group 2:

Terence: Through the WhatsApp I can send videos to those who cannot communicate through writing, but at work they do not allow the use of Internet; I have to use my own internet; a short while ago I asked whether I can use their internet but they thought that it would interfere with my work; that I would use it for Facebook etc.

And in Focus Group 1:

Carl: (...) or sometimes when they update the office software or Windows update then I get lots of new features and I have to see how I am going to work with them, because if you are a disabled employee who is working in an environment where the majority are non-disabled, you have to adapt to them and not them to you (...)

Researcher: So what do you do if you have a problem at work with this technology?

Carl: Today we have an advantage; if I have a problem on my iPhone or on Window Eyes? I open this [tapping on the laptop he was holding], I open Google, I write what the problem is, and in no time at all you get 10-20 different solutions.

So when they are allowed to use internet at work, disabled employees use it as a link to solve technical difficulties and not necessarily to chat on Facebook as

assumed by their managers. For all, but especially for disabled employees, the internet serves as a link that opens up many other links in their network.

Participants in other research such as Roulstone (1998) and Abbott (2010) agree with Carl, but others, for example Goggin and Newell (2003) and Macdonald and Clayton (2013) do not. They imply that because of the digital divide, digital technologies have created new disabling barriers. Most participants in the current study in fact complained of, for example, the expense of such rapidly-developing technologies being a major deterrent for either asking their employer or purchasing them themselves. However, others, for example, Lupton and Seymour (2000) and Michailakis (2001) found that notwithstanding the challenges, the benefits of new/digital technologies were much greater than the barriers.

6.8 Theme 4: Getting On

In order for them to move on in their jobs, participants indicated that more often than not, they have to take the initiative to find the support that they need. Some also suggested ways in which these initiatives and strategies could be shared with other disabled employees:

Researcher: Other participants told me that there are not enough technicians who can deal with these things so we always have to ask each other if we want to solve our problems.

Philip (interview): I don't see that as a negative thing. If you ask the right person, they can really help you. Because you are asking a person who has been through it; now the technician ok he can repair, repair the device and leave (...) so it is a good idea to explore how as disabled people we can have a website maybe regarding technology, what there is on the market, what type of equipment and how you can contact people and what the drawbacks are, I think that would be interesting.

These kinds of strategies were also discussed in Pols (2014, p.79), in which patients with chronic obstructive pulmonary disease had formed a 'caring community' via webcams that were placed in their homes following discharge from the clinic. Technology here enabled these patients to share experiences and 'homemade' practices that give life to what Pols calls 'messy knowledge'

(*ibid.*, p.75). Such knowledge has multiple sources including information they obtained from the medical field, techniques they have developed in their everyday life, their own values, and various devices that they find helpful 'to shape their daily lives with disease in a good way' (*ibid.*, p.75). Philip's recommendation above, therefore, could be useful in a context that is lacking specialised AT support and in which disabled employees could find a range of alternative solutions to their problems.

Technology and its related problems are not the only challenges that hinder disabled employees from 'getting on'. Unfortunately, because of the many attitudinal barriers they face, not many participants were promoted or moved to better jobs:

Researcher: so you remained where you were? Even when she left? [referring to an inconsiderate manager who had been a barrier to the participant being promoted to a post which was more in line with her grade]

Gertrude (interview): yes, yes. With regard to work I am at an Executive Officer grade but I still work as a typist. (...) I say, 'There's nothing I can do about it'.

There were stories, however, where the participants said that by time they had become more self-determined and were finding the inner strength to be more assertive, for example, with their requests for accommodations. Here the processual nature of 'becoming more self-determined' emerges and confirms that one is not either self-determined or not as if this was inherent in particular individuals. This was identified in other studies as well, for example in Driscoll *et al.* (2001). Participants also understand that this process is not only beneficial for themselves but also for disabled employees who will come in the future and who will then be able to follow the traces they would have left behind them in that workplace. The next section will also include some of these experiences of 'getting on' because participants showed that they did not solely rely on the availability or otherwise of enabling technology and accommodations, but also on attitudinal factors. Attitudes, they claimed, strongly contributed to the creation of dis/ability at their workplace and throughout the whole employment process. They will therefore be discussed as a separate overarching theme.

6.9 Attitudes

The majority of participants felt that a change in attitudes and mentality towards disability is urgently needed in Malta. In other studies, attitudinal factors have been found to be more disabling than not being accommodated for their needs at work (e.g. Roulstone, 1998; Shier *et al.*, 2009). As Ruggeri Stevens (2002, p.780) put it, 'technical assistance will not guarantee social inclusion at the company level'. It will therefore take much more than technology to change employers' and other stakeholders' mentalities about the employment of disabled people.

Researcher: and then you said, 'However much we stress on the social model of disability, I think we are still really backward.' Can you tell me more about this?

Harold (interview): For example to remove this mentality from employers' heads, in this sense we can still improve (...) it will take time, you cannot expect people to change their mentality from one day to the next but I think that before we change our mentality it will be difficult to implement the social model because if you do not understand why you are doing certain things (...) and you have to understand, not because KNPD will come and fine you if you don't employ disabled people; you have to understand that this is a need.

But this does not only apply to Malta nor is it only about employers' attitudes:

We, the disabled, have assimilated a consciousness in which we think we are unable to do this or that. That is, we deserve help, pity. All we do is request. And when you think only of requesting help, you put yourself in a position of begging. You are always begging, not only for money. (...)If we do not overcome this individualist attitude we have, we will continue to be the target of charity. This can only be overcome through political activism. Otherwise we will be paralysed. (Arnaldo Godoy, Belo Horizonte City council member, participant in Charlton, 2000, p.73)

As shall be seen below, cultural influences, such as religion, family, and living on a small island, weave themselves into disabled people's mentalities and shape identities that may not always be conducive to, for example, speaking up for what is theirs by right. Roulstone (1998) asserts that if the social barriers model 'is to improve our understanding of disabled people's lives'

it 'also has to acknowledge that a number of disabled people will have absorbed able-bodied ideologies which emphasise disability as a personal tragedy' (p.9). It is what Reeve (2002, p.495) calls 'internalised oppression'. This can be seen, for example, in the disabled employees feeling reluctant to request for the accommodations that they need in order to carry out their job. Participants demonstrated a variety of attitudes related to the topic.

Gertrude, for example thinks that 'since it is for work I expect the employer to buy me the equipment so that I may do my job just like everybody else'. She is implying that for 'job accommodation strategies and use of assistive technology resources and services' to be able to 'help to level the playing field for persons with disabilities so that they can compete on an equal basis in finding and maintaining employment' (Langton and Ramseur, 2001, p.27), employers must be the first to support disabled employees both financially and in attitude. Cecilia, on the other hand, thinks that 'it depends on the character of the person, for example I am too shy to ask [for accommodations], it's like I am afraid that they will laugh at me'.

And from the interview with Carl:

Researcher: in the focus group you said, 'I know that it is the employer who should be paying for these accommodations' so you seem to know what your rights are (...)

Carl: but, there is a but (...) you can ask, it is your right on paper but between what is your right on paper and how much that right becomes a reality there is a world of difference. (...) For a lot of disabled people, it is already a big thing if they find a job and are accepted at the place of work, so if you are going to ask for extra things it is like you have this piece of elastic band that you are stretching, stretching, stretching (...) in the end it is going to snap. Then when it snaps you are the one who is going to get hurt, so you say, let me make an effort, let me make the sacrifice myself, rather than risking the job further, do you understand what I am saying? At least that was my experience (...) you have to stay balancing all the time (...) with all the rights that we have!

The following excerpts from the focus groups demonstrate that the problem arises also from the disabled employees' attitudes; that employers assumed that the responsibility regarding AT needs and provision at work lies with the

individual employee but also that the disabled employees were accepting this responsibility by either procuring it for themselves or 'making do' without it:

Ann (FG 1): (...) I had sent an email [to her boss re her AT needs at work] but it was ignored(...)

Researcher: and what did you do about it?

Ann (FG 1): nothing (...) you're lucky if he gives you the job [laughter from the group]

Carl (FG 1): (...) let me tell you, it's already a big thing that you manage to find a job, if you are going to ask for more, equipment and stuff (...)

Cecilia (FG 1): (...) it would be too much.

William (FG 2): now I work in the stores. The only thing I need is an alarm with flashing lights. But I don't feel comfortable to ask my boss because I am still new (...) you know, you feel shy about asking.

Researcher: Do you not think it is your right to ask?

William (FG 2): (...) it's not that I feel shy really but I feel that only I am asking for these things; only I need it; the others do not; so I don't feel comfortable about it; maybe in the future they will exclude me or they will see me in a bad light (...) this is what I think (...).

Anthony (FG 2): can you imagine what a fuss he'd make. No, I would be too embarrassed, too embarrassed. I am the only deaf person there you know. Do you think he is going to do it just for me? He might fire me, he would say, 'you're going to start inventing things now?!' I am too shy to ask. (...) a lot of dust, a lot of bulbs, a lot of wires, all because of me!

These experiences especially those from Focus Group 2 are very similar to other studies such as Harris and Bamford (2001) in which a participant says, 'I am the only deaf person who works here as far as I know. I don't want to make myself unpopular by making demands and drawing attention to my problem'.

There were however more positive stories, such as the one narrated by Terence in response to the other members of the focus group above:

Terence (FG 2): I am not shy of asking; I don't feel awkward to ask. I go, I speak to the manager and I even spoke to the human resources manager. I speak up, I say, 'this is my right because I am Deaf'. Once, about a month ago, there was an alarm, a fire alarm, for training purposes it was. I stayed there, I did not want to go out, I stayed there on purpose and my colleagues asked me

because I had asked 'is this for real or is it training?' and my colleague said 'no it's training' and I said 'ok you go I am going to stay here' and everyone was asking me 'why?' and I said 'because I have been saying I need a flashing light alarm, so I am staying behind'. So then they started saying the names to see who had come out and who had not (...) there's an assembly point (...) and I was not there, I was still in the garage. And when they started reading out the names, 'did Terence come to work today?' (...) they said 'Yes' and he came to get me, the general manager he came for me, 'Why did you not come out?' he asked me. I said, 'I am sorry but I did not hear the alarm, where is the light?' He said, 'You're right, you're right.' It's not my fault eh? Sometimes they even organise meetings at the last minute and I go and there is no interpreter so what do I do? I stay there and chat and laugh and when they ask me 'what are you laughing at?' I say, 'I do not have a clue what you are saying.'

The story above shows that when disabled employees find their way through the network to their employers, they do get what they need in the end. This they do in different ways, one of which is by resisting disabling practices at work in order to achieve their goals (Beckett and Campbell, 2015; Winance, 2016).

By unplugging himself from the work assemblage at that specific time, in that specific event, Terence made himself 'visible' to the employer who had no choice but to give Terence the attention he had previously been trying to get by using more conventional methods. In fact, by the time the individual interview with Terence was held, he had managed to get them to install a flashing light alarm at his place of work. The following quote from Charlton (2000, p.82) aptly summarises Terence's experience:

Oppression has a logic that creates formidable barriers to raised consciousness through its economic, social, and cultural formations and institutions and at the same time creates the necessity and impulse for political activism. It is oppression itself that has created the everyday lived experiences out of which disability rights activists have emerged. Oppression has always engendered both passivity and resistance.

In her interview, Tonia also indicated a gradual increase in Maltese disabled people's awareness about their rights as workers and citizens:

Researcher: part of your job is to deal with anti-discrimination complaints. How many of those come from disabled people who have problems at the place of work?

Tonia (interview): yes we do receive complaints like that (...) I think by time more people are becoming aware of what they can do, of their rights; there is not a huge amount but it is growing year by year (...) because they know, they are more aware of their rights at the place of work, so they come, because they are aware.

6.9.1 Professional attitudes

Barriers coming from professional attitudes and the issue of the 'expert knower' were also discussed by the participants. This has long been one of the important debates in DS, as Finkelstein (1980, p.1) explains, 'The growth of professional 'expertise' in the field has also meant that these helpers have had an almost absolute monopoly in defining and articulating the problems of disability to the public at large.'

By time a hierarchy of power was constructed with doctors at the top, followed by professionals such as therapists and social workers and the 'patient' at the bottom. This became a taken-for-granted construct as one of the participants, Ray, said, 'yes I need the professionals because that is what society demands (...)' In turn, this power, at times leads the professionals to treat disabled people in a paternalistic, 'I know it all' attitude, thus perpetuating the very same disabling attitudes of the disabling society around them. The following story by an indignant Avril, following her and Norman's visit to ETC, illustrates the above in a very powerful manner:

Avril (interview): when we went to register at ETC there was an OT and he did an assessment for us. (...) oh it was horrible, horrible! He asked all these obvious questions, for example he is seeing me there in front of him I cannot even move my arms; I cannot move and he asks, 'So if you had a file, you cannot move it from here to there?' I thought, 'Are you serious?', and all these pointless questions; the whole questionnaire is ridiculous; if I am telling you that I cannot move any part of my body how can you ask me whether I can lift a file?

Researcher: he was still following on the questionnaire?

Avril: yes, like a parrot, even though I told him in the beginning that I cannot do anything; the only thing that I can do is that if I have a computer that is well set up for me I can do everything, once I have everything around me. He went on and on with these really banal questions [very angry tone of voice] really senseless (...) it's ridiculous isn't it? Now he even knew who we [herself and her husband, Norman] were but since he had that assessment, I don't know how many pages; he had about 20 pages (...) and he was ticking away, most of them were absurd.

Researcher: and from then on what happened?

Avril: nothing. We go and register once every 3 months but we always forget to go.

Researcher: how did you feel after that experience?

Avril: really humiliated (...) it was pointless, we went for nothing eh? Norman (her husband) sometimes receives some job offer (...) but ridiculous ones (...) a disabled person finds a job today not because of ETC but because the parents know someone or know about some post (...)

The above experience demonstrates an 'us' and 'them', or rather an 'us' against 'them' kind of relationship. The frustration and negative comments that emerged show the gulf that still exists between disabled people and professionals. Disabling attitudes and the strong feelings they evoked are seen to be a major barrier in the exchange above.

Another issue that this experience brings up is that regarding outcome measures, i.e. the assessments that are used by health and social care professionals at the beginning of, and at any interval during, an intervention programme. Dale and Latham (2015) focus on the assessment form designed and used by a UK disability service provider to identify participants who fit their inclusion criteria for their project. They comment, 'The form therefore is an instrument of organ-isation - it confines embodiment into a particular set of categories: it decides the undecidable' (*ibid.*, p.174). This could be applied to the questionnaire that the OT above was using with Avril and Norman. Because of the mismatch between what was being asked and the life experience of the interviewees, this interaction produced 'dis-embodiment', 'bad' capacities and strong emotional reactions.

Conversely, these types of assessments are supposed to give 'objective' results upon which the intervention programme/OT service is based (College of Occupational Therapists, 2013). OT literature has been challenging OTs to rethink the focus of OT outcomes and consider the importance of individuals' subjective occupational experiences and ambitions (Doble and Santha, 2008). This challenge was also applied to the process, from assessment to follow-up, regarding the provision of aids and equipment by OTs. Siebers (2006) claims that this is at times done without taking into account the reality of living with this equipment and the meaning it has for the user.

The participants' accounts raised an important question as to professionals' status and power and 'who knows best' in the relationship between professionals and disabled people. But 'who knows best' about what? This depends on where professionals place their priorities. As seen in the literature review chapter, for almost thirty years, there have been calls for OTs to become advocates with disabled people (Jongbloed and Crichton, 1990; McCormack and Collins, 2010), but, notwithstanding this, Hammell (2003) claims that:

we remain mired in the medical model, squarely focused upon 'health care services' and one-to-one clinical interactions and thus are at odds both with our own theoretical model and the social model of disability. (p.47)

This resonates with what the participants in this study had to say about professionals, although some still have hope for the future:

Ray (interview): (...) I think it was more the professionals in the olden days, you know, 'I am the doctor. I am the professional' (...) today I think this is changing. I really believe in the young ones who are graduating now (...) you know they do research; and I have often participated in their research and then I meet with them after some time and they tell me 'Good job you had told me that, because I had never looked at it in that way' and that makes me really happy, you know it gives me hope, it gives me hope that one day we will make it (...) because it is not just me, there are a lot of us disabled people who participate and give our views, even if it is just with one individual we can make a difference so it is changing, yes, it is changing I think.

6.9.2 Disabled people as 'experts'

Agreeing with Evans (2003), most participants emphasised the fact that they are the persons who know best about their own needs. Fox *et al.* (2005, p.1304) speak of 'expert patients' when referring to people in weight loss programmes who become very knowledgeable about their condition and who share this information with peers. Albeit in a different context, these terms are also used by disabled people when referring to enabling technologies. Participants in my study also viewed their peers as the 'expert knowers' because of their daily experiences of living with their disabilities and technologies:

Ann (FG 1): I have never met any OTs giving this type of advice [on equipment] at least here in [name of locality] (...) Where blind people are concerned I think it is we [NGO] who give most advice.

Harold (FG 3): I prefer to ask for advice from someone who has a similar condition to mine because he has some experience; I think that he might have a more suitable reply for me. It could be that in certain things he can help me and in certain things I can help him. I don't believe that you can say no to professionals' advice and yes to disabled people's advice. You need to have a mix of both, but I think that I would rely more on the advice of someone who has my same condition.

In view of this, the disability literature has often indicated that professionals need to listen to disabled people's voices:

Disabled people and their organisations are increasingly insisting that we are the experts on disability and that if we had control over the response to our needs, we would develop very different policies from the ones which currently dominate our lives. (Morris, 1991, p.173)

Back in 1981, McKnight reported that professionals are themselves evaluating whether their services were 'effective' (p.32) without any consideration of their clients' feedback, implying that the latter were unable to evaluate whether the professional services had been beneficial for them or not. Unfortunately, in 2018, the participants in this study are still expressing the same concern. Galis (2011, p.835), however, encourages disabled people and their associations, 'as

carriers of disability knowledge and experience', to use this 'expertise' in the formulation of disability-related policies and in their political activism.

6.10 Wider influencing factors

Having delineated the main structural and attitudinal factors that create dis/ability in the experiences of technology users with impairments in the workplace, participants also mentioned other factors in the wider environment, that are specific to Malta and that they perceived as having impacted on their current being. Among these wider influencing factors, participants indicated the education received and cultural influences such as the family, religion and living on small islands like Malta and Gozo.

6.10.1 Level of education

The educational system is another barrier that let down some of the participants. The older ones (over 40 years) had their educational opportunities interrupted when they were diagnosed with their impairment. This, they said, had then affected their employment possibilities. The younger generation seem to have more access to technology and therefore more access to information and knowledge (see also for example Seymour, 2005). It is not enough to have access to technology though; one has to have access to the knowledge, how to use it and how to access information through it, as Cecilia and other participants asserted. Some of them stopped their education because they did not have sufficient support, such as lack of sign language interpreters.

Maltese disabled people also have to learn English as a second language because as Lionel said, 'today at work I spend half of my day corresponding and communicating in English'. Maltese being Maltese disabled people's first language (and at times the only language they know) may also be disabling, for example, in the use of speech synthesisers which they have to use in English. Although there is now a Maltese speech synthesiser, it is apparently not as efficient as it should be, with the users still preferring to use the one in English to read their Maltese text. Findings from studies such as Kaye *et al.* (2008) in which 2000 adult Independent Living Centre users participated in a survey on technology usage among Californian disabled

people, substantiate this study's findings. They also indicated the importance of acquiring robust educational levels since this was found to be one of the factors that facilitated their access to technology and subsequently to employment and other opportunities.

Philip (interview): I became blind when I was 7 years old and here it is good to talk about technology and the lack of education and the impact that it leaves on the disabled person. When you have a disabled person who has not been to school, who does not have a good background, then he will lose on technology; (...) so education has to be the first key that takes you to technology and through technology to work.

And from Cecilia's interview:

Researcher: but did you not work because it was your choice or because you tried to find work and did not manage?

Cecilia: no, to tell you the truth I did not even have any schooling; I don't have any 'O' levels, nothing. (...) when he diagnosed me, the ophthalmic consultant had told my mum, 'Do you have a school for the blind in [name of locality]?' and she said 'no' and he said, 'So I am sorry to say that her life is wasted'. That is what he told her. (...) Today when I go with Ann to a school to give a talk about disability etc. I start getting very anxious because I think, 'Look how I have wasted my life', because when you're young you have a lot of high hopes which then end up vanishing into thin air.

Through her experience, Cecilia is implying that people with less education may be less confident and have fewer skills in using technologies that may in the first place help them get into a job, and then, by using them, carry out that job.

6.10.2 Context: small size of island, culture and family

Another strong sub-theme describes enablers and disablers that emerge from the fact that Malta and Gozo are small islands. Although the barriers mentioned in the sections above, were seen to be common to many countries, most participants think that abroad things are very different, with societies being more inclusive than Malta (Miriam, Tonia, Harold). Others point out that technology is much more expensive here because the market is so small.

Others, then think that the isolation that comes from living on an island is even more real for Gozo, the smaller island:

Elias (interview): finally we will be getting the Agency for community services for disabled people [which includes an enabling technology financial assistance service]; in Malta it's been there for ages and that's great; in Gozo we are only getting them now; we are always 50 years behind; this is a reality. This is not justice. We have been whining and clamouring for it for ages.

And **Tonia (interview):** I think that abroad societies are more inclusive. For example, employers are more aware of certain things but in Malta because we are so small (...) on the other hand you would think, since we are such a small population why can't we be more aware? We should be more aware of disabled people's rights, no? But somehow we're still (...)

Tonia here is indicating that because of the small size of the island it should be easier to spread the word and to raise awareness regarding disability issues. In a place where everybody knows everybody else, contacts are easier to make (even with politicians), links are easier to build and therefore we should be seeing more possibilities in the construction of relationships and alliances in the networks. The proximity that is so real in the lives of Maltese disabled people because they live on a small island is considered as a significant advantage by many of the participants. Most of them come to know each other, and, through the exchange of experiences and knowledge, form a strong peer support network which becomes their primary source of information on technology and other disability issues (rather than professional links).

Other participants mentioned that there are also advantages when living on a small island, such as less distances to travel and easier networking. Robert thinks that, 'The fact that we are small, then you do not have far to travel; I do not live far from work so I am here in ten minutes. That is an advantage.' For others, this close proximity means that, as easy as it is to get help and share information and resources, including on technology, it might turn out to be a barrier if one's impairment is still considered to be a shame on the individual and their family:

Researcher: and how do you get to know about each other?

Ann (FG 1): (...) sometimes you meet someone in the street and they tell you about someone who has acquired a disability; naturally not all of them accept help; when the disability is acquired, then it is more difficult to accept; when you are not totally blind, many hide it. Here in [name of locality] it happens because everyone knows everybody else (...) our villages are very small; and we know everyone even those in different parishes, do you understand? So that is how we get to know each other, by word of mouth, someone says 'listen there's this one or that one', you see that is how we get to know, because we are small (...)

Elias (FG 1): yes, but many don't show it. I know of two people who do not even want to apply for the disability pension because they are too shy to show they have a mental impairment. This is really serious you know; that you remain in a state of poverty so long as you don't tell about your disability!

An invisible but active factor in the development of Maltese disabled people's being is culture, and specifically, religion. But how does culture affect this?

(...) culture (...) has individual and social implications (...) The beliefs, ideas and values of society at large not only reflect the dominant culture, they help to reproduce it (...) Beliefs and attitudes they spawn are not solely determined by religious convictions or education or class or words, symbols and expressions or even the mass media. They are informed by the interplay of all these. (Charlton, 2000, p.51).

The language used by a number of participants demonstrates just how much impairments are still considered to be an act of God:

Elton (interview): This is an attitude problem. He [employer] told me, 'Sight is a gift from God, and if you have a problem with your eyes, then that is a very serious problem.' (...) I think in Malta there are very strong links between disability and religion; there are very strong links between Maltese culture and religion; when it comes to disability, religion still considers it as something tragic and there's a lot of spirituality of the bla, bla, bla type that I have been through believe me. For example, it is not the first time I went to a prayer group and they get to know that I have a disability and the priest would tell me, ' Listen, God considers you to be very special'.

Cecilia (FG 1): we do not know the ways of the Lord eh? (...) but if you don't have faith, you despair, because life is very hard. (...) but then for example

when I open the laptop and it starts talking, the people around me stop and are amazed because they say, 'Oh look, how is that possible?' and I say, 'Because the Lord takes away one thing and gives you another'.

This belief then at times transfers into their resignedly accepting their fate with very little energy to change their present and future lives. Some of the participants are shaped by these beliefs, lack of opportunities and other cultural factors, thus becoming persons who are submissive, with low self-esteem, accepting the minimum instead of aiming for the maximum:

Cecilia: (...) now I am old [she is 51], it's too late now. I was born too early (...) you always feel less than other people eh; that is what I tell my sister when I hear the gospel at mass and it refers to 'the marginalised'. I tell her, 'we are like these Rita (...) we are these marginalised people.' What can you do? You can do nothing eh (...) this is my life now [resigned tone of voice].

It can be assumed that the beliefs that shape these attitudes also trickle into the world of employment. It is not surprising that so many participants find it difficult to transform what in principle they know is theirs by right, into making their voices heard in practice, such as when they need to make requests for technologies and other accommodations.

Another important factor that is very influential in Maltese disabled people's lives and that, directly or indirectly, affects their getting into and keeping a job, is the family. Some of the participants are grateful that their families pushed them towards being independent (as in Solstad Vedeler and Mossige, 2010). Others rely on them to access the place of work or to purchase the needed technology for them (to go physically, to pay for it or to fix it for them) as described in their experiences above.

Researcher: so it's not just about having the actual services that provide you with the technology; it's also about the people around you?

Daphne (interview): (...) I think that attitude towards ensuring that your children are independent is something that needs to be worked on. In Malta I know a lot of people in their late thirties who are prevented from doing an awful lot of things by their parents, because their parents are frightened that they will hurt themselves or that they won't manage or that somebody else will hurt them and it would appear that the normal risk-taking behaviours of getting on a bus er

without getting run over that is perfectly natural for a 19 year old, er is not natural for a Maltese disabled 19 year old because of the way their parents mollycoddle them and because they still live with their parents, which makes a huge difference.

Researcher: so you are saying that Maltese disabled people are not very empowered, is that what you are saying?

Lionel (interview): let me tell you, they are not. But there's another thing, there is a lot in their environment that discourages them, because there are circumstances like I have sometimes had myself ok? Two and a half years ago I did a professional mobility and orientation course, something which in reality I needed 25 years ago. 25 years ago I tried to do a mobility and orientation course on my own in the village where I live and I had started but my relatives and other people discouraged me so much that I stopped (...) and you may ask so what is different from then (...) the difference is that when people see you are doing the training with a professional person then it is as if their mentality changes, if they see you doing something on your own they think you will hurt yourself or you are going to die and they invent all the obstacles in the world ok? That's it.

Parents have also been identified as influencing their children's vocational choices:

Anthony (interview): At the moment I have this job which I really like but I have a dream to work as a hairdresser; it has always been my dream. I've been saying it since I was a little boy; but my parents never allowed me; they saw it as a bad thing (...)

Researcher: you can do a part-time course if you like

Anthony: yes, yes, that is what I am going to do but I haven't yet told my mum [chuckle]

Researcher: but you're 24! You're an adult now.

Anthony: yes, I'm an adult. But she will grumble for sure!

The sub-themes of overprotection and lack of expectations as mentioned above, was also brought up in other studies, for example, Milner and Kelly (2009, p.57) in which vocational service users felt 'wrapped in cotton wool (...) and made me feel as if I was useless by telling me you can't do this'. Maltese disabled people's ties with their families are complicated with the fact that most

disabled people depend on their relatives to act as their personal assistants, for their housing and transport arrangements and at times even economically.

Therefore, it would be too simplistic to conclude that the solution for 'overprotection' is to urge disabled people to move away from their parents' homes.

Breaking up the disabled person-family assemblage is messy and complex not only because of economic factors but also because of emotional ones. Most disabled people negotiate this situation by looking for other openings where they can prove themselves, such as with peers and within their NGOs, where they find encouragement and self-esteem which then motivates them to move on. This, however, is still dependent on the individual's self-determination. Wider factors such as the media, policies and legislation were highlighted by some of the participants as possible supporters and enablers for disability issues in general and, specifically, for the accessing and use of technology at work.

6.10.3 Media

Media is seen by the participants as a potential advocate which together with disabled people themselves, can spread awareness regarding their rights:

Philip (interview): They [at the factory where he worked at the time] did not understand this thing; they did not try to see the potential because they might say, 'oh this is a blind person'; and here we can mention the importance of awareness about disability on the place of work, what are we capable of doing in the world of work? And I think it is very important that we disabled persons show our abilities you know. On programmes, on newspapers, on all the media; ok, not eulogise ourselves but to attract people's attention, 'Listen I work in this place I am doing this job(...)'; because then even other companies would be able to learn and they might be encouraged to employ disabled people.

Researcher: do you think that Maltese disabled people know about their rights at the place of work; about their right to technology and so on?

Vincent (interview): I think the majority of them yes but there might be some of them not so much; maybe because they do not socialise so much, so they do not know about certain things but I think the majority do, because of the media and adverts of devices and equipment.

Researcher: so we have mentioned the employers' side, do you think there is lack of information on disabled people's side as well?

Tonia (interview): let me tell you, in those days we did not use to see as much publicity on disabled people or what they need but with the passing of time we started to realise that there are certain things; even through media programmes and so on, they started showing different aspects of life for disabled people; the media surely helps; it does help a lot.

6.10.4 Legislation

The participants also showed they are aware of the potential role of legislation in making their lives as disabled employees easier. However, they are also aware that much more enforcement of that law needs to be put in place before any real benefits are felt on their part. Michailakis (2001) further suggested one reason why legislation and other 'macro-level' factors have not been successful in resolving disabled people's employment-related issues. This is due to the fact that, 'The expectations which technological optimism has given rise to are all related to the micro-level with an almost total disregard of the effects on the macro-level' (*ibid.*, p.493). Even though, for example, in Malta there is the Equal Opportunities (Persons with Disability) Act (2000), it does not cover the details such as who should pay for what when it comes to AT and other supports at the workplace. The participants in this study are also aware of this gap because work-related AT services are not improving. This was also found in Harris and Bamford (2001) where Deaf/hearing impaired people indicated that there was a lack of awareness on both employers' and disabled employees' part regarding the responsibility for AT provision and that the existing 'service provision (...) is still service-led rather than needs-led' (p.975).

Ray (FG 3): There has to be legislation and rules to protect those who buy this technology and bind them regarding making the necessary maintenance and follow-up support (...)

Terence (FG 2): But now there is the UN Convention so he should do it [flashing light alarm], although it [CRPD] does not specify which accommodations should be carried out at the place of work, but still with the UN Convention they are now obliged to do them.

6.11 Conclusion

The findings from this first-level analysis indicate that numerous structural and attitudinal barriers persist, in Malta and, even more so, in Gozo. What Söderström (2016, p.95) suggested for inclusive education can be applied for an inclusive workplace: 'barriers to an inclusive education are attributed to the persistence of a medical model understanding of disability as an individual phenomenon'. Many of the factors mentioned by the participants have a knock-on effect on disabled people's quality of life, including at the workplace, and it is sad to see that twenty years later, the barriers mentioned in this study are the same as, for example, those mentioned by the participants in Roulstone (1998).

This makes it even more imperative that another layer is added to the social model approach; that barriers are analysed in a different way. In this study, as shall be seen in the next chapter, this was done by focusing on the networks and processes as they are being enacted in the workplace. These were seen to offer new possibilities for disabled people to navigate around the barriers especially when it was difficult to remove them completely. Barriers somehow give the idea of fixed, static 'walls' whereas networks and processes give the idea of movement, fluidity and entanglement that are therefore all the time being enacted and open to transformation.

In this Chapter, participants have unveiled the intra/interdependent relationships and interferences between employees and employers, colleagues, family and so on, and the capacities that are produced (or otherwise). They were shown to be constantly changing and opening up the links/possibilities for all to become a different, (hopefully) better, employee. They have also indicated that it is not only the immediate environment (both physical and social) at work that has to be designed for all to use, but also the layers further out in the network like transport and homes. Participants highlighted the relational aspect in the networks and the fact that many of the components in the assemblages, like sign language interpreters, colleagues, policies and practices, act as mediators (or not) that enable (or not) disabled employees to function at the place of work.

It was therefore crucial for this study to first map out and analyse the individual barriers and enablers that disabled employees meet with in their engagement with technology. It was during this process that I could appreciate the complexity of relations, assemblages, alliances and entanglements being enacted in the participants' working lives. New materialist thinking, which was then adopted in the second stage of the research to study these processes, suggests that society concerns itself with the study of relationships (Kien, 2016, no pagination) and the 'creation of larger and stronger networks' (Sismondo, 2009, p.81). Therefore, the questions about what can create larger and stronger networks for disabled people to work in a manner equal to their colleagues' at the place of work became: What are the components of these assemblages; what are the relations? What are the processes and capacities produced thereof?

For this reason, I decided to visit and observe the participants at their workplace, and to analyse the data gathered there according to new materialist perspectives. The next chapter sums up the second-level analysis that emerged from this data.

Chapter 7

Dis/abled Employees-Technology Assemblages at Work

7.1 Introduction

Even technology makes the mistake of considering tools in isolation: tools only exist in relation to the interminglings they make possible or that make them possible. Tools are inseparable from symbioses or amalgamations defining a Nature-Society machinic assemblage (...) a society is defined by its amalgamations, not by its tools. (Deleuze and Guattari 1988, p.90)

In this chapter, the second stage data analysis will be presented. The new materialist concepts of assemblages and networks, so beautifully articulated by Deleuze and Guattari in the opening quotation above, will be used to explore the complex relationship between the body, technology and the workplace environment as narrated by the participants in this study (interview data) and as observed by myself (observation fieldnotes). The data has been 'dredged' (Fox and Alldred, 2017, p.172) to identify what components make up an assemblage, what relations emerge between the components of the same assemblage and other assemblages in the network, and what capacities are produced via these affective relations, in events happening within the workplace (see Figure 7.1). The chapter will show how these affects are always contextual and relational, and that they can produce both 'abling' and 'disabling' consequences for the assemblages within the network.

Finally, it will demonstrate how these assemblages are always open to opportunities of new becomings, producing new properties/outcomes, because of the way assemblages are entangled with multiple and heterogeneous human and non-human entities and practices. The findings will be presented and analysed through a series of four vignettes in which technology users with impairments enact their daily life at work. Each vignette will serve as the basis for the presentation of the major themes that emerge, not only from the observation fieldnotes, but also from the interviews. Apart from the participants in the observation sessions, therefore, other participants in the interviews will contribute to the discussion in this chapter. It is important to note here that the sign '-' does not mean a fixed entity rigidly and permanently linked to another

fixed entity. An assemblage according to Deleuze and Guattari (1988) is the result of the meeting (i.e. linkage, exchange and connection) of the two (or more) entities. Jackson and Mazzei (2013, p.262, italics in original) substantiate this by stating, 'An assemblage isn't a thing – it's the *process* of making and unmaking the thing'. This note applies to wherever this sign appears to describe an assemblage in these final chapters.

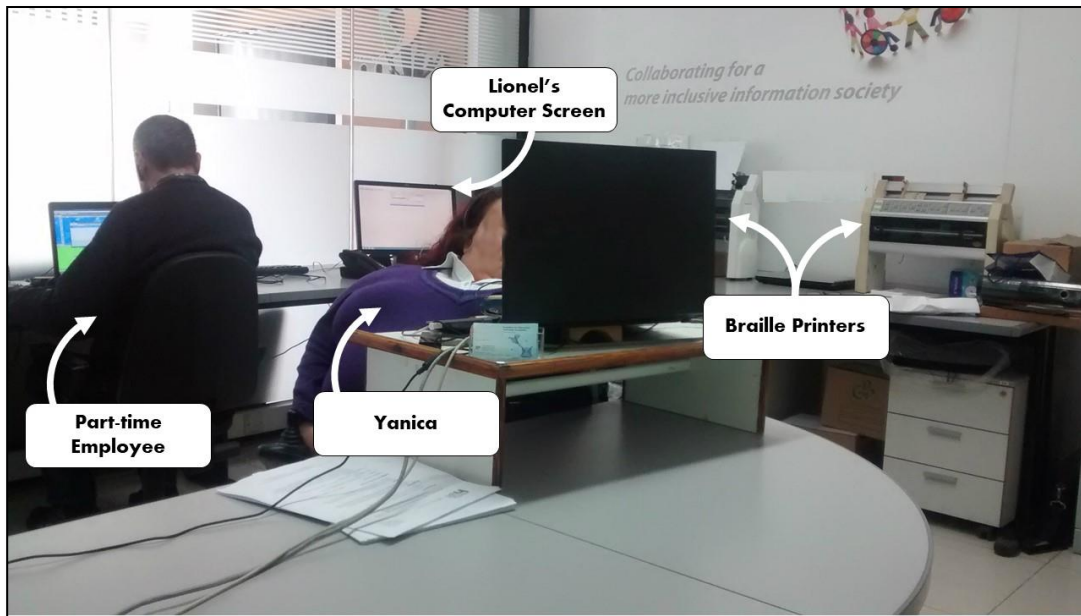
7.2 Vignette 1: Yanica and Lionel

Arrangements that matter

Yanica and Lionel's stories will be presented in the same vignette because they work in the same office. When I visited them in their office, both participants knew me because I had already been to their workplace to carry out individual interviews with them.

When I arrived, I explained the purpose of my visit to both and took their written consent to be observed while they work. They also agreed that I could take photos of the technical and environmental arrangements they were working in, but we agreed that I would leave out their faces and anything that would jeopardise their anonymity. So I first jotted down a plan of the office and then took some photos of the general layout.

Photo 7.1 Yanica and Lionel's Office Layout



Lionel is a gentleman of 40+ years, who has visual and hearing impairments. Having been blind and hearing impaired since birth he is known to many blind and visually impaired people in Malta and Gozo as a reference point when it comes to IT access and related AT. Lionel seems to be very much oriented to the space around him since he moves around the office in a fast manner and can find everything quickly. He has everything in its particular place and he told me that everyone in the office knows that that is how everything should remain so that he does not get disoriented. His work revolves around his computer and the telephone. Lionel was noted to type very fast. He explains that he uses a standard computer with a screen reader, the Window Eyes. He also says he uses a lot of other small gadgets such as a talking watch, talking mobile, and talking calculator. When he moves out of the office, he uses a white stick to navigate his way around.

Yanica is a 30+ year old lady who works as a customer service officer in the same office as Lionel. She has a severe congenital physical impairment and uses a powered wheelchair to get around. She is unable to use her arms for typing but manages to manoeuvre the chair with the index finger of her right hand. Otherwise she can move her head and shoulders to carry out most of her work tasks which are mediated through technology and her colleagues.

The first thing I noted was that, although it was an afternoon, the level of activity and noise going on outside their office was significant. Their office is situated on the opposite side of the corridor where there is the reception of the organisation they work within. I also noted that there are various beeps and sounds that are produced by the many technologies being used in the office. So I asked whether this distracted them from their work. Lionel joked that he had no problem with that since he could not hear well and Yanica said that she had got used to it. Also, since both used headphones, the interference was reduced.

They had just got into the office after their lunch break so Yanica manoeuvred her powered wheelchair at a 45-degree angle to her desk and asked a colleague to put on her headphones, place the mouthstick in her mouth and the mouse on her keyboard. Both computer screen and keyboard are placed on an elevated wooden table so that Yanica can type without too much strain on her neck. The small keyboard that she uses is positioned at the level of her chin.

Yanica holds the mouthstick between her teeth on the right side of her mouth. Since it is made of metal, I asked her whether this caused any discomfort especially to her teeth. In the interview Yanica had told me that she had tried other 'proper' mouthsticks but could not get used to them whereas these were adapted knitting needles that her boss's grandmother had given her. During the interview she had also told me how she had bought a cooker which had two long chopstick-like accessories, which she had had adapted for use as mouthsticks for her laptop at home.

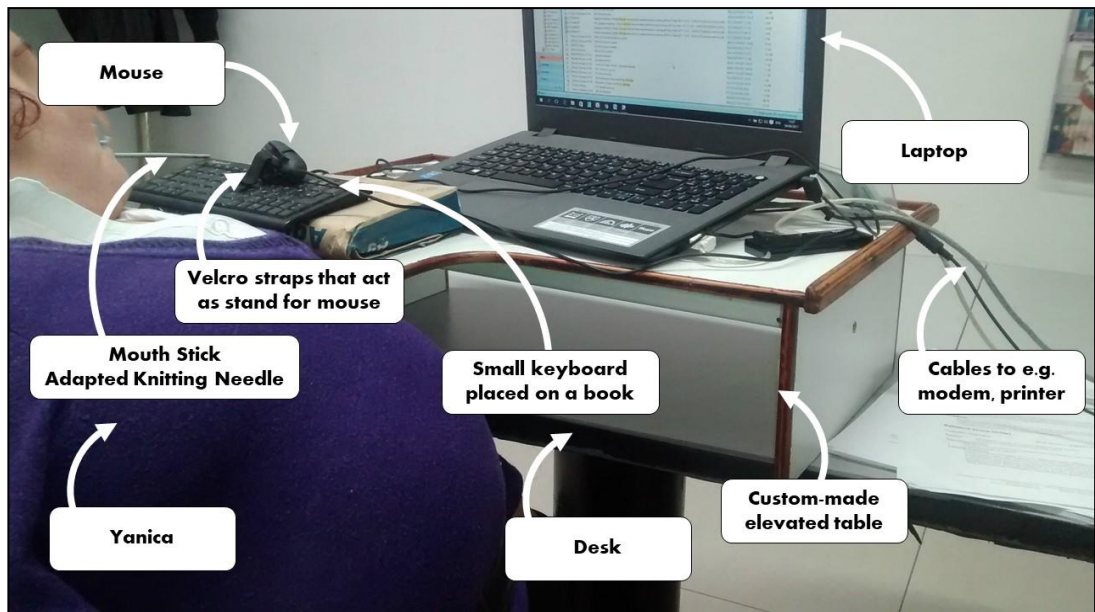
Yanica managed to speak to me whilst still holding the mouthstick in her mouth. She showed me how she responds to telephone calls via an online telephone keyboard on her computer screen. All her colleagues' telephone numbers and other frequently used ones are memorised in the system such that she only has to click on the name to call or pass a phone call to them. Yanica initiates the movements of her mouth which set in motion a series of events. Through the mouthstick, she engages with the keyboard which in turn operates

the receive button of the telephone on the computer screen. With the click of a button and through her headphones, Yanica is connected and can do her work as customer service officer through this process.

Part of Yanica's job is also receiving/replying to and writing emails. She types at an incredibly fast speed with her mouthstick and a tiny mouse. Yanica explained that this had been given to her by a colleague's mother who could not understand how it worked but for Yanica it had resulted in being a very useful piece of equipment. This tiny mouse has two pieces of Velcro which any other user would tie around the thumb but which Yanica uses as a stand to keep the mouse still on her keyboard. The keyboard is a mini one such that Yanica has a small area within which to turn her head to type. She turns the mouse around with her mouthstick and moves the needle in front of the laser which is situated on the front of her mouse until she clicks on whatever she wants to click on, on her screen. The keyboard is placed on a book wrapped in a paper bag to elevate the keyboard to a comfortable height.

Other tasks Yanica is involved in are finding and booking venues for her manager and colleagues' meetings, and taking care of the calendar of events/timetables and appointments of everyone in the office.

Photo 7.2 Yanica-technology-set-up assemblage



The components of the 'Yanica assemblage' here include:

Yanica-wheelchair-headphones-mouthstick-elevated small keyboard-small mouse-laptop-homemade elevated table.

In this arrangement, one can see relational materiality in the regional materiality of the computer screen, the network materiality of the workstation and the fluid materiality of the online virtual environment, as in Sørensen's (2007) classroom arrangement. This relational materiality is made up of the forces between the body and the device and between this assemblage and other entities around it (Winance, 2006). Yanica's vignette (and those of others being discussed in this chapter) are a testimony to the relationality that this technology enables/facilitates in the assemblage and how the technology is in turn affected by the other components in the assemblage/network. As in the work of Moser and Law (e.g. 1999, 2003) based on ANT, dis/ability here is shown as emerging from the relations and associations that people (disabled and non) have with other beings (human and non).

Yanica can work from a tiny area and can perform her tasks given that all the bits of the arrangement are set up for her. She needs human assistance to put the headphones on and to place the mouthstick in her mouth but, once all this is in place, she can work just like anyone else.

Because she still needs her colleagues to set up the headphones and mouthstick for her before she can start working, the assemblage also includes 'colleagues'. If we look further, the assemblage components also include 'the boss', 'relatives of colleagues', 'the service-users', 'transport', 'the carpenter' who made her elevated table and 'the personal assistants' at home who help her get ready for work in the morning. There are also the physical cables and virtual networks that connect the 'Yanica assemblage' to the printer, to the organisation's database, to her colleagues' computers, and to the internet. Yanica's 'abilities' as an employee depends on each of these components. Any physical or emotional affect in any one of the components transforms not only itself but the whole of the assemblage, consequently dis/abling Yanica to work efficiently and effectively (or otherwise).

For example, Yanica told me that her only problem currently is that the office modem was changed, and this upgrade had caused some interference with the telephone system. Although a temporary interference, this meant she would not be able to answer the phone through her laptop. Before the upgrade, the system was enabling Yanica to answer the phone. After the upgrade, that same task was no longer possible, even if her 'personal' set-up had not changed. This is an unintended consequence of the advancement of technology, which has closed-up the opportunity for Yanica to perform as well as she used to with the old system. This is transitory, however. She said, '(...) but that is until they get a new one (...)'. Therefore, here dis/ability or in/capacity are transitory too, depending also on the temporal relations among the components of the assemblage which include the person/s who will re-set the system to be compatible with Yanica's needs and the time it will take for this to happen.

Another deconstruction of the assemblage had occurred when Yanica had her wheelchair changed to a new one. Here the 'Yanica assemblage' included the 'wheelchair supplier' and the 'physiotherapists'. She recounted that she had made it very clear to the supplier and the physiotherapists that she wanted it with exactly the same characteristics as the old one. However, when it arrived, she was sitting much lower, such that:

I could not function, not at all; sometimes I had to work till midday and then go home because I was in a lot of pain and I could not work (...) I had to remove one of the footrests because it was causing a pressure sore on my knee and the seat was a bit slippery. My boss gave me a non-slip mat to place underneath me but with summer dresses it started chafing my skin and it became very itchy.

Here, the inappropriate 'footrest' and 'seat' components of the Yanica-new wheelchair assemblage were producing 'pain', and 'itchiness'. The mismatching of the new technology with Yanica produced undesirable and unintended affects that in turn shaped a not-very-efficient employee because she could only deliver half a day's work. Adaptations were eventually made to the new wheelchair following her feedback. Winance (2006, p.54) calls this 'the process of adjustment' in which Yanica's and the new wheelchair's materialities are tinkered with until an arrangement is found that not only enables action/performance, but is also one in which Yanica's sensations are accommodated such that she is painless and comfortable.

She still had, however, to have a new laptop table constructed so that the whole set-up would accommodate the measurements of the new wheelchair. The table (otherwise perceived as a passive and fixed feature in the room) here became a live component as it was affected by the height of the wheelchair such that the entire workstation had to be re-set for it to become an 'abling' arrangement for Yanica. The Yanica-in-new wheelchair had to fit not only physically within the surrounding environment; she also had to fit in emotionally: 'At first I could not accept that I had to sit so low; with the other wheelchair I was much higher (...) but then the seating is much better in the new one'. Yanica does not like sitting lower than before, but knows she must negotiate a compromise between the capacities that emerged from the new arrangement and her personal preferences. She blames these inconveniences on the fact that the wheelchair suppliers came from abroad once every 6 weeks or so and she was not given sufficient time to try out the new wheelchair with the resultant disappointing results. Time here is again a (disabling) component of the assemblage.

The other two components that Yanica mentioned above were 'the physiotherapists' and 'the wheelchair supplier'. This takes us back to the literature regarding models of AT and OT. These models do not specify where the service providers above fit. The HAAT, for example, was seen to acknowledge the interactions between the person and the technologies s/he uses in a specific context to carry out a specific activity. Its anthropocentrism, however, does not allow for 'equal' interdependent relations between the components involved. NM may contribute here in calling for a review of the current AT models that they may adopt the 'assemblage approach' to the person-technology-activity-context analysis.

This form of analysis would not only identify *which* are the components involved, but it would also explore *how* the components relate with each other to produce, in this case, an enabled employee. OT theoretical models, such as the Person-Environment-Occupation Model (PEO) (Law *et al.*, 1996; CAOT, 1997), also indicate the interdependence of the person and the environment but they are all fundamentally client-centred. The post-anthropocentrism of NM seems to be counter-intuitive to the idea of client-centredness. So can new models of OT and AT reconcile this divergence? In Chapter 8, I will explore the implications of this question for a more nuanced understanding of the relationship between people and technologies through the development of such models.

Now, let us go back to Yanica. Notwithstanding the above mishaps, Yanica said that this technology had made her 'more independent', allowing her to 'meet with other people and carry out normal work, just like everybody else'. Before she started working there, 'I did not even know what the internet was; today I cannot do without it. (...) Ever since I started working here, I have seen a lot of improvement in myself; I have been on different courses (...) and it has opened up a lot of opportunities for me.' Yanica also told me that she has 7 'O' levels and 1 'A' level and that she has just successfully completed her Accounts 'O' level exam. She said she intends to continue following courses to improve her work situation although she does not see herself moving from her present job because here, she said, she feels safe and accommodated with all that she needs. She said she prefers to hold on to a lower paid job with the securities around her, rather than move on to somewhere where these are not

guaranteed. Yanica asked me to inform her if I got to know about a course that she could take. She also told me she wishes to get accommodation on her own with a personal assistant and I promised I would ask about how she could get on with this plan.

This 'reminded' me that as a researcher I too was an active component that had the capacity to transform/affect the research assemblage, as has been discussed in the Methodology chapter. It can also be seen that the Yanica-work assemblage has not only made of her an efficient employee (her being in the present) but also a potentially more qualified one (her becoming in the future). She was not only becoming a better employee but also a more self-determined person who is looking out for further opportunities of becoming.

Although I observed Yanica and Lionel separately, I could not help also observing the interrelations between them since their desks are back to back on opposite sides of the office. Yanica in fact commented that they compensate for each other's impairments. She said that she helps Lionel sometimes, by 'seeing' for him when he cannot find something. He helps her by picking up things from the floor for her following her verbal guidance, or by switching on the computer for her to start the day's work in the morning or after a power cut. Yanica said that most of the time it is Lionel who puts on her headphones and mouthstick in the morning and the food in front of her at lunchtime so that she can then eat independently. She said that when Lionel has difficulty accessing a website, she tells him what there is on the screen. Therefore, the fact that Yanica and Lionel are in the same office enables them to use their different impairments to help the other. They are a 'human-human assemblage' or a Yanica-Lionel-workplace assemblage.

An interesting thing they told me is that the security officers across the corridor do not have access to the internet, so sometimes they come to the office to ask Yanica to find some information for them. At times when Yanica is alone in the office, the receptionist is aware that she needs to go and put on the headphones and the mouthstick for Yanica to be able to start work. So, even though the security officers and the receptionist are not part of Lionel's and Yanica's team, they are important components that 'plug' and 'unplug' themselves in the participants' assemblage as the needs arise.

In Lionel's case, while he was working, I noticed that he was wearing headphones and commented on this, to which he answered, 'Yes, those are very important because in an open plan office like ours one would not want to disturb colleagues, and apart from that I also find they help me concentrate on what I am doing.'

Here, the 'Lionel assemblage' consists of:

Lionel-hearing aid-headphones-white stick-computer-Window Eyes-Braille printer-talking devices-colleagues (disabled and non).

As seen in Lionel's vignette, maintaining consistent order on his desk and in the office is very important. This arrangement matters to Lionel and it dis/ables his capacity to be an autonomous employee depending on his colleagues' reliability/consistent behaviour in not moving things around. Spatial and behavioural issues therefore become important components in this assemblage.

The space component of the Yanica-Lionel-workplace assemblage, that is, the open-plan office layout can also produce incapacities and be disabling because of the noise. But it can produce capacities and be enabling at other times because the employees who share the office can help each other by compensating for each other's impairments. The various technology components used can also be dis/abling at the same time. For example, although the headphones help Yanica and Lionel to cut out the background noise and concentrate on the tasks they are doing, they can also 'isolate' them from each other such that one might not notice when the other needs help.

During the observation session, I noticed there was a great deal of interaction going on, everyone was involved in the network of employees (disabled and not) working together. Dis/ability is enacted/produced/performed in multiple, complex ways by many different arrangements and people. Therefore, disability in this context is not seen to be something that Yanica and Lionel have all the time because of their impairment, but it is something that is enacted (or not) all the time, depending on the relations and arrangements of devices, furniture and people around them. The non-disabled people at the

workplace at times need help which the disabled colleagues can provide, such that dis/ability is made and unmade all the time by everyone.

The above assemblages, arrangements and practices have produced affective capacities that have enabled Yanica to become who she is today, a fulfilled young lady who is making plans for the future and who is not only 'needing help from others' but is contributing to the operation of the organisation and the wellbeing of her colleagues. Lionel in turn is enabled through the components of his assemblage not only to carry out his work but also to act as a reference point to many disabled people in Malta when it comes to accessible ICT services. Most of the blind people I interviewed for this study, in fact mentioned that it was Lionel, rather than professional people, who had helped them with these issues when they needed help.

The two stories above highlight multiple important themes, but in the following sections I will focus on two specific ones: technology as an extension of the body, and the double-edged nature of technology. Citations from other participants' interviews will also be presented to further substantiate the data from the vignettes.

7.2.1 Technology as extension of the body

A striking theme that emerged from the data was that most of the participants considered the devices that they use as parts/extensions of their bodies. This also means, however, that the more technologies they use, the more their body has to carry around. In order to offset this problem, participants told me about devices that they wish to have, which integrate more than one function into one device:

Lionel: for example, recently I have discovered this piece of technology that you hang around your neck and this serves as an interface to communicate with many, with about 10 devices at one go (...) the computer, the iPhone, the radio, the television etc. and this replaces the head phones; why? Because when you are linked to the hearing aid and this device that is like a necklace, you are linked with all these devices and so you don't have to stay plugging and unplugging every time.

And Philip, during his interview said:

I dream of buying a watch that is connected to the mobile like Apple or Samsung. I would be able to use it as a watch, manage my emails from it, it is another piece of interesting technology because you don't have to stay holding the mobile in your hand, you have the watch strapped to your arm.

The more integrated the technology is, therefore, the closer it is to the body, with the distance of the body from the devices becoming always less. Instead of holding the mobile in their hand, using the new device, they would be wearing a watch around their wrist; instead of holding remote operators in their hand they could wear a device around their neck. Here technology is not only an extension of the body, but it is opening up new capacities for action by leaving the hands free to do other things.

And at another instance Lionel actually remarked:

technology has become my whole life, let me tell you why; because since I do not see anything these days, I have to 'see' everything through technology, whether it is the computer, the internet or going to a shop.

It is not only Lionel who is affected here; the technology Lionel uses is also affected by becoming 'eyes'. This was also mentioned by another participant in relation to his guide dog (disabled person-guide dog assemblage):

Researcher: about your guide dog, you said it has made a difference to you even more than the white stick. Why?

Elias (interview): because he sees for you. You can walk wherever you want, you don't need to stay feeling around where you are stepping. With the white stick you have to feel around; the dog guides me himself (...) I trust it 100% (...) As a mobility aid, forget technology, I prefer the dog (...) with the dog it's like you have a man who sees for you and helps you go where you want.

Researcher: and do you take it to work as well?

Elias: yes, yes sure; it is he who takes me, not I him [laughing].

Disabled people therefore use a variety of tools which do not only include technology, but also animals. Elias considers the guide dog as another type of support. In this relation, Elias is opened up and enacted to trust the dog to take

him to places as in Schillmeier (2007) where blind people open up their personal spaces to trust the people they are dealing their money with.

Disabled people's assemblages have to include both human and non-human components as supports, depending on their preferences. The relation of Elias-guide dog components produces an emotional capacity, that is trust, which enables Elias to arrive at work safely and in time. It is however curious that none of the participants mentioned the assistance they could get from workplace personal assistants and job coaches, as in for example Strobel and McDonough (2003). This might be due to the fact that very few exist in Malta, and it indicates a need regarding awareness about these types of supports as well.

Yanica's experiences with the change of modem and the change of wheelchair indicate how participants became even more aware of just how much this technology has become a part of them, a part of their bodies, when something went wrong with it. It also underscores the fragility and transient nature of the links between the components in the disabled person-technology assemblage. Extracts from Daphne's and Miriam's interviews also highlight this:

Daphne (interview): (...) absolutely, absolutely, there is a huge perception of difference with regard to the various devices. I don't think most people would view crutches as assistive technology. I do. In fact, I would be lost without crutches. In fact, the only time(...)I'm a very calm person, very calm, nothing ever ever rattles me; I think in the last 15 years the only time I felt a real sense of panic was when I was in my house and I had to go out and one of the handles fell off my crutch. I didn't have a spare pair and walking with one crutch is actually harder than walking with none and holding on to the wall. I had to go from my house to my car in order to be able to go and find another pair of crutches from a shop. I think probably in the last fifteen years, I think, that is the only time I can ever remember feeling absolutely terrified (emphasis) and it proved to me how much a part of me they are; they are actually something that I don't even consider, they're so much a part of me that it's not something that I would consider as separate from me; they are an extension of me.

And Miriam:

Researcher: Miriam, during the Focus Group you mentioned the prostheses, you said, 'I have artificial legs, but I don't know whether one can call them technology'. Why did you say that?

Miriam (interview): I think I see them as both. I see them as an extension of myself today, now it's been nine years, so it is natural that they have sort of become a part of me you know? In the morning I don't even think that I have to put on my legs; I mean it is something natural, so they have become an extension of my body, but they are also a technological thing, especially when something goes wrong with them, then I realise just how much they are a piece of technology and how much I have to rely on a technician to fix them, so they are very much technological but that does not bother me. Today there is this idea that, for example, a mobile is something technological but it is an extension of ourselves; when I go out without it, it's like I have forgotten a part of me at home; er (...) and most of the technology, whether it's assistive or not has become part of us, and it's the same with my legs; it's like they are on both those tracks (...) they are a part of me yes, but when something goes wrong with them or I need something or I need to have something fixed, then yes, I realise just how technological they are (...) I cannot just put a stick and go [laughing] (...) I need to go to someone to get it repaired; to a certain extent it's like when you go to the doctor, but they (technicians) are not as accessible.

Even more than an extension (add-on) the prostheses are now her: Miriam is now a different person with them.

As Shildrick (2015, p.19) puts it:

Referring to technics (...) signals very much more than the symbiosis of artefact and user; it stands for the whole indeterminate plethora of interlinked practices, materials, events, discourses and bodies that co-constitute the choreographies of action.

This was also commented on in the last chapter, when Lionel referred to having forgotten he was wearing a hearing aid because it was such a part of him. Yanica, Daphne and Miriam, above, all describe their feelings of disappointment, fear, and panic when their devices did not fit well or broke down. And this was not just about not being able to function, but it also brought

about emotional (in)capacities that transformed their very being. Here again, the person is seen as a collective/an assemblage of interdependent components, in which in/capacities for action and change emerge from the interactions between the body and technology, and where body and technology are equally affective and affected (Haraway, 1991; Braidotti, 2013).

7.2.2 The double-edged nature and unintended consequences of technology

A number of participants mentioned the fact that although technology has been beneficial in their lives, it has another side to it. Devices at times solve one problem but create another (as in, for example, Maseide and Grotland, 2010). Amongst the dilemmas mentioned by the participants are the fact that technology is constantly evolving and, therefore, might not remain compatible with their previously purchased devices; that the latest versions do not necessarily mean the best for their purposes; that the more devices one has the better; that there is a fundamental need for constant maintenance and repair.

Researcher: and you also use the hearing aid (...)

Lionel (interview): This is the first digital hearing aid that I am using because the one before this one was an analogue hearing aid. (...) with the analogue one I almost tend to say that you get a better listening environment. In what sense? With the analogue one, if there is a noise in the background further away, you get the sense that that noise is coming from afar; the digital ones tend to amplify sounds all at the same level with the result that you don't get realistic feedback of your surroundings; in fact, I do not use two hearing aids but one in the left ear. The reason I do not use two is because with one hearing aid I can balance sound much better, let me put it this way.

And as Gertrude commented, it is not worth buying a very expensive device such as a mobile because, 'it [technology] develops so quickly that you cannot keep up with it.' This indicates that the disabled person has to become a different assemblage with every new technology adopted and vice versa. This was also seen above when there was an upgrade to Yanica's modem. If there is a new technology adopted by the place of work, then the disabled person and the place of work become different entities every time; they are dis-assembled

and re-assembled anew every time. Latour (1994, p.33) describes this accurately:

You are different with a gun in your hand; the gun is different with you holding it. You are another subject because you hold the gun; the gun is another object because it has entered into a relationship with you.

Disabled people, therefore, have fluid identities which change depending on the interactions they have with the objects, humans, and environments around them. The same applies for the technology and environments in those assemblages. An experience that gives evidence of the transformations that emerge from this making and unmaking of the person was related by Yanica earlier on, when she changed her old wheelchair in a lengthy process of trial and error. Mol *et al.* (2010) call this process 'tinkering' which is how disabled people establish relations with professionals and vice versa, and thus achieve their goals. Yanica's experience is very similar to the stories narrated in Winance (2006, p.54) about people with neuromuscular diseases and their wheelchairs, where the trying-out period of new devices became the period during which they are 'opened' and 'shaped' anew. These stories also show that the persons involved (many a time having severe physical impairments) are autonomous in their decisions and choices and that the trying-out period is an emotional process that requires both a physical and psychological adjustment/transformation.

Researcher: you also mentioned the powered wheelchair that you have at home and that you try not to use it so you keep on walking for as long as you can. Can you tell me a bit more about this?

Robert (interview): yes (...) I guess I don't consider myself as a disabled person yet, on the one hand yes but on the other no; as much as possible I do not want to be dependent on technology. I know I am dependent on certain things, there's nothing I can do about that, but on the other hand, if I can not be dependent on them, I won't eh?

For Robert, technology, at this particular stage of his condition, means disability. There is a resistance to the use of technology because it would make him someone else, someone he does not yet identify with. This shows that the

adjustment required to live with a new impairment and with new aids and equipment is an ongoing affective process, a constant becoming.

7.3 Vignette 2: Tonia

‘... little things that make a lot of difference.’

Tonia is a 20+ young woman who works in the customer complaints unit of a disability rights organisation. She has left-sided hemiparesis due to cerebral palsy.

I had interviewed Tonia on the 20th of October 2015, so that it was a year and a half since I last saw her. She was visibly glad to see me again and when I asked her how she was, I was struck by the fact that she felt comfortable enough to tell me about the personal family difficulties she was currently going through. The first part of the session was mainly listening to her story, when she mentioned how important the support she was receiving from family and colleagues is for her to keep going. She also mentioned the fact that she had recently learnt how to drive with adaptations and now that she needs it even more, she is independent in transportation.

Tonia's job consists of managing the complaints that come in to the organisation and so I observed while she worked at the computer, receiving and responding to emails, checking files and responding to the telephone.

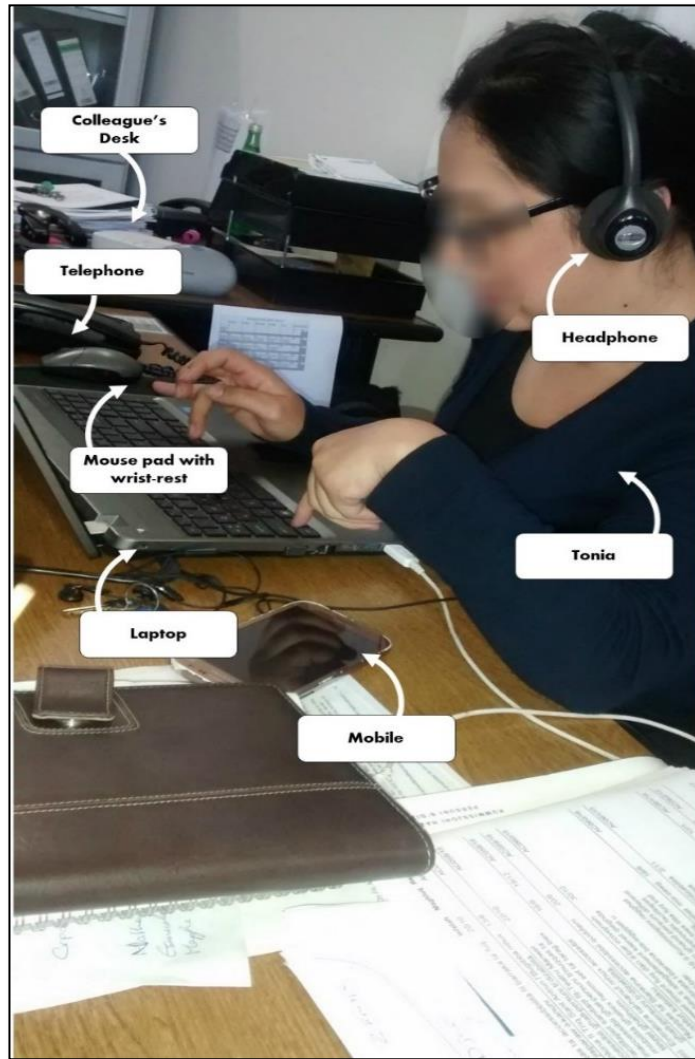
The set-up in Tonia's office is open-plan, with 4 other desks and a big table for meetings. The room is lined with bookcases because it is also a public lending library of disability-related resources. On the day of the observation, the office was empty except for Tonia, since her colleagues were all out doing work outside the office. I commented on this fact and Tonia said that, because it is a separate room from the rest of the organisation's offices, sometimes they are forgotten, for example, during tea rounds. Although she said this with a laugh, I

could feel she sometimes wishes she was physically closer to the rest of the team.

At her desk she uses a laptop on which she types with her left index finger on the left and with all five fingers on the right. The telephone set is also on her right side. She puts on and off the headset by bending forward slightly since she has difficulty in reaching overhead on the left-hand side. This is because of the increased muscle tone on the left side of her body which keeps her shoulder, elbow and wrist permanently bent. She has a mousepad with a wrist rest on the right-hand side of the keyboard and a file tray on the right of the laptop. Her mobile phone is kept close to her so that it is easily available for her to take/respond to calls and messages. The spatial arrangement of the various devices on Tonia's desk enable her to work with the least effort possible. Apart from the clicking on the keyboard and the ringing of the telephone, the office is quiet for the rest of the session.

The 'Tonia assemblage' therefore consists of: Tonia-computer-keyboard-mousepad with wrist rest-headphones-telephone-mobile.

Photo 7.3 Tonia working at her desk



At the time of the observation session, service users with whom Tonia was communicating were also included in the assemblage. At a certain point, for example, Tonia phoned one of the clients whose case she was working on. I could feel how kind she was while dealing with the client. I could feel the great empathy that Tonia's voice expressed in response to the client on the other side. As the conversation was being concluded, Tonia told her client, 'oh, you do not need to thank me; this is what we are here for (...)'. I thought how wonderful it was that the client could still sense the kindness that was being shown to her, even though they were not face to face. In this case, the telephone (technological component) was enabling this conversation that would have made the client's day a bit better (emotional capacity). It seems the client

felt understood and appreciated the kind service that Tonia was offering her. Kindness had formed part, and become a key component, of the Tonia (employee)-technology-service assemblage. In turn, this assemblage had produced the emotional capacities of 'being understood' and 'feeling grateful' in the service user.

On her part, Tonia could efficiently carry out this task because, although she could not use her left arm as quickly or effectively as her right one, yet she was enabled through her headphone and computer to take notes and speak to the client at the same time. The material and spatial arrangement around Tonia was producing in her the capacity to be an efficient employee. The following extract from the interview with Tonia shows the multiplicity of actions that are enabled/mediated through technology and the skills it facilitates in the participant as a worker:

Tonia (interview): yes, I was not aware of them [assistive devices] before I came here; but in this job, because there is a lot of work involved, with this system that they bought for me, with the headset, I could work faster and it was less strenuous on my neck, because I only use one arm and I can type at the same time as I answer the phone.

Researcher: so you are saying that technology has facilitated your ability to multitask?

Tonia: that's right, that's right, yes.

Researcher: and how is it compared to other jobs you had in the past?

Tonia: compared to other jobs I had in the past, I have increased my production; I can be more productive with it and at the same time, because of this technology, the headset that I use, I can understand and (...) I have the telephone and at the same time I am typing, how do you say (...) I can write certain details much better because I can listen and type at the same time, I don't forget, do you understand? I don't have to concentrate on the telephone fearing that it is going to fall from my shoulder/ear etc.

Researcher: so apart from your productivity you have also increased your efficiency; is that what you are saying?

Tonia: yes, that's right, that's right.

This quote shows how digital technologies (especially) not only may enable disabled employees to be more effective and efficient but can also save them

further disability and transcend impairment-related consequences such as pain and fatigue.

This is an example of how technology is used to prevent disability. The absence of components such as pain and fatigue are in themselves producing capacities of increased production in the employee with an impairment. Another capacity that is being produced is the 'remembering' of details from the conversation more precisely. Here technology is enabling in that it is cancelling the time lag between when the conversation happens and when Tonia writes down what has been said. Another important component is the headphones that are worn so close to her body, almost as an extension of her head. This produces the capacity in Tonia to concentrate on the conversation better than when the telephone was an external/mobile device that she had to balance on her shoulder to keep it close to her ear. Other participants such as Lionel and Philip mentioned this above when they showed their wish for more compact devices that could be worn around/closer to the body. The image of the cyborg (Haraway, 1991) and the concept of the posthuman (Braidotti, 2013) are evoked through these 'events' where technology and body become two interdependent components in the disabled employee assemblage.

Colleagues are also an important part of Tonia's assemblage as they bring in an emotionally supportive component which Tonia is very appreciative of, given what she was going through at the time. This component in the assemblage is very important for Tonia. The fact that she mentioned that sometimes they are 'forgotten' during the tea rounds because their office is set away from the rest of the offices shows just how much she values the emotional and social relations with her colleagues.

The following excerpt from Tonia's interview also brings to the fore a particular emotional capacity that emerges from the relation employer-disabled employee. During the interview Tonia told me that she had not had to ask for the accommodations because her employer provided them as soon as she started her job there. When asked how this had made her feel, Tonia had commented, 'the fact that the suggestion came from him, it shows he is aware of these things and it shows that he is taking care of you, so to say.' So the capacity that emerged from this employer-Tonia assemblage was one of

'belonging'. She felt 'taken care of'; therefore, not only provided with devices that enabled her to perform and be a productive employee but one who was made to feel 'looked after' and 'part of the family' at work. As she reported during the interview when talking about other disabled employees' experiences, this 'trait' was not always part of the employer-disabled employee assemblage:

Researcher: have you ever had particular complaints about employers not wanting to carry out accommodations at the place of work? Adaptations or technology?

Tonia (interview): yes, yes, let me tell you, they are usually small things, but the employer would not be realising just how much these little things help; for example, sending notes over via email. (...) the employer does not realise how much this facilitates things for the disabled person (...) the accommodations at the place of work do not usually cost a lot of money, sometimes it is lack of thought on the part of the employer (...) but in reality, most of the time you need little things that make a lot of difference.

Here I realised how the emotional and social part of the assemblage, the person, her personal story, her colleagues and the arrangement of her work setting were all entangled and were all enabling Tonia to continue with her job notwithstanding her personal difficulties. Ability was being enacted within this setting via the various technologies that she was using, but also through her colleagues'/employer's support and the encouragement which she was then able to radiate out to her service users. What she had received, she was now giving to others. The assemblage here was affecting the capacity to show care to others and to receive gratitude.

The data from the interviews and especially from Tonia's vignette brought out two other related important themes, those of technology as 'mediator of action' and 'relational autonomy'.

7.3.1 Technology as mediator of action

This theme emerged most clearly during my observation sessions. It was here that I could see how the assemblage body-technology-environment (physical and social) works as a mediator of action (Gomart and Hennion, 1999) in a complex network of actions and relations without which each component of

the assemblage would remain an individual, passive entity, an entity which can only come to life in the interaction with other human and non-human beings. Every part needs the other to function. Callon and Law (1995), also disciples of ANT, call it a 'hybrid collectif' similar/interchangeable to assemblage since it 'is an emergent effect created by the interaction of the heterogeneous parts that make it up' (p.485). All are interactions which transform/affect.

As Tonia claimed above, the technology in her assemblage had brought out in her the capacity to be more productive and more efficient. She had also commented that it prevents impairment-related consequences such as pain and fatigue interfering with her assemblage. Other participants also commented on this issue:

Norman (interview): at the place of work technology really helps; it really facilitates in one way or another; for example, before I used to input all the work manually and that was more effort, I used to get really tired (...) on screen it is much easier.

The technology component also mediates the capacity to remember, as Lionel comments after having told me about the extensive list of tasks he is responsible for at work, 'obviously I can do all this with the help of the computer because, had it not been for the computer's help, I would not be able to remember all this'.

The same applies to Ann who, in the interview, describes how technology as mediator of action has a knock-on effect on other capacities for other people in her network:

I cannot do without it [technology] at work because I cannot work without it; I use it to do everything, for example, if we are talking about services, my bosses gave me access to fill in applications online, for when people who do not know or who cannot write come to apply for services. Because I cannot see printed material, had I not had the technology, then I would not be able to do this work. That is why I said that I would not have been able to work were it not for the computer. The computer gave me access to printed material; naturally I had to ask for it because before, this option of filling in applications online was not available so I asked my bosses to make this format available so I can fill in the application on the computer, then print it and then the clients just have to sign it.

Here Ann has adapted the present system to her needs and, through her resourcefulness, has changed the network so that other disabled people can access the services more easily. It then seems that the computer has enabled most of the participants to work, just as in Näslund and Qais al Said (2017) it enabled the participants to continue with their studies or in Moser (2000, p.203) where Olav (one of the participants in that study) claims, 'If I didn't have this computer, I don't know how I'd get through the day (...)'.

7.3.2 Relational Autonomy

Because of the various interchangeable terms that are used when referring to autonomy, and as discussed in the Literature Review (Chapter 4), autonomy in this thesis is being understood from a relational perspective and not as an inherent characteristic of an individual. Moser (2003, p.158) refers to autonomy as agency:

agency is not a capability or property that belongs inherently in some exclusive human bodies. First, in addition to humans, many things act, and are attributed agency. And second, many things act together, as agency is made possible and emerges in practices and activities that precisely link many and heterogeneous actors and elements.

The emerging capacities in the participants can most of the time be perceived as relational autonomy and have been described by Tonia and other participants as 'independence'. This they depicted as either self-sufficiency (doing, without needing anyone else) or self-determination (being), which very often go hand in hand.

Philip (interview): (...) recently I had this [blind] client who told me 'I want to learn how to use You Tube.' So I stayed here quietly, (...) I considered the best way to do it and I showed her and she learnt how to use You Tube. So it was quite an experience and I felt pleased that, through this work, I am giving something back.

So, work for Philip is not only about 'doing' and earning his salary, it is also about 'giving something back'. There is an element of reciprocity, he gives and receives back. In this interaction, however, both client and Philip are changed, they have both increased their 'doing' and their 'being'. They have

become different beings. For the participants, technology not only enacted what they could do (mediator of action) but also who they could be (Mol, 2008).

Tonia (interview): being independent for me means that I do not need anyone else, for example to take me to places or if I have some errand with my daughter, I can go and do it myself; I can go to work on my own; that sort of thing, for example, the car, learning how to drive, was essential to me; when I was younger I used to think I will never be able to drive and I sort of was very sad about it because you see everyone else driving, you see them doing certain things and you cannot do them; so that was the thing I was most looking forward to and, that whatever the cost, I wanted to do it, to succeed in doing it, however much time it took. And it took me three years [chuckle].

Researcher: you had felt it was diminishing your self-esteem?

Tonia: that's right, that's right, that's exactly it!

And Vincent had this to say about the topic:

Vincent (interview): (...) at work I use a powered wheelchair because if I use the manual wheelchair, it would be difficult to carry files around. I would still end up asking my colleagues to pick them up from the floor for me [smiles] (...) and this is not a matter of pride, but as much as possible I like to be independent. (...) it is giving me the possibility to have greater independence, in the sense that I don't rely on other people as much as I would without it.

Andre's story in Winance (2006) and Petra's story in Struhkamp *et al.* (2009) are very much like Vincent's in that, through the devices they use, the people who would otherwise be helping them are released to do other things, and so technology is also seen as a bridge between immobility and independence (not only theirs but other people's as well). The autonomy that the technology-disabled person assemblage affords is also considered by the participants as 'liberating' and as providing a sense of satisfaction and accomplishment. At the same time, this liberation does not come without a price. As Gibson *et al.* (2017) assert, it means hard work for the participants and can never be taken for granted:

Researcher: and when we were talking about driving during the focus group, you also mentioned you feel a sense of liberation (...)

Miriam (interview): apart from my legs, that is if we are going to count them as technology, yes, they give me a sense of liberation you know, that is why I feel bad when something goes wrong with them; I remember once recently when I was driving and it was very hot (...) and this was the first time it happened, with the sweat, my leg came out of the socket and I panicked at that moment because I rely so much on them; I really don't think about them and when it came out and I was driving and I had my friend with me, at that moment I felt 'oh my! I am really depending on these things!' so yes, they do give me a sense of liberation and so does the car in itself; when something goes wrong with the car, really [emphasis], it is as if you have amputated my hands and legs again. Every time I get in the car, yes that is the word, liberated (...) that I can go from A to B, that I don't have to depend on anyone (...) Probably this comes from the fact that since I lost my legs, this has diminished my independence a bit but the car, you know, it 'gives you a ride' on that independence'.

And Ann (interview):

For me, independence through technology means that you don't depend on other people; that you are not all the time ordering people about, 'do this' 'do that'. I know that I will never be 100% independent because the impairment will remain but at least I know that, as far as I can, I can be independent; when I can do something myself I want to do it myself, even if it takes me twice the time someone else would take when doing it for me, but still I would want to do it myself (...) because that gives you satisfaction at the end of the day.

Harold also commented on this during his interview:

Researcher: and you said that this technology for you means independence. Can you tell me a bit more about this?

Harold: independence for me means that I can do those things that with the abilities that I have I can do. And through this technology that is more advanced than the mainstream, I can find that help that I need to do these things because mainstream technology is more suited for non-disabled people while I need that little bit extra help (...) and that to me means a lot even with regard to my self-esteem. I believe that along the years it has helped me a lot because, before, I used to be more dependent on my parents while today I feel that the fact that I am not as dependent as I used to be has helped me also in my self-esteem.

Harold and the others are indicating that it is more dignified to have human-non-human assemblage rather than human-human assemblage. In a study by Jonsson and Hedelin (2012), men with hearing impairments reported that their self-esteem was affected because of their need to be connected. With the help of hearing/conference devices 'I could hear everything (...) it was an enormous difference (...) it was completely different to be able to participate in the entire conversation.' (*ibid.* p.320).

Researcher: and then the computer, what does it enable you to do?

Etienne (interview): it enables me to check out the economic system across the world; especially when one wants to invest locally or overseas, because that is my world, my cup of tea; and so at least I know what I have to do. I know how to do it on the computer and making a phone call locally or overseas I can do that (...) even contacting somebody and checking that everything is ok with the system: some stocks or bonds, on the computer, on the phone I can clarify certain things; it makes me feel good.

Being connected and being in control bring out in Etienne the capacity to feel good. Autonomy is about being in control. It is therefore not only about function but also about identity and emotion. Autonomy is about the ability to affect. What the participants are revealing is that so much of the entanglement in the network is psycho-emotional and not structural. This is why it is difficult to solve all disabled people's problems by simply removing the structural /societal barriers. This is an important implication for the SMD (Thomas, 2004a), which will be expanded upon further in the next and final chapter.

Other participants reported that being self-sufficient does not necessarily mean not needing anyone else:

Researcher: but you still need the help of a personal assistant?

Avril (interview): yes, that's right, to bring the things over for you and so on; but in the evening, for example, I am on the bed say from 9pm till 1am until we go to sleep; once I have a table next to me with the iPad and the mobile and the TV remote control (...) that is all I need for 3-4 hours, I don't need anything else.

And Duncan:

Researcher: you said that since you acquired your visual impairment, you had to stop going to meetings in the evening, so you had to adapt (...)

Duncan (interview): exactly. But the other side of that was that whoever thinks they need me to go to a particular meeting, they come, get the car, take me and bring me back and so we are both served (...) my boss told me, 'as much as possible we will continue to work hand in hand'.

After having listened to my participants I concluded that, for the Maltese culture, the term 'relational autonomy' (or interdependence) is more suitable than the term 'independence' because of the close-knit relationships with families and friends whom disabled people are still (inter)dependent on, notwithstanding the capacities that are affected through technology.

7.4 Vignette 3: Ray

'for me, feeling degraded is the worst thing.'

Ray is a 30+ year old young man who has quadriplegia due to a diving accident he had on his 16th birthday. He is employed as a customer care officer in a government department.

When I visit him, Ray is sitting in his powered wheelchair behind a desk with a computer screen in front of him. He is set up in a small room that is the first place where clients of the organisation he works with go, whether they come personally or contact the organisation via email or telephone. In front of his desk, Ray has two chairs for clients to sit on while they are being served. Outside of his office a few other chairs form a waiting area.

Ray's job is to filter the customers' requests; whatever he can deal with himself, he does and, whenever it is a more complicated case, he passes it on to his colleagues in the inner offices. He acts, therefore, as a gatekeeper, preventing the public from just going into the offices and wander around as they please.

Clients come in and out of this office continually and Ray deals with all efficiently. I could see that some of the information being given to clients has to be repeated many times a day and so Ray was tending to just quickly pass on the information in an almost tape-recorded fashion. I could also hear his low voice and the need to stop and catch his breath at times, as a consequence of his impairment.

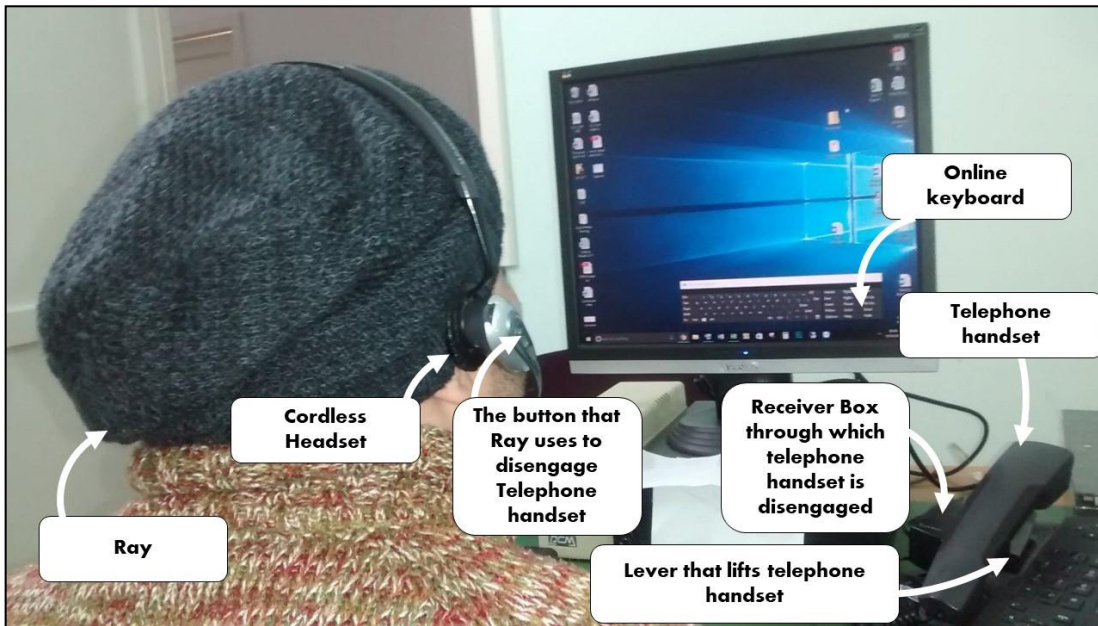
Ray uses a standard mouse but holds it at an angle such that he steadies it with the palm on the side of the little finger and then clicks onto the right and left buttons with the little finger of his right hand. He also uses a cordless headset so that he can reply to the telephone whilst using the computer. On the right-hand side of the headset he has a small button which he clicks on with his right hand to disengage the telephone so that he can reply without the need to hold the receiver with his hand. Because of his quadriplegia, Ray told me, he gets easily tired if he has to hold a receiver for a long time. The fact that it is cordless also enables him to move from his desk and continue speaking on the phone.

The telephone set has a little receiver box attached to the side of the set which receives the message from the button on the headset and clicks up a small lever underneath the telephone headset. This gets disengaged from the set so that Ray can phone and reply independently. Ray said he uses the small online keyboard for short emails and the standard keyboard when typing longer emails or documents; this he does by using his knuckles to type on the keyboard buttons. Both his hands are clinched tight because of the increased muscle tone.

The components of the 'Ray assemblage' here are:

Ray (including his low voice, shortness of breath and tight hand muscles)-
powered wheelchair-keyboard-mouse-computer-cordless headset-telephone
receiver-telephone set-service users-colleagues.

Photo 7.4 Ray and his set-up at work



The devices he is using allow Ray to transcend barriers resulting directly from fatigue and spasticity in order for him to function as a competent employee. He does not just sit there waiting to be set up, but is active in solving IT problems for himself and for others in the office. He does not only receive, he also gives. He tells me that, because he has an IT background, he ‘always find[s] a way to solve any technical problems that crop up with these devices’. While I was there in fact he went into his boss’s office to repair some fault in his computer set-up. Ray comments on the fact that a more complicated arrangement does not necessarily mean a more efficient assemblage:

Researcher: Ray, you said that at work you always try to keep your computer as basic as possible. Why? Did I understand you well, that you try not to install too much assistive technology?

Ray: (...) yes, because I have a background in IT and so for example if I get something from Apple, then everything else is from Apple, don’t mix up; (...) because then it conflicts or it does not install immediately and a lot of such hassle; and by time if it breaks down, you end up at square one, to repair it I mean, so I like to keep it simple with things from Windows, maybe with some simple adaptations.

What was interesting in Ray's set-up was that within such a small space so many things were going on; he was carrying on with his work in an efficient and effective way because of these devices – and they were all invisible because they were all working reliably. One could not tell that a disabled employee was responding to the phone or working on the computer unless they were actually observing closely. Disability disappeared unless one or more components malfunctioned. Disability is thus not a permanent state for Ray. It depends on the configuration of the set-up and the relations within the assemblage.

I reflect how the little buttons and hardware that Ray uses are the visible technology while the connections are much more complex than that and spread out far wider than the tiny room he is in; through the internet connections and the telephone lines, through his colleagues whom he called when he needed something from the inner offices or when he needed help with toileting - the networks reached out much further than the four walls of his small office. This is a clear example of what Moser (2000, p.225) calls a 'hybrid collective' - a collective/assemblage in a network that has affected new capacities for Ray, making his body boundaries fluid through the materiality of cables and virtual networks.

At a certain point, Ray brings up an issue that really 'matters' to him:

I wish I had more gadgets here [at the place of work]; not necessarily those that have to do with the computer or the telephone, but others (...) for example, one task that I struggle a lot with, is to open my catheter bag to empty it. I manage to do it but I get all sweaty, so I only do it when I am in dire straits. And I often ask, 'Why hasn't anyone come up with a gadget that can help with this task?' I really think about these things (...) When I tell my boss, he says, 'Oh just ask one of your colleagues to help you' (...) he cannot understand that it is not only about productivity, about being independent from your colleagues; it is also degrading, for me that is the worst thing.

For Ray, this is not just about getting the task done. For him, in this situation, the emotional component is much more important than the physical one; 'being' is more important than 'doing'. As Latour (2004, p.231) proposed, bodies are not just 'matters of fact' but also 'matters of concern'.

Ray considers what is at stake when he has to ask a colleague to help him empty his catheter bag. Here is a very relational situation which is not only about a 'hard-to-open' valve in a catheter bag and a colleague as a mediator of action, but it is also about Ray's 'feeling degraded'. This arrangement is therefore both enabling and disabling at the same time; dis/ability is being negotiated and re-negotiated in a very relational manner. Here is a situation where dignity and function interact to produce a different Ray from the efficient employee we saw at work further up.

This experience leads to another important theme that emerged from Ray's and various other participants' stories; this is the stigma related to the use of AT.

7.4.1 Stigma and 'Fitting in'

Participants felt that because of their assistive devices (or because of having to request them), they were standing out at the place of work. Stigma occurs when the use of accommodations or the request for them is seen as the individual's problem and when the individual is compared to the norm, to non-disabled bodies. An important theme here, is therefore, deflecting stigma, that is, the management of stigma as a theme around the concept of 'fitting in'. As mentioned in the literature review for this study, Garland-Thomson (2011) signposted the event of 'misfitting' as a relational one.

Misfitting (event) and the consequent stigma ([in]capacity) are produced when the interaction between social and technical (components) such as bodies, technologies and environment, does not 'work' as expected. This brings us to the concept of stigma. The thread of stigma is difficult to extract from the fibre of society's (or in this case, the workplace's) networks. It can be considered as the (in)capacity produced when 'employees-with-an-impairment-AT' assemblages interact and come to 'stand out' in the workplace. This disables them in more ways than one, as shall be seen below. In the participants' experiences, one can see that stigma at the place of work can be lessened via, for example, the integration of accessibility features in mainstream technology (Harris, 2010). It will be noted that stigma is not so much attached to medical equipment as it is to AT, and that there is a perceived difference

between the use of digital technology (which looks mostly like everyone else's) and analogue devices (which are more visible). Therefore, certain technology, at a certain time, in a certain place, can turn misfits into fits and vice-versa. Stigma is as material as it is social, in the sense that it produces exclusion.

For example, as Etienne's condition progressed, he started using a wheelchair and his impairment became more visible. Since his work consisted mainly of interactions with customers, his bosses started to insistently 'hint' that 'it would be better for him' to stop working. He eventually resigned because he could not take the pressure. To date, he is still unemployed.

Stigma also depends on the type of technology disabled people are using. The experiences below demonstrate that some technology makes disabled people look more 'visible', look more 'different'. An example of this is Robert's debating whether to continue to use an office chair to walk with or whether he should start using a rollator at work. Using the chair looked more normal but was noisy so it was attracting colleagues' attention to his impairment. The rollator, although more silent, would remind him and his colleagues that he is now disabled. This equipment helps disabled people's function (doing) but the stigma that is associated with its use may also affect their identity (being). Stigma becomes a component in these assemblages. It has 'affect', but in turn can be challenged/'affected', via resistance, such as certain configurations of human-technology that disrupt stigma even if it is present (Robert-office chair above).

Although not focused on the workplace, other studies reported similar findings. For example, McMillen and Söderberg (2002), in their study about disabled people's dependence on assistive devices in Sweden, found that some of their wheelchair user participants experienced a changed reception from the people around them, at times feeling they were in the way and having to apologise for it. Ravneberg (2009) also reports on a young man who insisted on using crutches even though using a wheelchair would have been less tiring for him. He considered the wheelchair as a 'stigmatised means of transportation' (*ibid.*, p.106) that indicated the permanence of his disability.

The following excerpts show just how much stigma is still existent among disabled people themselves and among the people around them. It was interesting to see that most comments on the subject came from people with either physical or visual impairments. This might be the result of such impairments being the more visible amongst impairments. This was highlighted by Terence in focus group 2:

For us [Deaf] it's not about technology, it's about people getting to know some basic sign language, more awareness, that they know a bit more about the Deaf.

Participants' contributions also showed that there is an informal hierarchy among the different types of devices, so much so that one participant said she was lucky to be able to stand and walk with crutches rather than having to use a wheelchair:

Daphne (interview): On average every three years I moved from one company to another. Disability never seemed to be an issue (...) ever (...) but I think that, because I always walked into an interview and quite often I had to walk up a flight of stairs to get to the interview room, people were generally satisfied that I was not going to be particularly traumatic [chuckle] for them to fit into their organisation. I had friends who used wheelchairs who found it much more difficult, but I, by using just crutches, was never in a position where I was discriminated against and I think, apart from one job interview, I always got the jobs that I applied for, so I was very lucky. (...) I think that throughout my career I found that because I walk and because, apart from the fact that I am very short which actually does not affect you that much if you are sitting down doing a desk job, er (...) I've been very lucky, very lucky.

Researcher: you said something 'because I use crutches and not wheelchairs' so you think different technologies pass on different messages?

Daphne: absolutely, absolutely, there is a huge perception of difference. (...) fortunately for me employers don't see a pair of crutches in the same way as they see a wheelchair. I think that they perceive that a wheelchair will mean that people will have problems getting around buildings because of lifts and stairs and things like that and they will have problems getting into toilets, and the perception of additional cost and risk that is associated with a wheelchair is so much higher than when you use crutches. Because I think that even an employer would say that all that you use crutches for is to help you walk, and

walking is something that they are comfortable with. So if you can walk you are at a huge [emphasis] advantage looking for work and getting around in general (...) I don't really use a lot of devices. I've been very lucky; chairs and foot stools and hand controls were all I needed [laughing].

Daphne is implying that employers can 'understand' crutches more than they understand wheelchairs. This is an example of the messages that these devices send out, and how they are interpreted by the other components in the assemblage. This is because technology is not just about function and doing, it is very much imbued with meanings, interpretations, and social characteristics (Hocking, 2000; Woods and Watson, 2004).

Vincent (interview): I think that it [people's attitude] has improved a lot but maybe what makes a difference is the mentality of your workmates (...) not everyone accepts you because they see you are different, they don't treat you as one of them because you use a wheelchair (...) er (...) still, personally, here I don't have any problem but in other places I think there may be problems (...) I feel it is discriminating to be treated differently and this is not a matter of pride but I think that it is very important that one is treated like everyone else, you know?

Colleague perceptions here are affecting inclusive or exclusive relations at work. For his colleagues, Vincent-wheelchair assemblage at work could be different than Vincent-without wheelchair assemblage, depending on the meaning that wheelchairs have for those colleagues. Vincent wants to be treated like everybody else: to be invisible in the network. In order to make this happen, disabled employees use self-made strategies, even if these take more of their time.

Examples of this include Robert using an office chair to walk with instead of a rollator (which is more stable and safer enabling him to move faster), or Etienne preferring to type one-handedly rather than using a speech-to-text programme. As they implied, they prefer to do it this way because it is closer to what they used to do before their condition regressed. It looks less 'weird'. Other studies have yielded the same findings (Söderström and Ytterhus, 2010, p.303) because these devices become 'symbols of identity and belonging'. This is what matters to Etienne and Miriam as they explain below:

Researcher: can you tell me about that experience of using the speech-to-text program?

Etienne (interview): it was an interesting experience, but I was not as willing to use it as I should have been. I used to think, 'What am I doing speaking to this computer?' it was so strange you know? (...) unfortunately, I am not using this software any longer.

Researcher: so how do you type now?

Etienne: I use the manual keyboard, and basically, I am right handed but now I use my left hand you know, one letter at a time. I move along slowly (...) but I've put the Dragon software aside.

Researcher: and you mentioned that for you it is sufficient to use the laptop keyboard rather than using particular assistive technology?

Miriam (interview): personally, I do not use any extra-terrestrial things [laughing] (...) Even if you go for an interview on a wheelchair or with a white cane or with a guide dog, I think it's as if you've fallen from the sky.

With her choice of words like 'extra-terrestrial' and 'as if you've fallen from the sky', Miriam brings to the fore the fact that disabled people have historically been looked at as not being fully human (Swartz and Watermeyer, 2008). Disabled people then internalise these disabling discourses as added components to their assemblage. Internalised oppression becomes part of that assemblage. In turn, this then impacts the way they are received when they request technology that is different from their colleagues':

Researcher: and you mentioned that in your previous job when you requested a laptop instead of a personal/desk computer, you did not have such a pleasant experience; can you tell me more about it?

Miriam (interview): yes, it's like I had to (...) I remember that the department I had started to work in was relatively new; there were 4 of us, and they had to buy new equipment for us because it was a new department and the policy was that they bought desk computers for everyone. When I mentioned that I prefer a laptop (...) I had to explain and re-explain myself which unfortunately made me feel very uncomfortable. I was just out of university and I had never had any experience of working in a government department before and the fact that I had to explain myself and make a case why I needed a laptop, that surely does not cost more than a computer, I felt (...) yes, I remember going home

rehearsing how I was going to tell them that I needed a laptop, as if I had to make a good argument. It wasn't a pleasant experience and also, perhaps, because it was my first job; today I have more confidence in myself, er (...) I know how these things go and I would not think twice if I had to say 'Listen, I need a laptop to work', but in those days because it was my first job I found myself in a difficult position because I used to think, 'What if they tell me (...)', I don't know, they fire me; you know you start getting these thoughts (...). and I'm sure that there are people out there who maybe do not have the support that I have, or who do not know their way around, or who do not know their rights; that this is reasonable accommodation, if I am asking for a laptop. Yes, maybe they are given a computer and then they do not give their maximum, they then tell them 'Because you are not giving your maximum' and it becomes a vicious circle.

It is in fact a vicious circle. Not being provided with accommodations and technology, not knowing their rights, or not having enough assertiveness skills, leads to their not giving their 100%. This in turn leads to failure to succeed at work leading to their job being terminated, with the disabled person feeling even less agentic/affective. Through knowing about these experiences, Miriam is guiding us through the traces of the past and what shaped her to be what she is today at work. As Sismondo (2009) puts it, 'agency is an effect of networks not prior to them' (p.90). Here we see autonomy as an always emergent, constantly shaping capacity because the disabled employee is being transformed/affected by the experiences/events she has had in her first job.

Miriam (interview): No, it was not a pleasant experience, but I also learnt a lot from it.

Researcher: you said you felt you almost had to beg?

Miriam: yes that's right, disabled people go through this a lot I think to achieve what is expected of them. In the end I am not asking them to send me on a rocket or to send a taxi for me at home! You know, these are normal things and the fact that you have to beg for these things, obviously yes it decreases your confidence, it affects your output at work, I think it makes all the difference.

Miriam is here indicating that by decreasing 'your confidence' these experiences shape you into a different person. They close up the opportunity for the disabled employee's capacity of becoming/continuing to be an efficient

employee. Another point here is that, because of stigma, whatever disabled people ask for is considered extraordinary or unreasonable, simply because it is coming from someone who is 'not in the norm'. Emotions like 'feeling less confident' and 'feeling different' become components of the disabled employee assemblage and affect/exert their influence on what s/he does, on who s/he becomes at work and beyond.

Other participants have described their requests for accommodations at work as a reminder to them that they are no longer 'in the norm', leading them to view the need for AT as a 'symbol of deterioration' (Pols and Limburg, 2016, p.369):

Robert (interview): (...) because I know that I limp, but sometimes I see other people who limp and I say to myself, look how strangely that man walks. And so I think that other people are thinking the same thing when they see me. So the less I stand out the better, I think.

Etienne (interview): (...) before, Vickie, even going to work with a stick; because before the wheelchair, I was able to use a stick; I was afraid to see people or have people see me walking with a stick; you know it was always in the mind psychologically; you know I was always petrified.

Researcher: you didn't want people to see you walking with a stick?

Etienne: you know I was a graduate, you know I was able to do things by myself, so how could I (...)? I already looked like an old man you know with a stick; you know what I mean (...) we started at 8.30am; I used to go there at 8.10am to ensure I was on my own.

Researcher: so that nobody saw you (...) do you still feel like that about the technology that you use?

Etienne: no, now it is getting better; if people don't want to see me like that, to hell with them, er (...) it's their business.

Here Etienne is associating the use of technology with old age showing that the stick does not only have a material meaning but a symbolic one! So the disabled person-technology (assemblage) makes these two components actually become someone/thing else (Etienne-stick = old man; the stick becomes a 'symbol of old age' instead of a 'mobility aid') and this results in stigma (both within the disabled persons and the people around them) being

attached to them. It is also interesting to note that, as the disease progressed, even Etienne's attitude 'progressed'.

Similarly, Pols and Limburg (2016, p.362) mention this issue with regard to the participants with Amyotrophic Lateral Sclerosis in their studies, 'The feeding tube [just like Etienne's walking stick and wheelchair, or Robert's rollator] becomes a different thing as patients move through the various phases of their illness, due to changes in their condition, living circumstances, and concerns and values'. Etienne later claims that this shift took place thanks to meeting with other people who have the same condition (at an NGO); there he realised that he was not the only young person using these aids and equipment. This helped him to become more self-determined by time:

Researcher: can I remind you about something you said earlier (...) when you're using the wheelchair, the stick, you said you didn't want people to see you (...)

Etienne (interview): I would ignore them now (...) now they know my situation, if they want me in, in the place of work, they know that they will have to accept me with all that I have.

Elias (interview): because in [name of locality] I am unique [having a guide dog]. (...) the others all hide it and try to say they can see, we still have a big problem in [name of locality]. (...) I'll give you an example with [name of another participant in the focus group]; she does not walk one block, or across the street, or go to church about 200-300 metres in all, she does not do it alone.

Researcher: she has to hold onto someone?

Elias: yes. She doesn't use the stick because she is too shy. Then she tells me, 'it's because we are women eh!' (...) because they are women, they feel shy, and I tell her 'just go and get on with it' [chuckle]; I tell her, 'just get on with it'.

Elias is being identified through his guide dog. On the other hand, Anne (and others) are trying to go on playing what Goffman calls the 'normalcy show' (Goffman, 1971, p.282), 'a show in which all participants have the task of acting unfurtively' (*ibid.*, p.331). This, Anne is doing through what she considers to be appropriate gender behaviour. As in Moser (2006b, p.539), I can claim that 'dis/ability was not the only difference being made - or unmade - in the data that I collected'. Here, gender is intra-acting with dis/ability and is negotiating and

mediating the decisions that Anne takes regarding the use (or non-use) of assistive devices. A similar example is found in Näslund and Qais al Said (2017) where blind women find it hard to use the white stick because of gendered values and traditions. On the other hand, in Hoogsteyns and van der Horst (2013) two women who use arm prostheses claim that they can 'pass as normal' when their prosthesis is on, something which they cannot do when their prosthesis is off (p.67). Along similar lines, when participants spoke of technologies that were actually implanted in their bodies, these were presented as technologies that normalise. Robert's baclofen pump, for example, affects a reduction of muscle spasticity such that he is 'reconfigured' and can continue to walk (thus making him appear 'normal') without other assistive tools (which he felt would have made him appear 'not normal'). As also mentioned in the studies by Struhkamp *et al.* (2009), Mauldin (2014) and Dalibert (2016), these devices do not cease to matter even if they are not visible from the outside.

The participants' stories above lead to an important reflection. Whilst agreeing with the SMD that a person with an impairment is not inherently disabled but becomes disabled because of her/his interaction with the environment (in its widest sense), the concept of stigma and misfitting pushes this further, in regarding dis/ability as a shifting, relational concept which is as material as it is social (as in new materialist thinking).

7.5 Vignette 4: Elton

'without it [technology], I don't know where I would be right now.'

Elton is a 30+ year old young man who has a severe visual impairment due to a progressive condition since he was 21. He works in a government department as a research officer. His desk is one of five others arranged around an open-plan office.

Elton was typing away at his computer when I arrived. He greets me and asks whether I would like something to drink. I say I'm fine and he tells me that,

when he wants to make a cup of tea, he uses a liquid level indicator whose beep indicates to him when he has filled his cup sufficiently. He says this with a certain pride in his voice.

He then shows me his set-up which includes an anti-glare screen on his right side and a standard laptop. He tells me he goes around the offices using a telescopic white stick. Then he bends towards his bag to get a toolkit with extra accessories which he carries with him all the time. He shows it to me and explains its contents which include a rounded tip for the end of the stick and some extra elasticated band just in case the one in the stick breaks and he has to replace it. Whilst he is working, he places the stick leaning on the cupboard behind him. Elton brings out his tablet from his bag and places it carefully near him on the left-hand side of his desk. He says, 'this is my library, my notetaker, it is my eyes, wherever I go it comes with me'. He explains to me that he also has the Kindle installed and another app called iBooks from which he can download articles and other documents. He says he also uses the tablet as his scanner. He can enlarge and shrink the font as much as is necessary for him to read pdf files comfortably from it.

He proudly shows me another app called Aipoly which he can place over printed paper and it reads aloud to him, or he can switch to inverted colour mode to read himself. It is also able to read the colour of the object he places it over. He says it helps him in the morning to match his clothes. I comment that it is fantastic but, chuckling, he says, 'Yes on the advert it looked fantastic but in reality it does not always work'. He says the fastest way he found to read printed material is to take a photocopy of the document, scan it and send it by email to his laptop or iPad to read later. In this way he also converts pdf documents which the screen reader would not be able to read since they are interpreted as images. He opens his tablet and switches it on. I notice that he uses an inverted colour option to view the writing on the screen. I ask whether he also uses the text-to-speech option but he says he rarely uses it since the inverted colour mode is more practical for him. This confirms what he had told me during his individual interview, 'I use the settings on my personal computer to switch to high contrast mode. It switches the background to black and the

letters to white because, with my condition, I cannot tolerate bright light and glare. In fact I avoid computer screens with a white background and when I go out, I wear dark sunglasses.'

He pointed to his mobile phone and said that he does the same thing on it, 'I use an iPhone because it has the invert colour as a feature and when I come to dial a number to phone, you know, the numbers are white on a black background, and this really makes my life much easier. My mobile has no other special software because the accessibility features I need are all integrated within it.'

The phone on Elton's desk rings. His colleague needs to check something with Elton in order to reply to the caller. I notice that, because of the anti-glare screen installed on his right side, his colleague who sits at a right-angle with his desk, has to come to the front to speak to him.

He works for a while on his laptop and then it is time for him to go to a meeting in the chairperson's office which is next door to his. He rises slowly from his chair, turns around and reaches out for his white stick. He walks carefully, swinging his white stick in front of him. The sound of the stick hitting the door jambs or any other obstacle guides him through to the other office. A colleague quickly grabs a bag that has been left beside a desk and without a word places it closer to her chair so that it is out of Elton's way. When he enters his boss's office, Elton is in fact guided to a chair with the help of another colleague and he sits down. During the meeting Elton uses his tablet to find a presentation which he promises to send to the other team members, and participates actively in the discussion that ensues regarding the improvement of training courses that are delivered regularly to their clients.

I observe that, although Elton's movements are slower and more careful than his other colleagues' because of his impairment, he is able to participate fully in the day's work. Technology, which, as he commented earlier, had become 'his eyes', has enabled in him the capacity of becoming who he is today:

Elton: Let me put it this way, technology means, one, independence and two, apart from independence, it makes your life easier (...) I think without the technology I wouldn't even have my first degree [laughing]; let me tell you, without it, I don't know where I would be right now! I don't know who I would be now!

The components of the 'Elton assemblage' therefore consist of: Elton-anti-glare screen-standard laptop-iPad-iPhone-accessibility features in laptop/iPad/iPhone (e.g. high-contrast feature)-apps (Kindle, iBooks, Aipoly)-white stick-spare parts kit.

Photo 7.5

Elton's Desk Set-Up

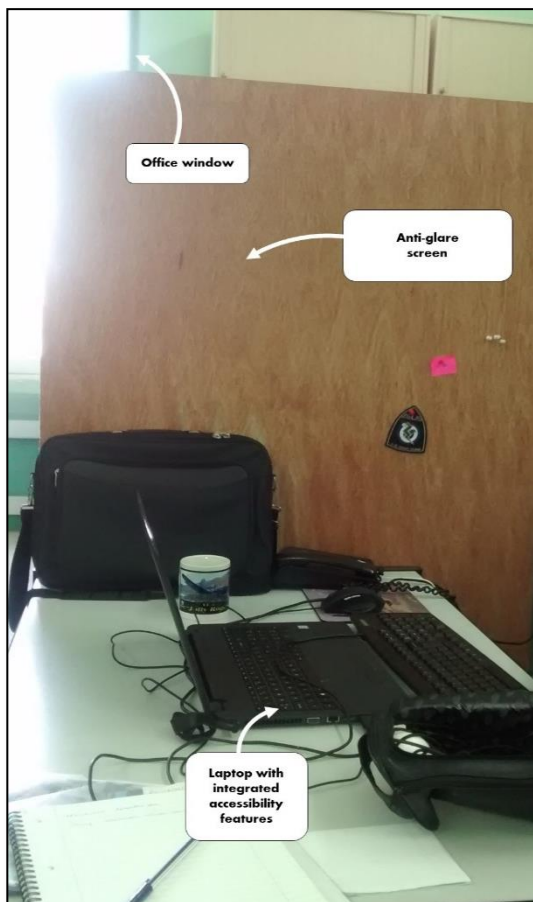
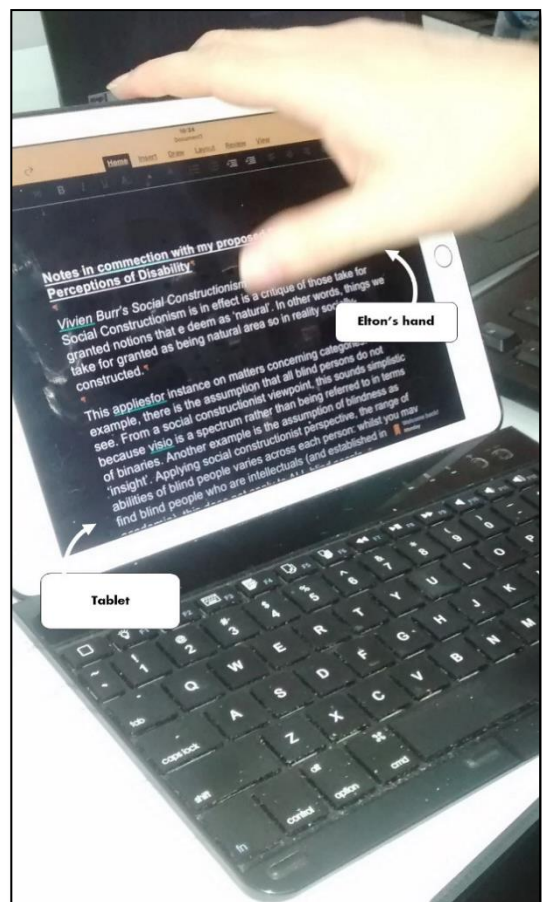


Photo 7.6

Elton's Screen with Inverted Colour Option



The spare parts kit that Elton has to carry around with him is a reminder of the fragile and transient nature of the technology he depends on. 'Planning ahead' and 'being resourceful' are capacities that emerge from the Elton-technology-workplace assemblage and which enable him to be an efficient employee. In the Elton-technology assemblage, the spare-parts kit can be seen as an alternative component which Elton can 'plug into', if the current technology component breaks down.

These alternative resourceful skills and strategies emerge from the 'misfitting' of people with impairments (Garland-Thomson, 2011) which people who are not-yet-with-impairments have not developed to date. Elton in fact commented that the accessibility features are not only useful for people with impairments but can be comfortable for all. 'Last time, a technician from IT Services came to adjust something on my computer and he told me, 'Elton do you know how comfortable it is for me to work with your setting? I spend hours working in front of the computer, so this will be useful to me because my eyes tire less quickly.' The presence of this disabled employee with his adapted way of working has affected an enabling opportunity for his non-disabled colleague when he temporarily interacted with the Elton-technology assemblage.

At times, however, disabled employees find themselves having to negotiate between an arrangement that is enabling for them but is disabling for their colleagues. The desk set-up with an anti-glare screen is enabling Elton to work comfortably because he cannot tolerate strong sunlight. Here 'climate' can be considered another component of the Elton-work assemblage. The anti-glare screen, however, is hindering the interactions with his colleague who sits at the desk next to Elton's. She in fact has to come to the front of his desk when they need to exchange documents and other such tasks. It is a negotiation that he has to make, even if it is not the perfect solution. As shall be seen below, this is a negotiation that his colleagues understand. Elton's being in that workplace has affected 'caring' and 'sensitivity' capacities in his colleagues which they would not necessarily have developed had Elton not been there. They are also, however, capacities that emerge because the colleagues (as components of that workplace assemblage) are open to develop in their relations with Elton. This is also seen when he moves from his desk to go to the meeting next door.

His manoeuvring around the office is not just his business. His safety is everyone's business. The bag that had been carelessly left in the passageway, is removed by another colleague before Elton could stumble over it. The action is so quick and quiet that it showed just how much the relations in this place have become entwined in all the colleagues' daily work life. This is a reciprocity that Elton had not encountered in his other places of work, as he had told me in his interview while sharing his experiences with previous employers. This 'caring' capacity seems to form part of the current workplace assemblage and extends to the other office where the meeting is to be held. But this 'caring' is not unidirectional. Elton receives, and he gives back.

This has been noted in the majority of the participants' stories, where interdependence or relational autonomy was highlighted as being a characteristic not only with regard to the employees with an impairment but also with regard to all who work with them. The entire workplace network is transformed/affected. This is a characteristic that employers need to become more aware of, if they are to become enabling components and mediators at the workplace. The assumptions in employers' minds act as barriers and close up opportunities to disabled people's accessing and retaining a job. They do not allow them to see the potential capacities in disabled job-seekers. Elton's vignette is a testimony of this.

7.6 Conclusion

In this chapter, we have analysed the body-technology assemblage in the workplace through the eyes of the participants and the researcher. We have seen how disabled people are being shaped by their technologies at the place of work but also how they, in this form (body-technology), are shaping their place of work and the people therein. We have seen the productive and transformative potential of these assemblages in their ever-becoming event-forms.

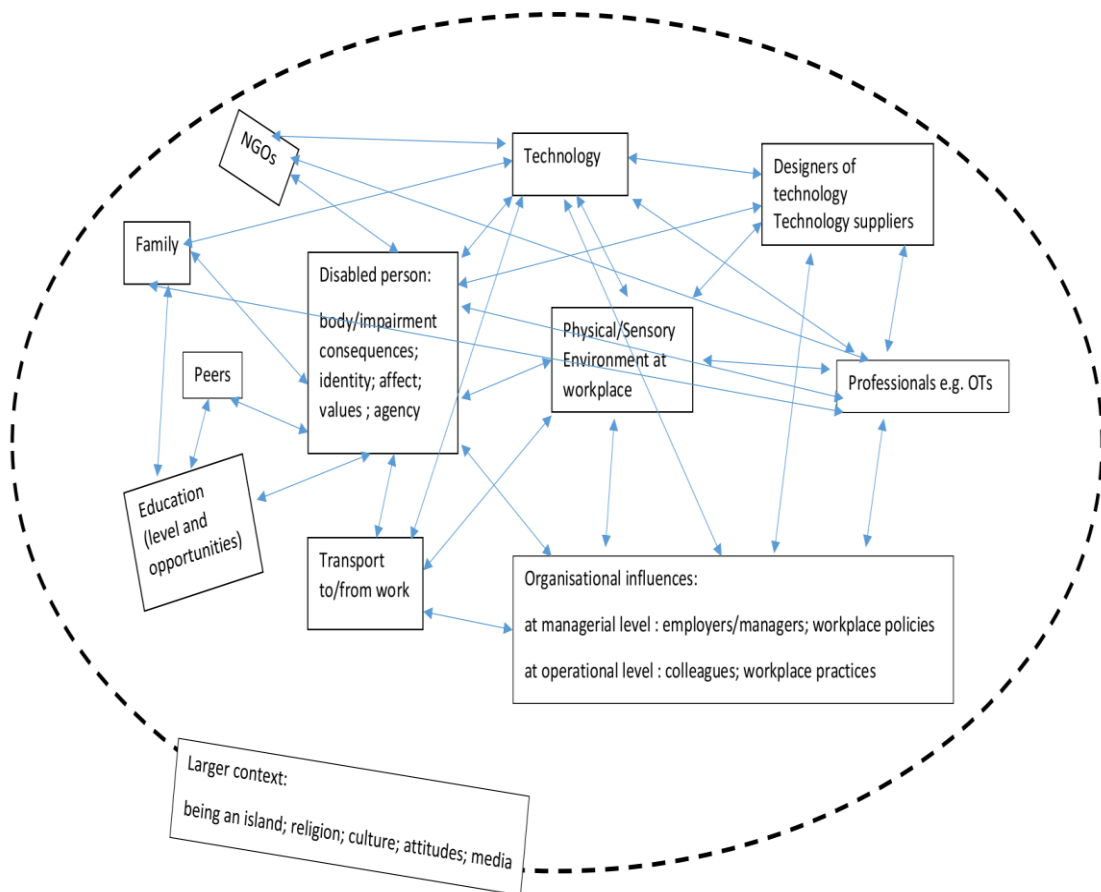
We have also seen the person-technology assemblage become the person-technology-environment (human and non) assemblage and how these get entangled together to continue shaping these disabled employees' experiences at work. The stories highlight the multiple linkages and relations

between the assemblages in the network and the capacities that are produced thereof. They also draw attention to the variety of psycho-emotional components that further entangle the person-technology-workplace assemblage. The capacities produced from the assemblage have been seen to go beyond the 'doing' with their devices. They included feeling grateful, liberated, being taken care of and being kind. They also included, however, feeling frustrated when their technologies broke down, when they had to 'beg' for them or when they were 'standing out' because of them. So feelings and emotions were shown to matter and were as potentially productive of capacities (affective) as the physical components in the assemblage. In all four vignettes, we have seen that, apart from technology, furniture set-up, feelings, choices, employers and colleagues formed important parts of the network at the workplace. Other factors such as cultural influences, families, professions, policies and employment schemes were also working in the 'here and now' of events and affecting assemblages and networks.

'Employees with impairments assemblages' were seen to be enacting dis/ability by constantly negotiating and re-negotiating with the multiple human and non-human components, assemblages and networks which they formed part of. They were not disabled all the time, but became dis/abled depending on the in/capacities produced during these interactions. This sheds light on the importance of looking at disabled people at work in a new way; not as fixed, abnormal states but as potentially productive, active, diverse beings/becomings; forever reminding the workplace and related stakeholders that things could be different.

The next chapter will build on the findings chapters to present policy, practice and research recommendations to the numerous interested parties that are involved in the disabled person-technology-workplace assemblage and in the networks within which it is entangled.

Figure 7.1 Disabled technology user-work assemblages and networks (from the data that emerged from the interview and observation sessions)⁸



⁸ The blue lines do not only represent 'connection', but interaction and potential to affect and be affected.

The outer discontinuous line represents the possibility of the network to enter into other relations with other assemblages/networks. It is not defined or closed up; there is always a possibility for transformation/becoming.

The figure's 'messiness' represents the nature of the interactions of the assemblages and the entanglements across the network/s.

Chapter 8

Discussion and Conclusion

8.1 Introduction

Through this research, 25 employees (or ex-employees) with physical or sensory impairments have shared the enactment of their daily lives at work and especially their interactions with various technologies therein. This chapter will summarise the main findings of the study and will reflect on theoretical and methodological issues that emerged during the research process. Limitations of the study and recommendations for future research will then be presented. Implications for activism, policy and practice will conclude the chapter.

Analysis of the data from Stage 1 of the research will be primarily beneficial for the local disability scene since it has mapped out the barriers (and enablers) that exist for Maltese disabled people to access and use technology in their jobs. This analysis has largely confirmed the persistence of the same barriers on the island as those that have been documented (some more than 20 years ago) in other countries. Other barriers identified were specific to Malta, such as the influence of overprotective families and social visibility issues that arise as a consequence of living on a small island. Stage 2 of the study and its analysis then built on the first stage and attempted to understand how these barriers (and enablers) operate, whilst offering a new way of analysing the complex relationship between disabled employees and technology - that proposed by NM perspectives. This topic, in this particular context, has never been analysed from this perspective either locally or internationally. As a result, this study will be a contribution to the limited DS research that engages with STS and NM, and also to the (even more) limited rehabilitation research that engages with these fields.

Empirical research on the topic to date has shown what barriers, varying from environmental to attitudinal, exist for disabled employees in need of AT. Few studies have shown what works for disabled employees and the majority focus on looking at this technology either from a medical/individual lens or

through a technical lens, i.e. aiming at the use of specific devices and their specific outcomes. The majority of research has explored disability and technology in the education setting or in the field of geriatrics, while the methodologies, designs and methods used varied widely.

In this study, both the participants and myself as researcher were viewed as components of the research assemblage. The intra/interaction of these components in turn shaped relations and produced capacities that will be presented in this chapter as the outcomes of this research process. In the epilogue, I will describe how I 'affected', and was 'affected', by this process. Through its novel approach of doing research, this study is hoping to speak, not only to rehabilitation studies and DS researchers, but also to disabled people, their organisations and the various stakeholders and professionals involved in the field of employment.

8.2 Summary of Findings

The data from this study has generated various perspectives on the disabled person-technology assemblage. Very little distinction was made by the participants between assistive and mainstream technology, mostly because they carried most of their devices as part of their bodies, from home to work and vice versa. They described technology as an extension of their body, 'my life', their 'everything' and 'would be lost without it'. They questioned why society treats mainstream technology differently from AT, when it is considered just as indispensable, for example when Miriam refers to her mobile phone, 'when I go out without it, it's like I have forgotten a part of me at home'. Others indicated the existence of a 'hierarchy' among different AT devices and among medical and AT equipment. Most stated that they preferred to have access features/devices integrated in mainstream technology and, also, that they would like to have more functions integrated in one device. For the participants, AT was more than just a compensation for their impairments (a concept coming mostly from the rehabilitation domain). Participants appreciated that they could function more effectively and efficiently with technology (as mediator of action), but they also cared about how these devices looked, because, through these technologies they were also negotiating their identities. For the participants it

was not just about the 'doing' but it was also about their 'being' and their 'becoming' and 'belonging'.

Many showed their disappointment, and sometimes anger, at the continuous struggle they had to live with in Malta and Gozo because of the multiple barriers that persisted at various levels in the workplace and beyond. These barriers were identified in the analysis of the data at Stage 1 of the study: at an organisational level, participants pointed out employers, colleagues and workplace policies and practices as the major factors that help or hinder their participation at work. Participants claimed that, in principle, the majority of employers and colleagues were in favour of disabled people being included in workplaces. In practice, however, they were still hindering them, especially through attitudes based on stereotypes and assumptions about dis/ability. Participants felt they were still dependent on the goodwill of the people around them. They felt that lack of information to employers was a major barrier, but data also showed that not all disabled employees were sufficiently self-determined to request the technology and accommodations that are theirs by right.

At an institutional level, participants called for more detailed guidelines in the Maltese anti-discrimination legislation, for example, regarding employers' duties and responsibilities about accommodations at the place of work; and also for more enforcement of the law. Service provision was shown to be fragmented and still based on the individual/charity model, with lack of choice and expensive equipment being major hindrances to access and use AT. Other barriers mentioned at this level were lack of information/knowledgeability and training about available AT, insufficient funding, lengthy procedures, abuse of the system by suppliers and lack of technical expertise for the follow-up/maintenance/repair of the devices.

The educational system was indicated as the 'key' to other sectors in their life and especially to employment opportunities. Provision and training on AT were therefore deemed to be of fundamental importance in schools, for example, in order for them to learn how to use ICT for eventual workability skills. Participants strongly recommended that the Maltese educational curricula

should include more 'independent living skills' in preparation for life after school for children with disabilities.

At an environmental level, apart from the individual access needs of the disabled employee, findings pointed at the importance of the wider accessibility issues around the workplace. Transport, for example, was identified as one major barrier, both as an infrastructure and also with regard to the disabling attitudes of transport-related service providers. Cultural factors were also indicated as part of the environment. These included the role of the family, religion and the size of Malta and Gozo. These barriers featured as the major influencers of Maltese people's attitudes and mentalities around disability. On the other hand, media and peer support networks were identified as the key enablers in disabled people's lives, both as a source of information on enabling technology and as a source of awareness raising to the Maltese population at large.

Another major theme that emerged from the data in this first stage of the study was that related to health and social care professionals. This was considered a major theme due to the 'absence' (or presence for the wrong reasons) of these professionals. Participants showed their disillusionment with the mediators who were supposed to be there to inform them about their AT needs, and thus enabling them to access and retain a job. OTs were especially highlighted through their absence in the field. OTs were seen to intervene mostly in-home modifications and through the use of an individual rehabilitation approach. A wider societal approach to intervention was called for. The outcome measures and assessments used by the professionals were not always appropriate, still emphasising the dis/ability dichotomy. The Maltese OTs' lack of experience with AT, especially in the case of the more specialised technology, was indicated, this notwithstanding their role as the main gatekeepers/assessors of AT requirements. The need to involve users and their expertise/knowledgeabilities with different devices in the entire AT process was emphasised by the participants, together with the importance of user involvement in the education of OTs.

The issue of the 'expert knower' and the problem of disabling/paternalistic attitudes also came up at this professional level. There

was, however, an indication that these attitudes might be changing among the younger generation of professionals. The need to 'flatten' professional hierarchies that have been built over time was stressed. Participants also indicated the need for professionals to see the transformative potential in service users in order to affect new possibilities and opportunities in employment.

Lack of resources, both human and economic, was indicated by the participants as a likely reason for the absence of professionals in vocational and AT services. Most participants, however, showed that they do not need very expensive technology to carry out their job, also because they generally use their own devices even for work. This implies that professionals, when present, need not necessarily be equipped with expensive hi-tech devices to 'solve' their service users' problems. In this regard, professionals were also 'encouraged' by the participants to use their creative skills for solutions in the form of do-it-yourself devices and re-arrangement of current set-ups at work.

Different understandings of important concepts such as 'independence' and 'rehabilitation success' were indicated by participants as being significant barriers between users and professionals. Although many participants claimed that the self-sufficiency afforded to them through the use of enabling technologies was important to them, issues of choice, control and self-esteem were also emphasised as fundamental values that they cherished in their working lives.

After almost 20 years since the establishment of the Equal Opportunities (Persons with Disability) Act (2000), and more than 10 years of CRPD, numerous barriers are seen to prevail in Malta, notwithstanding the efforts by institutions to change environments (both physical and social). This has also been seen in other countries such as UK (Roulstone, 2000) and Canada (Shier *et al.*, 2009). Findings at this stage have shown that the issue of technology and disability is further complicated because of the many stakeholders involved: users, families, peers, designers, manufacturers, suppliers, technicians, professionals, service providers, standards authorities, legislators, funding agencies and so on.

Furthermore, it has been seen that, over time, AT got entangled in the cultural and historical contexts of the Maltese islands, such as religious influences and charitable attitudes, which have given it various symbolic meanings and values. Above all, findings have substantiated the fact that disabling barriers are not only political-economic and socio-cultural (Charlton, 2000) but also socio-material (Latour, 1993). A step beyond identifying the existing barriers was therefore deemed necessary.

For this purpose, Stage 2 of the study analysed the topic from new materialist perspectives, looking at disabled employees, their technologies and environments as assemblages within networks. Findings from Stage 2 have revealed the heterogeneous components present in these assemblages, their affective potential, the relations that are formed within them and with the surrounding networks, and the capacities that are produced during these processes. The assemblages that emerged from the findings consisted of:

Disabled employee-technology-work set-up-environment-employers-colleagues-managers-family-health professionals-OTs-transport systems-guide dogs-cultural factors-identity-stigma-self-esteem-attitudes and so on.

Findings have shown that dis/ability emerged as a result of the various interactions and alliances formed and not as an inherent characteristic of any one component in the assemblage. In consonance with new materialist thinking, both ability and disability had the same potential of existing in an assemblage or event.

Participants indicated that they felt included and valued in the workplace in as much as these processes affected for them possibilities of belonging and becoming and not just of functioning. They showed that the components of the assemblage were not contained within boundaries - it was in fact because they were not, that they were always open to new connections, new relations, and consequently new capacities. They could always 'affect' and 'be affected'. This was a process of constant re/negotiation which could be seen unfolding during the observation sessions at the workplace. I could see the processes of events being enacted as I observed. They were primarily all relational, depending not

only on the user or only on the technology but at the point of interaction between both as it happened.

Therefore, there was no hierarchy of human over non-human or vice versa but they depended on arrangements/adjustments that mattered. The nature of these arrangements was not only seen in physical networks (material affects) but also in virtual networks (virtual affects). They were seen to be transitory not fixed (temporal affects) and they did not always depend on the sophistication of the technology but sometimes on arrangements (size or position of devices/furniture) that closed or opened capacities in an assemblage (spatial affects). Sometimes they depended on how users felt about their devices (emotional affects) or the consistent behaviour of their colleagues, for example, to not move things around in the office (Lionel, Ann) (behavioural affects). They were a chain of events that could be dis/abling at any one point. Dis/ability was seen to be fluid.

The capacities that were generated via affective relations, as reported by the participants and those observed by myself, were numerous. Apart from the capacity to mobilise, to speak, to 'hear', to 'see', to memorise, participants mentioned the capacity to feel good, liberated, satisfied, accomplished. Capacities were said/observed to make participants more independent, more social, more equal to non-disabled colleagues. The capacities to multitask, to be more productive and more efficient and to prevent further impairment were also mentioned (Tonia: 'less strenuous on my neck'; and Norman: 'manually was more effort, used to get really tired, onscreen it is much easier'). Some other capacities included looking forward to a future, to have plans, wanting to continue studying, not feeling content with being but looking out to becoming. Yanica, Miriam, Etienne, Philip and others mentioned the capacity to improve as a person ever since they started working and leaving traces not only for themselves but for others.

Assemblages were also made up of non-human components which also had the capacity to affect and be affected. The knitting needle in Yanica's vignette, for example, gained a new capacity - it became a mouthstick for Yanica to type with, a capacity which it was not intended to have when it was originally designed. Robert's office chair became a mobility aid, a capacity it

acquired only through its relationship with Robert. Material devices, therefore, did not only affect capacities within the participants, they themselves got affected and became something different from their original purpose.

Furthermore, capacities were not only produced within the disabled employee but also in colleagues, for example, the capacity for sensitivity and empathy, to become 'allies' and not merely co-workers (as in Lionel and Yanica's vignette and also in Elton's). Likewise, the assemblage 'Lionel - assistive IT' opened up the capacity of 'expertise'/knowledgeability not only for himself as an employee, but through him, for other disabled people who refer to him for advice on IT-related AT. Lionel became a vital component of other assemblages - his knowledge and willingness to share it became important in the production of ability elsewhere.

Most of the participants in the vignettes had to deal with customers, so the resultant assemblage produced the capacity to give a service to clients as well as to their bosses and colleagues. Relations, for example Tonia's support from colleagues, resulted in the capacity in her to be kind to customers and in turn to receive gratitude. The relation with the employer who provided accommodations without the disabled employee having to ask for them, made her/him feel that s/he is 'taking care of you' (Tonia). So the capacity that emerged was not only one of increased production but also one of belonging. A cycle of giving and receiving, receiving and giving was produced in most of the participants' jobs and this in turn made them feel 'pleased that through this work I am giving something back' (Philip). This was a cycle in which the one affected was not seen as 'the dependent one' and the component (in this case individual) generating the affect as 'the autonomous one', but one in which, at any time, the receiver could be the giver and vice-versa. In this cycle, dependence and autonomy were transient capacities and not 'bad' or 'good' characteristics of any one person.

Many a time the capacities were unpredictable and unplanned - they were emergent capacities; an example of this was Elton being the mediator through which a non-disabled colleague found a more comfortable way of working on the computer via inverted contrast mode. Other examples of this were the opportunities for work that developed for the participants in an

unpredictable way through personal connections, and not through pre-planned programmes and services.

Some components, however, were also reported to hinder capacities, and these were not always visible. What was visible was at times only a small part of the network. Impairment-related consequences such as pain and fatigue were seen as very active parts of the assemblage, just as feeling degraded at being assisted by a colleague to empty the catheter bag was for Ray. Shame (resulting from ability-expectations of 'continence' and independent toileting), here, became part of the assemblage. Another example was the fragility of technology which was not visible when it worked, but, when it broke down, became visible, and disabled not only the assemblage but the network as well.

Findings showed that a capacity was not merely an addition to the component. It changed the component, and subsequently the assemblage, the network, to become someone/thing different, creating a new potential for affect. Capacities that emerged can therefore be summed up as doing, being, belonging and becoming. It can be assumed that the disabled employees then took these capacities with them in other areas of their life and affected other assemblages and networks not related to employment.

The intricacy of the assemblages (that had no closed number of components) was further complicated by visible and, many a time, less visible entanglements. Examples varied from employers' and colleagues' assumptions about disabled employees' needs, cultural and religious influences, disabled employees' internalised oppression, and stigma. Professionals' understanding of concepts that are fundamental for disabled people such as independence/autonomy, rehabilitation success and their (sometimes) disabling attitudes were also considered to further entangle the assemblages that these disabled employees were a part of.

And yet, even these entanglements served to bring out other capacities in the disabled employee, such as being resourceful, planning ahead (*e.g.* Elton always carrying a spare-parts kit), keeping technology assemblages as basic as possible, taking more time to carry out a task (rather than using AT or asking a colleague), not obeying rules in order to make a statement regarding their

rights, playing the normalcy show and so on. These capacities indicated that arrangements, interferences, influences, relations in a network did not leave the components in a passive state but produced in them the ability to react, to be active, to transform themselves and others (human and non) from essential to relational affective/autonomous beings.

8.3 Theoretical Reflections

The data from this study, viewed through a new materialist lens, allows for alternative understandings of a number of important concepts in DS. These include, among others, re-thinking dis/ability, barriers, independence/autonomy, and stigma.

Because of rapid technological progress and its ubiquity in all aspects of daily life, it is difficult to separate the human from the non-human. It has become more appropriate to refer to assemblages of human and non-human entities. Together they form networks that are active and constantly changing. It is no longer a matter of biological (individual/medical model) or social determinism (SMD) when it comes to understanding dis/ability. Instead, it is about understanding how the biological, psychological, social, political, cultural, technological, *all* play a role in producing dis/ability, via 'affective economies'. The SMD makes a clear distinction between the biological and the social; and this was vital in making the SMD an effective political tool. In this study, however, findings indicated two issues regarding this debate. The first, as seen above, is that there are many more components that are interacting, than just the biological and the social. The second issue is that the relations between these components are not unidirectional, as the distinction made in the SMD implies, but they are much more complex, much more 'entangled'. This does not in any way undermine the SMD or negate the idea that the outcome of these relations can be disabling. If the capacity produced from a relation is disabling, then it is oppressive. On the other hand, if it produces ability, it is liberatory and emancipatory.

The findings from this study may be encouraging us to refine the SMD in such a way that the relational character of the components making up the disability assemblage re-emerges, as Carol Thomas (2004a; 2004b) suggested.

In these relations each component is affecting the other and together becoming something different. Deleuze and Guattari (1988) call this movement of differing as becoming, keeping opportunities open for change and new becomings, as against something that is fixed and unalterable. On the other hand, the 'something different' is not just a 'mere variation of existing formations' but 'being of another order, radically new in and of itself' (Currier, 2003, p.334). This is another way of rethinking 'difference' and can be applied to rethinking dis/ability. Disabled people are not different from 'others', from the 'norm', but are different in themselves like everyone and everything. They are different but equal components in the same assemblage who become dis/abled depending on the capacities produced (or not) through the relations with other components and assemblages and who in turn affect (and are affected by) societal networks (material and not).

In such an entangled state of affairs, it is difficult to separate/remove barriers (structural, institutional, professional and attitudinal) from the rest of the network. The 'macro' filters down into the 'micro' politics of everyday life activities and practices. Factors such as culture, family, religion, climate, professions, policies, services, government schemes thus work in the 'here and now' of events to:

produce ability and disability, the normal and abnormal. They order, arrange, and create links and connections between actors and identities, and they distribute properties and ascribe qualities among subjects and objects, enabled and disabled, humans and non-humans. They are performative and get embodied in people and embedded in institutions and technologies. (Moser, 2000, p.201).

Furthermore, according to this line of thinking, it can be deduced that, as components of assemblages, barriers (or enablers) are also not fixed entities but can affect and be affected, thus always open to transformation. They can produce dis/ability depending on the interactions and relations they involve themselves/are involved in. They are dynamic and unpredictable. It is difficult to map them out neatly as the causation of dis/ability or as constraints to affect/autonomy. In this light, rather than only working to remove barriers (or provide enablers), stakeholders and users in the dis/ability field could also be

asking whether a certain policy/practice/curriculum is acting to generate capacities (or not) for all in the assemblage/network and how this could be re-arranged and re-configured to become enabling if it is disabling.

Being open to new alternatives, disabled people's autonomy is always possible, even if it is used to oppose or resist (recalcitrant autonomy). Autonomy can be considered as the ability to act (not necessarily physically) and as affect/agency which is socio-material (Latour, 1993). NM in fact proposes that all components in an assemblage (human and non) have the capacity for autonomy depending on the relations within/out the assemblage. Autonomy is therefore relational and not the inherent characteristic of any one of the components. This understanding of autonomy also has important implications for professional policy and practice that will be discussed in more detail in the final section of the chapter.

Another theoretical reflection that emerged from the findings regards the concept of stigma. According to Moser (2000) above, disabled people using AT may be stigmatised because of deep-rooted barriers within/out the assemblages in the network. As a result of this stigma, disabled people are seen to misfit in their environment. Findings from the current study showed that stigma, like dis/ability, is as material as it is social and that it happens in some places more than others, for example, in Gozo more than in Malta (Elias, interview). For the purpose of this study the term 'misfitting' was adopted from Garland-Thomson (2011, p.592), who claimed that:

although misfitting can lead to segregation, exclusion from the rights of citizenship, and alienation from a majority community, it can also foster intense awareness of social injustice and the formation of a community of misfits that can collaborate to achieve a more liberatory politics and praxis' (*ibid.*, p.597).

This is indeed what happened at the time when the original SMD was proposed by UPIAS (1976), and it is the reason why the SMD continues to be an important foundation stone in the construction of disability politics.

I, however, found the social-relational idea of Carol Thomas (2004a; 2004b) and the description of disability as in the CRPD (2007) inspirational in guiding me towards an understanding of dis/ability in this thesis as the product

of events in the 'here and now'. As discussed above, what NM thinking is doing is that it indicates that all components in the assemblage have the capacity to affect and be affected, therefore, removing any hierarchies of power of one component over another. Here, the assemblages of bodies, things (including technology), feelings and dispositions, produce capacities that may be conducive to or limiting of dis/ability. Perhaps the time has come to develop SMD into 'the relational socio-material model of disability'.

8.4 Methodological Reflections

It was my goal and aspiration that ER would be the 'golden thread' that ran through this study. Because ER is not explicit about which methods are to be used in such research, I used focus groups and interviews in the first stage of the study to give disabled technology users at work a voice about their experiences and concerns. I also aimed to work as equally as possible with my participants by validating the data and findings generated as much as possible. It is also hoped that the outcomes of this research will leave an impact on various stakeholders for the benefit of disabled people, as will be seen in the final chapter. Being myself a disabled person and an OT, however, cannot be taken as an assurance of 'equal' power between the researcher and the participants.

Because I have a physical impairment, I cannot know what it is like to be a blind or Deaf person (as some of my participants). I could be the 'same' (as with participants with physical impairment, for example, when they said to me, 'you can understand what I am saying'), but I could still be the 'other' (as with blind and Deaf participants). Although every person lives the experience of impairment differently, it can still be said that I was closer to reaching ER aspirations in my study than, for example, a non-disabled researcher, since I shared their experience of disablement. On the other hand, it cannot be said that I shared ownership of the research with my participants, because this would have gone against data protection legislation and it would have jeopardised the participants' anonymity. It is also because a PhD is not a perfect vehicle for ER because the very nature of a PhD demands that it is conducted by a sole researcher and reflects their conceptualisation. The fact

that this cannot be done, and that ER goals are very difficult to accomplish fully, does not mean that researchers should stop striving to apply its principles as much as possible. If this were to happen, we would ourselves be perpetuating the oppression that we are trying to eliminate through our work. In striving to stay close to ER aspirations in this study, I found that I could be critical about what I had done and reflexive about professional practices among other issues.

Furthermore, the methodological research process of this study was enacted because I allowed myself to be open and be led by the 'actors'. It was important to start by hearing what disabled employees had to say (Stage 1), then, through that and through observation, I realised that I could identify components, assemblages, relations, capacities and entanglements that were occurring in the events at work (Stage 2). In line with the SMD, findings from Stage 1 of the study have demonstrated the multiple positions in the assemblages that the participants found/plugged themselves in and that participants are oppressed by the multiple barriers that still exist in the field of employment for Maltese disabled people.

If what Fox and Alldred (2017, p.179) say about power, is applied to the oppression of disabled people, it can be deduced that this oppression does not solely come from some higher structural force *e.g.* capitalism (as in Oliver's articulation of SMD), but must also be analysed micropolitically 'focusing on the actions, interactions and events' and in the 'exercise of affectivity by one relation over another'. Both macro (such as cultural ideas, policies, laws) and micro forces are viewed as components in assemblages that create dis/ability in the 'here and now'. For NM, there are no hierarchies but a 'flat' understanding of reality - of what 'is' society. Components, relations and assemblages are not pre-determined but are constantly shifting. They have no inherent characteristics or properties, but, because they are in continuous negotiation, they become as they do (DeLanda, 2006). All have the ability to affect and be affected.

The data generated in this study was therefore analysed to explore what was going on at the micropolitical level of everyday events. Close attention was given to recording components (human and non-human) of these events, analysing what each component does, the relations between parts and the

emergent capacities generated within individual components. Finally, the multiple data-sources (focus group and interview transcripts and fieldwork notes) were dredged to identify and understand the consequences of the entanglements of people, things and emotions, thoughts and feelings. Participants have shown that what works for disabled people and technology at work can be brought to life as long as disabled people (and other components in the assemblage and in the network) start and continue to replicate it in the various events that occur at the workplace. According to my ontological position, employees with an impairment will become dis/abled as they relate to, as they enter into/detach from an alliance with technology, the work environment, their colleagues, their managers, their family, professionals, systems and practices at the place of work/beyond, and how these on their part influence/affect employees with an impairment to un/make them dis/abled.

This research was not only about applying a theoretical concept to find a solution towards enabling Maltese disabled people to be more self-determined at work with regard to their accommodation requirements. What happened in this research was that, as the study progressed, the participants showed they were part of assemblages that were all the time negotiating with the other assemblages around them. At times these assemblages were productive of ability, other times they produced disability. The participants' stories are evidence of the many positions of the participants within different assemblages. They are evidence of relationality and not of essence. What can come out of this research is also about making stakeholders, and indeed disabled people themselves, aware that this could be an alternative way of looking at/being disabled employees/jobseekers.

Another methodological reflection revolves around the issue of the dissemination of research findings. Its importance is emphasised in ER and also in new materialist research. In the former, this stage of the research is considered key to the spreading of knowledge (and therefore power) and to the further politicising of disabled people's struggle against oppression (Stone and Priestley, 1996; Barnes, 2002). In the latter, the dissemination of the findings is in itself considered to be a capacity-producing event. The dissemination of the findings of this study, which in fact are left open-ended, will hopefully make

disabled people, their organisations, professionals and stakeholders, ask questions. They are not offered a ready-made solution but a new way of how to look at the issue of disabled people, technology and employment. They will need to ask how disabled people-technology-workplace assemblages are interrelating in order to produce ever more enabling capacities for themselves and for the networks they are entangled with. In this way, it is hoped, that the knowledge (findings) generated from this study and its dissemination will have produced the capacity in all involved to ask questions and be open to change and transformation. Furthermore, this study is another contribution to DS and an example of how it can engage (methodologically and conceptually) with other disciplines, such as, STS and rehabilitation studies.

8.5 Limitations of the study and recommendations for future research

As with any research project, this study is not without its limitations. These limitations, however, can open up new possibilities for future research. First to be noted is that this study did not involve disabled people from all impairment groups. People with intellectual impairments and mental health issues were intentionally not invited to participate in this study. Research with these impairment groups would require different research methods from the ones used in this study. Future research would therefore have to be carried out with these two impairment groups with the use of methods that would guarantee/enable their full participation. This research would also be able to explore whether the components in the assemblages they form part of, operate/are similar or different to the ones indicated in the current study.

Although it was exciting to explore new research avenues in stage 2 of the study, it was not easy to find literature that indicated how to carry out new materialist research. The Fox and Alldred (2017) account served as a fundamental text in this regard. Additionally, practice-based professions and service providers might not find this approach extensively helpful in that new materialist research does not offer ready-made solutions. It instead opens up possibilities for critical reflections on the service being provided.

Another factor related specifically to new materialist research is that I did not know where the actors were guiding me because of the unpredictability of relations being un/made by the components of the research assemblages. This could have resulted in my becoming entangled in the research network and not following all traces as thoroughly as they deserved. For example, one trace that the participants left in the data was the one regarding cultural influences that are specific to Malta. I feel that I did not unfold the disabled person-cultural influences assemblage as exhaustively as I had originally wished. The findings that emerged, showed there are interesting and important further lines of inquiry into these issues that are worthy of future research.

A major recommendation for future local research in the field of technology and the employment of disabled people involves the recruitment of participants. The major part of the fieldwork for this study was carried out in 2015. This was the year when, for the first time, a full-time OT was recruited with Jobsplus to take over the assessment and intervention services (related to AT and other accommodations) offered by the Inclusive Employment Services. It was also the year when the Lino Spiteri Foundation was established in partnership with Jobsplus to strengthen the employment-related services for disabled people. This Foundation was deemed to be essential for the enforcement of the quota system that was put into action in that same year's national budget. Future research in this field would therefore need to include disabled people who had made use of these services. This would shed light on the outcomes of these new initiatives and analyse whether they are producing (or not) more enabling capacities/opportunities for Maltese disabled jobseekers and the field of employment in general.

8.6 Implications for activism, policy and practice

This final section will communicate how the findings from this research may prompt disabled people and their organisations to call for the necessary change and improvements in the availability and operation of technologies supporting their participation in work. Furthermore, the implications of the findings for employers, health professionals especially OTs, policymakers and service providers are set forth.

As a general implication for all those to whom this study speaks, I suggest that whichever activism, policy and practice initiative is proposed in the field of employment and disabled people, it starts by exploring the current situation from a 'flat' perspective. This means that it puts aside any hierarchies, and considers all the components, human and non, that are involved in that event, on an 'equal' basis - 'equal' in the sense that they all have the ability to affect and be affected through interaction. It should also analyse the relations within the resultant assemblages and within the surrounding networks to identify and use the enabling capacities that are/could be produced thereof.

8.6.1 Disabled people and their organisations

According to the general implication above, disabled people would be able to establish a new/alternative way of being 'able'. They would be able to demonstrate that it is not their 'impaired' body that makes them disabled, but the 'bad passages' that may be shaping their relations with the many other components in their assemblages. They (as one of the components in these assemblages) would be able to demonstrate that dis/ability emerges through the interactions that they negotiate (or are negotiated), and that the number of resultant capacities/possibilities through this relational way of being/becoming would not be a finite one.

Negotiations on disabled people's part could consist of lobbying for what is theirs by right, even if at times this would mean going against/resisting existent hierarchies and structures. Other negotiations could include involving themselves in policy-making committees and disability equality training initiatives, and making themselves available in peer support activities. In other words, they need to be on the lookout for alternative possibilities in the assemblages they may be part of, and be ready to unplug themselves from disabling components to plug themselves into other arrangements ('good passages') through which their capacities/potentialities could emerge, not only for themselves as individuals but also for the whole network, whether at the workplace or beyond. This is not to say that it is solely disabled people who are responsible to create change but, rather, that disabled people *can* affect change

in several ways. Other people, systems, practices can also be allies with disabled people in affecting this change.

Participants in this study presented some recommendations for what they see as potentially enabling components in their assemblages. Deaf participants suggested the setting up of what they called a 'Deaf Office' through which Deaf people themselves could offer services to other deaf people in Malta and Gozo. The Office would serve as a reference point and source of information/knowledgeabilities regarding issues related to Deaf people, including information about AT for all areas of their lives. Two of the participants, Ray and Philip, suggested the setting up of a website through which disabled people could access information about the latest enabling technologies. This website would also serve as a platform through which technology users can ask questions, share information and knowledge about suppliers/services and write reviews of assistive devices they had tried/used themselves. Participants here were raising questions as to how disabled people's knowledge, which is not necessarily the knowledge found in books, can be used in better ways both for themselves and for others, professionals included. The recommendations proposed in the previous chapter, for example, called for more holistic enabling technology services in which disabled users themselves could have leading roles.

As Milner and Kelly (2009) point out, however, the expectation that disabled people can fight their way up within a disabling society, without non-disabled counterparts doing their part, needs to be challenged. The following sections will deal with other components in the assemblage/network, usually in the hands of non-disabled people, that could produce (or not) capacities for their disabled counterparts. These include the education and employment sectors, enabling technology services and professional policies and practices.

8.6.2 The Education and Employment Sectors

Participants in this study strongly affirmed that the education sector is a fundamental assemblage in their networks. They recommended that greater investment should be made in the education system, to prepare disabled students for the world of work. This preparation, they suggested, could include

training in independent living (including vocational) skills, and training in technical skills such as in ICT and disability equality training. Increased collaboration between the various educational levels and between education and employment entities, was called for, to ensure a smoother transition for disabled students from the world of education to the world of work.

Although, in Malta, the legislation regarding disabled people's equal opportunities/anti-discrimination and employment is in place, and although the CRPD has been signed and ratified, findings have highlighted the fact that disabling policies and practices are still found at the workplace and related services. Lack of awareness and information on the part of employers was seen to be a major disabling factor. The assumptions in employers' minds, that act as barriers/interferences to disabled people's accessing and retaining a job, are part of the entanglement that does not allow them to see the potential capacities in disabled job-seekers.

Recommendations by participants that could help to disentangle the above issue included the importance of disability equality training for employers and the availability of practical standards/guidelines regarding what is minimum reasonable accommodation at work and how it could be implemented. A website for employers with information related to these guidelines, such as where to ask for information, where to go for training, and good practice examples, was suggested. Legislation and quota systems do not seem to be sufficient enablers for employers to 'make theirs' the issue of disabled people's employment. It was indicated that employers in Malta have not yet understood why they should provide support/reasonable accommodation to level the playing field for disabled people. The role of disabled people and their involvement in the implementation of the above are crucial. Once a part of the employment network, disabled employees in this study have shown that they themselves enact possibilities (and resistances) and leave traces for others who will come after them. Moreover, participants also suggested that the government, being the largest employer and the largest buyer of goods and services, should lead by example.

Recommendations given by the participants on this issue were that government should be the first to have quotas in place. It should also choose to

purchase its goods and services only from companies who are both accessible and disability-friendly. They also recommended that government should focus on strengthening what is working for disabled employees and give them a more formal recognition, such as mobility and orientation training for blind employees, user-led technology services for work purposes and peer support networks.

It is hoped that the new Lino Spiteri Foundation together with Jobsplus would serve as a more holistic vocational services system that will bring together not only the rights of disabled people but also the expectations of employers and related stakeholders. I intend to disseminate the findings from this study with this Foundation such that the new perspectives gained through them can be applied in the Foundation's endeavours.

8.6.3 Enabling technology services

Enabling technology services have been described by the participants as fragmented and based on the individual/charity model.

Many people argue that charity plays a positive role in the lives of the "disadvantaged". Some might see that it is contradictory to point out that most disabled people do not have access to a safety net while at the same time criticising charities and social service agencies. It is undoubtedly true that some individuals are helped by charities. But it is precisely in this way that charities function as an agency of control. Charities at best create dependency; at worst, they further degrade and isolate. (Charlton, 2000, p.93)

Charity therefore tends to transmit a 'you should be grateful' kind of message, and this was felt strongly in some of the participants accounts. Given that Malta is one of the 78 countries that are categorised by the World Bank as high-income economies (The World Bank, 2018) and a country that has signed and ratified the CRPD, one would expect that disabled people in Malta would not have to resort to charity to acquire the tools they need to be able to participate in work life on an equal basis with non-disabled people. On their part, participants said they felt degraded, 'this thing as if you are begging for charity [shudders], I hate it' (Gertrude). Technology acquired via a charity system, in interaction with disabled employees, was producing incapacities (*e.g.*

feeling degraded) instead of opening up 'good' possibilities for them. A lobby for technology-related services based on rights is urgently needed.

As a final recommendation in this section, I am therefore proposing the setting up of a rights-based enabling technology policy in Malta, which focuses not on eligibility tests (needs-based policy) but on the wider environment (physical, cultural, social, institutional) access. This would be an enabling technology policy 'that can be productive of new opportunities and becomings' (Fox and Alldred, 2017, p.187), whose implementation is more important than its formulation; an enabling technology policy that is based on disabled people's experiences and on lessons learnt from other countries such as the UK (e.g. Access to Work scheme). It is imperative that disabled people are involved in the policy formulation, but, in order for them to continue to oversee that it is being implemented, they have to be given the opportunity to be part of the government assemblage. In this way, through their relations, they can open up opportunities for change and transformation and see that the policy is being followed up and changed again if necessary. In this way, as Fox and Alldred (2017, p.185) suggest, 'policy is not just something that is 'made' once and for all. Rather, policy-making needs to be understood as an always unfinished project; continually under review', depending on the events that are enacted following its formulation.

8.6.4 Professional policies and practices

Through the findings of this study, OTs (and other health and social care professionals) are being invited to analyse professional policies and practices in a more relational socio-material manner, rather than either through the medical model (essentialist) or through the social model (constructionist). NM cuts across this traditional dualism. Instead of aiming at fixing the individual into a normative body, or fixing the environment, professionals are being called to analyse the assemblages/networks as they emerge in the various events/tasks/activities/occupations they are 'assessing/intervening on'.

We have seen how the absence of OTs in the field of enabling technologies and the workplace, has affected disabled employees. When present, OTs were not sufficiently prepared. By adopting a more open (new

materialist) way of thinking, OTs would immerse themselves in the 'here and now' of their clients and be able to propose, not necessarily more sophisticated technology, but more enabling solutions. In this new light, professional interventions may not always consist of adding a new device to an existing arrangement, but it may mean being creative and fabricating a do-it-yourself solution. It may also mean simply re-arranging what is already in place. It may mean helping disabled people develop what Pols (2014, p.80) called the 'know-now', that is, the development of a variety of possible contingent solutions for different situations (a 'spare parts kit' similar to that which Elton carries with him wherever he goes).

This way professionals would be assessing/intervening in the production of experiences as they come alive in their interactions with disabled people and between the different components and assemblages. Assessing/intervening, therefore, by asking: what are the affective potentials of this technology - how does it operate as part of this assemblage to either enable or disable? What intervening components are enhancing or limiting the affective potential of this technology (e.g. negative or positive attitudes of co-workers)?

A starting point for health professionals would be a revision of the definition of important concepts. The European Association of Service Providers for Persons with Disabilities (EASPD, 2008) have specifically recommended common definitions and principles for health professionals and disabled people. 'For what concerns disability, EASPD suggest using the definition of disability as provided in the UNCRPD, article 1, paragraph 2' (*ibid.*, p.4) and that training for health and social care professionals be based on the principles of the CRPD, such as participation and full enjoyment of human rights.

Another definition/understanding that needs to be revised in professional curricula and practice is the one regarding 'independence'. The adoption of 'relational autonomy' would come as a consequence of viewing dis/ability as the product of the interaction of the person with an impairment with her/his environment be it physical/material (human and non), emotional, technological, political, cultural or institutional. Applied to OT, these revised perspectives would mean devising models and 'assessments of independence' that do not only consider the degree/quantity of independence, but also the kind/quality of

independence that the disabled person values and the complex entanglements of both. They mean basing their models/frameworks, assessments and interventions on processes and relations rather than fixed entities, like the body or the workplace environment. These perspectives would also urge OTs to question the tools they are using such that they would choose to use more observation than standardised questionnaires.

This would allow them to view 'autonomous occupation' as emerging from the heterogeneous alliances within the components of the assemblage being assessed and the network surrounding it. Professional caring/intervening is not a matter of giving independence to passive receivers:

To care is to tinker, i.e. to meticulously explore, quibble, test, touch, adapt, adjust, pay attention to details and change them, until a suitable arrangement (material, emotional, relational) has been reached. (Winance, 2010, p.111)

During this process of interdependence/relationality it is not only the disabled person who is transformed, but also the different people and objects involved, including the professionals and the non-human entities like technologies.

Furthermore, through the application of NM perspectives, professionals would understand that their 'power' is only transient and 'may quickly evaporate as and when an assemblage's affect economy changes' (Fox and Alldred, 2017, p.180). They would understand that this shared work therefore does not place one entity above another, but all are involved in a continuously shifting, relational, affective manner. Professional hierarchies are flattened out. As a consequence, this might put an end to what Avril called professionals' 'crap attitudes'. As Moser (2005) suggested, since disability has generally been considered a DISorder, we now need to REorder lives for disabled people. This is especially relevant to health professionals' policies and practices.

Some recommendations that the participants put forward include the provision of more training for medical and health professionals both in disability matters and in specific AT issues. They recommended that OT students' curriculum includes practice placements with disabled activists such that they may experience what right-based activism consists of and may learn how they

could be allies to the disabled people's movement. OTs can also support disabled people by making them aware of the services and legislations that exist in this field, that can be both enabling and disabling, thus supporting them as affective agents who are knowledgeable about their rights and are able to speak up/act in order to attain them and, when necessary, lobby for their transformation. There was an indication towards the need for the formation of 'hybrid forums' in which disabled people's knowledgeabilities assemble with professionals' 'expertise' to modify the enactment of disability politics. Another strong message regarded the need for Maltese OTs to move out of hospitals into the community with a special call for more OTs to work in the vocational services system.

So what else can OTs do?

'A Deleuzian question (What else can a body do?) suggests a collaborative process of experimentation which aims, not to rehabilitate, but rather to increase the capacities of embodied subjects to affect and be affected in new and exciting ways.' (Feely, 2014, p.213).

Academic OTs could do this by orienting OT assessments, practices, courses/curricula, and models which are less anthropocentric and more 'assemblage-centric' (body-technology-environment-culture-religion-family-feelings-emotions...). OTs could start with reviewing their OT and AT models in view of the implications above.

These models need to show that the relations between components in an assemblage are complex, multi-dimensional and multi-directional rather than uni or bi-directional (as in current models). They would focus more on tracing the relations between the various components (human and non) to explore which of these are the most productive of 'good' capacities. This would train future OTs to give equal importance to each component in their client's assemblage/s and to view them not separately but in their capacity-producing relations in the here and now (*not a priori*). They could do this by orienting their assessments to identify the components in their client-life assemblages and the capacities/affects that are produced thereof. They could do this by orienting their practices to evaluate the opportunities that bring about dis/abling

capacities for their clients, to facilitate/reconfigure relations between various assemblages in order to open up new alternatives in their networks. This new materialist way of developing and implementing models, curricula, assessments, and practices, seems to go against the focus on client-centredness in OT and AT.

The client-centredness of current practices in these two fields indicates an underlying assumption that it is the individual who should be in control of her/his situation. In the neoliberal, capitalist societies we are living in, this could add pressure on the individual to 'succeed'; otherwise, s/he is made to feel a 'failure'. It may mean, therefore, that it is time for a new OT/AT paradigm shift where 'the person', 'technology' and 'environment' are delegated more equal affect/agency and in which they are seen to do, be and become as they relate with each other and with their surrounding networks. The solution to the question in Chapter 7, 'So can new models of OT and AT reconcile this divergence?' cannot be resolved here, but, as a result of the findings from this study, the challenge is being launched. Thus, this study serves to, not only propose policy and social change, but also to challenge professionals to add a political role to their practice. On my part, as Fox and Alldred (2017) suggest, I commit myself to continue this work in my disabled person-OT-academic-activist assemblage role.

8.7 Conclusion

The right to work and the right to technology/other accommodations that can help level the playing field for disabled people to participate in jobs that reflect their wishes and potentials, are both safeguarded in the CRPD and other national legislations. It is yet to be seen, however, whether the CRPD, as with any global-level policy tool, has affected technology design, policy and procurement. Disabled employees have highlighted the barriers related to these rights. The SMD was fundamental for this, however, since these barriers were seen to persist, a new materialist approach to research was applied in order to analyse the situation from another perspective. As it unfolded, the analysis showed that disabled people are engaged at the workplace in multiple, complex ways and by multiple stakeholders.

The participants were not disabled at work all the time as fixed essences, but shifted between ability and disability depending on the relations they involved themselves in, or in which they were involved by human and non-human others. They became, as they enacted and were enacted; as they affected and were affected. An enabling workplace made possible the doing of work and the being, belonging and becoming of the workers, *all* workers.

In the end, analysing these events through a new materialist lens has shown that the possible capacities produced for the components in the assemblages/networks can still be summed up as ones of reciprocity, gain and empowerment (Oliver, 1992). New materialist research approaches and ER principles are therefore not incompatible. It is hoped that the new materialist perspectives used in this study will urge all involved to view disabled employees and related events in a new relational way. As we have seen from the participants' stories, issues are complex, relations are inconsistent, and processes are messy. The future is therefore unpredictable. The responsibility of the various components in work assemblages is ultimately to continue making connections and looking out for possible becomings.

Epilogue

In line with ER principles and as part of the research assemblage, I also 'affected' and 'was affected' during the course of this research. For example, I disseminated my findings and what I have learnt, in conferences, local and international; in meetings with local Members of the European Parliament; with stakeholders in the AT field and the employment sector; with healthcare professionals, disability activists and fellow academics. I have had the chance to keep in contact with the participants even when the fieldwork was completed, and I passed on information that they had raised as concerns during their interviews, such as issues related to their AT devices, issues about AT services and other matters related to independent living. Hoping that the consequences of this research will continue to unfold, not only for me as a disabled person-OT-activist-academic assemblage, but also for the participants and stakeholders, I would now like to share some personal reflections on my research journey over the past 6 years.

It is difficult to write about what this research venture has meant to me. It has certainly been the most significant learning experience of my whole life. Coming academically from a medically-oriented profession, having to shift my thinking to a social science-based study and then to also wander into STS and NM was no mean feat. But I learnt so much. I learnt, not only from the knowledge generated about the topic, but also (if not more) how to do research. Through this work, I strongly wished to contribute to both DS and OT. At various stages of the process I found myself asking, 'Whose side are you on - the disability side or the professional side?' As the research proceeded, I became aware that being a disabled person myself would not automatically increase the importance of this project for DS. Being an occupational therapist influenced my choice of, and my views on, the topic.

The research process itself was messy and entangled. It had multiple stops and starts. There were numerous crisis points on a personal, academic and professional level along the way. But upon meeting with NM, I understood that, as part of the research assemblage myself, I had to let the actors guide me

to follow their traces, as Latour (2005) suggested. I found new materialist perspectives to be positive, dynamic and oriented to the future. I started seeing assemblages and networks everywhere. I came to appreciate that matter matters too. I now realise that I have become someone different from that person who started out on this journey in 2012.

With profound gratitude to all the people (and things) who made this endeavour possible, I hope I can continue to view life in this way - on the lookout for new possibilities, always open to new opportunities and the capacity to transform and to be transformed.

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Appendix A

Invitation to Presidents of DPOs

Dear Sir/Madam,

My name is Vickie Gauci, I.D. 155366M, Occupational Therapist and PhD student at the School of Sociology and Social Policy of the University of Leeds, U.K. I am a disabled researcher and am writing to invite your DPO to participate in a study that I will be conducting entitled 'Enabling Technology and Employment in Malta: from Charity to Empowerment?'

This study will be exploring the role and value of enabling technology in the field of employment of disabled people in Malta. Enabling technology consists of both ordinary technology, such as mobile phones and computers, and assistive technology, which includes any aids and equipment that are made specifically for disabled people, such as wheelchairs, hearing aids and speech synthesizers. The need for this study was felt by service providers and service users in Malta who are constantly faced with barriers in accessing enabling technology that may assist their daily independence in the field of employment. I will be basing the study on the Social Model of Disability which suggests that it is these barriers, both physical and attitudinal, that hinder disabled people from participating in community life like non-disabled people. I would like this research study to help give a voice to disabled people on the subject and would therefore like to involve them as much as possible during the whole research process. The study will be investigating the ways in which society disables people of working age with physical and sensory impairments in their potential/use of enabling technology on the place of work. The study therefore will be exploring working aged disabled people's experiences with enabling technology on their place of work; what are the facilitators and barriers that help or hinder the value of this technology; and how much professionals such as occupational therapists, and workplace practices influence disabled people's views and use of such technologies.

The sample of participants for the first stage of the study will consist of working-aged people with physical or sensory impairments, who are members of 5 DPOs in Malta. They will be invited to participate (once) in focus group sessions of 1-2 hours to discuss the theme of the study. The focus groups will take place at the DPO premises if you so agree. Kindly note that a nominal contribution of Euro 50 will be made to the DPO for the use of the premises. Following the focus groups, participants may be invited to participate in individual interviews to clarify, expand and have the chance to talk more deeply on any issues that were brought up in the focus group discussion and that are

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of particular relevance to the research study. The interviews will happen at a place and time of the participant's choice. Participation in both the focus groups and the individual interviews is totally voluntary and participants will be able to withdraw from the study at any stage of the research. Names and details of the DPOs and the participants will remain anonymous and the data collected will be destroyed when the study is completed. It is hoped that the findings from this study will provide recommendations for a policy, which is currently non-existent, regarding enabling technology in Malta, built not on concepts of charity but on concepts of empowerment.

Therefore, if you would like your DPO to take part in the study kindly forward the attached invitation and information letter to the members of your DPO aged between 18 and 60 years of age so that they can decide whether they would like to take part in the study. I will be contacting you again to make arrangements for the focus group discussion in the near future.

If you require assistance (personal, or assistive technology) to carry out the above or would like the letters in an alternative format, kindly let me know.

Thank you for your time and cooperation.

Sincerely,

Vickie Gauci

Email: vickiegauci@gmail.com

Appendix B

Information/consent letter to DPO/KNPD prospective participants

Dear Sir/Madam,

My name is Vickie Gauci, I.D. 155366M, Occupational Therapist and PhD student at the School of Sociology and Social Policy of the University of Leeds, U.K. I am a disabled researcher and am writing to invite you to participate in a study that I will be conducting entitled 'Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?'

This study will be exploring the role and value of enabling technology in the field of employment of disabled people in Malta. Enabling technology consists of both ordinary technology, such as mobile phones and computers, and assistive technology, which includes any aids and equipment that are made specifically for disabled people, such as wheelchairs, hearing aids and speech synthesizers. The need for this study was felt by service providers and service users in Malta who are constantly faced with barriers in accessing enabling technology that may assist their daily independence in the field of employment. I will be basing the study on the Social Model of Disability which suggests that it is these barriers, both physical and attitudinal, that hinder disabled people from participating in community life like non-disabled people. I would like this research study to help give a voice to disabled people on the subject and would therefore like to involve them as much as possible during the whole research process. The study will be investigating the ways in which society disables people of working age with physical and/or sensory impairments in their potential/use of enabling technology on the place of work. The study therefore will be exploring working aged disabled people's experiences with enabling technology on their place of work; what are the facilitators and barriers that help or hinder the value of this technology; and how much professionals such as occupational therapists, and workplace practices influence disabled people's views and use of such technologies.

The study will consist of two stages: the first stage will consist of 3 focus group discussions and the second stage will consist of 20 in-depth interviews. The sample of participants will consist of working-aged people (18-60 years) with physical or sensory impairments, who are either currently employed or have worked in the past 10 years, and are service users at KNPD or members of Disabled People's Organisations (DPOs) in Malta. They will be invited to participate (once) in focus group sessions of

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1-2 hours to discuss the theme of the study. The focus groups will take place at a public place such as the DPO or KNPD premises. Data from the focus groups will be used to construct the questions for the interviews in the second stage. For the second stage, participants will be invited to take part (once) in an interview of 1-2 hours to discuss in further depth the issues brought up in the focus groups and any other issues they would like to discuss about the theme of the study. The interview will take place at a public place and time of their choice. Participation in both the focus group and the interview is totally voluntary and participants will be able to withdraw from the study at any stage of the research. Names and details of the participants will remain anonymous and the data collected will be destroyed when the study is completed. It is hoped that the findings from this study will provide recommendations for a policy, which is currently non-existent, regarding enabling technology in Malta, built not on concepts of charity but on concepts of empowerment.

Therefore, if you would like to take part in the study kindly fill in the next page and return to me via the email address below within the next three weeks. I will then be contacting you again to make arrangements for the focus group discussion in the near future.

If you require assistance (personal, or assistive technology) to carry out the above or would like the letters in Maltese or in an alternative format such as Braille, kindly let me know.

Thank you for your time and cooperation.

Sincerely,

Vickie Gauci

Email: vickiegauci@gmail.com

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If you would like to take part in the study kindly reply to the questions below by ticking the relevant box/es:

1. Are you male female other ?
2. What is your age ?
18-29 30-39 40-49 50-60 61+
3. Are you currently employed ? Yes No
4. If you replied No to question 3, have you been employed in the past 10 years?
Yes No
5. Do you use/Have you ever used any form of technology at work? If yes, what type?
 - Mobility related (e.g. wheelchair; adapted seating; pressure relief cushion)
 - Communication (e.g. alternative or augmentative communication aid)
 - Daily living equipment (e.g. personal care devices)
 - I.T. and/or computer access equipment (e.g. special software; adapted mouse or keyboard)
 - Transportation (e.g. adapted vehicle controls)
 - Technology aiding sensory or information access (e.g. aids for people with visual/hearing impairment/loss)
 - Other enabling technology, please specify (might include other mainstream/standard hardware or virtual and software support which is directly related to your job)

6. What is/was your job title?

7. How would you describe your impairment?

- Physical
- Sensory:
- a. Visual impairment
 - b. Blindness
 - c. Hearing impairment
 - d. Deafness
 - e. Physical and sensory

8. Would you like to take part in the **study**?

Yes No I would like to ask more questions before I decide

If you agree to take part or would like to ask more questions, **please write your name, contact number or email address here so that I can get in touch with you**

Name:

Tel/mobile no.:

Email address:

(Kindly note that this information will not be passed on to any other organisation and will be kept confidential)

Please click 'save' and send the saved copy back to me in the following email address vickiegauci@gmail.com or complete in writing and send it back in the self-addressed envelope provided with this letter. If you require assistance (personal, or assistive equipment) to complete the above or would like it in an alternative format, kindly let me know. Thank you for taking the time to reply.

Sincerely,

Vickie Gauci

Appendix C

Information/consent letter - Chairperson KNPD

Dear Mr. Scicluna,

My name is Vickie Gauci, I.D. 155366M, Occupational Therapist and PhD student at the School of Sociology and Social Policy of the University of Leeds, U.K. I am a disabled researcher and am writing to request permission to access the sample of participants for the second stage of a study that I will be conducting entitled 'Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?' through the Assistive Apparatus Service (SGhS) of the National Commission Persons with Disability (KNPD).

This study will be exploring the role and value of enabling technology in the field of employment of disabled people in Malta. Enabling technology consists of both ordinary technology, such as mobile phones and computers, and assistive technology, which includes any aids and equipment that are made specifically for disabled people, such as wheelchairs, hearing aids and speech synthesizers. The need for this study was felt by service providers and service users in Malta who are constantly faced with barriers in accessing enabling technology that may assist their daily independence in the field of employment. I will be basing the study on the Social Model of Disability which suggests that it is these barriers, both physical and attitudinal, that hinder disabled people from participating in community life like non-disabled people. I would like this research study to help give a voice to disabled people on the subject and would therefore like to involve them as much as possible during the whole research process. The study will be investigating the ways in which society disables people of working age with physical and sensory impairments in their potential/use of enabling technology on the place of work. The study therefore will be exploring working aged disabled people's experiences with enabling technology on their place of work; what are the facilitators and barriers that help or hinder the value of this technology; and how much professionals such as occupational therapists, and workplace practices influence disabled people's views and use of such technologies.

The study will consist of two stages: the first stage will involve the use of 3 focus groups and the second stage will involve the use of 20 in-depth interviews. The sample of participants will consist of working-aged people (18-60 years) with physical or sensory impairments, who are either currently employed or have worked in the past 10 years, and are service users at KNPD or members of Disabled People's Organisations (DPOs) in Malta. They will be invited to participate (once) in focus group sessions of

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1-2 hours to discuss the theme of the study. The focus groups will take place at a public place such as the KNPD premises if you so agree. Data from the focus groups will be used to construct the questions for the interviews in the second stage. For the second stage, the sample of participants will consist of 20 beneficiaries of the SGhS or have participated in the focus groups. Beneficiaries will be invited to participate (once) in an interview of 1-2 hours to discuss the theme of the study. The interview will take place at a public place and time of their choice. Participation in the interview is totally voluntary and participants will be able to withdraw from the study at any stage of the research. Names and details of the participants will remain anonymous and the data collected will be destroyed when the study is completed. It is hoped that the findings from this study will provide recommendations for a policy, which is currently non-existent, regarding enabling technology in Malta, built not on concepts of charity but on concepts of empowerment.

Therefore, if you accede to my request, kindly sign below and return this letter to me in the self-addressed envelope. I will then forward the attached invitation and information letter to the Manager of the SGhS, Ms. A. Powell, so that she may forward it to beneficiaries of the SGhS aged between 18 and 60 years of age. They can then decide whether they would like to take part in the study. I will also provide self-addressed envelopes with the letter to the beneficiaries or letters in an alternative format if they so prefer.

Thank you for your time and cooperation.

Sincerely,

Vickie Gauci

Email: vickiegauci@gmail.com

I, Mr. Oliver Scicluna, Chairperson of KNPD, give permission to Ms. Vickie Gauci to access her sample of participants for her research study as described above and to carry out the focus group/s and interviews at KNPD premises if necessary.

Signature _____

Date _____

Appendix D

Consent Form - Focus Group

Pseudonym of participant: _____

CONSENT FORM

Title of Project: Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?

Name of Researcher: Maria Victoria Gauci (k/a Vickie)

I.D. Number: 155366M

YES NO

- | | | |
|---|--------------------------|--------------------------|
| 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any adverse consequences. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that I have the right to not answer particular questions if I do not want to. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I am willing to participate in the focus group discussion. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am aware that this discussion will take between one to two hours and that I may be required to have another interview after the validation of data collected during the focus group discussion. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I am willing for my comments to be tape recorded. | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I am aware that my name and details will be kept confidential and will not appear in any printed documents. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I understand that the data will be destroyed at the end of the project. | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I agree to take part in the above study. | <input type="checkbox"/> | <input type="checkbox"/> |

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix E

Points for Focus Group Discussion

Introduction

Hello everyone,

Thank you once again for accepting to take part in the study and for coming here today.

My name is Vickie Gauci. I am an Occupational Therapist and PhD student at the School of Sociology and Social Policy of the University of Leeds, U.K. The theme of the study in which you have kindly accepted to participate is enabling technology and employment of disabled people in Malta. This study will be exploring the role and value of enabling technology in the field of employment of disabled people in Malta. For the purpose of this study, enabling technology consists of both ordinary technology, such as mobile phones and computers (hardware and software), and assistive technology, which includes any aids and equipment that are made specifically for disabled people, such as wheelchairs, hearing aids and speech synthesisers; i.e. special aids and equipment that might, or might not, have been suggested to you by a therapist to help you carry out your work independently; and any other technology that you feel can help you, is helping you or helped you in the past to carry out your job independently.

I would like this research study to help give a voice to disabled people on the subject.

Therefore during this discussion I would like you to tell me about:

- your experiences with enabling technology on their place of work;
- what are the facilitators and barriers that help or hinder the value of this technology;
- how much professionals such as occupational therapists, and workplace practices influence your views, access and use of such technologies.

May I remind you that following the focus groups, you may be invited to participate in an individual interview to clarify, expand and have the chance to talk more deeply on any issues that were brought up in the focus group discussion and that are of particular relevance to the research study. The interviews will happen at a public place and time of your choice. Both focus groups and interviews will be tape-recorded. Participation in both the focus groups and the individual interviews is totally voluntary and you will be able to withdraw from the study at any stage of the research. Your names will remain anonymous and the data collected will be kept in a safe place in the duration of the study and then destroyed when the study is completed.

Thank you once again for your time.

Page 2 of Appendix E

May I now ask you to switch off your mobile phones or put them on silent mode. May I also ask you to speak one at a time so that the recording is clear.

For the focus groups with Deaf and People with physical impairments:

I have written the theme and the key topics to be discussed during this session on the flipchart in front of you as a reference point. However, I will also be asking other questions during the discussion to help us cover as many important issues as relevant to the theme as possible.

For the focus group with Blind/people with visual impairments:

I have sent you the theme and the key topics to be discussed during this session in an email prior to this meeting, but if you like I will read them out to you as a reminder. However, I will also be asking other questions during the discussion to help us cover as many important issues as relevant to the topic as possible.

Prior to the discussion, can you kindly introduce yourselves, say what your job is? And/or what jobs you have had in the past? If you feel comfortable about it, can you also say your age.

Questions for myself (the researcher) that might help participants during the discussion:

- What sorts of technologies do you use/think you could use/have used in your job/s? Do you use only mainstream technology or have you also had to apply for 'special support'?
- How would you describe the journey you went through to obtain and use the technologies in your job? (Who helped you choose the technology? (professionals such as OTs, supplier, technical person) Did you have training on it? What helped? What hindered?)
- What was your experience regarding the procedure you had to go through to obtain funding for the technology devices for your work?
- What was your experience regarding the procedure you had to go through to obtain advice regarding choosing, trialling, installing, using and maintaining the technology devices for your work?
- What are your experiences in terms of the use of enabling technologies at your place of work? (Employer/Colleague reactions/attitudes) How do you feel about having to ask for accommodations including technology?
- What situations or people have influenced or affected, positively or negatively, your experiences with technology in your job? How? (Did you have follow-up by professionals; maintenance and upgrade services? where (at the place of work; at home?) who funded these?)
- What meaning do the technology devices have/have had in your work life?
- What is enabling about technology?
- Anything disabling?
- Did you have any other or do you think you need other job training/preparation other than technology related support?
- Is there anything you would like to add?

Appendix F

Consent Form - Interview

Pseudonym of Participant: _____

CONSENT FORM

Title of Project: Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?

Name of Researcher: Maria Victoria Gauci (k/a Vickie)

I.D. Number: 155366M

- | | YES | NO |
|---|--------------------------|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any adverse consequences. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that I have the right to not answer particular questions if I do not want to. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I am willing to be interviewed. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am aware that this interview will take about an hour and that I will be given the possibility of validating the data collected during the interview. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I am willing for my comments to be tape recorded. | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I am aware that my name and details will be kept confidential and will not appear in any printed documents. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I understand that the data will be destroyed at the end of the project. | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I agree to take part in the above study. | <input type="checkbox"/> | <input type="checkbox"/> |

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix G

Interview Schedule⁹

1. Can you tell me a bit about your job ?

In the questionnaire attached to the invitation letter, you said that your job title is What is your seniority? How long you have been working there? What type of tasks are you expected to carry out as part of your job?

2. What mainstream technology do you use at work, if any?

Do you only use this technology at work or do you also use it elsewhere? Is there any other mainstream technology that you think would be useful in your job? Do you use it consciously and/or more as a disabled employee and why?

3. What assistive technology do you use at work, if any?

Do you only use this technology at work or do you also use it elsewhere? Is there any other assistive technology that you think would be useful in your job?

4. Do you think technology makes you more/less independent at work?

How does this technology, (*probe for multiple types of technology*) make you more/less independent ? What do you understand by independence?

5. Who introduced you to the technology you are using?

Have you ever had any experiences with professionals such as OTs/others to help you with choosing your technology and train you in using it? Did you get what you expected from them? Can you tell me more about your experience with OTs or other professionals? Do you think professionals are sufficiently trained/skilled in this aspect of re/habilitation? How did you first realise a technology may be beneficial for you as a disabled worker? Were there any other support and professional intervention that may have helped? What was the role (if any) of clinical/employment rehab/support?

6. What are the systems, in/out of work, that help/hinder you in acquiring, using, maintaining, upgrading the technology you use/can use?

Do you have any experience/s in this regard? Can you tell me more about it? How did you feel when this happened? Whom/Where do you refer to, when you encounter any difficulties in this regard? Do you think there is enough awareness about this subject from both the disabled people's and employers' side? Do you think they should know about it? Why?

7. What are the practices, in/out of work, that help/hinder you in acquiring, using, maintaining, upgrading the technology you use/can use?

What about colleague and employer understandings and constructions about this technology? Any other helping and assistance behaviour that supports technology use?

8. Who do you think should fund assistive technology for work: you, the employer, the government, NGOs? Mix?

What should they fund and what not? Do you know of any entity that can help you financially to purchase the technology that you need? Can you get the technology you need any other way (i.e. without having to purchase it)? What were your experiences when you approached these entities?

9. Do you think that because we live in Malta/Gozo we experience more/less difficulties when it comes to acquiring, using, maintaining, upgrading technology at work?

Are there unique factors in technology support/access due to living in Malta/Gozo? Can you give me examples of what helps/hinders specifically because we are in Malta/Gozo?

10. Are there any recommendations that you would like to make regarding this topic?

Are there any other issues apart from technology that you think help/hinder disabled people to get/stay in work? What do you wish existed in Malta in relation to the topic we discussed, to help disabled people find/keep a job? What do you think is lacking? What can be better? What other main issues are there for disabled people in Malta?

⁹ I did not ask all these questions to the participants. They emerged from the focus group data as a guide for myself.

Appendix H

Invitation and Information letter to Employer for Observation session/s with Participant/s

Dear Sir/Madam,

My name is Vickie Gauci, I.D. 155366M, Occupational Therapist and PhD student at the School of Sociology and Social Policy of the University of Leeds, U.K. I am a disabled researcher and had corresponded with you when you had kindly given me permission to carry out the interview/s of participant/s for the study that I am conducting entitled 'Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?' at your workplace.

As you will remember, this study is exploring the role and value of enabling technology in the field of employment of disabled people in Malta. Originally, the study consisted of two stages: the first stage that involved focus groups and the second stage that involved in-depth interviews. Following the completion of the first two stages, I felt that the data would be further enriched if I added a third stage which would consist of observation sessions. This would consist of me coming to observe the participants while they work and I could also discuss with them any issues that arise during the session, particularly those related to the use of technology and their work. I may also ask the participants for their consent to take photos of the technology/work set-up that they use. However, may I assure you that this will be done in such a way that the identity of the place of work, of the participants, of their colleagues and any service users remains anonymous. The observation session will therefore happen at your place of work, at a time of your choice. It will not take longer than half a day (3-4 hours maximum). Participation in this session is totally voluntary and participants will still be able to withdraw from the study at any stage of the research and/or to withdraw data shared at any time up to date of publication. Names and details of your organisation and of the participants will remain anonymous and the data collected will be destroyed when the study is completed.

For ease of reference, I am also attaching with this correspondence, the first information letter through which you had given me permission and in which you can find the full details about the study.

Therefore, if you accept that I carry out this observation session at your place of work, kindly let me know by replying to this email within the next two weeks. I will then be contacting the participants to make arrangements for the observation session in the near future.

Thank you for your time and cooperation.

Sincerely,

Vickie Gauci

Email: vickiegauci@gmail.com

Appendix I

Information Letter to Observation session Participants

Dear Sir/Madam,

My name is Vickie Gauci, I.D. 155366M, Occupational Therapist and PhD student at the School of Sociology and Social Policy of the University of Leeds, U.K. I am a disabled researcher and we had met when you had kindly accepted to participate in the study that I am conducting entitled 'Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?'

As you will remember, this study is exploring the role and value of enabling technology in the field of employment of disabled people in Malta. Originally, the study consisted of two stages: the first stage that involved focus groups and the second stage that involved in-depth interviews. Following the completion of the first two stages, I felt that the data would be further enriched if I added a third stage which would consist of observation sessions. This would consist of me coming to observe you while you work and we could further discuss any issues that arise during the session, particularly those related to the use of technology and your work. I may also ask you for your consent to take photos of the technology/work set-up that you use. However, may I assure you that this will be done in such a way that the identity of the place of work, your identity, that of your colleagues and of any service users remains anonymous. The observation session will therefore happen at your place of work, at a time of your choice. It will not take longer than half a day (3-4 hours maximum). Participation in this session is totally voluntary and you will still be able to withdraw from the study at any stage of the research and/or to withdraw data shared at any time up to date of publication. Your names and details will remain anonymous and the data collected will be destroyed when the study is completed.

For ease of reference, I am also attaching with this correspondence, the first information letter through which you had accepted to take part in the study and in which you can find the full details about the study.

Therefore, if you would like to take part in this observation session kindly let me know by replying to this email, within the next two weeks. I will be contacting you again to make arrangements for the observation session in the near future. If you wish to receive this letter in an alternative format, kindly let me know via the email address below.

Thank you for your time and cooperation.
Sincerely,

Vickie Gauci
Email: vickiegauci@gmail.com

Appendix J

Consent Form - Observation Session at the Workplace

Pseudonym of Participant: _____

CONSENT FORM

Title of Project: Enabling Technology and Employment of Disabled People in Malta: from Charity to Empowerment?

Name of Researcher: Maria Victoria Gauci (k/a Vickie)

I.D. Number: 155366M

- | | YES | NO |
|---|--------------------------|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any adverse consequences. | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that I have the right to not answer particular questions if I do not want to. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I am willing to be observed by the researcher whilst at work. | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I am aware that this observation session will take about half a day and that I will be given the possibility of validating the data collected during the observation period. | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I am willing for my comments to be tape recorded. | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I am aware that my name and details will be kept confidential and will not appear in any printed documents. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I understand that the data will be destroyed at the end of the project. | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. I agree to take part in the above study. | <input type="checkbox"/> | <input type="checkbox"/> |

_____ Name of Participant	_____ Date	_____ Signature
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_____ Name of Person taking consent	_____ Date	_____ Signature
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Appendix K

Route map - Access to Technology Services in Malta

Organisation	Service	Service Provision Process ¹							Repairs/ Maintenance			
		Referral ²	Assessment		Funding		Implementation / Procurement			Follow-up / Review		
			Low tech	High tech	Financial Assistance	Loaning of technology	Ordering and Setting up of the technology	Delivery and Fitting of the technology			Training in the use of the technology	
		AT	MT	AT	MT	AT	MT					
KNPD	STILC	✓	✓						✓			
	SGHS ³	✓	✓	✓								
	ERT/FRL	✓	✓	✓	✓							
MCCF		✓		✓	✓							
FITA		✓	✓			✓	✓				✓	
MDH/GGH		✓					✓					
NGOs		✓	✓				✓					
Suppliers		✓	✓				✓	✓		✓		✓

Abbreviations (that are not in the main List of Abbreviations)

- MT Mainstream Technology
- ERT Exemption from Registration Tax for adapted vehicles
- FRL Free Road License for adapted vehicles
- MDH Mater Dei Hospital (Malta General Hospital)
- GGH Gozo General Hospital
- NGOs Non-Government Organisations namely the Hospice Movement, the Multiple Sclerosis Society and the Muscular Dystrophy Group

¹ Service Provision Process as according to Cook and Polgar (2008)

² Referrals: All the organisations receive referrals from other entities such as medical/health/social care professionals, or from disabled people/families/carers

³ Now called Empowerment Scheme and delivered by Agenzija Support

Appendix L

Types of Technologies used by Participants

Mobility/Mobility-related Equipment

Mainstream Technology

good office chair and desk, footstool, automated doors, lifts

Assistive Technology

White stick, walking stick, manual wheelchair, powered wheelchair, prosthesis, pressure relief cushion

Communication Aids

Mainstream Technology

mobile, laptop, tablet, What's App, email, internet, headphones, Bluetooth technology, cordless headset, voice amplifier

Assistive Technology

speech synthesiser, hearing aid

IT and Computer Access Equipment

Mainstream Technology

mobile, laptop, tablet, WhatsApp, email, internet, headphones, Bluetooth technology, cordless headset, inverted contrast mode, big screen (TV and computer), integrated access features in computers

Assistive Technology

speech synthesiser, Zoom Text, Magnifier, adapted keyboard, Braille printer

Transportation and Adaptive Driving Equipment

Mainstream Technology

car with automatic gear, Bluetooth technology, light and sight package in car

Assistive Technology

car hand controls, van with ramp, car adaptations

Technology for Sensory Access

Mainstream Technology

mobile phone, smartphone, laptop, tablet, WhatsApp, email, internet, Bluetooth technology, big screen (TV and Computer), good lighting

Assistive Technology

speech synthesiser, talking technology (e.g. talking watch, talking calculator), Zoom Text, Braille printer, Perkins Braille, Magnifier, White stick, hearing aids, vibrating devices, light alerting alarm, emergency call with video (e.g. in lifts)

Daily Living Equipment

Mainstream Technology

key rings (used with zippers), air conditioner

Assistive Technology

adapted sanitary facilities, stairlift, bathlift (the last two items were mentioned by the participants and, although they are not used at work, they help them get to work)