WHAT ARE THE VIEWS OF AUTISTIC YOUNG PEOPLE, THEIR PARENTS AND PROFESSIONALS ON WHICH DAILY LIFE SKILLS NEED TO BE TAUGHT, AND WHAT ARE THE PROMOTERS AND BARRIERS TO ACHIEVING SUCH SKILLS?

by

YANIKA ATTARD

A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF PHILOSOPHY

Autism Centre for Education and Research

Department of Disability Inclusion and Special Needs

School of Education

College of Social Sciences

University of Birmingham

January 2022

ABSTRACT

There is a lack of research on why a gap exists between the verbal and cognitive abilities of autistic young people and their level of independence skills. Literature suggests that relative to their non-autistic peers of a similar age and intellectual ability, many autistic adults fail to achieve desired outcomes in various areas of independent living. They often lack friends, have lower rates of post-secondary education, are seldom in full-time employment, and continue to live with their parents. A recent report by the Office for National Statistics in the UK (2021) revealed that only 22% of autistic people were in employment – the lowest among other special needs groups, and 75% still lived with their parents. The literature revealed a need to explore the views of key stakeholders on what supports the development of independence skills. This study was conducted in Malta and gathered the views of autistic young people, their mothers and fathers, and professionals who specialised in autism. They were asked which daily living skills (DLS) should be prioritised and what they felt the main promoters and barriers to developing such skills were. A convenience sample of 34 participants was recruited, 9 autistic young people aged between 16 and 30 years, with good spoken language and cognitive abilities, their mothers (n=9), their fathers (n=7), and 9 autism professionals.

Q sort methodology was used to identify the views of the participants on what helps or hinders the development of DLS. In-depth interviews were carried out with eight participants, two from each of the four different groups. A DLS checklist consisting of 50 items was developed and used to identify which DLS participants believed were high or low priority for independence. Personal hygiene, money and budgeting skills, and household safety were rated high priority by all stakeholders. Driving their own car, and skills related to this, were rated low priority by the young people and fathers. Mothers, fathers and professionals all agreed that caring for clothes was also a low priority relative to other areas. The Q sort revealed 7 distinct subjective viewpoints, four for the Promoters, and three for the Barriers - two of which were bi-polar. The dominant Promoter Factor was that parents should teach DLS, despite the challenges, and have professional support. The dominant Barrier Factor was related to parents' beliefs, attitudes and fears, and the fact that DLS were often not taught through direct teaching. Interview data revealed that DLS acquisition is not merely about skill building, but many other factors affected this, such as their experiences since childhood, particularly feelings of failure.

These findings suggest that more communication is needed between stakeholders to identify their different perspectives and to develop a consensus on what might be worked on and how. Recommendations are made on the basis of this study to support the development of DLS in young autistic people. These include teaching Executive Functioning (EF) and DLS directly and from a young age, addressing their past negative experiences, acknowledging the culture, beliefs and attitudes of the family system, and helping the young people to embrace autism as part of their identity. Recommendations for the future include developing methods to reach a consensus among stakeholders; examining how DLS are best taught and developed; and longitudinal studies following up young autistic people into adulthood to find out which DLS they still need support with and from whom, and which skills they can do unaided.

For my loving and devoted husband, Melvin and

our little ‘pride and joy’, Sophie Ella

Your endless love, care and tenderness sustain me.

ACKNOWLEDGEMENTS

This PhD has been a life-changing journey for me, which would not have been possible without the support, guidance and encouragement of many people.

I greatly acknowledge the financial funding I received for my Doctoral studies from the Malta Government Scholarship Scheme (Postgraduate) (MGSS – PG), which enabled me to make this project possible.

My heartfelt thanks go to my supervisors Dr Despina Papoudi, Dr Glenys Jones, Dr Lila Kossyvaki, and Dr Prithvi Perepa for their guidance and valuable feedback. I am especially grateful to Dr Glenys Jones who was there from the inception of this project guiding me through every little step of the way, reading through all the versions of my writings, and providing me with detailed and valuable feedback. Above all, I would like to thank her for her constant encouragement and her continuous belief in my ability to complete my studies successfully.

I would like to thank all the participants of this study - the autistic young people, their parents, and the autism professionals for their time and involvement in this study. Their generous collaboration and participation are truly valued and appreciated. This PhD study would not have been possible without their invaluable contribution.

My warm thanks go to my students and their parents at the Malta Autism Centre for accommodating to my time schedules so that I could keep up with my study deadlines. I also wish to thank my colleagues for their encouragement, particularly Mr Jean Pierre Spiteri for taking on some of my work responsibilities so that I could dedicate more time on my PhD.

Further thanks go to a special friend and colleague, Dr David Cassar, for his endless support, and valuable words of encouragement, and for believing in my resilience and strength during the most difficult times of this journey.

My thanks also go to my brother-in-law Glenn Micallef for assisting me in the final layout of my thesis, and to my sister Lee Ann for meanwhile organising play dates with Sophie Ella.

Heartfelt thanks go to my parents Josephine and Joseph who have supported my education and believed in my achievements since I was a little girl. I am deeply grateful for their support, and for being alongside my husband and myself through all the ups and downs of this PhD journey. We are indebted to their continuous willingness to adjust their personal plans to take care of our little daughter so that we could dedicate valuable time on our studies, while having our minds at rest that Sophie Ella was being loved and cared for.

Warm thanks go to Melvin’s parents Therese and Emmanuel for their endless encouragement, support and daily prayers throughout these past years of this PhD journey. Grateful thanks go for their care and understanding particularly during those times when time dedicated to our studies made it less possible for us to spend valued time with them.

My final and most special thanks go to my husband Melvin, also a PhD student, who has been by my side, living every minute of this PhD journey with me. His encouragement, support and his continuous presence and love, made it possible for me to persevere and survive the most challenging times of these past years to finally make it till the end. And lastly, but most importantly, my darling Sophie Ella who has walked this journey with us since the day she was born. My warmest thanks go to her, for despite being a little girl, she grew up to understand how much our studies were important to us, but which nonetheless, could never take her place in our hearts.

My promise to you, now that I have finally reached the end of this long, but rewarding PhD journey, is to make up for any missed moments and memories with my two most beloved people, Melvin and Sophie Ella.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

GLOSSARY OF TERMS

AED	Adult Entitled Dependence
AS	Asperger’s Syndrome
ASD	Autism Spectrum Disorder
AYA-ACS	Adolescent and Young Adult Activity Card Sort
AYAPS-T	Adolescent and Young Adult Participation Sort – Taiwanese version
CFA	Centroid Factor Analysis
DLS	Daily Living Skills
EF	Executive Functioning
EV	Eigenvalue
FST	Family Systems Theory
ID	Intellectual Disability
IEP	Individualised Educational Plan
IT	Information Technology
IQ	Intelligence Quotient
LD	Learning Disability
LSE	Learning Support Educator
MAC	Malta Autism Centre
NAS	National Autistic Society
NSO	National Statistics Office
NT	Neurotypical
SEN	Special Educational Needs
TA	Teaching Assistant
UK	United Kingdom
US	United States
VABS	Vineland Adaptive Behaviour Scales

NOTE ON TERMINOLOGY

There is no consensus on the terminology used to describe autism. This was evident in the outcomes of a study published in 2016 (Kenny *et al.,* 2016). Through a large-scale online survey to the United Kingdom (UK) autism community, the term ‘autism’ and ‘people on the autism spectrum’ were the most accepted terms by all groups. Both terms are used in this thesis to refer to the whole autism spectrum. The terms disorder and disability are avoided to eliminate the negative connotations that such words have. Such terms are only used when referring to the work of other researchers.

Another debate in autism is on the use of person-first language versus condition-first language. Kenny et al. (2016) found a difference between autistic people and their parents’, and professionals’ preference. While many autistic people and their families preferred the term ‘autistic’, professionals chose ‘people with autism’. Professionals favour the use of person-first language to emphasise that first and foremost autistic people are human beings. However, a good number of autistic people seem to disagree with this line of thinking (Bestow, 2021; Brown, 2011; Sainsbury, 2000; Jackson 1992). Lydia Brown, an autistic disability rights activist, explains that many autistic people consider autism to be part of their identity while neurotypicals may not view it that way. Brown (2011) emphasises that her identity is who she is and not something additional to that. Taking this line of thought, that identity cannot be separated from the person, this study will use the term ‘autistic people’.

CHAPTER 1

INTRODUCTION

This introductory chapter introduces the topic of the thesis and argues why this is important and timely. It gives the rationale behind my motivation for doing this research and its relevance to my profession and the people I work with. It refers briefly to existing studies on the topic and indicates gaps in the literature this study attempts to address.

1.1. Motivation for the study

I started working in the autism field in 2002, in an early intervention programme for autistic children aged 3 to 6 years. Later, I moved to an intervention programme for autistic teenagers. In 2009, I completed a Masters degree in autism studies at the University of Birmingham. Back in Malta, in 2011 I set up an autism Centre together with my husband, who also specialises in autism. Until then, in Malta, autistic children and young people received intervention and support primarily from organisations which catered for people with various intellectual and physical differences.

The main aim of setting up the Malta Autism Centre (MAC) was to give autistic people and their families the opportunity to receive intervention and support in an autism specialist centre, where professionals have expertise on how autistic people experience the world around them. The MAC offers tailor-made interventions to children as young as two years old right through to adults up to fifty years. The main aim is to address the needs and challenges that arise from autism, and to equip autistic people with the necessary skills to become independent and have a good quality of life.

Over the years, I have worked with a large number of autistic children and adolescents. Today many young people receive autism specific intervention from the MAC where I am Co-Director. A good number of these young people have good verbal and cognitive abilities and have made their way to post-secondary education or employment. Notwithstanding their cognitive ability and academic achievements, these young adults lack many of the daily living skills (DLS) which are essential for a person to function independently in life. *Daily living skills* is an umbrella term which comprises a wide range of skills that a person needs to be independent in everyday life (Green and Carter, 2014). These relate to personal care, household chores and food preparation, time and money management, travelling, and keeping safe. My motivation to conduct this study originated from my professional aspiration to understand what obstacles autistic young people with average verbal and cognitive abilities were coming across, that were limiting their journey towards independence.

Through my experience of working with these autistic young people, I often observed how they have ordinary expectations and express wishes very similar to their neurotypical peers, in terms of DLS. They often express their desire to pursue simple everyday routines independently, such as, buying their own clothes and cooking a simple meal. They want to be able to travel independently, have a job and live in their own home. I was often struck by the ordinariness of such wishes and saddened at the realisation that currently only a few of these young people manage to achieve these DLS. Indeed, many remain dependent on their parents for simple everyday necessities like choosing what to wear and cooking a good meal. This issue is a concern to the young people themselves, their parents and the professionals who work with them.

Being unable to perform DLS often affects their self-confidence. They compare themselves to same-aged peers, and wish to become more independent. Meanwhile, parents often dread their child's transition to adulthood. They enter this period with concerns about how they can help their child to have a good life as an adult, and with fears about what will happen to their adult child when they are no longer able to support them. Professionals at the MAC on the other hand, are aware that the key to alleviate at least some of this concern and apprehension, is to equip these young people with the necessary DLS. They are constantly exploring different strategies to train them to carry out these skills. Yet, the process does not seem to be a straightforward one, as the functional level of independence often remains low within the personal, domestic and community domains. It is unclear to the MAC professionals what is keeping these young people from developing these skills.

1.2. Aims and relevance of this study

The key aims of this study are to explore the views of parents, professionals and autistic young people on the barriers and promoters in developing DLS. DLS have an influence on adult outcomes in autism (Bal *et al.*, 2015), contribute to a person's well-being (Järbrink *et al.*, 2009), and appear to be responsive to intervention (Duncan and Bishop, 2015). The performance of autistic people in DLS is relatively stronger when compared to their social and communicative adaptive skills (Farley *et al.*, 2009). However, many autistic people, show considerable impairment in DLS compared to their intellectual and verbal ability (Matthews *et al.*, 2015; Kanne *et al.*, 2011; Hume *et* *al.*, 2009). Interestingly, this gap appears to be more pronounced in autistic people who have average cognitive ability, than in autistic people who also have an intellectual difficulty. The latter group are more likely to have adaptive behaviour skills relatively proportionate to their cognitive abilities (Kanne *et al.*, 2011; Klin *et al.*, 2007). Despite having the necessary intellectual and verbal ability to acquire DLS, autistic people find it difficult to apply such skills to function independently in life without support.

This thesis sets out to explore this gap which Duncan and Bishop (2015, p. 64) refer to as a 'daily living skills deficit'. Despite the progress made in recent years in the area of independence, there remains an open question as to which factors are responsible for the disparity between the cognitive ability of autistic people and their level of performance in DLS. It is clear that this gap is an important and significant phenomenon identified by various researchers (e.g. Duncan and Bishop, 2015; Henniger and Taylor, 2013; Smith *et al.*, 2012) who argue that more research is needed to explore which factors are likely to contribute to this disparity, if autistic adults are to function more independently in everyday life:

> …it is critical to gain a clearer understanding of which factors are related to better or worse DLS in children and adolescents with ASD (Duncan and Bishop, 2015, p. 65).

1.3. Rationale for the study

This study is relevant and timely for a number of reasons. Firstly, it aims to fill a gap as stated above. It gives a voice to autistic young people, a group that has until recently been neglected in research. Despite autism being lifelong, the majority of research and literature focus on children. Studies on adult outcomes often rely on data gathered from parents and caregivers (Eaves and Ho, 2008; Howlin *et al.*, 2004). The views of autistic people themselves, are ‘a frequently neglected source of information’ (Roux *et al.*, 2015, p. 11). If autistic people are given the opportunity to communicate their experiences and wishes, it is likely that they will have a greater opportunity to transform their own lives and those of others. The thesis also explores the views of mothers and fathers and professionals as they are key stakeholders in the development of DLS of autistic people. The level of agreement between the four key stakeholders can be explored to gain a comprehensive view on how DLS might best be developed.

1.4. Location of the research

This study takes place in Malta which has a population of 516,100 (NSO, 2021). There are cultural factors within the country that may influence attitudes and beliefs in relation to DLS.

Within Maltese families, women are mostly responsible for household chores (Gatt and Gatt, 2006), and Maltese children, particularly males, are not encouraged to be involved in daily chores. Moreover, Maltese parents have a tendency to be over-protective of their children (Muscat, 2017). This trend is likely to increase when children have a disability, and they may be allowed little opportunity to explore their ability to perform DLS independently (Grech and Aquilina, 2011). So far, no research has been carried out in Malta to explore whether such cultural factors contribute to a lack of DLS in autistic young people.

In Malta, there are no exact figures regarding the prevalence of autism. However, based on epidemiological studies in other countries, such as the UK (e.g. Pinborough-

Zimmerman and Bakian, 2011), the approximate number of autistic people in Malta within a total population of 516,100 is estimated to be 5,161. Specifically, there are an estimated 950 in the age range 0 – 17 years and 4,211 over 18 years (based on NSO report, 2021). These figures suggest that a significant number of autistic young people will be transitioning to adulthood in a few years in Malta. This necessitates a more thorough understanding of the experience of autistic individuals as they transition into the adult world.

1.5. Type of research

This is largely a qualitative study which gains the views of both parents, professionals and autistic young people. As such it gives four different perspectives on the topic which will strengthen the data. The research takes place in the real world as it takes a convenience sample from those already known to me through my place of work. The key purpose of the research is to enhance the understanding and knowledge in relation to the development of DLS in order to inform the future work of the MAC.

1.6. Thesis structure

This thesis comprises eight chapters, including this introductory chapter. Chapter 2, the literature review gives an overview of past studies and literature related to the development of DLS in autistic young people. Chapter 3 is the Methodology chapter which starts with an overview of the methodological considerations and gives the rationale for the methods chosen for the study. The chapter outlines the design, sampling procedures, participants, and how the data is analysed, followed by ethical considerations, the researcher’s positionality and potential bias.

Chapters 4, 5 and 6 present the findings of the study which comprise: an overview of the factors which promote and hinder the development of DLS as seen by the four stakeholder groups (Chapter 4), the high and low priority DLS identified by the stakeholders through a DLS checklist (Chapter 5), and the findings from eight in-depth interviews with two participants from each stakeholder group about their views on the acquisition of DLS (Chapter 6).

Chapter 7 discusses the findings in the light of previous studies in the area of DLS and autism. Finally, Chapter 8 presents the conclusions and implications of the study for practice and research.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

This chapter reviews the literature on the development of independence skills in autistic young people with average intellectual and verbal abilities, in terms of daily living skills. Firstly, different definitions of independence will be reviewed and the definition of independence adopted for this thesis will be presented. Factors that may promote or inhibit the performance of DLS in adult life will be considered. Additionally, this review will provide a critical appraisal of the methodology of research studies in the field.

When considering the role of the family, the Family Systems approach (Bowen, 1978), will be used as a theoretical framework, since it views the family as a system made up of a group of individuals, where a change in one member, such as an autism diagnosis, will influence the whole system. The behaviour of one member is viewed as the possible cause of and the precursor to the behaviour of other family members, thus, leading, a change in which, demands a readjustment of the whole family system (Van Velsor and Cox, 2000).

Moreover, through the lens of this theoretical framework, the family is also seen as part of a larger *'suprasystem'* (Millberg *et al.*, 2020, p. 2, my italics), such as the extended family, the larger community and the MAC. For families within the autistic community, the professional support system, also explored in this study, is another example of a *suprasystem* in which the family is nested (Millberg *et al.*, 2020).

2.2. Definitions of independence

The term independence is often used to sum up an individual's ability to act in various circumstances without requiring prompting, assistance or monitoring of significant others (Hume *et al.*, 2014). However, there are variations both in the terminology and in the way that independence is defined. Variations in terminology include *autonomy*, *adaptive functioning* and *independent functioning*, which have all been used in the literature to imply one's ability to be self-reliant and self-supporting, and to have control over one's life. Two major definitions of *independence* derive from developmental theories and behavioural approaches.

2.2.1. Developmental theories of independence

In essence, *developmental theories* focus primarily on the concept of *autonomy* with an emphasis on an individual's ability to identify one's beliefs, preferences and competences, and to take personal decisions accordingly. Zimmer-Gembeck and Collins (2003, p. 176) define autonomy as: 'Enacting self-governed, self-regulated behaviours that are based on one's personal decisions.' Moreover, Steinberg (2011, p. 278) maintains that autonomy is mainly achieved by, 'feeling independently and thinking independently'.

These definitions incorporate milestones expressed particularly at two stages of an individual's life: (i) in toddlerhood: identified by various developmental milestones, such as walking, self-feeding, expressing choice, and identifying preferences, which give the young child a sense of independence (Erikson, 1963); and (ii) in adolescence, when independence is characterised mainly by one's ability to decrease emotional dependence on their parents, develop one's own beliefs and values (Steinberg, 2011), make independent decisions and behave independently in various social contexts (Zimmer-Gembeck and Collins, 2003).

These definitions, while they convey the message of doing things on one’s own accord, they do not serve to specify the meaning of terms such as *self-governed* and *self-regulated*. This provides challenges as to how to define such constructions and convert them into concrete actions and behaviours. Such definitions do not offer clarity in terms of whether the person is expected to carry out particular activities without support, or to simply take independent decisions about something, which is then carried out with others’ support. Moreover, terms such as *feeling independently* and *thinking independently* can be defined as one’s ability to make choices and take decisions, and to form one’s own opinions and hold on to them. However, such terms can also be interpreted subjectively depending on one’s personal experiences, the cultural context, and differences in family cultures, opinions, and understanding of such concepts.

2.2.2. Behavioural approaches to independence

In the *behavioural* literature, *independence* is generally considered to be attained when an individual functions independently on a day-to-day basis across different settings, without requiring support and monitoring (Matthews *et al.*, 2015; Sparrow, Cicchetti and Balla, 2005). Hume and Odom (2007, p. 1172) define *independent functioning* as: ‘on-task engagement in an activity in the absence of adult prompting.’

This definition explores the concept of independence from a functional perspective and places an emphasis on the absence of external support to perform a task.

Similarly, the term *adaptive functioning* is used in the literature to refer to and measure the extent to which an individual functions independently on a day-to-day basis across different settings, without requiring support and monitoring. Matthews et al. (2015, p. 2349) define adaptive functioning as a: ‘multifaceted construct that includes skills necessary for age-appropriate independent living.’

Bal et al. (2015) narrow down the concept of ‘adaptive functioning’ and maintain that:

> Adaptive behavior encompasses daily activities important to functional independence, including communication, social, and daily living skills (DLS) (Bal *et al.*, p. 774).

These definitions place more emphasis on the actual autonomous functioning in different day-to-day scenarios of specific activities, rather than merely one’s potential ability to acquire and perform such skills (Sparrow *et al.*, 2005). Direct reference to examples of daily activities makes these definitions less ambiguous and less subject to one’s opinions and experiences thus, making it more quantifiable.

2.2.3. Daily living skills as a vehicle for acquiring independent functioning

A major area of ‘adaptive behaviour’ encompasses a wide range of DLS which are considered crucial for independent functioning. Bal et al. (2015) emphasise that:

> DLS, such as personal hygiene, meal preparation, and money and time management, are important to living independently and obtaining employment (Bal *et al.*, 2015, p. 2).

Life skills or *daily living skills* are umbrella terms which include a wide range of skills that need to be carried out regularly to allow the person to maintain good health and safety across various everyday settings. Green and Carter (2014) define daily living skills as:

> …age-appropriate self-care activities needed to function at home and in the community, and which include behaviors such as washing, dressing, following safety rules, and completing household chores (Green and Carter, 2014, p. 256).

Sparrow and colleagues (2005) divide DLS under three subdomains namely, personal, domestic, and community skills. These include activities of self-care such as, personal hygiene and appearance, managing household duties and chores, preparing a meal, time and money management, keeping safe, and engaging in leisure activities, among others (Bal *et al.*, 2015; Sarris, 2014a). The Vineland Adaptive Behaviour Scales (VABS; Sparrow, Cicchetti and Balla, 2005) is a widely-used measure of adaptive behaviour, which takes the form of a semi-structured interview with parents or carers. The term *adaptive* implies one's ability to recognise the demands of a particular situation or environment, including the social context, and to adjust one's functional skills accordingly to complete the task independently (Bashe, 2011).

Literature shows that the concepts of *adaptive functioning* and *adult outcomes* may well be correlated, and studies reveal that the ability to perform life skills independently has a positive impact on adult outcomes in terms of education, employment and independent living of autistic adults (Taylor, Lounds and Marsha, 2014; Cannella-Malone *et al.*, 2011; Sutera *et al.*, 2007). Furthermore, literature on the development of self-determination skills in individuals with intellectual disability suggests that opportunities to take responsibility for, and participate in DLS independently, could contribute to the development of choice- and decision-making skills, and is likely to promote the individual's self-confidence (Wehmeyer *et al.*, 2004; Sowers and Powers, 1995). Consistently, Duncan and Bishop (2015) contend that daily living skills are crucial to success in the adult world.

2.2.4. The importance of independent functioning in autism

Literature suggests that many young people with disabilities have the same ambitions and desires for their future in relation to independence and opportunities for meaningful choices and decision-making, similar to the wider population of young people (Stokes, Turnbull and Wyn, 2013). However, research indicates that adult outcome of functional independence and involvement in decision-making for individuals with disabilities (Pilnick *et al.*, 2010), including those on the autism spectrum (Henniger and Taylor, 2012; Eaves and Ho, 2008) are poor.

The majority of the literature on the independence of autistic young people adopt the behavioural definition and focus on measuring the level of adaptive functioning (Bal *et al.*, 2015; Matthews *et al.*, 2015; Duncan and Bishop, 2015; Kanne *et al.*, 2011) and independent adult outcomes (Gray *et al.*, 2014; Henniger and Taylor, 2012; Howlin and Moss, 2011). The functional use of life skills is reflected in adult outcomes research which defines and measures independence outcomes mainly in terms of living arrangements, paid employment, leisure, friendships and relationships (Howlin and Moss, 2012).

Literature suggests that many autistic adults fail to achieve desired outcomes in various areas of independent living and continue to live with their families. A recent report by the Office for National Statistics UK (2021) revealed that only 22% of autistic people were in employment – the lowest among other special needs groups, and 75%

still lived with their parents. They often lack friendships and recreational activities, have lower rates of post-secondary education, and are seldom engaged in full-time employment (Gray *et al.*, 2014; Henniger and Taylor, 2012). Wang and Berg (2014) found that autistic young adults with average cognitive abilities had lower participation rates in daily activities across various domains, such as driving, going out and using public transport, than their typically developing peers.

2.2.4.1. Comparison of outcomes in autism with other special education groups

A substantial number of research studies in this area make comparisons between autistic young people and peers from other special education groups, including those with learning difficulties or emotional difference. These comparative studies consistently reveal that autistic young people have the lowest rates of participation and independent functioning in daily activities (Anderson *et al.*, 2014; Orsmond *et al.*, 2013; Shattuck *et al.*, 2012; Wagner *et al.*, 2004). Accordingly, Anderson et al. (2014, p. 4) maintain that, ‘the ASD group is unique’.

Consistently, studies on the independent functioning of autistic people indicates that adults with varying levels of cognitive abilities remain prompt dependent and rely heavily on the support of others for day-to-day functioning in terms of independent living arrangements, employment and social relationships (Hume *et al.*, 2014; Howlin *et al.*, 2013; Kanne *et al.*, 2011). More so, research suggests that although autistic people may have the necessary intellectual and verbal ability to acquire DLS, they find it difficult to apply such skills to function independently in life without the support of significant others (Matthews *et al.*, 2015; Kanne *et al.*, 2011; Hume *et al.*, 2009).

Duncan and Bishop (2015, p. 2) claim that more research in this area is crucial to explore the ‘observed gap’ between the intellectual ability of autistic people and their actual level of independent functioning in their adult life. Indisputably, the area of DLS is considered imperative for optimum adult outcomes. Moreover, researchers distinguish DLS from other adaptive behaviour skills, claiming that these are responsive to intervention, as they are not heavily reliant on the individual’s social and communication skills, which are a core difficulty in autism (Duncan and Bishop, 2015).

Notwithstanding these contentions and the significance of DLS for successful adulthood life (Gray *et al.*, 2014) research has centred more heavily on the core difficulties in autism relating to the social and communication domains than on the development of DLS (Jasmin *et al.*, 2009). In this context, Duncan and Bishop (2015, p. 2) maintain that: ‘Unfortunately, very little is known about what factors are related to DLS deficits in individuals with ASD.’

2.2.5. Definition of independence adopted for this thesis

Given the potential link between adaptive behaviour, particularly in DLS, and adult independence outcomes in autism, this thesis will adopt the behavioural definition of independence, that is, one’s actual autonomous functioning in daily life in terms of DLS. For the purpose of this research, DLS will include skills within the personal, domestic and community domains. These skills pertain to personal hygiene and appearance, health care, cooking, housekeeping and caring for clothes, money, budgeting and travelling. DLS were adopted for the focus of this thesis because they are considered critical for independent living and are associated with adult independent outcomes in autism, while they appear to be responsive to intervention (Duncan and Bishop, 2015).

Several studies on functional independence in autism measure the individual's ability to perform life skills, in relation to their cognitive ability and age-appropriate societal expectations and rules (Bal *et al.*, 2015; Matthews *et al.*, 2015; Duncan and Bishop, 2015; Kanne *et al.*, 2011). Meanwhile, more research is required to explore which life skills are mostly needed for autistic people with average cognitive abilities and what factors constitute the actual barriers to the development of independent life skills.

Of the qualitative research that has been conducted, most have focused on the reports of parents and autistic adults on their level of functional independence in terms of living arrangements, employment and leisure (Bancroft *et al.*, 2012; Barnard *et al.*, 2001). The views of key stakeholders on those underlying factors that may lead to the reported lack of life skills in these young people were not generally considered in these studies. Exploring the viewpoints of autistic young people with average cognitive and verbal abilities, their mothers and fathers, and professionals, on the most important life skills, and the promoters and barriers to acquiring such skills, has the potential to expand understanding of what is keeping these young people from achieving independence, and thus, shed light on those factors that could potentially reduce barriers and promote life skills. Moreover, the views of professionals, parents and the young people themselves, can provide insight into the family cultures, and differences that may exist in the perceptions and expectations of the different stakeholders, in terms of the acquisition and performance of DLS in everyday life.

2.3. The Maltese Context

As this thesis is conducted in Malta, an overview will be given of the sociocultural context within which Maltese families live, together with the current trends and views on disability in Malta, including autism.

Malta is a small country located in the centre of the Mediterranean Region, with distinctive environmental characteristics shaped primarily by its size, and embedded social and cultural rules which may originate mainly from the influence of the Catholic Church on the Maltese communities. For many decades, the Catholic Church has been of great influence on the daily life of Maltese families. This is believed to have led to an entrenched association of disability with sin within the family or the individuals with disability themselves. These are believed to have resulted from literal interpretations of the scriptures (Camilleri, 1999). Similar influences are reported in other Catholic countries such as Kenya (Otieno, 2009). In the Old Testament, disability is attributed to sin and is mostly viewed as an expression of God's anger towards those who disobey Him (Sassoon, 1920). An example is seen in the expression of one of God's punishment for Israel's disobedience: 'The Lord will inflict you with madness, blindness and confusion of the mind' (Deut. 28:28-29, quoted in Otieno, 2009). Quotes from the New Testament also refer to the link between disability and sin: 'Rabbi, who sinned, this man or his parents, that he was born blind?' (John 9:1-3, quoted in Otieno, 2009).

Overpowered by a sense of shame and guilt, prior to the 1960s, parents of children with disability would keep them hidden away in cellars from the rest of the society (Camilleri and Callus, 2001). Despite reforms in the Church and a marked progress in

Maltese attitudes towards disability, people with special needs continue to be viewed by many as ‘objects of charity’ (Cardona, 2013, p. 281). Such social attitudes are often reflected in phrases used even in the secular media, such as ‘less fortunate’, which portray people with disabilities in need of help and pity. This mindset is consistently considered by many Maltese people with disability as a major barrier to their autonomy and independence (Cardona, 2013). Cardona’s (2013) study which gathered the views of four ‘disabled people’ and a parent of a child with disability revealed that the participants considered the attitudes of the Maltese towards disability as a major constraint to their independence. Although this is not a large sample, the participants’ views are an eye-opener to potential factors that could be undermining the independence of disabled people.

Autism is still under-researched locally and there exists a lack of research attention of evidence on the topic of DLS and independence. The little research that is available on autism has been mainly carried out by under-graduate psychology or education students. Moreover, prevalence studies have not yet been carried out in Malta. However, it is believed that the prevalence rate of autism is similar to that found in other countries, of one in one hundred (Fombonne, 2003). A step in the right direction was marked recently with the presentation of a White paper in the Maltese Parliament proposing a law which aims to*:*

> …empower persons within the autism spectrum by providing for their health and well-being in society, the betterment of their living conditions, their participation and inclusion in society (Parliament of Malta, 2016, p. 1).

However, an observed increase of autism recognition at the Government level in Malta, is not on a par with that of the general public, which still lacks awareness and understanding about autism. Autism is often mistaken for a mental health condition, and that in itself is still associated with high levels of misconception and public stigma within the Maltese community (Farrugia, 2017).

Saaltink et al. (2012) in their study in Canada, found that parents' preoccupation about society's perception of their family and their young adult with intellectual disability influenced the extent to which parents encouraged independent functioning. Specifically, parents were reluctant to promote their child's autonomy unless it was conforming to the family's values and principles. This would lead parents to take decisions and perform daily tasks, such as choosing what to wear, for their young adults. Thus, minimising their opportunity to practise independent skills and promote their self-confidence.

As a result of Malta's central location in the Mediterranean Sea, the phenomenon of honour and shame existent in the countries of this region, plays a central role within the Maltese culture (Moxnes, 2010). Malta is a country whereby the physical layout facilitates observation of others' daily activities, and where gossip has an influential means of social control (O'Reilly Mizzi, 1994). Overridden by the value of having a good name and reputation, brings into question whether Maltese parents' willingness to encourage their autistic young adults to carry out life skills independently particularly in the community, could be surpassed by fear that their atypical behaviour could bring about 'shame' on the family. Similar to Saaltink et al.'s (2012) findings, experience as a practitioner has indicated that very often families would discourage their autistic young adult from engaging in daily routines that would otherwise promote their independence, such as using public transport or going shopping. Often, parents would prefer to do such daily tasks themselves, thus encouraging dependence.

Moreover, in Malta, the traditional family values persist quite strongly, and the mother figure still plays a central role within the family (Abela, 2000). Although the percentage of Maltese women in employment is on the rise particularly among the younger generations, the percentage of women who work outside the home is still low in Malta, compared to other European countries like Cyprus and Sweden (European Commission, 2011). A survey on gender stereotypes shows that Maltese women are still almost solely responsible for household chores (Gatt and Gatt, 2006). This caring role is believed to be a predominant factor in Maltese women's identity, causing feelings of guilt and shame when they diverge from that role (Borg and Clark, 2007). This suggests that Maltese children, particularly males, may be brought up in environments which fail to promote involvement in everyday chores, thus reducing their opportunities to perform life skills independently. This phenomenon may be predominant in Malta as a result of an entrenched paternalistic attitude which may originate from its Catholic roots. Notwithstanding this culture, international studies (e.g. Wade, 2015; Klein, Graesch and Izquierdo, 2009) conducted in the United States (US), suggest that children's involvement in household chores is nominal, indicating an increase in responsibilities in older and female children. This brings into question specifically what factors are contributing to autistic young adults, males in their majority (Meng-Chuan, Lombardo and Baron-Cohen, 2014) to acquire and perform daily living skills to function more independently in everyday life.

Moreover, Maltese parents have a tendency to be over-protective of their children. This trend is inclined to increase when children have a disability. Grech and Aquilina (2011) argue that Maltese parents and carers often opt to carry out everyday life skills for the person with disability, allowing them little opportunity to explore their ability to perform such skills independently. However, a Maltese study on parents' over-protectiveness found that this was adversely affected by the negative attitudes and insensitive communication of carers in service provisions where their autistic adults with intellectual difficulties attended (Spiteri, 2019). Moreover, another Maltese study demonstrated that the range of emotions that parents go through during the autism diagnostic assessment of their children are not well acknowledged and catered for. The parents reported that there was a great lack of practical and emotional support for them during such a delicate process, which affected the way they perceived this new experience (Ciantar, 2018). All these cultural and familial factors may well interact to place Maltese autistic young people at an increased possibility to remain dependent on others, particularly their parents for everyday life skills.

2.4. Factors which may influence independent functioning in autism

In addition to family and cultural factors discussed above, there are a number of other factors which can influence the development of independence in young autistic people. The transition to adolescence and adulthood are major periods in the life of an individual characterised by various changes, the acquisition of new skills and societal expectations particularly in the area of independence. The distinctive features of autistic young people may well contribute to the achievement level of functional independence in adulthood (Woodman *et al.*, 2016). This section will give a brief overview of the core differences in autism, and other elements including intellectual ability and family factors that could potentially contribute to the difficulties in performing DLS and acquiring independent functioning in adult life. Besides within-individual and familial factors, this section will also consider the perception of autism and societal issues, by exploring the potential effects of factors external to the individual, on the development of DLS, such as the way society views and relates to autism.

2.4.1. Social communication difficulties and restricted interests

Researchers suggest that communication difficulties in autism may well contribute to the lack of functional independence in autistic people with average verbal and intellectual abilities. Such difficulties are likely to hinder them from understanding instructions, expressing ideas and choices, and enquiring about clarifications, to be able to carry out tasks independently (Hurlbutt and Charmers, 2004). In addition, lack of social initiations is likely to increase the likelihood of missing out on learning opportunities that would ultimately increase independent functioning (Hume *et al.*, 2009).

Moreover, restricted interests (Spiker *et al.*, 2012) and a ‘monotropic’ or single channelled attention style (Lawson, 2011; Murray, Lesser and Lawson, 2005), usual characteristic of autistic people, are likely to further restrict an individual’s opportunities to attend to and observe functional skills being carried out by others. Observational learning, which encompasses the acquisition of skills through the observation of others, is universally recognised as a means through which children with typical development learn various skills (Greer, Dudek-Singer, and Gautreaux, 2006; Bandura, 1977). Therefore, due to difficulties in observational learning, autistic individuals may be deprived from learning functional skills by simply observing others (Plavnick and Hume, 2013).

2.4.2. Generalisation and executive functioning difficulties

Inflexible thinking together with difficulties to relate new events to past experiences, also result in a difficulty to generalise learnt skills to new situations (Hume, Plavnick and Odom, 2012). In this context, autistic people may master a skill in a particular setting and under specific conditions. However, if circumstances change, such as the place, activity or people involved, they are likely to respond to it as a novel experience, requiring support and further instructions to carry out the task. Hume et al. (2009) argue that generalisation difficulties are likely to impact on the independent functioning of autistic people in their everyday life, which is underpinned by unexpected changes and novel circumstances.

Moreover, it is widely agreed that autistic people experience difficulties in the executive function (EF) processes, which impact on the various domains of adaptive functioning and thus, contribute to difficulties in independence outcomes. (Pugliese *et al.*, 2015; Hume *et al.*, 2009). The term *executive function* refers to a number of cognitive processes such as, planning and sequencing events, mental flexibility, initiating and inhibiting responses, and controlling impulses (Robinson *et al.*, 2009). These cognitive processes are linked to frequently manifested everyday situations which involve behaviours that are goal-directed and underpinned by a purpose, and which require problem-solving skills (Hume *et al.*, 2014; Lezak *et al.*, 2012). Thus, they are likely to have a significant impact on DLS, such as, preparing a meal, money handling, shopping and using public transport (Pugliese *et al.*, 2015). These difficulties are likely to become more obvious in the adolescent years, particularly in secondary settings when students are expected to perform a number of skills such as, organise their study material and follow multistep sequences, without assistance (Rosenthal *et al.*, 2013).

2.4.3. One-to-one direct teaching and prompting

Given the core difficulties and unique learning style of autistic people and how these intertwine with the teaching styles that autistic students are often exposed to, it was considered necessary to include this section. Some theorists have attributed difficulties to achieve functional independence in autism to the teaching style and approaches that autistic children experience during their school years. In most circumstances, autistic students spend the majority of their school hours with a teaching assistant in close proximity (Giangreco and Broer, 2005). They experience one-to-one direct teaching, adult prompting, and repeated reinforcement (Smith, 2001). While direct one-to-one teaching may be beneficial for students to acquire novel concepts and learn new skills, they may become dependent on the support and prompts of paraprofessionals to complete tasks (MacDuff, Krantz and McClannhan, 2001). Interesting findings from the Blatchford Report (Blatchford, Webster and Russell, 2012) in the UK, reveal a negative correlation between the level of support students received from teaching assistants (TAs) and achieved progress in English, Mathematics and Science.

Autistic people are likely to rely on others' prompts to carry out a task rather than initiate a behaviour as a response to environmental cues. Additionally, it is argued that due to the often reported resistance to change and lack of flexibility in autistic students, the 'acquired' prompt dependency may hinder the individual's ability to achieve independent functioning of learnt skills when prompts are faded out or eliminated (Hume *et al.*, 2009). Consequently, resulting in difficulties to perform skills independently later on in life.

2.4.4. The link between cognitive ability and everyday performance on DLS

A number of studies on the acquisition of DLS and functional independence in autistic people set out to explore the potential link between independent functioning and the individual’s cognitive ability or autism symptomology. While studies report that a childhood IQ of at least 70 is necessary for autistic people to acquire independent living skills (Howlin et al., 2004), research in this area indicates that their ability to function independently in life is not directly determined by their cognitive ability or autism symptomology. Studies reveal that adaptive behaviour across the various domains on the VABS (Sparrow, Cicchetti and Balla, 2005) is significantly delayed in autistic people with average or above-average intelligence (Kanne *et al.*, 2011; Saulnier and Klin, 2007). More specifically, research in this area indicates a gap between individuals’ cognitive ability and their everyday performance on DLS (Duncan and Bishop, 2015). Kanne et al. (2011) found that this identified gap is more prominent in individuals with average cognitive and verbal abilities.

Overall, literature on the functional independence of autistic people identifies an overarching difficulty in the area of DLS despite an absence of intellectual difficulties, which Duncan and Bishop (2015, p. 6) describe as a ‘significant cause for concern’. In line with this, researchers emphasise the significance of addressing the gap between intellectual ability and the independent performance of DLS by studying various factors that may potentially be involved in this disparity, if autistic adults are to live more independent lives (Duncan and Bishop, 2015; Henniger and Taylor, 2013; Smith, Maenner and Seltzer, 2012).

2.4.5. The role of the family on the independent functioning of autistic people

On the basis of this review, literature on the functional independence of autistic people has focused primarily on factors within the individual. These are related mostly to the condition of autism, as a major contributing factor to the lack of performance of DLS and independent functioning. Similarly, over the years, psychiatric and psychological approaches to age-inappropriate dependence of neurotypical adult children focused primarily on the factors within the dependent individual. His/her diagnostic characteristics such as anxiety and depression, were often considered as the principal cause of the experienced dysfunction (Lebowitz *et al.*, 2012).

Adult entitled dependence (AED) is a recently coined term to describe a condition which involves an adult child who is partially or completely dysfunctional, and at least one parent who accommodates and adapts to the demands of the dependent adult child by carrying out age-inappropriate services for them (Lebowitz, *et al.*, 2012). In this context, Wesley (2013) emphasises the significance of studying AED and providing intervention in the primary environment within which it takes place, precisely within the family. It is not the purpose of this review to explore the diverse dissimilarities or potential comparisons that may be present between AED and the lack of functional independence of autistic young people. Nevertheless, this study will implement the same ideology adopted by recent research in AED (Lebowitz, *et al.*, 2012) and explore the area of independent life skills in able autistic young people, particularly in terms of what promotes or hinders their development, by understanding the family system rather than solely the autistic family member.

2.4.6. The importance of the family

From birth, a child's life is influenced by multiple environmental factors, with the family possibly being the first and most significant. The family is perhaps the most universal social unit that shapes human behaviour, believed to have a direct and lasting impact on the overall development and outcomes of children (Sameroff, 1990). Research within the field of independence and autonomy, points to the significance of children's opportunities within the family to undertake varied responsibilities for everyday chores and life skills (Brannen, Heptinstall and Bhopal, 2000; Brannen, 1996) to promote good autonomy and independence outcomes (Brannen, 1996). Studies in the field of intellectual disability have yielded similar results suggesting a link between one's opportunity and ability to manage DLS and the development of self-determination skills (Farlow and Snell, 2006; Sowers and Powers, 1995). As noted by Curryer and colleagues (2015), a broad plan to promote the functional independence and autonomy of individuals with intellectual and developmental disabilities, emphasises working with families to understand the significance of their role in encouraging opportunities for independent life skills.

For this purpose, this review will draw on the family systems theory (Bowen, 1978) detailed in the next section, to explore factors that could potentially constitute the promoters and barriers of independent life skills of autistic young people in everyday life.

2.5. The Family Systems Theory (Bowen, 1978)

Family systems theory derives from the general systems theory, which was originally postulated by Ludwig von Bertalanffy in 1928. He proposed that a system is made up of interrelated and interdependent components which cannot be understood in isolation from each other but as a unified whole through the interactions between the parts (Walonick, 1993). Through the lens of general systems theory, the family is viewed as an interactional system made up of family members who are mutually dependent on each other. The development of family systems theory is devoted to the works of pioneers in family therapy like Ackerman (1959), Minuchin (1974) and Bowen (1978).

The focus of this theory is on the philosophy that the individual members of a family and the way they behave can be understood by looking at the entire family and the relationships and interactions within it, rather than focusing merely on the individual members (Doherty *et al.*, 1993). Family systems theory provides an explanation to why family members behave the way they do (Fingerman and Bermann, 2000). Predictable patterns of behaviour and interaction develop, a process through which balance is maintained within the family. However, any change in the behaviour and functioning of one member is bound to create a *ripple effect* whereby the whole family system needs to undergo a readjustment process (Kerr, 2000). Furthermore, this theory makes reference to 'subsystems' (Millberg *et al.*, 2020, p. 2) which include two to three members of the family, and 'suprasystems' (Millberg *et al.*, 2020, p. 2) which refers to other systems outside the family, such as the extended family, the children's schools, and the community with which the family interacts. Allen (1982) noted that systems affect each other and this entails that the family responds effectively to changes within itself and to outside pressures, if it is to maintain a sense of equilibrium.

The family systems theory recognises the uniqueness of every family. Nonetheless, it proposes a number of characteristics of the family system which are pertinent to understand families better. This review will explore four characteristics which may be the most relevant to understand the concept of developing life skills for functional independence in families of autistic individuals: family boundaries, role organisation, rules, and communication processes. Every characteristic lies on a continuum, an aspect which distinguishes families from one another, and the same family over a period of time (Garris Christian, 2006). Moreover, each characteristic is highly influenced by factors which may be internal to the family such as, family values, traditions and different circumstances that a family goes through, or external like cultural and societal expectations (Allen, 1982).

2.5.1. Functional independence in autism through the lens of the Family Systems Theory

Through the lens of family systems theory, the family is viewed as more than a gathering of individual members but as a system with its own distinctive structures. Boundaries, roles and rules guide patterns of interaction within the family, generating a sense of balance (McDaniel and Pisani, 2012). Functioning styles are often established early in the life of a family. However, when the family goes through a major episode, as is an autism diagnosis of a child, it is likely that that family needs to adjust and restructure established family patterns (McDaniel and Pisani, 2013). In this context, Altiere and von Kluge (2009) note that the development of an autistic child impacts on the family system in a mutual way as the family impinges on the child's progress.

Family systems are characterised by boundaries, which are unwritten rules about the nature of relationships within the family, as well as the family's relation to other outside systems, defining who is *inside* or *outside* of the family (Walsh and Giblin, 1988). External boundaries describe the family's relationship to other systems such as the community, the church, the children's schools and other services, such as professional support, that the family has regular contact with. When a family member has a condition which necessitates the assistance of outside support services, like in this case the MAC, the family's external boundaries may become more permeable. These would allow more opportunity for sources outside the family to impact on the characteristics of the family system and the relationship dynamics between parents and the young person with a disability (McDaniel and Pisani, 2012). As an example, the school's practice in terms of the independent functioning of students with special educational needs may directly or indirectly influence the parents' motivation to empower their son or daughter to take part and practice daily life skills. For instance, Wittemeyer, Charman and Cusack (2011) found that very often Individualised Education Plans (IEPs) of students with special educational needs (SEN) fail to consider goals for long-term functioning to enhance adult outcomes. More so, from the population of students with special education needs, autistic students are among the least likely to be given the opportunity to take part and contribute to the process of their IEP (Test, Smith and Carter, 2014; Held, Thoma and Thomas, 2004). This in turn is likely to promote a practice among parents to take decisions and make choices for their autistic adolescents.

The family's internal boundaries are particularly pertinent in the study of functional independence. Minuchin (1974) describes two extremes of family dynamics, namely, highly 'enmeshed' versus 'disengaged' families. Disengaged families value the individual members' identity and encourage autonomy. Such family environments are more likely to promote independence (Garris Christian, 2006). Minuchin (1974) suggested that disengagement in families of a child with disability could be underpinned by feelings of anxiety. On the other end of the continuum are what Minuchin describes as 'enmeshed' families, in which the individual's identity and behaviours are perceived as a reflection of the family rather than a quality of the individual member (Minuchin, 1974, cited in Sturge-Apple, Davies and Cummins, 2010, p. 1324). Moreover, independence is less encouraged in these families than in disengaged ones.

Families may become more enmeshed in times of stress and anxiety (Garris Christian, 2006), and an autism diagnosis could instigate enmeshment. External structures such as society's views and expectations of disability are also likely to impact on the family's internal boundaries. This may be of particular relevance in societies like Malta where families of persons with disability are perceived as 'chosen by God' to care for a person who is 'blessed by God' (Cardona, 2013, p. 281), which could further encourage a sense of enmeshment within the family. According to Minuchin (1974), extreme cohesion in families often results in over-protective parents, which can also encourage a sense of helplessness and dependence in the child with a condition or disability, which may well be socially acceptable (Minuchin, 1974, cited in McDaniel and Pisani, 2012).

In addition to boundaries, family systems are characterised by roles and rules which are entrenched in the cultural and familial contexts. These are often established through communication processes within the family system (Allen, 1982). Every member within the family has roles which define the responsibilities and expectations of that individual within the family system. Fingerman and Bermann (2000, p. 9) claim that roles are assigned in accordance to how each individual member is viewed in terms of competence, one's position within the family, and other factors arising from 'within-family differences'. In a qualitative study about those factors that make persons with a learning difficulty content with their lives, Haigh et al. (2013) found that participants were not assigned any valued roles and duties at home which in turn impacted on their level of happiness. In this context, cultural and familial perspectives about the competences and expectations for autistic people are likely to influence what roles are assigned to these members of the family, and the extent to which they are involved in the everyday family life through the allocation of everyday chores and responsibilities.

A change in the established patterns and roles such as, involving the autistic young person in DLS and promoting their functional independence is likely to bring about a change in the roles of other family members who were formerly responsible for those needs and chores (Lebowitz *et al.*, 2012). This is also likely to bring about a change in the internal boundaries of the family with the members mainly responsible for the daily needs of the autistic member being compelled to become ‘disengaged’ (Sturge-Apple, Davies and Cummins, 2010, p. 1321) to encourage independent functioning. McDaniel and Pisani (2012) remark that families might find it difficult to attain a balance between the demands of encouraging and training an individual member with a disability for functional independence, and the competing needs of other family members. This situation may become more pronounced in families with time constraints such as when both parents are in employment, or when siblings are still young and dependent on parents for their basic needs. In similar circumstances, attending to the daily needs of the autistic young adult may be less time consuming than allowing them to explore the possibility of completing the task independently.

Family systems are guided by rules. Within this context, Garris Christian (2006, p. 5) defines rules as ‘sets of standards, laws, or traditions that tell us how to live in relation to each other’. In families, rules may be communicated or implied. They guide the members about the way they should relate to one another, and define power, decision-making and gender roles within the family. In relation to the area of life skills in verbal and intellectual autistic young people, familial rules about gender roles are particularly significant. UK and US based research as well as surveys conducted in Malta consistently show that women are expected to do and still do household chores almost exclusively (O'Grady, 2015; Gatt and Gatt, 2006). This gender variance exists from a very young age, with girls being assigned routine chores forty-two percent more than boys (Wade, 2015).

2.5.2. Differences in role relating to gender

Given that the number of diagnosed autistic people varies significantly between the genders, with a higher prevalence rate in boys (Chakrabarti and Fombonne, 2001), stereotypic rules about gender roles within the family could possibly be reflected in measures of adaptive behaviour skills in autistic young people, particularly within the domestic domain. On the basis of this review, many studies on adult outcomes and adaptive behaviour skills in autism failed to provide sufficient information on the gender of the participants in their sample. Only one study on adaptive behaviour skills in autistic individuals (Pugliese *et al.*, 2015) specified the gender of the participants, whereby out of 447 participants, only 73 were female. However, this study did not provide comparative data about the development of adaptive behaviour skills in male and female participants. Investigating gender related differences or similarities in terms of adaptive behaviour measures and adult outcomes in autism could provide insight into whether culturally embedded rules about gender roles within the family impact on the development of DLS and independent functioning of autistic individuals.

McDaniel and Pisani (2012) argue that as a system, the family of an individual with a disability, needs to be adaptable to the changing developmental needs of its member.

Thus, rules and roles may change over time and the family may go through the stages of a family life cycle in an atypical manner. Within the context of independence in autistic young people, this may be particularly relevant for the stages of raising adolescents and young adults whereby the demands and needs of the young person may not be in accordance with the family's life cycle stage. Understanding the family as a system characterised by roles, rules and boundaries and identifying how the family deals with tensions and how it relates to 'suprasystems' (Millberg *et al.*, 2020, p. 2) is useful for effective intervention with students (Garris Christian, 2006). This lens is particularly pertinent to explore the area of independence. The development of DLS and functional independence is complex particularly in the field of autism, and although independence happens primarily in the family, research clearly indicates that it is not tied to a single cause.

2.6. Societal issues that may affect the independent functioning of autistic people

Oliver (1990) contends that the differences and challenges brought about by the autism condition are often amplified by societal barriers. Literature shows that autistic children are often perceived negatively by NT peers, and these negative perceptions persist among NT adolescents and adults who hold several misconceptions about autistic people, such as being *awkward* and *unintelligent* (Dickter et al., 2020). A study among university students found similar attitudes, and autistic people were described through negative labels, such as *obsessive*, *with poor communication and emotional intelligence,* and *withdrawn* (Wood and Freeth, 2016). Autistic adults in a study by Treweek et al. (2019) emphasised that such stereotypes tend to pave the way to other negative experiences such as bullying, humiliation and social exclusion.

Indeed, autistic students are considered to be particularly vulnerable to bullying (Hebron and Humphrey, 2014). Studies show that the rate of bullying among autistic people is notably higher than that of NTs and learners with other SEN (Humphrey and Symes, 2010; Humphrey et al., 2010). In a National Autistic Society (NAS) parental survey, the rate of bullying was found to be 40%, rising to 59% for those diagnosed with Asperger's syndrome (AS) (Reid and Batten, 2006). Similarly, Wainscot et al. (2008) found that 87% of students with AS were bullied at least once a week. Research shows that bullying leaves a scar that may take long to heal. Bullied children in general are at a higher risk of developing internalising problems, anxiety disorders or depression (Wolke and Lereya, 2014; Gini and Pozzolli, 2009).

Autistic participants in various studies recall being misunderstood, bullied and teased by peers (Berkovits et al., 2020; Cameron, 2014). They are also distinguished from their peers or sometimes given unnecessary help by the teachers, who at times patronise them (Brownlow et al., 2021; Cameron, 2014). Han et al. (2021, p. 12) found that such negative experiences often lead autistic people to hold 'negative beliefs about themselves, which may affect their self-worth and mental health.' Research shows that fears of prejudice and stigmatising behaviour often lead autistic people to internalise such stigma and to camouflage their diagnosis and decide to keep it secretive (Han et al., 2021; Cage, Di Monaco and Newell, 2019). This in turn affects the extent to which they succeed in integrating autism in their self-identity (Leedham et al., 2020; Mogensen and Mason, 2015). In a recent study, autistic people expressed their wish to be treated and accepted for who they are 'without being underestimated or over-glorified' (Lee et al., 2022, p. 8).

2.7. Search strategy for this literature review

A thorough review of the literature was undertaken on the topic of the development of independence in autistic young people. Electronic database searches were conducted mainly through the University of Birmingham database and Google Scholar, PsychInfo and PsychArticles. The keywords used for the searches were “autism”, “Asperger’s syndrome” and “disability”, paired with the following key search terms: “independence skills”; “adult independence outcomes”; “daily life skills”; “adaptive functioning”; “barriers to independence”; “promoters of independence”; “promoters of daily living skills”; “transition to adulthood”. The key search terms used are shown in Table 1 (below) together with the number of studies found and the number of duplicates. Throughout the search a large number of studies were rejected by examining their title due to their lack of relevance to the study topic. From those which were retained, some were rejected at the abstract stage. The remaining articles were retained to be included in this literature review. Initially, no publication time limit was applied to get an overview of the timeframe in which the topic of independence in autism and disability have been researched. Through this search, it was observed that the concept of independence within the area of disability gained prominence in more recent years, and so the review was subsequently limited to studies done during the last two decades at the time of the literature review, from 1997 to 2017.

To acquire a comprehensive view of the topic, initially the concept of independence was searched within the wider topic of disability. Studies in this field have explored a wide range of disabilities including physical dysfunction due to medical conditions such as stroke (e.g. Parker, Gladmon and Drummond, 1997), and cerebral palsy (e.g. Kerr, McDowell and McDonough, 2007); visual impairment (e.g. Al-Zboon, 2016);

intellectual disability (e.g. Murray *et al.*, 2013) and gerontology (e.g. Wolinsky *et al.*, 2005).

Through this search it was found that the literature focuses primarily on the individuals' rights to have wishes and preferences and to make their own decisions accordingly. This was observed most when the focus was primarily on physical disabilities, in which mobility problems limit the persons' independence in performing daily tasks. Due to the nature of the needs arising from such disabilities, *independence* was defined more in terms of making choices rather than one's ability to perform DLS for themselves, without requiring assistance. For instance, the Disability Rights Commission defines independence in terms of:

> All disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community. This does not necessarily mean 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations (Morris, 2003, p. 4).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) which promotes the rights of people with disability in terms of choice, decision-making, and independence, has been ratified by many countries, including Malta in 2012. This international growing recognition of the rights of people with disabilities to achieve a sense of independence and control over their lives (Curryer, Stancliffe and Dew, 2015) has given rise to studies which seek to explore the concept of autonomy in individuals with intellectual and developmental difficulties.

When the search was narrowed down to intellectual disabilities, this review revealed that recent studies adopted the developmental definition of independence (see Section 2.2.1). The aim of such studies was primarily to acquire an understanding of the development of *self-determination* mainly characterised by skills of decision-making, problem-solving, and choice-making (Curryer *et al.*, 2015; Mitchell, 2012; Saaltink *et al.*, 2012). The majority of these studies on self-determination skills in the field of disability included participants with varied special educational needs. This suggests that such studies are unlikely to bring out the diverse experiences of individuals with different intellectual and developmental differences, particularly autistic individuals who may encounter unique challenges to achieving self-determination skills.

On the other hand, a search for literature within the field of autism and independence revealed that studies focused primarily on *functional independence* (see Sections 2.2.2). Many studies focused on the effectiveness of different interventions (such as, structured work systems, video modelling and prompting, and mobile technologies) to increase the independence skills of autistic people (e.g. Hume, Plavnick and Odom, 2012; Bereznak *et al.*, 2012; Carnahan *et al.,* 2009; Ayres, Mechling and Sansosti, 2013). This initial unrestricted search of the literature also revealed that several papers focused on adult outcomes, spanning over a period of forty-five years (1960s – 2005). Research was thereafter restricted to the past two decades. Following changes in the service systems and a decrease in institutionalisation of autistic people (Levy and Perry, 2011), studies focused on more standard measures of functional independence, adopting criteria pertaining mainly to one's social relationships, residential arrangements and employment (Henniger and Taylor, 2013). These were considered more relevant to my interest and thus, to this thesis.

Thirty papers were found on adult outcomes and adaptive behaviour in autism. Studies on adult outcomes consisted mainly of longitudinal studies and revealed that the number of autistic adults achieving encouraging levels of independence may be growing (Billstedt, Gillberg, and Gillberg, 2010; Farley *et al.*, 2009). However, the majority of these adults experience a number of challenges throughout their life, resulting in poor outcomes (Duncan and Bishop, 2013; Howlin *et al.*, 2013; Howlin *et al.*, 2004; Eaves and Ho, 2008). Studies on adaptive behaviour in autism were mostly correlational studies which sought to investigate the association between IQ and levels of adaptive functioning. Consistently, these studies revealed a discrepancy between intellectual ability and adaptive functioning (see Section 2.2.4.1). A search for literature about the topic of independent functioning drew further attention to comparative studies (e.g. Anderson *et al.*, 2014; Orsmond *et al.*, 2013; Shattuck *et al.*, 2012) which reported that the independent functioning of autistic people within the leisure, work and independent living domains were the lowest when compared to other special education groups.

2.7.1. Main life skills required for independent functioning in autism

The relevance of the abovementioned studies and their findings was mainly to provide the context for this thesis. Moreover, studies such as the one carried out by Duncan and Bishop (2013) highlighted the significance and importance of exploring the topic of independent functioning of verbal and intellectually able autistic people. Duncan and Bishop's (2013) reported findings revealed that notwithstanding their average IQ, autistic people fail to develop DLS which are critical for their independent functioning. Moreover, they shed light on the significance of a deeper understanding of those factors that could potentially be impacting on the reported difficulty to develop DLS and acquire independent functioning in adulthood. This study was influential in motivating me to further explore the topic of DLS in autistic people with average verbal and intellectual abilities, particularly those factors that are likely to promote or hinder the development of such skills.

Literature indicates that the rates of independent living for autistic adults across the spectrum remain low for *high-functioning adults* (Howlin *et al.*, 2013) and exceptionally low for autistic adults with intellectual disability (Beadle-Brown, Murphy and Wing, 2006). Moreover, autistic adults remain heavily reliant on others for day-to-day functioning (Hume *et al.*, 2014; Kanne *et al.*, 2011). More so, research consistently shows that autistic individuals with at least average cognitive ability still fail to achieve the expected levels of independence based on their IQ (Matthews *et al.*, 2015; Duncan and Bishop, 2013; Perry *et al.*, 2009; Howlin *et al.*, 2004). Consistently, Kanne et al. (2011, p. 1015) concluded that adaptive behaviour is: ‘substantially deficient in intellectually-able individuals with ASD.’

As it has already been outlined in Sections 2.2.2 and 2.2.4, independent living requires the functional use of several DLS and a significantly high level of adaptive behaviour, ranging from cooking a meal to paying bills and keeping safe, which allow the individual to carry out every day needs and routines independently. On the basis of this review, few studies have set out to explore the lived experiences of autistic adults with average intellectual and verbal abilities, and their families, in terms of life skills, to gain insight into those factors that could potentially be hindering the development of DLS vital for independent functioning. Duncan and Bishop (2015) emphasise that:

> …more research is needed to understand the observed gap between these individuals’ “potential” for success (e.g. as measured by IQ) and their actual rates of independence in adulthood (Duncan and Bishop, 2015, p. 2).

Table 1. Number of papers found and duplicates

Search Term	Database	Refined by	No of studies found	Duplicates
Independence skills + autism	University of Birmingham	Type: included Dissertations & Articles Subject: included 'autism spectrum disorders' excluded medicine & children	282	0
	Google Scholar	With the exact phase: 'independent-living' Without the word: 'children'	326	12
Independence skills + Asperger's syndrome	University of Birmingham	Type: included Dissertations & Articles Subject: included 'Asperger syndrome' excluded medicine & children	183	0
	Google Scholar	With the exact phase: 'independent-living' Without the word: 'children'	31	5
Independence skills + disability	University of Birmingham	Type: included Dissertations & Articles Subject: included activities of Daily-living Excluded: children & medicine	872	0
	Google Scholar	With the exact phase: 'independence skills' With at least one of the words: 'disability'	1,130	23
Adult independence outcomes + autism	University of Birmingham	Type: included Dissertations & Articles Subject: included autism & adults	1,476	0

		excluded children		
	Google Scholar	With the exact phrase: ‘independence outcomes’ With at least one of the words: ‘autism’	21	10
Adult independence outcomes + Asperger’s syndrome	University of Birmingham	Type: included Dissertations & Articles Subject: included adults & Asperger syndrome	221	0
	Google Scholar	With the exact phase: ‘independence’ Without the words: ‘children’	504	21
Adult independence outcomes + disability	University of Birmingham	Type: included Dissertations & Articles Subject: included disability and then refined more by included ‘disabilities’	147	0
	Google Scholar	With the exact phrase: ‘independence outcomes’ With at least one of the words: ‘disability’	128	9
Daily living skills + autism	University of Birmingham	Type: included Dissertations & Articles Subject: included Daily living skills	229	0
	Google Scholar	With the exact phrase: ‘daily living skills’ With at least one of the words: ‘autism’ in the title of the article	33	8
Daily living skills + Asperger’s syndrome	University of Birmingham	Type: included Dissertations & Articles Subject: included ‘Asperger syndrome’	285	0
	Google Scholar	With the exact phrase: ‘daily living skills’	577	12

		With at least one of the words: ‘Asperger syndrome’ Without the words: ‘disability’		
Daily living skills + disability	University of Birmingham	Type: included Dissertations & Articles Subject: included ‘Activities of daily living’ ‘daily living skills and ‘disability’ Further refinement included ‘intellectual disability’ and ‘disabled persons’	684	0
	Google Scholar	With the exact phrase: ‘daily living skills’ With at least one of the words: ‘disability’ Without the words: ‘children’, ‘medicine’	885	18
Adaptive functioning + autism	University of Birmingham	Type: included Dissertations & Articles Subject: included ‘autism spectrum disorder’ Excluded: ‘medicine’ ‘child’ ‘children’	729	0
	Google Scholar	With the exact phrase: ‘adaptive functioning’ With at least one of the words: ‘autism’ in the title of the article	55	4
Adaptive functioning + Asperger’s syndrome	University of Birmingham	Type: included Dissertations & articles Subject: included ‘Asperger syndrome’	613	0
	Google Scholar	With the exact phrase: ‘adaptive functioning’ With at least one of the words: ‘Asperger syndrome’ without the word ‘autism’	175	0

Adaptive functioning + disability	University of Birmingham	Type: included Dissertations & articles Subject: included ‘disability’ Further refinement: excluding subjects: ‘pain’ ‘depression’ ‘children’ ‘medicine’	876	0
	Google Scholar	With the exact phrase: ‘adaptive functioning’ With at least one of the words: ‘disability’ in the title of the article	16	1
Barriers to independence + autism	University of Birmingham	Type: included Dissertations & articles Subject: included ‘autism’	721	0
	Google Scholar	With the exact phrase: ‘barriers to independence’ With at least one of the words: ‘autism’ Anywhere in the article	93	14
Barriers to independence + Asperger’s syndrome	University of Birmingham	Type: included Dissertations & articles Subject: included ‘Asperger syndrome’	61	0
	Google Scholar	With the exact phrase: ‘barriers to independence’ Anywhere in the article	20	3
Barriers to independence + disability	University of Birmingham	Type: included Dissertations & articles Subject: included ‘disability’	1,872	0
	Google Scholar	With the exact phrase: ‘barriers o independence’ With at least one of the words: ‘disability’ Anywhere in the article	540	0

Promoters of daily living skills + autism	University of Birmingham	Type included: Dissertations & Articles Subjects excluded: ‘school administration’ ‘Molecular biology’ ‘Communication and the Arts’ ‘Medicine’ ‘Genetics’ ‘Biological Sciences’	205	0
	Google Scholar	With at least one of the words: ‘autism’ Without the words: ‘medicine’ Anywhere in the article	1,250	5
Promoters of daily living skills + Asperger’s syndrome	University of Birmingham	Type included: Dissertations & Articles	37	0
	Google Scholar	With at least one of the words: ‘Asperger’ Without the words: ‘medicine’ Anywhere in the article	192	8
Promoters of daily living skills + disability	University of Birmingham	Type included: Dissertations & Articles	2,073	0
	Google Scholar	With the exact phrase: ‘daily living skills’ With at least one of the words: ‘disability’ anywhere in the article	242	3
Transition to adulthood + autism	University of Birmingham	Type included: Dissertations & Articles Subjects included: ‘young adults’ ‘adults’ ‘transition’ and ‘excluded: ‘children’ ‘Medicine’	472	0
	Google Scholar	in the title of the article	47	9

Transition to adulthood + Asperger's syndrome	University of Birmingham	Type included: Dissertations & Articles Subjects included: 'adults'	101	0
	Google Scholar	With the exact phrase: 'transition to adulthood' With at least one of the words: 'Asperger' Anywhere in the article	1,650	0
Transition to adulthood + disability	University of Birmingham	Type included: 'Dissertations' 'Articles' Subject included: 'transition' 'disability'	1,311	0
	Google Scholar	With the exact phrase: 'Transition to adulthood' With at least one of the words: 'disability' In the title of the article	27	2
Views of adults with autism about independence	University of Birmingham	Type included: 'Dissertations' 'Articles' Subject included: 'Asperger syndrome' 'adults'	162	0
	Google Scholar	With the exact phrase: 'views of adults' With at least one of the words: 'independence' Anywhere in the article	80	5
Parents' views + autism + independence	University of Birmingham	Type included: 'Dissertations' 'Articles' Subject included: 'parents'	319	0
	Google Scholar	With the exact phrase: 'Views of parents' With at least one of the words: 'independence' Anywhere in the article	1,190	11

2.7.2. Overview of the included studies in Table 2

Of the studies found through the searches described above, 17 studies were identified as most relevant to the study topic of this thesis. These studies are presented in Table 2 (below) which displays the main themes that have been studied, where and when the study was conducted, and which perspectives they sought to obtain.

The decision to include these studies (see Table 2) was made on a number of factors. Firstly, they were considered the most relevant to this study in terms of their main aims and methodologies. Studies were included in Table 2 if they explored the concepts of independence or autonomy of youths and adults with special educational needs. Studies which adopted the developmental definition of independence, as opposed to the behavioural definition adopted for this thesis, were also included if they provided insight into the lived experiences of the main stakeholders in the field of disability.

The overall objectives of these studies were to explore the views of various stakeholders, including parents, carers, professionals, autistic people, and people with intellectual or developmental difficulties, primarily in terms of factors surrounding potential promoters and barriers to different aspects of independence. Studies were included if they used qualitative methods of data collection or a mixed method design. The majority of the reviewed studies on life skills and independent functioning of individuals with various disabilities and special educational needs have been carried out in the UK and the US, while only one published study has been found to be carried out in Malta to date (as seen in Table 2).

Table 2. Focus of studies on functional independence

Theme	Author/s	Date and Country	Views of persons with autism / disability	Views of parents	Views of professionals
Priority life skills	Wittemeyer, Charman, Cusack, Guldberg, Hastings, Howlin, et al.	2011 UK	✓	✓	✓
	Barnard, Harvey, Potter and Prior	2001 UK		✓	
	Wang and Berg	2014 Taiwan	✓	✓	
	Haigh, Lee, Shaw, et al.	2013 UK	✓		
	Bowey and McGlaughlin	2005 UK	✓	✓	
Barriers to independence	Di Gennaro Reed, Strouse, Jenkins, Price, Henley and Hirst	2014 US		✓	
	Bancroft, Batten, Lambert and Madders	2012 UK	✓	✓	
	Foley	2012 UK		✓	
	Haigh, Lee, Shaw, et al.	2013 UK	✓		

	Saaltink, Mackinnon, Owen and Tardif-Williams	2012 Canada	✓	✓	
	Bowey and McGlaughlin	2005 UK	✓	✓	
	Mitchell	2012 UK		✓	
	Shogren and Broussard	2011 UK	✓		
	Bowey, McGlaughin and Saul	2005 UK		✓	✓
	Hurlbutt and Chalmers	2004	✓		
	Cardona	2013 Malta	✓		
	Jingree and Finlay	2012 UK		✓	
	Wang and Berg	2014	✓	✓	
	McCollum, LaVesser and Berg	2016 US	✓	✓	
Participation of young adults with autism/disability in everyday activities and routines	Wang and Berg	2014 Taiwan	✓	✓	
	McCollum, LaVesser and Berg	2016 US	✓	✓	

Challenges of transitioning to adulthood	Cheak-Zamora, Teti and First	2015 US	✓	✓	
	Jingree and Finlay	2012 UK		✓	

2.7.3. Factors related to DLS that may be perceived as important

Two UK based studies reported a consistent difficulty in autistic adults to carry out life skills independently (Bancroft *et al.*, 2012; Barnard *et al.*, 2001). Bancroft and colleagues (2012) found that the majority of the adult participants were unable to perform life skills independently within the community domain, such as shopping for food and using public transport. Similarly, the majority of parents in the study conducted by Barnard et al. (2001) claimed that their adult autistic child was unable to manage everyday household chores vital for independent living such as, cooking a meal and doing the laundry, without support.

While both studies underline the existent difficulties of autistic adults to manage life skills, it is not clear which life skills are considered a priority for them or their parents. Moreover, both studies included autistic participants of varying cognitive abilities. However, the reported data are nonspecific in terms of the potential relationship between difficulties to manage specific life skills and the nature of the adults’ autism. It would have also been interesting to gain insight into parents’ views in terms of what is impeding their autistic adult children from developing these skills, and which factors are believed to hinder their future prospects for independent living.

In a study about adult outcomes in autism, adults pronounced community skills such as going shopping, doing socially expected behaviour in public, and using money and public transport, as the mostly desired skills for their independent functioning (Wittemeyer *et al.*, 2011). Participants in a study conducted by Haigh et al. (2013) also considered skills like cooking and independent travelling important. From the findings of the UK-based studies under the theme of priority life skills in Table 2, it seems that skills within the domestic and community domains are brought up the most by participants. However, these studies were only able to take a snapshot view of important DLS as they were based on random examples given by participants. A more systematic instrument such as the Adolescent and Young Adult Participation Sort-Taiwanese version (AYAPS-T) used in the study conducted by Wang and Berg (2014) is more likely to capture which skills (from a given list) are considered to be most important for the participants. Results of the study based in Taiwan by Wang and Berg (2014) suggest that priorities may also be culturally embedded. Participating autistic high-functioning youths who relied on their parents for everyday self-care needs, but who were able to use public transport independently, claimed learning to drive a car or ride a scooter, (which is a typical means of transportation for Taiwanese youths), to be a priority skill for bettering their vocational opportunities (Wang and Berg, 2014). Moreover, priorities are likely to be unique to the respective population, and the heterogeneity of the autism group necessitates more research in this regard.

More comparative qualitative research is needed to identify what life skills are prioritised by autistic adults and their parents to inform autism practice about the potential differences and similarities in the perspectives of the two generations. Literature suggests that many autistic adults share similar aspirations to those expressed by most neurotypical young adults, of living in their own home, having friends, getting married and finding a desired job (Bancroft *et al.*, 2012). Nevertheless, research is still lacking in terms of what DLS young people believe to be important to develop, to be able to reach their aspirations in relation to their independent functioning in adulthood.

More so, the viewpoints of parents in regard to their aspirations for the development of daily life skills for their young people is of particular relevance. As it has already been outlined, families play a crucial role in their children's development of life skills. The family culture, beliefs and attitudes are likely to influence the extent to which parents encourage their children to learn and take on responsibilities of chores and daily routines. More research is needed to explore the similarities and tensions that may be present between the viewpoints of autistic adults with verbal and intellectual abilities and their parents in terms of the development of important life skills. Parents may not share the same aspirations as their autistic adult child, and although they may express a genuine overall desire for their young adult to be independent, they may be reluctant to watch their child walk out of their childhood home. In line with this, Wittemeyer et al. (2011) found that only one percent of the participant parents listed independent accommodation as a priority for their adult child on the spectrum.

In this context, Bowey, McGlaughin and Saul (2005) observed that terms associated to *'independence'* may cause anxiety in parents. This in turn could directly or indirectly undermine the promotion and development of vital life skills for independent living. This underlines the significance of exploring the area of promoters and barriers to the development of life skills in autistic young adults through the framework of the family systems theory. This would afford the opportunity to study the potential influence of family beliefs and values in terms of gender roles, protection of members with special educational needs, and changing family roles and responsibilities, to explore factors that may constitute the actual barriers and promoters to independent functioning.

2.7.4. Factors which might promote or hinder the development of DLS

Research suggests a consistent concern among the main stakeholders, that is, parents, professionals and autistic people themselves about their functional independence in everyday life. Parents emphasise the necessity for more research into those skills that would promote the independence of these young people, ranging from basic skills such as getting dressed, to more complex ones such as, getting to work by train (Pellicano, Dinsmore and Charman, 2014).

Several studies have explored the area of independence in autism, particularly in terms of adaptive functioning and adult outcomes, with most of them revealing that the majority of autistic children, with average or above-average cognitive ability continue to live with their parents or guardians and remain unemployed into adulthood (Howlin *et al.*, 2013; Howlin, Alcock and Burkin, 2005). Despite this observed difficulty to acquire the necessary life skills for independent functioning, very few studies have set out to gather the ‘voices’ of autistic people about those factors which foster or undermine their ability to manage important DLS. A study that inquired into this subject matter used generic phrases, such as ‘lack of support’, to describe those factors that were reported by autistic adults as barriers (e.g. Bancroft *et al.*, 2012, p. 19). These adults also reported that their needs were not assessed, which subsequently resulted in lack of adequate support to develop skills that would promote their independent functioning.

Two recent studies (McCollum, LaVesser and Berg, 2016; Wang and Berg, 2014) revealed a more profound understanding of personal and environmental barriers, identified by autistic adults. However, these studies explored barriers to participate in different activities such as chores, social, work and leisure activities, rather than to develop vital life skills for independent functioning, which this thesis intends to explore. Nevertheless, their findings revealed that a deeper exploration into these adults' perspectives about what they themselves believe to be hindering their development of life skills is likely to generate implications for practice.

Other studies have identified barriers arising from the condition of autism in learning specific skills. For instance, the findings of a study carried out by Cox et al., (2012) attributed difficulties in learning to drive to multi-tasking and attention difficulties in autistic people. Others focused on a specific area of adult outcomes such as employment, and identified barriers to keeping up a job, such as, overwhelming social demands at the workplace, and bullying due to a lack of understanding among co-workers (Gotham *et al.*, 2015; Hurlbutt and Charmers, 2004). However, there is dearth of research about what parents and young people believe to be helping or impeding them from achieving independent functioning in terms of priority life skills within the personal, domestic and community domains. As a result, practitioners lack insight into those factors within the family system and its *suprasystems*, which may promote or hinder the development of life skills in autistic young adults. Moreover, it is not clear whether these young people and their parents share similar viewpoints on those factors that promote or undermine the development of these DLS.

More so, as Table 2 indicates, little research has been conducted to explore the views of professionals about priority life skills and promoters and barriers to their development. However, from the few studies which have included the perspectives of these stakeholders on independence, it is revealed that educational practitioners suggest that the training of autistic people for independence should start in the beginning of early childhood. Furthermore, they highlight the importance of teaching simple basic DLS to young children, and gradually building on those skills as the child gets older (Sarris, 2014a; Wittemeyer *et al.*, 2011). This is consistent with anecdotal accounts of successful autistic adults who attribute their success in achieving independent skills to childhood opportunities of being taught such skills (Grandin and Parek, 2013; Blackburn, 2010).

Nonetheless, research indicates that parents may focus on immediate childhood issues. For instance, behaviour management, and academic skills are often considered a priority during school years (Sarris, 2014b). Consistently, Wittemeyer and colleagues (2011) found that independent life skills were not perceived as a priority for parents of autistic school-aged children. Although independence was a priority for when their children become adults, their immediate concern was about educational progress and getting the necessary help (Wittemeyer *et al.*, 2011). These perspectives may well coincide with many school practices which often work toward the National Curriculum and limit the teacher’s flexibility to give more importance to life skills in the IEP of autistic students (Wittemeyer *et al.*, 2011). This may well be a typical scenario for autistic students with average intellectual ability educated in mainstream schools, whereby the national curriculum is enforced more than it is for autistic children with learning difficulties. Within the framework of the family systems theory, this practice is likely to be generated and reinforced through the interactions between the family and the school systems. However, this raises the question on how well the current education system is empowering parents and training autistic students for better independence adult outcomes.

Collecting the views of parents of autistic young people in retrospect in terms of the relevance of learning and practising DLS independently as from a young age, could provide valid data for professionals who support parents and train educators of autistic younger children. In addition, more qualitative studies are needed to gather the perspectives of autistic young people on the role of school in promoting life skills for their future independent functioning. One study which explored the views of adults in this regard revealed that the majority of the participants were dissatisfied and claimed that the school system had not equipped them with the necessary life skills to function independently in adult life. And of those who were given this opportunity, learning life skills was rated as one of: '…the most useful thing(s) that I did at school/college that has helped me as an adult' (Wittemeyer *et al.*, 2011, p. 39).

Moreover, research suggests that the expectations of teaching professionals, and opportunities offered throughout the school years, are also fundamental factors in the overall well-being and independence achievements of autistic individuals (Test, Smith and Carter, 2014). Within this context, Test and colleagues (2014) emphasise the importance of providing autistic students with opportunities to develop skills related to self-advocacy, problem-solving, making choices and setting goals, which are fundamental in life.

On the basis of this review, literature on the promoters and barriers to the development of self-determination skills in individuals with learning and developmental difficulties is more extensive than research on what fosters or hinders life skills in the autism population. Wehmeyer (1992) describes self-determination skills as a collection of attitudes and abilities that serve as the ‘primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference’ (Wehmeyer, 1992, p. 305).

Although the independent management of life skills is not synonymous with self-determination, Wehmeyer’s (2003) Functional Theory of Self-determination proposes a relation between one’s ability to practise everyday life skills without support and the future ability to become autonomous in outcomes relating to family care activities, leisure, employment and managing life in general. Moreover, the functional ability to manage DLS, whether it is cooking a meal, doing the shopping or travelling by bus, is underpinned by various decisions and choice-making opportunities.

A number of studies on self-determination explore the perceptions of families and support professionals, while the views of the individuals with intellectual difficulties are included in a few (refer to Table 2). These offer insights into various familial factors that influence the autonomous functioning of youths and adults with a range of learning and developmental difficulties. To this end, this review of the literature relies to some extent on research which explores promotors and barriers to self-determination skills, mostly in terms of choice and decision-making. These were used to inform this thesis on the key findings and methodological techniques that could be pertinent to studying what factors promote or impede the development of life skills in autistic young people.

2.7.5. Summary of past research on DLS

Looking across the literature in Table 2, studies varied in terms of the participating stakeholder groups taking part. A few gathered the perspectives of either the parents (Barnard *et al.*, 2001; Di Gennaro Reed *et al.*, 2014; Foley, 2012; Mitchell, 2012) or the young person/adult with varying learning and developmental difficulties (Haigh *et al.*, 2013; Shogren and Broussard, 2011; Hurblutt and Chalmers, 2004). Others set out to explore the viewpoints of both the parents and the autistic young adult (Bancroft *et al.*, 2012; Wang and Berg, 2014; Mc Collum, LaVesser and Berg, 2016; Cheak-Zamora, Teti and First, 2015) or those with intellectual difficulties (Saaltink *et al.*, 2012; Bowey and McGlaughlin, 2005), while only one study (Wittemeyer *et al.*, 2011) gathered the views of professionals in the field. In the study carried out by Saaltink et al. (2012), interviews with young people with intellectual disabilities were conducted in the parents' presence, which is likely to have led to a bias in the participants' responses. Moreover, of those which included more than one group of participants, the majority failed to highlight the similarities or differences in their views, except for three studies (Wang and Berg, 2013; McCollum, LaVesser and Berg, 2016; Cheak-Zamora, Teti and First, 2015). The two studies carried out by McCollum et al. (2016) and Wang and Berg (2014) to gather the views of autistic young adults with average intellectual abilities, and their parents about their participation in daily activities, revealed consistency between the responses of the two stakeholder groups. However, the findings of Cheak-

Zamora, Teti and First (2015) showed that parents and autistic young people may hold incorrect perceptions and opinions about each other's views and sentiments in terms of the adolescents' independence and transition to adulthood.

Moreover, the perspectives of fathers were significantly underrepresented in the reviewed studies. When the sample consisted of both parents, (Cheak-Zamora, Teti and First, 2015; Foley, 2012) studies did not report whether there were any differences in the responses of male and female respondents and whether the parents' beliefs and opinions differed in relation to their adult child's gender. It is not clear whether the under-representation of fathers is related to a more active involvement of mothers in the care of young people and adults with special educational needs. This needs to be explored more thoroughly. Further exploration into paternal perspectives in terms of the functional independence and daily management of life skills in autistic young people is likely to provide more insight into the family dynamics, role organisation and issues relating to over-protective parenting.

2.8. Family factors that may foster or impede functional independence

Above and beyond an autism diagnosis and individual characteristics, environmental factors including the family culture and school experiences, and the expectations of significant others, appear to be implicated in the developmental course and independence outcomes of autistic adults (Woodman *et al.*, 2016; Chiang *et al.*, 2012). Expectations for autistic people are likely to vary between families. While some families strive to empower their children to become independent, others may feel responsible for their protection (Curryer, Stancliffe and Dew, 2015). Over-protective parenting is considered by many young people with intellectual disabilities as a major barrier to their independence (Shogren and Broussard, 2011; Cardona, 2013). Living with parents has been implicated in lower DLS for people with learning difficulties and autistic people alike (Smith, Maenner and Selzter, 2012; Haigh *et al.*, 2013).

In line with this, Bowey and McGlaughin (2005) found that parents often continue to shoulder responsibility for the everyday matters of their adults with a learning difficulty into old age. Many adults with learning difficulties express their wish for more opportunities to carry out DLS, such as cooking and using public transport, and to learn new skills. At times, they point at the caregiver’s help and protection as the primary barrier to their functional independence (Haigh *et al.*, 2013; Shogren and Broussard, 2011). Such lack of opportunity is implicated in lack of confidence. Research suggests that youths and autistic adults often experience uncertainty, fear and doubt about whether they possess the necessary skill to manage a particular task independently (McCollum, La Vesser and Berg, 2016; Cheak-Zamora, Teti and First, 2015). Shogren and Broussard (2011) found that lack of confidence in their participants with intellectual disability often resulted from others’ negative attitudes and expressed doubts about the young people’s ability to do something. In this context, more research is needed to explore the experiences and views of autistic individuals about those factors which could potentially be underpinning their anxiety, and consequently undermining their ability to manage daily skills independently.

On the other hand, research shows that parents may be of a different opinion as to what hinders the independence and autonomy of their adult children with learning difficulties. The majority of studies which explore the perspectives of parents focus on choice- and decision-making skills, rather than functional DLS. Nevertheless, they offer insight into the parents' willingness to empower their young people with a range of intellectual and developmental disabilities to carry out life skills particularly within the domestic and community domains. Literature suggests that parents often doubt their young person's ability and skill to carry out household chores safely (DiGennaro Reed *et al.*, 2014). They also express uncertainty about their awareness of consequences, and their ability to distinguish between right and wrong decisions (Mitchell, 2012; Saaltink *et al.*, 2012). Although these studies highlight the views about what they believe to undermine their young person's ability to function independently, they do not enquire into the parents' views about what could be done to alleviate these barriers.

Parents' hesitation to encourage their young person's autonomy appears to be elevated in relation to skills that are carried out in the community. These pertain mainly to two preoccupations, precisely: (i) fear for their youth's safety and a perceived increased vulnerability of being abused, and (ii) concern about society's reaction to their young person's potential atypical behaviour and public appearance (Van Bourgondien, Dawkins, and Marcus, 2014; Foley, 2012; Saaltink *et al.*, 2012). This relates to the previously discussed phenomenon of honour and shame (Moxnes, 2010), and implies that parents' concerns about society's judgments are likely to influence the extent to which they encourage the independence of life skills such as travelling by bus, and others that may be subject to the judgement of others, such as choosing what to wear. Parents' aspirations for their young people with special educational needs are likely to be embedded within cultural beliefs and expectations for people with different needs and disabilities (Cardona, 2013). However, no consideration was given to the cultural context in these studies.

Little is known about whether parents' willingness to take the risk and allow their young people to perform DLS without support, impacts on the latter's ability to develop and manage such life skills more independently. Woodman and colleagues (2016) found that youths with ASD whose mothers had a positive outlook to life and used praise and positive remarks about their son or daughter, had considerably better functional outcomes throughout adolescence and adulthood. Although this must be interpreted within the context that the youth's high levels of functioning could have generated more positive family attitudes, this relationship is likely to be plausible. Moreover, research shows that a lack of opportunity for youths with various intellectual disabilities to take responsibility for everyday matters like cooking, and to be given valuable roles within the family, impacts on their self-confidence (Bowey and McGlaughlin, 2005). This in turn is more likely to lead to dependence and learned helplessness (Saaltink *et al.*, 2012; Grech and Aquilina, 2011).

On the basis of this review, there is paucity of research on how much opportunity parents are giving to autistic young people to be assigned roles within the family. Interestingly, young adults in McCollum and colleagues' (2016) study identified lack of opportunity to carry out particular life skills as the main barrier to their participation in daily activities. Moreover, few studies have sought to gain the views of autistic young people on their motivation to learn new skills for more functional independence, and to perform DLS regularly, and these studies yielded mixed results. While two studies found that autistic young people had an aspiration to become more independent and expressed a sense of satisfaction at being assigned responsibilities (Humphrey and Lewis, 2008; Rossetti *et al.*, 2008), a more recent study reported that autistic adolescents felt comforted with the routine of having their daily activities being carried out by their parents (Cheak-Zamora, Teti and First, 2015). More so, Cheak-Zamora et al. (2015) found that those adolescent participants who wished for more opportunities to manage daily skills independently, were unsure how they could change the situation, and avoided communicating about it. This lack of communication has also been observed within families of adults with learning difficulties, whereby the adults themselves fail to express their aspirations to do DLS more independently (Bowey and McGlaughin, 2005). Additionally, Bowey and McGlaughin (2005, p. 146) found that caregivers may avoid discussions about independent living opportunities for their adult child with a learning difficulty, as they 'did not want the person to feel unwanted'.

Through the lens of the family systems theory, the family's communication processes establish rules and roles of the family members, and in families with 'closed' communication systems, messages may be unclear and misleading (Allen, 1982). In line with this, Cheak-Zamora and colleagues (2015) found that at times, autistic adolescents and their parents held incorrect opinions and perceptions about each other's views and sentiments in terms of independence and transition to adulthood. Moreover, parents tended to underestimate their adolescent's aspiration to achieve independent functioning. This observation sheds light on the relevance of exploring communication processes within these families, and highlights the necessity for more studies to explore the potential similarities and tensions between the perspectives of parents and autistic people with good verbal and intellectual abilities.

2.8.1. Addressing independent functioning as 'a whole-family'

Through the lens of the principal philosophy of the family systems theory, and drawing on the experience of my practice, it is suggested that the level of independent functioning of autistic youths is primarily a family phenomenon. The development and actual everyday management of life skills in autistic young people is likely to be both the cause and the precursor to the expectations, encouragement and provided opportunities of the other members, primarily the parents. Above and beyond within-family factors is the influence of other systems outside the family, such as the school and the extended family, which are two systems particularly influential on the beliefs and attitudes of Maltese parents. Included in the *suprasystem* of these families is the regular professional support they receive. This framework suggests that working towards a change in the overall independence outcomes of autistic people entails readjustment of the whole family system.

In an attempt to increase the independence of autistic people, research has focused primarily on the effectiveness of various interventions and practices such as video-modelling and video-prompting (Gardner and Wolfe, 2013). Within this context, Damian Milton, researcher and autistic adult argues that very often research about interventions does not focus on the views and wishes of autistic people and 'the answers given are from a non-autistic perspective' (Milton, unpublished). Furthermore, in practice it is often observed that the effectiveness of interventions to develop DLS is not entirely determined by the abilities of the young people and their response to the intervention. However, it is also dependent to a great extent on the encouragement and opportunities provided within the family to practise and generalise those learnt skills to everyday situations.

Continued qualitative research is needed to inform practitioners on the practical experiences of autistic people and their families on those factors that are believed to foster or undermine their independent functioning. Literature suggests that the views and aspirations of the parents may not always coincide with those of young people with varying special educational needs (Cheak-Zamora *et al.*, 2015; Mitchell, 2012). More insightful research is needed to illuminate professionals about support systems which are likely to alleviate the dependence of autistic people on their families, by addressing the whole family. The role of the family to encourage independence in DLS is pertinent, as many autistic young people continue to live with their parents into adulthood (Howlin *et al.*, 2013). More so, research implies that communication processes within these families may fail to encourage discussions about the necessity for functional independence, albeit siblings' (Gomez de la Cuesta and Michael, 2012) and parents' (Bancroft *et al.*, 2012) reported continual concern about the future of their family member when they are no longer able to support them.

Within a culture of protectiveness, which is a characteristic of the Maltese society, parents may feel obliged to protect their autistic children from the reality of their eventual passing. In this context, more research is needed to allow these young people and their parents an opportunity to share their perspectives on the challenges they face, their coping routines and support systems to the management of DLS, and alleviate the parents' anxiety. This would provide professionals with more insight into ways of supporting the family for the future through gradual adjustments to their long-established everyday roles and routines. Ros Blackburn (2010) a high-functioning autistic adult, who still relies on the support of her elderly parents and carers for a number of everyday activities emphasises the importance of addressing independence matters before ‘a total crisis’ occurs and insists that: ‘It doesn’t bear thinking about, but it needs to be thought about’ (Blackburn, 2010, p. 13).

Thus, this research aims to explore the views of autistic young people with average cognitive and verbal abilities, their mothers and fathers, and practitioners in the field about what life skills they believe are important for the young people’s independent functioning and what factors they consider responsible for the development of such skills. This research also aims to consider whether there are any shared viewpoints or contradictions between these four groups of stakeholders, to provide insight into what factors need to be considered to address the area of DLS and improve practice and outcomes.

2.9. Research methods used in past studies on the development of independence skills

Table 3 gives the main aims of past studies that were most relevant to this thesis. It also gives the sample size and nature, and the research methods used to gather data. Overall, the aims of the studies in Table 3 were to collect the views of one or more of the following stakeholder groups: autistic people / people with intellectual disability; their parents/carers; and professionals, about various aspects of independence. Table 3 shows the wide range of topics that have been studied including the level of independent functioning, participation in daily activities, barriers to independent living, employment and social inclusion, and aspirations and concerns about adult life. None of the studies looked at the participants' views on those factors that are likely to promote or hinder the development and functional use of DLS, which this study intends to explore.

Nevertheless, these studies were considered relevant as their findings provided insight into the lived experiences of autistic people/ people with intellectual disability and their families, and those areas which need to be further explored. For instance, Table 3 indicates that there is dearth of research about the views of autistic young people on their needs and wishes in terms of the development of DLS. In addition, more research is needed to identify what autistic young people believe to be the main factors influencing the development of acquired DLS, and the main barriers to developing other everyday life skills. More so, studies which bring out any similarities and divergences between the views of young people and their parents are scarce. And the views of autism professionals about areas surrounding the topic of DLS are narrowly explored.

Table 3. Summary of the aims, sample size and nature, and the research methods used in past studies

	Aims of the study	**Author and date**	**Research Methods**	**Sample size for each method**	**Sample details**
1	To gain the views of the main stakeholders on what they regard as good outcomes; and whether current policies & practices and schools are contributing to good adult outcomes in autism.	Wittemeyer, Charman, Cusack, Guldberg, Hastings, Howlin, et al. 2011	Literature review Online survey Focus Groups Interviews	900 (survey) 73 (Focus Groups) 46 Interviews	Children, young people (6 – 16 years), adults (18 – 64 years) with autism Parents Education Practitioners
2	To gain the views of adults with autism and their parents in terms of the way they are living – independence, friendship, employment, hopes for the future.	Bancroft, Batten, Lambert & Madders 2012	Survey Interviews	1,380 (survey young people) 1,412 (survey adults) 5,535 (survey carers) 11 (interviews - adults and carers)	Young people (17 years/ under) and Adults with autism (18+ years) Parents/carers
3	To gain views of parents on the independent functioning, choice and inclusion of their adult child with autism.	Barnard, Harvey, Potter & Prior	Survey	450	Parents of adults with autism

		2001			
4	To investigate participation in everyday activities of young adults with autism in six domains: including chores, leisure, social activity, health, education, and work. To compare participation in the abovementioned activities of youths with autism to that of their typically developing peers.	Wang and Berg 2014	The Adolescent and Young Adult Participation Sort - Taiwanese version (AYAPS-T)	33 (11 Youths with autism M = 73%) (11 Parents/carers) (11 typically developing youths)	Able youths with autism (18 – 25 years) Parent/Carer Typically developing youths
5	To compare activity participation reported by the young adults with autism to that reported by their caring adult. To explore the barriers to the young adults' participation.	McCollum, LaVesser and Berg 2016	Adolescent and Young Adult Activity Card Sort (AYA-ACS)	48 (24 young adults with autism M = 71%; F = 29%) (24 parents/carers)	Able young adults with autism (mean age: 20 years) Parents/Carers
6	To identify barriers to independent living (IL) for individuals with disabilities and seniors	Di Gennaro Reed, Strouse, Jenkins, Price, Henley & Hirst 2014	Online survey	152	Senior citizens Paid staff Family members of persons with disabilities
7					

	To gather the perspectives of youths with autism and their family members on the challenges of transitioning to adulthood.	Cheak-Zamora, Teti & First 2015	Semi-structured focus groups (Separate groups for youths and caregivers)	32 (13 Youths with autism – M = 11; F = 2) (19 parents/carers – F = 17; M = 2)	Verbally able youths with autism (15 – 22 years) Parents/carers
8	To gather the perspectives and experiences of parents of adults with Down syndrome on the difficulty to find a balance between empowering and protecting their adult child with intellectual disability.	Foley 2012	Semi-structured interviews (60 – 90 minutes)	10 (M = 5; F = 5)	Parents of adults with Down syndrome living in parental home (Purposive sample)
9	To gather the experiences and views of persons with a learning disability (who said they were happy and satisfied with their lives), on what helps them to feel like this.	Haigh, Lee, Shaw, et al. 2013	Interviews Questionnaires	23 (M = 52%; F = 48%)	Persons with a learning disability (23 – 67 years)
10	To study decision-making processes of young people with intellectual disability within the context of the family To identify how and when young people with ID were allowed to take decisions.	Saaltink, Mackinnon, Owen and Tardif-Williams 2012	Semi-structured interviews	10	4 verbal young people with ID (14 – 18 years – able to communicate) 4 parents (mothers)

	To study barriers to decision-making opportunities.				2 siblings [Participants were from 4 families (with aim of triangulating data)]
11	To explore the views of adults with a learning disability about their plans, aspirations and concerns about their future.	Bowey and McGlaughin 2005	Interviews A service-users questionnaire (to gain views about current and future housing)	103 41 adults with learning disability (M = 21; F = 20) 62 family carers	Adults with a learning disability Family carers
12	To examine the views of parents of young people with a learning disability about those factors they take in consideration when deciding the extent of their son/daughter's involvement in everyday choice-making.	Mitchell 2012	Longitudinal study (2007-2010) 3 semi-structured interviews	14	Parents from 11 families of young people with learning disabilities and a life-limiting condition aged between 13-21 years Convenient sample
13	To explore the perspectives of adults with		Interviews	17 (M = 9; F = 8)	

	intellectual disability (ID) on the impact of self-determination on their lives. To identify barriers to achieving their dreams for the future	Shogren, and Broussard 2011			Individuals with ID (26-56 years)
14	To explore the views of family cares and professionals about the barriers that adults with learning disability encounter to choose a living arrangement.	Bowey, McGlaughin and Saul 2005	5 Focus groups	Not specified	Professionals Carers
15	To study the employment experiences of adults Asperger syndrome (AS). To explore the barriers adults with AS face at the workplace.	Hurlbutt and Chalmers 2004	In-depth interviews	6 (M = 3; F = 3)	Adults with AS (25 – 65 years)
16	To explore the views of persons with varying disabilities about barriers to their independence and social inclusion.	Cardona 2013	Focus group	5	A physically disabled person Visually impaired persons A person with a mental

					health condition A non-disabled mother of a child with disability

2.9.1. Nature and size of the sample in past studies

For studies to be included in Table 3, study participants had to be autistic young people or adults, or people with intellectual difficulties, parents or carers and professionals. The studies’ sample size varied according to the research methods used. Studies which used surveys (Wittemeyer *et al.*. 2011; Bancroft *et al.*, 2012; Barnard *et al.*, 2001; Di Gennaro Reed, 2014) had the largest samples ranging between 152 and 8,473 participants. On the other hand, studies which gathered data through qualitative research methods such as interviews, focus groups and the Adolescent and Young Adult Activity Card Sort (AYA-ACS) had smaller sample sizes varying between 5 and 103 participants.

In the studies which gathered the views of autistic young people or adults or those with intellectual difficulties, a discrepancy was observed in the gender of the participants. While the ratio of males and females was equal in those studies which included persons with learning or intellectual difficulties (Haigh *et al.*, 2003; Bowey and McGlaughin, 2005; Shogren and Broussard, 2011), the overwhelming majority of autistic participants were male in all the studies which specified the gender of the participants (Wang and Berg, 2014; McCollum, LaVesser and Berg 2016; Cheak-

Zamora, Teti and First, 2015), except one (Hurblutt and Chalmers, 2004). The participants in the study of Hurlbutt and Chalmers (2004) were three males and three females, and were recruited through snowball sampling. The ratio of males and females in the other three studies mirrors the ratio of males and females diagnosed with autism worldwide as suggested by epidemiological studies which indicate a higher incidence of autism in males (Loomes, Hull and Mandy, 2017).

Table 3 indicates that the age of the participating autistic young people in some studies (Wang and Berg, 2014; McCollum, LaVesser and Berg 2016; Cheak-Zamora, Teti and First, 2015) ranged between fifteen and twenty-five years, while other studies (Wittemeyer *et al.*, 2011; Bancroft *et al.*, 2012; Hurblutt and Chalmers, 2004) also included participants older than twenty-five years. The majority of the studies (Wang and Berg, 2014; ; McCollum, LaVesser and Berg 2016; Cheak-Zamora, Teti and First, 2015; Hurblutt and Chalmers, 2004) explored the views and experiences of autistic young people and adults with average intellectual and verbal abilities. The studies carried out by Wittemeyer et al. (2011) and Bancroft et al. (2012) included autistic participants with various abilities across the spectrum. However, the majority of the young people and adult participants in Wittemeyer et al. (2011) were of average intellectual and verbal ability.

2.9.2. Research methods used in past studies

The studies outlined in Table 3 were regarded pertinent to guide me with the choice of research methods for this study. The main research methods employed by the majority of the reviewed studies were interviews, surveys, questionnaires and focus groups.

Some studies used mixed methods (Wittemeyer *et al.*, 2011; Bancroft *et al.*, 2012; Haigh *et al.*, 2003; Bowey and McGlaughin, 2005). For instance, Wittemeyer et al. (2011) used online surveys, focus groups and face-to-face or phone interviews to gather the views of autistic young people and adults. The same research methods were also used to collect the opinions of the parents, and education practitioners. Other studies utilised one research method only. Five studies (Foley, 2012; Saaltink *et al.*, 2012; Mitchell, 2012; Shogren and Broussard, 2011; Hurblutt and Chalmers, 2004) used interviews only, two (Barnard *et al.*, 2001; Di Gennaro Reed, 2014) used surveys only, and three studies (Cheak-Zamora, Teti and First, 2015; Bowey, McGlaughin and Saul, 2005; Cardona, 2013) used focus groups. Only two recent studies (Wang and Berg, 2014; McCollum, LaVesser and Berg, 2016) used the Adolescent and Young Adult Activity Card Sort (AYA-ACS; Berg *et al.*, 2015) to explore the views of autistic people. The AYA-ACS is a recently developed card sorting system to assess participation in everyday activities within different domains such as, chores, leisure, social, education and work. It consists of seventy photographs or line drawings which the participants are asked to sort according to whether they participate in the represented daily activity.

The main aims of the latter two studies were to explore the level and barriers to the participation of adults with autism in everyday activities thus, being somewhat diverse from the aims of this thesis. However, the methodology used in these studies widened my knowledge about alternative methods of data collection. While qualitative methods such as interviews and group dialogues are likely to provide opportunity for participants to express their views and lived experiences, such methods may be overwhelming for some autistic individuals. Other methodological techniques such as the AYA-ACS could make it easier for them to communicate their views, through the sorting of cards and the use of supporting photos to aid understanding.

The reported findings of these two studies highlighted specific barriers to the participation of autistic adults in everyday activities, such as having no opportunity to carry out household chores (McCollum, LaVesser and Berg, 2016) and a fear of falling when learning how to ride a scooter (Wang and Berg, 2014), as opposed to data gathered through methods such as surveys (Barnard *et al.*, 2001) which were rather thin and ambiguous. This could imply that the card sorting system made it easier for the autistic adults to identify what precisely helps or hinders their participation in everyday activities. Indeed, these studies reported high validity and reliability measures.

2.10. Summary and conclusions from the literature reviewed

A review of the current literature relating to the independence of autistic people revealed that most of the existing studies relating to this area focus on adaptive behaviour measures (Bal *et al.*, 2015; Matthews *et al.*, 2015; Duncan and Bishop, 2013; Kanne *et al.*, 2011) and adult outcome ratings (Gray *et al.*, 2014; Henniger and Taylor, 2012; Howlin and Moss, 2011). Fewer studies have set out to gain the views of the key stakeholders in autism, that is, parents, professionals and the autistic people themselves, on the practical day-to-day issues around independent life skills.

Research suggests that a lack of ability to manage DLS independently is consistently present in autistic people who may have the necessary intellectual and verbal ability to acquire such skills (Matthews *et al.*, 2015; Kanne *et al.*, 2011; Hume *et al.*, 2009). More so, comparison studies indicate that autistic people have lower rates of participation and independence in daily activities than their peers in other special education groups (Anderson *et al.*, 2014; Orsmond *et al.*, 2013; Shattuck *et al.*, 2012). Notwithstanding the significance of the independent management of DLS for optimal adult outcomes, little research has been conducted to explore the views of autistic people with good verbal and intellectual abilities and their parents. As a result, it is not clear which life skills are prioritised by these young people and their families, and which factors could be undermining, or which could promote the development of such skills.

The promoters and barriers to the development of self-determination skills in individuals with intellectual and developmental disabilities, through the perspectives of the main stakeholders is a more extensively researched area. Literature highlights a number of barriers to skills such as decision-making identified by persons with special educational needs, including over-protective parenting, lack of confidence and society's attitudes. Literature also shows that carers may be concerned about their adult child's safety and skill deficits, while they question their adult child's ability to make the right choices and decisions. Moreover, these studies point at culturally embedded expectations for persons with disabilities, and patterns within the family that could be implied in the development or lack of self-determination skills.

The role of the family appears to be important for the development of self-determination skills in persons with intellectual and learning difficulties. However, there is lack of research on those factors which are implicated in the development of DLS in families of autistic young people. The reviewed self-determination studies about choice and decision-making of persons with varying special educational needs provide insight into the experienced promoters and barriers to such skills. However, there are likely to be different factors which influence the development of DLS. Moreover, most of the reviewed studies explored the views of young people or adults with intellectual disabilities and their families, making this review less likely to bring out the unique priorities and experiences of families with autism.

Notwithstanding these limitations, the reviewed studies offer insight into important areas of study within the area of life skills in autistic people. Most significantly, this reviewed literature reveals the existence of multiple discourses and social constructs surrounding this topic of independent functioning in autism. Furthermore, it highlights a need for clarity in relation to those elements that could alleviate these barriers and promote such skills. More so, this review of the literature revealed a need for an exploration of the viewpoints of the key stakeholders (autistic people, their mothers and fathers, and professionals) to identify potential similarities or differences in order to inform practice on the need for a holistic system of support and intervention to improve independent outcomes in autistic adults with average verbal and cognitive abilities.

Overall, the research methods used in the reviewed studies facilitated my journey to the choice of data collection methods for this thesis. The main research methods adopted by the reviewed studies in Table 3 were interviews, questionnaires and focus groups. These highlighted the significance of using qualitative methods to allow more opportunity for participants to express their views about their needs and aspirations in terms of life skills. Moreover, I observed that methodological techniques such as the

AYA-ACS provides the participants with a more systematic way of communicating their views. Nonetheless, it was anticipated that triangulation of these methods with qualitative methods is likely to yield more insightful findings.

A literature search of studies which aim to explore the views of different stakeholders about various topics within the field of autism generated a number of studies (e.g. Milton, 2016; Scott *et al.*, 2015) which have used Q sort methodology (Stephenson, 1935). The studies carried out by Milton (2016) and Scott et al. (2015) were particularly influential on my choice of research methodology for this thesis. Milton (2016) explored the ideology and priorities of different stakeholders regarding the education of secondary-school aged autistic pupils. Similarly, Scott et al. (2015) used Q sort methodology to understand and contrast the views of autistic adults and their employers about the factors that contribute to successful employment. These two studies were considered relevant as their main aim was to explore the views of different stakeholders about a particular aspect in the life of autistic people, which is similar to what this thesis intends to study. Moreover, similar to the AYA-ACS (Berg *et al.*, 2015), Q sort methodology provides the participants with a systematic way to communicate their views and opinions about a particular topic. However, in contrast to the AYA-ACS which consists of a predetermined set of items, in Q sort methodology, the statements on sort cards are developed from everyday discourse around the topic, which renders it more representative of the views of the study participants. Thus, Q sort methodology, post-sorting interviews and a few in-depth interviews, were deemed to be the most suitable methodologies for this thesis.

On the basis of this review, the key Research Questions for this study are:

(i) Which independent life skills do key stakeholders (i.e. parents, professionals and able autistic young people) believe need to be developed?

(ii) What promotes the development of independent life skills in autistic young people and what are the potential barriers?

(iii) How can one reduce the barriers and promote the development of independent life skills of autistic young people?

CHAPTER 3

RESEARCH DESIGN, SAMPLE AND METHODS

3.1. Introduction

On the basis of the literature review presented in Chapter 2, it was found that the ‘voice’ of young autistic people about factors associated with their independent functioning is limited. Moreover, there is a paucity of research about the views of other stakeholders, namely, their fathers and mothers, and professionals working with autistic people. Thus, it is not clear what factors may promote independence or create barriers.

This chapter will begin with a brief outline of the context in which this study was conducted, followed by an introduction to Q sort methodology and the stages involved. An overview of the methodological considerations that were explored, and the decision to use Q sort methodology will be explained. The potential benefits and issues with Q sort methodology and its relevance to this study, details of the design, sampling procedures, participants, and details of how the data was analysed, will be given. This chapter ends with the ethical issues that arose from this study and the researcher’s positionality and potential bias.

3.2. The context for the study

This research was conducted at a specialist Centre for autistic people in Malta, where I work. The Malta Autism Centre (MAC), founded in 2011, was the only Centre in Malta at the time of this study which provided specialised intervention solely to autistic people, from as early as they are diagnosed until the age of fifty. In Malta there were three established service providers in the field of disability namely, *the inspire foundation*, *equal partners foundation*, and *hand in hand Malta*. They all catered for people with various physical and intellectual disabilities, including autistic people. In the latter organisations, from the age of sixteen onwards, autistic people are grouped with other students who may have other disabilities and needs, and intervention is thus not autism specific.

At the MAC, every student has an individualised plan which addresses a broad range of skills. Intervention is delivered in both one-to-one and group sessions during which autistic students are grouped according to their abilities and needs. A major aim of the intervention carried out at the MAC is to help students achieve functional independence and become socially included in society, as valued members. Moreover, support is extended to the parents and siblings of every student to enhance the family’s understanding and support towards their autistic family member.

While the majority of the young people and adults, with average intellectual ability, at the MAC made their way to post-secondary education or employment, their functional level of independence in DLS remains low within the personal, domestic and community domains. This is often seen to affect their self-confidence particularly when they compare themselves to same-aged peers, and many express their wish to become more independent. More precisely, they want to be able to travel independently, cook meals, have a job, buy their own clothes, and aspire to live independently in their own home. Moreover, parents often vent their concerns about the future of their young adult when they are no longer able to support them. Thus, this study intended to learn what promotes independence and what is keeping these autistic people from attaining life skills, and what type of functional independence they would like to achieve. This thesis aimed to identify similarities and potential differences between the different stakeholders that may help to provide insight into policy, practice and research in the field of independence and autism.

3.2.1. Research design of this study

Researching the subjective perspectives and accounts of participants does not allow researchers to generalise their findings to the entire population under study. As Wellington et al. (2005) argue:

> We cannot use one or even half a dozen life histories to say that this is how it is for everyone else who has the same social characteristics as our informant/s (Wellington *et al.*, 2005, p. 98).

The objective was therefore not to generalise the main findings to the entire population of the different stakeholders, but to identify key themes that can aid the understanding of practitioners and parents in the field of autism.

Adopting a *social constructionist* approach to this study was believed to be appropriate to explore ‘how the world is experienced and constructed by the people who live in it’ (Wellington *et al.*, 2005, p 100). Gergen (1985) defined social constructionism as a perspective which believes that social and interpersonal influences affect greatly the way human life exists. People are viewed as actors interacting with each other, and through such interactions, ideas, perceptions, impressions or conceptions of each other’s actions and behaviours are formed (Galbin, 2014). Galbin (2014) collated a description of social constructionism from the literature which claims that our realities are learnt and constructed through others around us:

> …realities are socially constructed; realities are constituted through language; knowledge is sustained by social processes; and reflexivity in human beings is emphasized (Galbin, 2014, p. 84).

Consistent with this approach, I chose Q methodology as a method that would allow me to explore the subjective opinions and views of participants through the sorting of the selected social discourse around the topic of DLS, while highlighting any shared or diverse patterns between their viewpoints.

3.3. General overview of Q sort methodology

The majority of the studies reviewed in Chapter 2 used one or more of the following methods: questionnaires, interviews or focus groups. While reflecting on the aims of this thesis and the research questions, an exploratory method – the Q sort, was chosen.

Q sort methodology is a mixed-method approach which collects the participants' subjective opinions qualitatively, and analyses these viewpoints quantitatively through factor extraction, to capture the main viewpoints (Fontein-Kuipers, 2016). The main aim of Q methodology is to explore the subjective opinions of participants about a topic of study and to uncover any shared or divergent patterns of thought among participants. Q sort methodology involves three phases: (i) the development of statements, (ii) the ranking of statements on a grid according to participants' preference, and (ii) analysis and interpretation of data.

3.3.1. Introduction to Q-sort methodology

Q-sort methodology was developed by the psychologist and physicist William Stephenson in 1935 (Stephenson, 1935), as a methodology that allows the systematic study of subjectivity. *Subjectivity* is understood as a person's way of formulating and communicating their opinions, views, attitudes and beliefs about a particular subject (McKeown and Thomas, 2013). Q methodology allows the researcher to objectively describe the subjective perspectives, experiences and viewpoints of the participants about a particular topic from the standpoint of the same person living through that experience.

> Q methodology does not impose meaning a priori, but asks participants to decide what is meaningful and hence what does (and does not) have value and significance from their perspective (Watts and Stenner, 2005a, p. 76).

The emphasis of Q sort methodology is on subjectivity which prompts 'a self-referential response' (Watts and Stenner, 2012, p. 30) and embraces the idea of multiple viewpoints. A self-referential response suggests that participants apply their personal feeling to each statement and the final Q-sort is a representation of how the statements stand in relation to the individual participant and his/her point of view. The projection of the participants' feeling onto the Q-sort items suggests that the same statements might be 'felt' and illustrated differently to different participants or to the same person on another day (Watts and Stenner, 2012). Subjectivity is brought out through the sorting process (referred to as Q sort) whereby participants are asked to sort out a number of statements about a topic (the Q set) according to the significance and meaning they personally attribute to each statement. This sorting process provides a graphic representation of each participant's viewpoints about the topic under study, which can then be compared and contrasted to those of the other participants to reveal common factors. The Q-sort is usually followed by discussions to qualitatively analyse the participants' reasoning behind their sorting of statements.

3.3.2. Stages of Q-sort methodology

Q-sort methodology encompasses everyday discourse and conversations about a particular topic. In Q methodology, the communication and discourse about any topic is referred to as 'concourse' (Brown, 1993, p. 93), from which a representative sample of statements is selected to make up the Q-sort. The concourse is obtained from 'the flow of communicability in the ordinary conversation, commentary and discourse of everyday life' (Brown, 1993, p. 93).

This comprises an array of statements that can be obtained from various sources including websites, media reports, published literature, interviews and focus groups, which represent the prevailing opinions and beliefs about a particular topic. According to Brown (1993), the concourse should include 'all manifestations of human life, as expressed in the lingua franca of a shared culture' (Brown, 1993, p. 95). The concourse is not restricted to discourse but may also include other elements such as photographs, pictures and musical selections.

The primary aim in selecting a number of stimulus items to make up the Q set is to produce a comprehensive and representative 'miniature' of the concourse. In this regard, Brown (1980, p. 186) describes the selection of statements as 'more an art than a science'. The exact number of statements to be included in the concourse is mostly determined by the topic itself. However, the typical number of statements ranges between 40 and 80 items (Stainton Rogers, 1995; Curt, 1994). Albeit the importance of a broad and representative Q set, the statements do not retain any particular meaning previous to the sorting process. It is the participants who impose their subjective meaning onto the stimulus items as they sort them according to the psychological significance they attribute to them. Brown (1997) highlights this by maintaining that:

> …the supposed a priori meaning of the statements does not necessarily enter into the Q sorter's considerations: participants inject statements with their own understanding (Brown, 1997, p. 11).

Similarly, Stephenson (1953) claims that through the active engagement of participants in the Q sort, Q methodology brings out the individual's subjective standpoint and understanding, by capturing 'operant' behaviours and 'states-of-feeling' (Stephenson, 2005, p.102) thus, limiting the researcher's intrusion. During the Q sort, participants which are referred to as the person-sample or *P set*, are asked to rank-order the stimulus items on a grid, generally of a quasi-normal distribution, according to their level of agreement with each statement. Each statement is written on a separate card. Participants rank statements in terms of its priority and significance in relation to the other statements. This process captures each participant's subjective viewpoint about every stimulus item, thus bringing out the subjective experience and perspectives of the participants. It is through this process, whereby participants interpret statements through their experience and understanding, that statements are ascribed meaning (Watts and Stenner, 2005b) and factors are extracted for data analysis which correlates the subjective viewpoints of participants (Stephenson, 1935). 'By correlating people, Q factor analysis gives information about similarities and differences in viewpoint on a particular subject' (Van Exel and de Graaf, 2005, p. 1).

In Q-sort methodology, persons rather than tests are correlated. Stephenson (1935) argues that when clusters of correlations exist, the subjective viewpoints can be factorised and outlined as shared perspectives, and individual viewpoints can be compared to them. Stephenson (1983) acknowledges that the participants' possible distribution of statements can vary infinitely, but he also recognises that the number of existing viewpoints is fewer than a given number of persons:

> It would be remarkable if any two sorts, from different persons, were exactly alike; and unlikely that all will be totally different. It is the purpose of factor theory to determine which distributions, if any, are approximately alike, on the theory that they have the same 'eigenwerken', the same 'characteristic' value, the same feeling (Stephenson, 1983, p. 78).

This proposes that the same statement can have a different meaning to different participants, emphasising the subjective nature of this method, while acknowledging the shared viewpoints that different participants may possess. Therefore, by-person factor analysis in Q methodology, which is carried out by means of a computer program, analyses the holistic sorting of statements, highlighting divergent viewpoints as well as consensus among participants and summarising the pattern of correlations (Kitzinger, 1999).

3.3.3. History of Q-sort methodology

Stephenson's initial motivation to create Q methodology developed from an unsatisfactory observation of R methodological factor analysis, traditionally used in psychology within the positivist tradition. R factor analysis, whereby relationships are sought across variables (e.g. testing whether the values of two test scores in the same participant are related) rather than participants, fails to reflect the divergent viewpoints of specific individuals (Watts and Stenner, 2012). In contrast to R methodology whereby participants are passively subjected to measurement, in Q-sort methodology the active ranking of the Q set reveals the 'psychological significance' of each stimulus item for the specific participant (Burt and Stephenson, 1939, p. 276). This process allows for a thorough and holistic understanding of each participant which Stephenson regarded as 'a necessary prerequisite of any full and genuine comparison of individual differences' (Watts and Stenner, 2012, p. 12). Unlike the analytical process carried out in principal component analysis (PCA) or factor analysis (FA), in Q-sort methodology, the participants of the study rather than the variables, are correlated to reveal the relationships between their viewpoints, whether positive, negative or neutral (Zabala, 2014). Coogan and Herrington (2011) argue that:

> No other methods capture the essence of what the participants feel about a topic from collective voices, while at the same time identifying subtle differences between some of these voices (Coogan and Herrington, 2011, p. 27).

In this regard, Q-sort methodology research brings out the subjective perspectives of participants through a structured quantitative framework, which allows it to bridge the gap between qualitative and quantitative methodology, while conjoining the strengths of both approaches, to elicit: 'empirical discoveries of a qualitative kind' (Stephenson, 1935, p. 205).

Recently, Q-sort methodology is gaining more recognition among social constructivist scholars within the field of psychology, compared to a time when Newtonianism and psychometric testing took precedence over it (Brown, 1997). Nowadays, Q-sort methodology is being used across various disciplines including health (Cross, 2005; Ahmed *et al.*, 2012), administrative ethics (de Graff and van Exel, 2008; 2009) and social work (Ellingsen, Storksen and Stephens, 2009). Moreover, it has recently been used in autism-related research, for example to study the key factors to successful employment from the viewpoints of autistic adults and employers (Scott *et al.*, 2015) and to explore the ideology and priorities of different stakeholders regarding the education of secondary-school aged autistic pupils (Milton, 2016).

3.3.4. Exploring different research methods

In the initial phase of this thesis, Likert-scale questionnaires, in-depth interviews and focus groups were considered as possible methods to gather the priorities, perspectives and lived experiences of the participants.

Likert-scale questionnaires could be used to explore the views of participants through the rating of statements according to their level of agreement. Likert scales are simple to construct, easy for participants to complete, and are likely to produce reliable measures (Johns, 2010). However, Likert scales were not chosen as these do not provide rich qualitative data, as participants are not able to elaborate on their responses (Oekel, 2009).

In contrast to Q sort methodology,

> …the Likert scale does not simulate the experience of simultaneously weighing an array of stimuli in relationship to one another in order to convey respondents' nuanced, subjective viewpoints (Oekel, 2009, p. 2).

Furthermore, data analysis of Likert scales focuses on the individual statements rather than the overall arrangement of items as in Q-sort methodology. Moreover, similar to other forms of surveys, when measuring attitudes, and when participants are not anonymous, Likert scales may be subject to *social desirability* that is, respondents may rate the statements in a way that they believe would be viewed favourably by others, rather than truthfully (McLeod, 2008). In contrast to this, in Q-sort methodology participants' focus of attention is not on giving each statement a rating but on the sorting of statements according to their level of importance in relation to one another. Furthermore, research indicates that Likert scales are subject to *central tendency bias* (Douven, 2017). Data gathered through Likert scales show that participants tend to avoid extreme rating scores and score towards the middle of the scale. Thus, it may be difficult to establish the validity of a study, to determine whether the study measures what it had set out to find.

Focus groups for participants were considered to observe how participants accepted or rejected each other's ideas (Steward and Shamdasani, 2015). Powell and Single (1996) define focus groups as:

> …a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research (Powell and Single, 1996, p. 499).

Kitzinger (1994;1995) describes interaction between participants as a central characteristic of focus groups which brings out the different viewpoints of participants.

Additionally, interaction highlights the values and beliefs participants attribute to the topic and the language used to communicate them. Such interaction allows participants to influence each other and thus, to reconsider their views about the subject (Steward and Shamdasani, 2015). However, when studying marginalised groups such as autistic people whose voice is often excluded from the world of research, I wanted to ensure that the voice of each of the autistic participants was provided an equal opportunity to other members in the group. Due to the social and communicative difficulties of autistic people, focus groups were considered more likely to be challenging for the young people in this study, particularly if they consisted of a heterogenous group of participants. Forming focus groups with the different stakeholders of this study could result in greater novelty and perspective (Levine and Moreland, 1998). However, it was thought that such heterogeneity could also put the young people at a disadvantage or affect the dynamics of the group due to participants' diversity related to age, social power, and the stereotypic characteristics of autistic people. To overcome this phenomenon, I could have opted for homogeneous focus groups consisting solely of participants within one stakeholder group. However, Stewart and Shamdasani (2015) argue that:

> *…*a group composed of individuals who are all alike with respect to background, experiences, opinions, and beliefs will produce a rather dull and certainly not very insightful discussion (Stewart and Shamdasani, 2015, pp. 18-19).

In-depth one-to-one interviews with participants from the three stakeholder groups were also considered. In-depth interviews provide the researcher with detail and information about the participants' lived experiences, attitudes and beliefs (Boyce and Neale, 2006). However, given the multi-faceted nature of the topic, it was considered important to cover a broad range of issues, which could possibly have resulted in an overwhelming number of questions which would have been impractical and unethical for both the participants and myself. Additionally, due to the demanding processes of transcription and data analysis, the number of participants would have had to be limited which would reduce the richness of the data (Kvale and Flick, 2008).

Being an insider researcher (the Director of the MAC), compared to Q-sort methodology, it was felt that in-depth interviews and focus groups would not afford me sufficient *ethical distance*. This was considered significant to ensure that the participants' responses are not elicited through my own *a priori* knowledge, which could also influence my interpretation of data. Although several different measures could be used to minimise such bias as much as possible, upon reflecting on the overall advantages and disadvantages of various research methods, Q-sort methodology was considered the most suitable as the primary data collection tool.

3.4. Benefits of Q-sort methodology and its relevance to this study

Q-sort methodology was identified as a potentially effective means to address the research questions. Q-sort methodology (Stephenson, 1935) which collects both quantitative and qualitative data on a topic, was identified as a method which would elicit the views of individual participants and allow an analysis of the similarities and differences between the stakeholders. Barry and Proops (1999) contend that:

> Q allows the researcher to see if there are any patterns shared across individuals, and what are the diversity of accounts, without this resulting in chaotic multiplication (Barry and Proops, 1999, p. 339).

Watts (2009) describes Q methodology as unique in its capacity to accommodate the constructivist (individual self-reference) as well as the constructionist (socially constructed knowledge and understanding generated through group interactions) approaches simultaneously, maintaining that such quality is pertinent for the holistic understanding of human experience.

Q methodology is clear and structured, thus easy to follow for participants. Additionally, the Q sort methodology allows the active participation of participants rendering it a dynamic, (Watts and Stenner, 2005a) innovative and pleasant experience (McKenzie *et al.*, 2011). Such participatory and exploratory (containing no a priori assumptions) characteristics make Q methodology advantageous when researching marginalised voices such as the voice of autistic people. Moreover, the supply of information through the Q sort statements makes potentially complex social constructions and discourses more accessible. Moreover, the Q sort process in itself provides structure and facilitates the communication of viewpoints for autistic people. This in turn ensures that the voice of every individual participant is equally heard and valued, making the Q methodology an effective vehicle for recording the shared and divergent views and perspectives among the various stakeholders in this study. Furthermore, towards the end of the Q sort process, participants have the opportunity to check and reconsider the visual representation of their viewpoints. This makes the process more *user-friendly* particularly for autistic people, allowing them more time and opportunity to establish how they would like their final Q sort to be displayed and recorded. Thus, this was understood to give them more opportunity to communicate their subjective views, than they would get from other methods such as interviews.

As an insider researcher, Q methodology was an ideal way to reduce the potential power dynamics between the participants and myself. The Q sort provides distance between the participants and the researcher in that it allows the participants to attach their personal meanings to the stimulus items and to decide how to sort them to portray their viewpoints.

Participants were asked to do the Q sorts individually. I gave out the grid to the participants and explained the sorting process. Thereafter, the participants were left to complete the sorting process on their own. Through this process, the bias and influence of my views and beliefs about the researched aspects on the participants' responses was minimised during data collection. Moreover, during factor analysis, data is analysed systematically, which allows the researcher a degree of objectivity by reducing the influence of my personal assumptions on the participants' responses. In this regard, McKenzie et al. (2011) maintain that the Q methodology presents the researcher with data:

> …which, although based on subjective responses, is objective in that the identification of different points of view is determined mathematically, and not through the possibly biased lens of the researcher's own perspectives (McKenzie *et al.*, p. 1).

According to Brown (1993, p.106), '…a completed Q sort should be followed where possible with an interview so that the Q sorter can elaborate his or her point of view.' In line with this, in order to acquire a better understanding of the rationale underpinning their sorting of items, post-sorting interviews were carried out with every participant. Moreover, in-depth interviews were carried out with eight participants, across the different stakeholder groups to explore their broader understanding around the topic of independence of these young people and to highlight important issues outside the context of the Q-sort. In-depth one-to-one interviews were chosen over other methods such as participants’ diaries, as they were believed to be a more sensible and efficient data collection tool.

3.4.1. Limitations of Q sort methodology

Q methodology may not be as popular among researchers as other research tools such as observations, questionnaires, focus groups and interviews, which are more commonly used in social science research (Bhattacherjee, 2012). Dziopa and Ahern (2011) and Watts and Stenner (2005a) argue that this increases the possibility for Q methodology to be misunderstood by both the researcher who adopts it and other researchers interpreting its findings. Moreover, Q methodology has been criticised for being time-consuming (McKeown and Thomas, 2013). More specifically, the initial stages of interviewing participants to elicit the concourse and the selection of the Q sort statements are time intensive (Barry and Proops, 1999). It has also been argued that the participants’ lack of familiarity with the Q sort process, could lead to misinterpretation, which could have subsequent implications for its validity (Dennis, 1986). Indeed, the validity, reliability and generalisability of Q methodology have been criticised. Specifically, Thomas and Baas (1992) maintain that Q methodology uses a small sample of participants to study subjectivity through the sorting of items which would not have been tested for reliability. However, Stenner and Stainton Rogers (2004, p. 102) argue that Q methodology: ‘lays no claims to be measuring anything, and hence adopts a completely different relationship to validity and reliability.’

Reliability and *validity* are fundamental principles in research. *Reliability* is defined as the extent to which a research tool generates the same results when carried out with different participants or by different researchers, or with the same participants at different points in time. Moreover, reliability indicates whether the results of a study are representative of the larger population (Shuttleworth, 2008). On the other hand, *validity* refers to whether the research tool delivers what it claims to find out.

In Q methodology, reliability is tested through test-retest studies (Valenta and Wigger, 1997). Such studies have revealed that when the same Q sort is administered to the same participant at two different points in time, the findings are consistent. For instance, Nicholas (2011) found that when the same student completed the same Q sort under the same instruction conditions two days apart, results were reliable. Although the two sorts were analysed using two data analysis methods (centroid factor analysis with hand rotation and principle components with varimax rotation), they correlated at 0.89. This is consistent with the test-retest reliability correlations of 0.80 and upward reported by Brown (1980; 1993).

Thomas and Baas (1992) refer to *reliable schematics* as the most significant form of reliability in Q methodology. This relates to the emergence of similar factors when comparable Q studies with the same condition of instruction are administered to the same or different participants. Q studies carried out with very similar groups of participants have been claimed to produce reliable and stable results over time, through the emergence of similar factors (Prasad, 2001; Watts, 2009) indicating consistency in the shared viewpoints ‘across time, place and repeated interrogation’ (Watts and Stenner, 2005a, p. 41). Brown (1980) contends that this reflects that the number of different viewpoints on a particular topic is finite. Furthermore, Q methodology reliability has also been proven through comparison studies about the same research topics which use different Q sort items and different participants (Thomas and Baas, 1992; Dennis, 1993).

In terms of validity, which assesses whether a research tool measures and represents the underlying construct that it is supposed to measure (Bhattacherjee, 2012), Brown (1980, pp. 174 - 175) maintains that in Q methodology: 'the concept of validity has very little status since there is no outside criterion for a person's own point of view'.

Due to the qualitative and subjective nature of Q methodology, each participants' rank order of the Q sort items is regarded as a valid expression of that participant's *feeling* and viewpoint about the studied topic. In Q sort methodology, *content validity*, which is the extent to which the Q sort statements represent all facets of the study topic (Bhattacherjee, 2012) is acquired through an extensive review of the literature and professional consultation about the research topic (Valenta and Wigger, 1997). Moreover, *face validity* of the statements refers to the extent to which the Q sort statements are subjectively perceived by the participants to measure what they are supposed to measure. In Q methodology face validity is attained through statements written in the participants' own words (Valenta and Wigger, 1997).

In terms of generalisation, the small number of participants and the nature of Q sort studies do not render the findings of such a methodology generalisable to a population of people. However, this does not preclude Q methodological studies from having wider implications for the professional practice in relation to the topic of study. Q methodological studies ‘must look to a different kind of generalization, which focuses on concepts or categories, theoretical propositions and models of practice’ (Watts and Stenner, 2012, p. 73).

3.5. The sampling method and study sample

3.5.1. The sampling method

Sampling for this study created a non-probability ‘purposive’ sample (Stenner and Stainton Rogers, 2004). Participants for this research were verbal and intellectually able autistic young people, their mothers and fathers, and professionals working in the field of autism. The sample of participants was a convenience one, in that participants were recruited from the Malta Autism Centre, an autism specialist organisation in Malta, where I work. Autistic participants were selected on the basis of their age and intellectual and verbal ability. Since the number of verbal young people with average intelligence, receiving intervention from the MAC totalled 10 at the time of the study, all the young adults who met the inclusion criteria and were between 16 to 30 years old were asked if they would like to participate in this study.

All the professionals working at the MAC were also approached to take part in this study. The number of professional staff at the MAC was rather small, amounting to nine in all at the time of the study: 5 autism educators: 3 on a full-time and 2 on a part-time basis, 2 part-time speech and language pathologists, 1 part-time educational psychologist and 1 part-time social worker). A recruitment letter was given to all the young people and their parents, and the professional team, explaining the main aims of the study and the nature of their role as potential participants (see Appendix 2 for a copy of this).

The nature of the sample for this study is not representative of the population of autistic young people living in Malta. The participating parents and young people in this study sample received regular autism specific intervention, and thus may have not represented individuals who receive support from other agencies or those who do not benefit from any support services. Similarly, the sample of professionals may not have been representative as there are several professionals working with autistic people in different settings whose varied experiences may have resulted in diverse viewpoints about the study topic. However, Martinez-Mesa et al. (2016) argue that:

> Still, unrepresentative samples may be useful for some specific research objectives, and may help answer particular research questions, as well as contribute to the generation of new hypotheses (Martinez-Mesa *et al.*, 2016, p. 327).

Indeed, this research did not seek to enable generalisations, but to highlight relevant viewpoints and to describe divergent views within and between the participating groups about priority life skills and everyday barriers to acquiring them. The findings would be of direct relevance to the work at the MAC.

Watts and Stenner (2012, p. 71) suggest that in Q methodology the approach to recruiting participants needs to be ‘very strategic’. In this regard, Brown (1980, p. 192) emphasises that a good P set should be more ‘theoretical…or dimensional…than random or accidental.’ To be able to discover relevant viewpoints, the selection of the P set in Q methodology should be made vigilantly, in that participants should be selected if they are likely to have a distinct viewpoint to express and more so, if their perspective is significant to the study topic and relevant to the research questions (Watts and Stenner, 2012).

The participants of this study were selected as their opinion was believed to shed light on those factors that aid or hinder the development of DLS in everyday life. The voice of the autistic young people was considered central to the study topic as the people who are living the experience. The views of their parents were also believed to bring fundamental information to this study, being those who monitor closely and play a central role in the development of their young people. The views of the young people and their parents were believed to bring out *factors experienced from the inside*, while autism professionals were likely to bring a more objective perspective to the study, characterised by their emotional distance from the autism condition and their professional background.

3.5.2. Inclusion and exclusion criteria

All the participating young people had received a diagnosis of autism from an educational psychologist at a young age (refer to Table 4 of participants). They have since been receiving intervention for their autism condition, and their diagnoses had been reviewed in their teenage years. All participating young people had been receiving regular intervention from the MAC for at least two years. All participants had good verbal ability and average intelligence, and were in mainstream post-secondary education or employment at the time of this research study. Young people between 16 and 30 years of age who receive intervention from the MAC amounted to fourteen at the time of the study. However, four young adults at the MAC did not meet the inclusion criteria as they were non-verbal or had limited verbal communication. I was interested in exploring the views of autistic young people with average cognitive and verbal abilities, since as discussed in Chapter 2, literature indicates that there is a discrepancy between the cognitive ability of these young people and their level of independent functioning.

The inclusion criteria were based on the fact that verbal and intellectual ability generally has an impact on the level of DLS and independence that can be achieved. Thus, these participants would be expected to have the cognitive ability to achieve basic independent DLS within the personal, household and community domains. Due to the importance of independent DLS in late adolescence and early adulthood to be able to transition to an independent adult life (Duncan and Bishop, 2013), participants between the ages of 16 and 30 years were included. All participants were still living in their parents' home at the time of the study.

The young people recruited in this study were all males. Females were not deliberately excluded from this research. Indeed, the participation of autistic females could have added insight into the potential similarities or differences in the identified priority life skills and barriers. Moreover, the inclusion of female participants could have explored whether the parents' beliefs and opinions differed in relation to their child's gender. The number of girls within the age range of 16 and 30 years attending the MAC at the time of the study was only three. However, they did not meet the inclusion criteria for this study. This reflects the general situation in Malta, whereby the number of adult females diagnosed with autism is limited, and autism diagnoses of young girls have started rising only recently. This mirrors the ratio of males and females diagnosed with autism worldwide as suggested by epidemiological studies which indicate a higher incidence of autism in males (Loomes, Hull and Mandy, 2017). Similarly, in most of the studies reviewed in Chapter 2 whose participants were autistic young adults, the overwhelming majority of the participants were males (e.g. Mc Collum *et al.*, 2016; Cheak-Zamora, Teti and First, 2015; Wang and Berg, 2014).

The professionals who were approached to take part in this study had diverse roles in the intervention and education of autistic people, including autism educators, speech and language pathologists, educational psychologists and social workers (Refer to Table 5). The main aim was to include participants who had different levels of experiences and contact with autistic people, and who thus held potentially different views and opinions about priority DLS and perceived promoters and barriers to achieving them. The participating professionals were recruited from the MAC. However, only three worked full-time at the MAC. The other six participants worked at the MAC on a part-time basis and worked full-time with autistic people and other intellectual difficulties in other settings. This was considered an added value to the research data as the experience of these participants was likely to be more diverse. The three full-time professionals (including myself) worked in the autism programme at one of the organisations which provides services to persons with disabilities before they joined the MAC. The part-time participants worked on a full-time basis in other educational settings, including primary and secondary schools, post-secondary colleges, and the University of Malta. The educational psychologist also had a private practice. The age of the participating professionals ranged between 22 and 55 years. Two professionals were relatives of an autistic person, namely, the social worker who is the mother of a verbal and intellectually able fourteen-year-old autistic boy, and myself who has a 15-year-old autistic cousin.

Table 4. Key characteristics of the autistic young people in the sample

Age at data collection	Current job / school
30	Has a full-time job as a clerk
29	Has a part-time job as a toy figurine assembler
28	Has a full-time job as a Human Resource assistant
19	Studies Arts & Design at College
19	Is pursuing a first degree in Arts & Design
21	Has a full-time job as an accounts clerk in the Accounts Department of a well-established company
27	Unemployed
25	Has a full-time job in an office
22	Has a full-time job as a clerk

Table 5. Key characteristics of the Professionals in the sample

Experience of autism in years	Current role
20	Autism Practitioner
13	Autism tutor
25	Autism tutor / Learning Support Assistant in a Secondary school
8	Autism tutor / Special Needs Mentor
15	Speech and Language Pathologist
19	Social Worker
5	Speech and Language Pathologist
30	Educational Psychologist / University lecturer
20	Autism Practitioner

Table 6. Key characteristics of the Mothers in the sample

Age range	Current occupation / role
60 - 70	Retired nurse
50 - 59	Maths teacher
50 - 59	Learning Support Assistant
50 - 59	Office clerk
40 - 49	Beautician
50 - 59	House wife
50 - 59	Shop owner
40 - 49	Learning Support Assistant
50 - 59	Bank Manager

Table 7. Key characteristics of the Fathers in the sample

Age range	Current occupation
50 - 59	Security guard
50 - 59	Business man (owns his own company)
40 - 49	Technician
60 - 70	Plasterer
40 - 49	Bus driver
50 - 59	Front office clerk
50 - 59	Insurance broker

3.5.3. The participants

In Q sort, the number of participants does not need to be large. Brown (1980) maintains that Q methodology necessitates:

> Enough subjects [or participants] to establish the existence of a factor for purposes of comparing one factor with another. What proportion of the population belongs in one factor rather than another is a wholly different

> matter and one about which Q technique…is not concerned (Brown, 1980, p. 192).

In Q methodology, a person-sample smaller than the number of Q set items is suggested (Watts and Stenner, 2012; Brouwer, 1999). The number of participants must be adequate to enable the extraction of factors (Brown, 1980) and a heterogenous group of participants varying in gender, age, experiences and opinions is likely to add value to the study (Watts and Stenner, 2005a). The P set of this study was 34 (Refer to Tables 4, 5, 6 and 7), and the number of Q set items was 50 for the Promoters and 50 for the Barriers of DLS Q sorts. The number of participants in Q sort studies reviewed in Chapter 2 varied between forty and eighty. However, a similarity between these studies was that they gave more importance to the quality rather than the quantity of the participants. More specifically, they all sought to include participants with distinct experiences and opinions.

For instance, Milton (2016) had a P set of 60, to explore the ideologies and priorities about the education of secondary-school aged autistic pupils. The P set included participants from different stakeholder groups such as mothers and fathers of autistic people, autistic adults, academics and practitioners, many of whom belonged to multiple stakeholder groups. Furthermore, Plummer (2012) who used Q methodology to explore the viewpoints of children and young people who cared for their chronically-ill parent, and the views of carers about young carers and available support services, included a diverse range of professionals from different occupations. The P set which consisted of 20 young carers and 20 professionals included children and young people (young carers) and various professionals such as, teachers (n=1), head teachers (n=2) and mentors (n=3), psychologists (n=8), and professionals within the healthcare setting (n=6) like social workers and speech therapists. Similarly, Scott et al. (2015) opted for a heterogenous group of participants to explore the views of 40 male and female autistic employees and 35 employers about the key factors to successful employment.

Similar to previous Q sort studies, this study sought to include a varied group of participants with diverse experiences and opinions about the topic of DLS of autistic young people. The P set of this study was made up of a heterogenous group of participants including 9 autistic young people with average intelligence between the ages of 16 and 30, their mothers (n=9) and fathers (n=7) with diverse educational and social backgrounds, and 9 professionals varying in age. The participating professionals had different professional backgrounds: autism practitioners (n=2) including myself, autism tutors (n=2), speech and language pathologists (n=2), educational psychologists (n=1), special needs mentor (n=1), and a social worker (n=1). Such a heterogenous group was believed to bring out more distinctly the subjective views of participants as well as potentially distinct or shared viewpoints between the different groups of stakeholders.

3.6. Q set design and content for this study

The initial step in conducting a Q-sort methodological study is to develop the concourse from the everyday discourse around the topic of study. Watts and Stenner (2012) explain that there is no standard or correct way to create a concourse. A concourse may be obtained from primary sources, such as informal group discussions and interviews, or secondary sources including academic literature, newspaper articles and drawings, or a combination of both. Stephenson (1952, p. 223) emphasises that the most important characteristic of a Q set is ‘to suit the particular requirements of an investigation’. The concourse for this study was obtained from both primary and secondary sources with the aim of collecting a broad and comprehensive list of statements that encompasses different opinions, arguments and views in relation to the research questions of this study.

3.6.1. Obtaining the concourse for this study

The concourse includes a wide variety of statements that could possibly be expressed about a particular topic (Fontein-Kuipers, 2016). Thus, the selection of sources was done systematically to ensure that the collected concourse is representative of existing opinions and arguments about the topic of DLS for autistic people. The choice of sources was underpinned by: (i) the aim of this study – to identify the promoters and barriers of DLS for autistic people, (ii) the target population – autistic young people with average cognitive and verbal abilities, their parents and professionals, and (iii) the purpose for doing a Q-sort study – to identify similarities and disparities between the views of different stakeholders for the development of an educational programme about DLS. To understand better and acquire a wide range of expressed ideas about the topic of DLS, I took a two-fold approach to collecting the concourse: (i) a systematic review of the literature and (ii) informal discussions with different stakeholders to acquire personal experiences.

3.6.1.1. A systematic review of the literature

Several sources were consulted to obtain the concourse statements for the Promoters and Barriers Q sorts. The initial process involved an extensive reference to the educational literature reviewed in Chapter 2 in this thesis. Watts and Stenner (2012) maintain that a thorough search of the literature around a specific topic aids the researcher to identify the key issues and themes related to the study topic. Other sources such as newspaper articles, periodicals, websites, and information packs issued by autism organisations about the independence of autistic adults were also consulted.

As has been previously discussed, the topic of independence includes a variety of areas such as, independent living, employment, friendship and leisure activities. For the purpose of this study, I opted to focus on DLS within the personal, domestic and community domains. Thus, since the topic revolved around a number of DLS, rather than opinions about them, it was deemed more practical to obtain the list of DLS solely from the literature.

3.6.1.2. Informal discussions with different stakeholders

The concourse for the Promoters and Barriers Q sorts was further obtained through informal discussions carried out individually with eight participants across the different stakeholder groups (2 mothers, 2 fathers, 2 young people, and 2 professionals). The first step in preparing for the informal discussions was to formulate a list of guideline questions. These were piloted with some of my colleagues, autistic people and parents to ensure that they are well-understood and that they led to the information which I intended to gather. Following analysis of their feedback, a review of the literature on existing DLS checklists was carried out. A list of DLS to guide the participants during the discussion was formulated. This was intended to support the guideline questions and lead the discussion to what I had planned to find out. The guideline questions and DLS checklist were submitted to The University of Birmingham Ethics Committee for approval. Some questions were reworded following suggestions made by the Ethics Committee to enhance comprehension. See Appendix 6 for a copy of the guideline questions used during the informal discussions.

Table 8. Participants for the informal discussion

Participants	Age	Occupation/Education
YA	30 years	Has a full-time job as a clerk
YA	19 years	Studies Arts & Design at College
PM	55 years	A secondary school Mathematics teacher
PM	62 years	A retired nurse
PF	59 years	A front-office clerk at a large construction company
PF	45 years	An electrician at Malta's public general hospital
Prof	56 years	Teaching assistant in a secondary school and part-time autism educator at the MAC. Has been working in field of learning difficulties and autism for twenty years
Prof	31 years	Has been working full-time at the MAC for four years and has worked in the field of autism for the past nine years

YA: Young Adult; PM: Parent Mother; PF: Parent Father; Prof: Professional

The eight participants in Table 8 were randomly chosen from the thirty-four participants who had given their consent to participate in this study. They were contacted and given the information sheet about the informal discussion and its purpose (see Appendix 4 for a copy of the information sheet and consent form for the informal discussions). The participants were also given a consent form to give their informed consent in writing. I agreed with each participant on a convenient date and place to carry out the informal discussion. Each discussion took approximately 45 to 90 minutes. All discussions were carried out at the MAC.

The informal discussions were planned to take the form of a relaxed discussion about the topic of DLS and the prepared questions were intended to guide the flow of the discussion. The structure of the discussions varied among the different stakeholder groups. The young people preferred a more structured question and answer format. This helped them to focus better on each question and give relevant information for the concourse. These discussions took 45 minutes to 1 hour.

Discussions with the professionals were around 1 hour long. They had a good flow and I managed to acquire relevant information for the concourse. Informal discussions with the parents were the most time-consuming, around 90 minutes long. Since I am known to the parents as a practitioner who gives regular intervention to their sons and support them as parents, it was not always easy to keep them focused on the topic of discussion. It was observed that both the mothers and the fathers felt very comfortable to share their worries and challenges of supporting a young autistic adult. This was very helpful to collect the concourse, however, there were moments when parents shared concerns relating to areas other than DLS. To overcome this, I took note of such concerns and assured the parents that a separate meeting will be held to discuss such concerns further. Being an insider researcher resulted in being more time-consuming. Nonetheless, it led to natural and open interactions between the participants and myself which is believed to have ultimately resulted in more profound data.

3.6.2. The selection of statements from the concourse

The selection of statements from the concourse to make up the Q set is crucial, requiring persistence and skill to ensure that the final set of stimulus items is representative of the concourse. Watts and Stenner (2012, p. 58) describe a ‘balanced’ Q set as one which ‘will come very close to capturing the full gamut of possible opinions and perspectives in relation to your research questions.’

The development of a Q set has been described as ‘an art’ (Brown, 1980, p. 186) and ‘a craft’ (Curt, 1994, p. 129) placing an emphasis on the ability of the researcher to draw a miniature of the concourse.

The selection process of the Q set may be structured or unstructured. In the former, the researcher breaks down the subject matter and groups the statements in accordance with some preconceived theories, and then selects the sample from the different groupings. Unstructured sampling, which was chosen for the purpose of this study, affords the researcher more fluidity. Although the researcher may begin the sampling process by identifying the key themes of the study topic, unstructured sampling allows the researcher more freedom. The main reason underpinning this choice was a preference for acquiring a more holistic understanding of the subject matter rather than dissecting it and drawing the statements from predefined subpopulations of the subject matter. This unstructured approach puts more weight on the researcher’s ability to be ‘rigorous, systematic and exhaustive’ to come up with a representative Q set (Watts and Stenner, 2012, p. 60).

3.6.2.1. Selecting and creating the Q sort statements for this study

Initially, I had planned to do two Q sort exercises, one for Priority DLS and a combined one for the Promoters and Barriers of DLS. However, during the collection process of the concourse statements from the literature, it became apparent that having two separate Q sorts for the Promoters and Barriers of DLS, would be easier for participants to sort and for me to write the statements and analyse the results. Thus, I created two separate initial statements to guide the separate sorting of statements for Promoters and Barriers. For the Promoters, the initial statement read: 'Autistic y*oung people will be helped to acquire DLS for independent functioning if they…*', and for the Barriers: 'Autistic y*oung people have difficulty to achieve DLS for independent functioning because they...'.* Aware that Q sorting can be a time-consuming exercise, I felt that three Q sorts would be too mentally demanding and time-consuming for the participants. It was therefore decided that the reviewed list of DLS would be used to create a DLS checklist (See Appendix 11), in which participants would be asked to mark whether each DLS is of *High* or *Low Priority* for the independence of young people.

A total of 196 phrases, quotes and sentences about the topic of Promoters and Barriers of DLS were extracted. The selected statements were taken verbatim from the different sources to minimise my influence. Sixty-five items were selected from the academic literature, websites, newspaper articles and periodicals. These were later refined and reduced to 50 statements. One hundred and thirty one were obtained from informal discussions with eight participants (23 from the young people, 37 from the mothers, 45 form from fathers and 26 from the professionals). Narratives from personal communication with autistic adults, parents and professionals during my daily work, were also documented, in order to include items with a more natural and spontaneous origin. From the informal discussions carried out with the eight participants, a total of 73 items were extracted for the Promoters and 58 items for the Barriers.

It is acknowledged that whenever a Q set is designed by different researchers, a different set of stimulus items may be drawn from the same concourse. Moreover, Watts and Stenner (2012, p. 63) argue that: ‘The perfect Q set is probably a thing of fantasy and fiction.’ However, the main aim is to draw a Q set that is representative of the range of opinions, viewpoints and beliefs that exist around a particular topic. This is reasonable in that, statements are not considered to have a priori meanings, but the stimulus items acquire meaning through each of the participant’s reflections, interpretation and understanding (Watts and Stenner, 2012; Thomas and Baas, 1992). Brown (1980, p. 54) emphasises that in Q methodology, meaning is to be ‘attributed a posteriori through interpretation rather than through a priori postulation.’

There is no pre-determined number of statements to be included in a Q set and opinions vary among theorists. However, as outlined earlier, a range between 40 and 80 statements has been identified as standard (Stainton Rogers, 1995; Curt, 1994). Fewer statements than the lower limit is not likely to be comprehensive enough to cover the broad array of discourses and opinions about a topic, while too many statements are likely to make the sorting process too time-consuming and demanding for participants (Watts and Stenner, 2012). Watts and Stenner (2012) suggest that it is sensible to withdraw a large number of statements at the initial stages of the selection process, and later on refine and reduce the Q set through piloting.

As recommended, the number of statements generated during the initial process of collecting the concourse (108 for the Promoters and 88 for the Barriers) was larger than that required for the final concourse (50 for each Q sort). In order to reduce the number of statements from the concourse to a manageable and *user-friendly* one for the Q sort process, a number of considerations were taken. This process included assessing and filtering the statements for duplication (Coogan and Herrington, 2011), and ensuring that statements were not *double-barrelled*, such as using two different propositions which carry a different judgement in one statement, which would make statements ambiguous to sort (Watts and Stenner, 2012). Moreover, statements were written in the third person to accommodate the different stakeholders, while complex and long statements, and items containing double negatives, were avoided.

3.7. Piloting the different stages of the Q-sort method

Piloting a research study is considered a salient phase to help the researcher identify aspects of the research tool that require refinement (Hassan, Schattner and Mazza, 2006). Moreover, it helps the researchers to familiarise themselves with the different stages of the study and to gather feedback from the pilot participants to make the research study tool more user-friendly to the participants. The process of piloting the Q sort was divided into different stages: (i) piloting the informal discussion questions, (ii) piloting the concourse statements taken from the literature (including the Q sort instructions and the post-sorting questions), (iii) piloting the concourse statements extracted from the informal discussions with the eight participants, and (iv) piloting the full set of concourse statements (a combination of statements taken from the literature and the informal discussions with stakeholders).

3.7.1. Piloting the informal discussion questions

The informal discussion questions were piloted with five participants: 2 autistic male youths with average intellectual and verbal abilities (14-year-old; 15-year-old), both attending mainstream secondary school, 1 mother of a 15-year-old male youth, 1 father of another 15-year-old male youth, and 1 professional who works with autistic students in a mainstream secondary school. Participants were approached through the MAC. They were given a brief explanation of this research study and were asked whether they would be willing to participate in the pilot study. For the youths, since they were minors, their parents’ consent was obtained. All those approached were very willing to take part.

The chosen youths fit the inclusion criteria of this study in terms of being students at the MAC and having average intellectual and verbal abilities. Both students did not fit in the age-range chosen for this study (i.e. 16 years to 35 years) as I did not wish to take students from the population of this study, so that I do not reduce the number of participants. Similarly, both parents and the professional were not taken from the population of this study because the main aim of piloting the informal discussion was to check time, wording, and relevance of the guiding questions to generate the concourse.

3.7.2. Observation and required changes

During the informal discussion pilot, I realised that the questions of the first section about priority life skills were not relevant to obtain information for the DLS checklists, as these had already been collected by means of a thorough literature review. Instead, I planned to start the informal discussion with a general introduction to the three different areas of DLS chosen for this research study (i.e. personal skills, domestic skills and community skills) to guide the discussion. It was also planned to replace the first four questions (see Appendix 6) with a more general question: ‘Which DLS do you consider most important for you/ your son/ autistic people to function independently in life?’

It was also observed that the section about *Learning DLS*, needed to be more structured and visual for the young people. During the two pilot discussions, both youths found it difficult to answer the prepared questions. Thus, I asked the youths to make a list of those DLS that they were able to do without help so that they could refer to their list to answer questions. Having a written list to refer to made it easier for them to identify those skills that were easiest or hardest to learn and what strategies they had found helpful. From the discussions, it resulted that two questions (‘Which life skills were most difficult for you to learn? Why?’ and ‘Which daily living skills have you found most difficult to do without the help of others? Why do you think you struggle with these?’) were quite overlapping. Thus, these were reworded as one question: ‘Which DLS do you still find very difficult to learn/do without the help of others? Why do you think you struggle with these?’

3.7.3. Piloting the Q sort statements taken from the literature

The Promoters and Barriers Q sorts (each consisting of 25 statements taken from the literature and my experience as a practitioner were piloted separately with: 1 autistic young person (15-year-old), 1 mother (of a 15-year-old male student) and 1 father (of another 15-year-old male student).

The participants were given a copy of the written instructions and I read out the steps one at a time, allowing the participants time to understand each step well and to ask for clarification when needed. All three participants found the instructions clear and easy to understand.

3.7.3.1. Participants’ feedback about the literature Q sort statements

All participants found the statements clear and easy to understand. The young person was not familiar with the word ‘neurotypical’ in one of the Promoters statements (‘…have neurotypical friends who serve as good models’) and asked for clarification. The term ‘neurotypical’ was then replaced by ‘non-autistic’.

The parents pointed out similarities between some Barriers statements:

(i) ‘…lack opportunities to learn DLS as part of their everyday school curriculum’ and
(ii) ‘lack opportunities at secondary and post-secondary levels to learn DLS and to function independently in the community’

After reflecting on the above statements, I identified the second one as double-barrelled since it includes two separate issues about lack of opportunity: (i) to learn DLS and (ii) to function independently in the community. Thus, the second statement was removed.

In the promoters of DLS Q sort, some statements were identified as similar in meaning:

(i) '…are encouraged from a young age to do age-appropriate DLS independently' and

(ii) '…are taught DLS from a young age'

While writing these statements I had intended to make a distinction between teaching DLS from a young age and encouraging the actual daily performance of DLS by being given age-appropriate responsibilities. However, this was not clearly understood by the participants. Thus, the first statement was reworded to: 'are encouraged from a young age to take on age-appropriate responsibilities related to DLS'. This was piloted again with other participants to ensure that my intended meaning reached the participants.

The second set of statements that were identified as similar were:

(i) '…are taught DLS directly through step-by-step visual instructions' and

(ii) '…are given step-by-step visual and verbal instructions on how to perform DLS'

These two statements were identified as indeed very similar and the second statement was omitted as participants thought that the first statement was clearer.

3.7.3.2. Participants’ feedback about the Q sort exercises and post-sorting interview

All three participants remarked that they found the Q sorts interesting and enjoyable and that it was a good way of helping them sort out their thoughts clearly about the topic. The participating parents required no assistance to complete the Q sorts and each Q sort took them between 10 and 15 minutes to complete.

The youth needed some assistance in the beginning to sort out the statements in three piles. Thus, I provided him with three trays labelled ‘most agree’, ‘least agree’ and ‘neutral’ to make the sorting exercise easier. Thereafter, he was able to complete the Q sorts without any further help. The use of sorting trays was deemed necessary to include in the final study to make the sorting visually clear and thus easier for the autistic participants. The youth described the Q sorts as “fun” and “a game which requires a lot of thinking”. He remarked that the most difficult task was to put statements in the ‘least agree’ pile as he thought that all statements were very important. However, he eventually managed to complete the Promoters and Barriers Q sorts in 20 and 25 minutes respectively, and was pleased with his final sorts.

The post-sorting questions were considered by the pilot participants as very straight forward and each individual interview took around 10 minutes. The questions allowed the participants to explain the rationale behind their sorting and provided me with relevant information about their way of thinking about the topic.

3.7.4. Piloting the concourse statements taken from the informal discussions

For the purpose of piloting the concourse statements extracted from the informal discussions, the same participants who took part in the pilot Q sort of the statements taken from the literature were asked to take part. The three participants (1 autistic young person (15-year-old), 1 mother (of a 15-year-old male student) and 1 father (of another 15-year-old male student) had communicated their willingness to take part in other stages of the pilot study. This proved to be beneficial as it was less time-consuming both for myself and the participants since these pilot participants were already familiar with the Q sorting exercise. Moreover, participants had a good understanding of the type of feedback I was after in terms of statement clarity, relevance to study topic and similarities in meaning. A professional working with autistic students in a mainstream school also took part in this pilot Q sort.

3.7.5. Piloting statements to generate the final Q set

Sixty-five Promoter and 65 Barrier statements from the concourse were piloted with eight volunteers similar to the three target populations of stakeholders, namely two autistic young people, two mothers, two fathers, and two professionals. Each participating volunteer was asked to complete two Q sort exercises by ranking the statements. Each sorting exercise lasted between 30 and 45 minutes for the professional and the parents, and around 1 hour for the young people.

Participants found the statements clear to understand except for the statement '…very sensitive to their surroundings' in the Barriers Q sort and '…have support from a young age to improve communication which will then help them to learn DLS' in the Promoters Q sort. These were thus removed from the list.

This process helped to make sure that the wording of the statements was clear and well understood by the various stakeholders. Additionally, piloting the Q set made it possible to identify whether statements encouraged the active participation of the participants rather than reducing them to passive respondents. In this regard, Watts and Stenner (2012) emphasise that:

> An effective Q-set item will always invite (or provoke!) a range of qualitatively different reactions and it will differentiate among Q sorters on that basis (Watts and Stenner, 2012, p. 65).

Moreover, the piloting process enables the researcher to develop new items and to ensure that the final draw of statements is representative and provides a broad coverage of the subject matter. Following these processes, the final Q sets were generated. (see Appendix 7 for the list of Q sort statements used in this study).

3.8. Administering the Q sort

The process of Q sorting requires the participants to physically sort out the statements, each written on a separate card, on a distribution grid according to a condition of instruction. Brown (1980, p. 17) describes this process as 'the technical means whereby data are obtained for factoring.' In order to answer the research questions of this study, participants were asked to complete two separate Q sorts, one to reveal their viewpoints about perceived promoters of DLS and another one to capture the participants' perspectives about perceived barriers of DLS for autistic young people with average verbal and cognitive abilities. The Q sets were identical for all the participants and each Q sort was carried out on an individual basis. I presented the grid and sorting cards to the participants and read out the instructions for the Q sort process. (Instructions for the Q sorts are given in Appendix 8). Participants were allowed some time to ask any questions about the sorting process. Thereafter, I left the room. Participants were informed that I was available if they encountered any difficulty to complete the Q sort.

In the beginning of the Q sort process, participants were given the Q sort cards and the typed question underlying the Q sort exercise to guide their sorting. It was explained to them that each card had a different statement on it as a response to the research question. Participants were reassured that there were no right or wrong answers, and the importance of their personal viewpoint during this process was emphasised. Participants were expected to rank-order the statements on a grid from '*least agree'* (-6) to *'most agree'* (+6). Participants were instructed to read the cards and initially sort them into three piles: statements they felt positive about, statements they felt are most unimportant or definitely disagreed with, and other items about which they were neutral or unsure. Participants were then asked to rank the statements on a standardised distribution, whereby participants assigned a predetermined number of items to each ranking value (see Appendix 10 for a diagram of the grid). A forced-choice distribution was preferred over a free distribution for this study as it facilitates the Q sort process both for the participants and the researcher (Watts and Stenner, 2012). Moreover, Brown (1980, pp. 288 - 289) has demonstrated that the 'distribution effects are virtually nil' in that the chosen distribution whether forced or free does not impact on the factors that are elicited from the study.

In the beginning of the actual Q sort, participants were guided to begin with the distribution of the items they felt most positive about and place them at the higher rank on the right-hand side of the distribution moving inwards toward the left-hand side of the continuum. The same procedure was used for the two separate Q sorts. It was explained to participants that placing the items closer to the left-hand side of the distribution does not indicate unimportance or disagreement, but that such items are perceived slightly less favourable when compared to the ones ranked before them. Additionally, it was clearly outlined that items within the same column are of equal ranking and thus, the position of items within the same column was insignificant. Next the participants were asked to rank the items in the *'least agree'* categories, this time beginning the ranking from the far left-hand side of the distribution. The remaining items in the 'neutral' pile were sorted last to fill in the middle area of the distribution. At the end of the sorting process, participants were reminded that they could revise the completed Q sort and move any items around the distribution until it portrays the best representation of their views. The final Q sort was then recorded onto a blank distribution grid using corresponding numbers for each statement.

3.8.1. Post Q sorting interview

Following the Q sort exercise, a *post-sorting interview* was held with each participant to gather supporting information about the sorted items. Examples of the questions asked are given in Appendix 9. Gallagher and Porock (2010) maintain that the interview adds quality and value to the data gathered through the Q sort. During this interview, participants were asked why they had sorted items as they did. They were also asked to talk about the items they had ranked at the extreme ends of the distribution.

Additionally, participants were asked to talk about the personal meaning they attached to particular items and whether there were any statements that they did not fully understand and other items which they would have included in the Q sort.

At the end of this interview, participants were asked whether they were willing to be included in a list from which a sample of eight participants (from the different stakeholder groups) would be drawn to participate in a semi-structured one-to-one in-depth interview to further explore the topic of independence. It was explained to the participants that such an interview would add depth to the study topic and could highlight important issues outside the context of the Q sort. However, it was emphasised that they were free to decide not to be included in this list. All participants accepted to be included.

3.9. In-depth interviews

In-depth one-to-one semi-structured interviews were carried out with eight participants (2 young people, 2 mothers, 2 fathers and 2 professionals). A copy of the questions used to guide the interviews is given in Appendix 12. The main aim was to understand the topic of DLS and independence in more depth from the participants' own experience. It sought to obtain a description of the participants' worlds through a discussion, which is close to an everyday conversation. Each interview lasted for approximately 50 minutes. The interviews were meant to be carried out face-to-face at the MAC. However, due to the Covid-19 pandemic they were conducted online via Skype. Participants reported that it was a positive experience which helped them to think deeper about the topic.

> A well-conducted research interview may be a rare and enriching experience for the subject, who may obtain new insights into his or her life situation (Brinkmann and Kvale, 2015, p. 35).

In the interviews I took the approach of what Brinkmann and Kvale (2015, p. 58) refer to as the 'interviewer-traveller'. As an insider researcher I thought that such an approach would be appropriate where I would 'walk along' with the participants and 'encourage them to tell their own stories of their lived worlds' (Brinkmann and Kvale, p. 58), keeping an open mind without focusing on my thoughts, ideas and opinions about the topic.

> The journey might instigate a process of reflection that leads the travellers to new ways of self-understanding, as well as uncovering previously taken-for-granted values and customs in the traveller's home country' (Brinkmann and Kvale, 2015, p. 58).

Indeed, the interviews revealed various topics about the promoters and barriers of DLS which go beyond the idea of skill-building. These were topics such as bullying, over-protective parenting, the importance of professional support and parents' persistence, which were all unexpectedly uncovered during the interviews and added more richness to the study.

3.10. The DLS checklist

The list of DLS was collected mainly by means of a thorough literature review of existing DLS checklists (e.g. Vineland: Adaptive behaviour scales, 2005; Independent living skills: A checklist for young people in care, 2019). Fifty DLS were chosen from the areas of personal hygiene and appearance, health care, money and budgeting skills, safety at home, safety on the street, and travelling skills (see Appendix 11). Participants were given the list and were instructed to tick whether they thought each DLS was of *high* or *low priority*. Following this task, participants were asked to write the 5 most important DLS from their high priority choice and the 5 least important DLS from their low priority list. Data were analysed manually by myself to bring out the high and low priority DLS and the five most important DLS for every stakeholder group, and highlight any similarities and differences between the participant groups.

3.11. Strategy adopted for data analysis

Data analysis of this study aimed at obtaining a thorough understanding of the lived experiences of the participants and how they make sense of it in their daily personal and social worlds. My aim was to gain insight into their lived experiences of promoters and barriers of DLS from the stakeholders' point of view, to capture their understanding and emotions.

The factor interpretation system used in this study, that is the *crib sheet* (Watts, 2010) adopts *abductive* logic (Blaikie and Priest, 2017) which involves studying the meanings and concepts that the participants, who are the *social actors*, apply to their everyday accounts and consequently devise a theory to explain them. Through the interpretation process, I gave attention to every single item and questioned why it was ranked as it is and what was it trying to tell me. Through such questions, I was able to build up a narrative by actively moving through the grid.

For the in-depth interview analysis, my approach was thematic analysis. My aim was to acquire a thorough understanding and close examination of the stakeholders' detailed experiences of the promoters and barriers of DLS, and how they made sense of it. The analysis of the interviews served to inform and illuminate the findings of the Q sorts by adding rich information about each stakeholders' experiences and narratives, and thereafter comparing them with the experience of others and those elicited through the Q sorts.

3.12. Data analysis of the Q sorts

In Q sort studies, the process of data analysis is carried out using specific computer software in which Q sorts are entered and thereon analysed to identify similarities and differences in the respondents' viewpoints. The computer program used in this study was the PQMethod, which is a free computer software available online for download (Atkinson, 1992). The first step in the process of data analysis is to convert Q sorts into factors. Watts and Stenner (2012, p. 95) compare a factor to a slice that is taken from the bigger cake describing it as: 'a portion of common or shared meaning that has been, or that could potentially be, extracted from the whole.'

The process of factor extraction begins by inputting all the Q sorts in the PQMethod software to obtain a correlation matrix, through the intercorrelation of Q sorts with each other. This process determines the relationship of each Q sort with every other sort and thus, measures the degree of similarity or otherwise, between the participants' viewpoints. During the process of factor extraction, groupings of Q sorts that are highly correlated with each other are extracted from the correlation matrix to indicate those Q sorts that belong to one *family* or factor (Brown, 1993).

Therefore, factors within Q methodological studies capture the main viewpoints and the shared meaning that the participants would have expressed through the Q sort. Thus, this implies that the *common variance*, which includes that portion of the Q sort to which the participants would have attributed a common meaning, is extracted from the correlation matrix (Watts and Stenner, 2012). This was performed through a Centroid Factor Analysis (CFA), which is the preferred method of Q methodologists as opposed to Principal Component Analysis (PCA). CFA affords the researcher the opportunity to explore the data further and select the most appropriate factor rotation for their study (Cuppen *et al.*, 2010).

Following the extraction of the first factor, the next step was to search for more portions of common variance within the residual correlation matrix, which would lead to the extraction of the next factor. Following the extraction of each factor, the subsequent step was for the program to provide the *factor loading* that is, the extent to which each Q sort is related to each factor. The most commonly used criterion that influences the researcher's choice about the number of factors to be extracted and interpreted is usually the *eigenvalue* (EV), which indicates the statistical strength of that specific factor. The *eigenvalue* is obtained by summing up the squared loadings of the factor. Generally, factors are extracted and retained for analysis if their EV is 1.00 or greater (Brown, 1980). Moreover, for a factor a be extracted, it requires at least two Q sorts that load significantly upon it (Watts and Stenner, 2005a).

The next step in the data analysis involved factor rotation which provides a way of looking at the data from a different perspective, making the subject matter ‘more focused, more specific and more faithful to the actual viewpoints of the participants’ (Watts and Stenner, 2012, p. 129). Watts and Stenner (2012, p. 126) propose that a combination of varimax and by-hand rotation is likely to be ‘a very useful and effective way of exploiting their complementary strengths’. Initially, I was inclined towards a combination of both. However, after further thought, mainly due to my lack of skill and practice to carry out by-hand rotation, it was decided to do varimax rotation only. Moreover, varimax is the preferred method by Q methodologists. Varimax rotation tends to highlight more the predominant viewpoints of the group of participants as a whole.

Following factor rotation, it is not the viewpoints within any Q sort that alters but the point from which one perceives it. This can be achieved through the comparison of factors with each other. The resulting final factors represent groups of viewpoints that are highly correlated with each other but not to others. Prior to factor interpretation, the normalised average weighted score or z scores for each item is calculated and converted into a single factor array. This factor array conforms to the quasi-normal distribution, constructed by the rank order of z scores to present the composite Q sort for each factor (Watts and Stenner, 2012). Analysis of each factor array resulted in the identification of the most agreeable statements within each factor, and thereon, each identified factor was given an appropriate name. Moreover, such analysis highlighted distinguishing statements (when the same statement scores significantly different on two factors) and consensus statements (when a statement has the same score on two different factors) (van Exel and de Graaf, 2005).

The interpretation of factors and an analysis of distinguishing and consensus statements uncovers the array of differences and commonalities in the viewpoints within specific participating stakeholder groups as well as between the different participating stakeholders of this study (the young people, their parents and professionals), in relation to the independence of autistic people. The interpretation of factors was analysed in relation to the supporting explanations gathered through the qualitative post-sorting interviews. Additionally, the data gathered through the semi-structured in-depth interviews carried out with a sample of eight participants were analysed and triangulated with the data obtained through the Q sort method and post-sorting interviews.

3.13. Ethical issues and procedures

Any research process, especially studies which involve human participants, some of whom might be deemed vulnerable, have a number of ethical issues which need to be addressed. Sieber (1993, p. 14) describes ethics as: ‘the application of moral principles to prevent harming or wronging others, to promote good, to be respectful and to be fair.’

In this study, ethical considerations in accordance with the British Educational Research Association (BERA, 2018) were applied throughout the research process. Moreover, this study underwent a procedure of ethical approval and clearance from the University of Birmingham. Appendix 1 has a copy of the confirmation letter of ethical approval by the University of Birmingham.

The key issues pertaining to this study concerned the participants' informed consent, confidentiality and anonymity, time taken to take part in the research, emotions experienced by the participants, and being an insider researcher. Each of these will be discussed below.

3.13.1. Informed consent

Israel (2015) contends that:

> Informed consent implies two related activities: Participants need first to comprehend and second to agree voluntarily to the nature of the research and their role within it (Israel, 2015, p. 79).

Participants for this study were approached by means of a standard information sheet explaining the main objectives of this research and information about what their participation would involve if they accept taking part in this study. The information sheet also included information about how the data will be used (see Appendix 2). Confidentiality was ensured throughout the process of data collection, analysis and reporting. Their right to refrain from taking part in this study was also highlighted and the participants were encouraged to ask any questions they had about their participation in this research. Upon their acceptance to take part, participants were given a consent form to complete (see Appendix 3), to gain their informed consent in writing. Participants were reminded of their right to withdraw from taking part in this research, at any point until four weeks after the data collection process, without providing any reason for their decision.

Webster, Lewis and Brown (2014, p. 88) maintain that ‘consent is not a single event but a process.’ They suggest that researchers should gain participants’ consent from time to time throughout the research process to allow participants to reflect on the potential costs and benefits of participating in the research. This study followed Webster and colleagues’ (2014) approach and informed consent was confirmed throughout the data collection process for every step of the research. More specifically, following the participants’ informed consent to take part in this research study, eight participants were randomly drawn to take part in an informal discussion to collect the Q set statements. These eight participants were given an information sheet to explain the aim of the informal discussion, what it involves and how their shared data would be used in the study. Following their agreement to participate in this informal discussion, participants were asked to give their informed consent in writing to take part in this exercise (see Appendix 4 for a copy of the information sheet and consent form).

Moreover, after completing the Q sort and post-sorting interview, participants’ consent was sought once again. Specifically, participants were asked whether they would like to be included in a list from which a sample of participants would be drawn to take part in a semi-structured in-depth interview. At this stage, participants were reminded of their right to refrain from taking part and that this would not alter the study in any way. Participants were provided with a sheet with information about the purpose of the in-depth interview and what their participation would entail. Those participants who were eager to be included in the list of participants for the in-depth interview were asked to complete another consent form (See Appendix 5).

Furthermore, this study adopted a ‘staged approach’ (Webster, Lewis and Brown, 2014, p. 88) to gaining informed consent and participants were allowed at least one week from the date of handing in their written consent to the researcher to actually participate in the research process. This allowed the participants time to weigh the pros and cons of taking part in this research study and to ask the researcher any questions they had about their participation.

3.13.2. Confidentiality and anonymity

Ethics codes declare *confidentiality* and *anonymity* to be a requisite in research. Webster, Lewis and Brown (2014, p. 96) define confidentiality and anonymity as: ‘…not disclosing who has taken part, and not reporting what they say in ways that could identify them or be attributed to them.’

I was very vigilant to ensure that each participant’s identity was protected throughout the data collection and data reporting process. Data were collected through the Q sort exercise, and in-depth interviews carried out in my presence. Thus, the data collection process could not be anonymous. However, confidentiality was ensured throughout the data collection process and in the release of its findings.

Data collected through the initial informal discussions to generate the statements for the concourse remained confidential and the chosen statements were anonymous. I was very vigilant to ensure that the chosen statements for the Q sort would not disclose the identity of the participants in any way. Statements were left in the original format that they were expressed by the participants as much as possible to ensure a true representation of the participants' viewpoints. However, any words or phrases that were considered likely to give away the identity of the participant, were removed.

For the Q sort exercise, the final Q sort of every participant was assigned a code known to myself only. Such codes were intended to allow me to identify important data for the results and findings, such as the stakeholder group that each participant belonged to and the gender of the participants (e.g. whether they were mothers or fathers) which added relevant information to the findings of this study. The collected data remained confidential and the reported findings were anonymised, in that it was made sure that they did not disclose the identity of the participants in any way. Data obtained from the Q-sorting activities were inputted into the computer software which was password protected and accessible only to me.

The in-depth interviews carried out with eight participants allowed more opportunity for disclosure of sensitive and personal information. Thus, I ensured participants about confidentiality of the shared information. Moreover, throughout the interview, participants were reminded that they could choose to refrain from discussing any issue which they felt uncomfortable to talk about. Data obtained from the interviews, which were video-recorded, were securely locked away in a place to which only I had access. In line with the University of Birmingham's Code of Practice for Research, all data will be securely stored for ten years and backed up to the University server. All data will be destroyed thereafter. During the write-up of the findings, I was very conscientious to protect the identity of participants while conveying accurate accounts of the viewpoints and lived experiences of the participants.

Wiles et al. (2008, p. 421) refer to ‘accidental disclosure’ in which the researcher accidentally discloses information that can identify the participant. Webster, Lewis and Brown (2014) maintain that accidental breaching of confidentiality is more likely to arise in studies where the researcher and the participant share social or professional contacts. Thus, being an insider researcher is likely to increase such possibility. Therefore, my awareness of this type of accidental disclosure was considered important to prevent it from happening.

3.13.3. Benefits and risks for the participants

Literature shows that the *voice* of young autistic people about factors associated with their independent functioning, in terms of what DLS they prioritise and the barriers they experience to achieve them, is limited. Thus, this research intended to share the voices of the young people and another three important stakeholder groups, their mothers and fathers, and professionals. No compensation in the form of money or any other benefit was offered to the participants for the time taken to participate. However, it is hoped that it was a positive experience for them. Moreover, this research allowed participants the opportunity to voice their views and to contribute to the identification of important information that would promote the independent functioning of autistic people.

On the other hand, the topic of independent functioning of autistic young people could possibly heighten the participants’ emotional responses, particularly in the case of the young people and their parents. However, since I knew the participants quite well, it was easier to observe and identify that a participant was becoming too emotional during the course of data collection and thus, support the participants and remind them of their right to withdraw from the study.

3.14. Researcher positionality and potential bias

In any type of social research, the researchers are part of the social world that they are researching and, ‘there is no way that we can escape the social world to study it’ (Hammersley and Atkinson, 1995, p. 17). A researcher’s positionality, including their social position, opinion, perspectives and assumptions they hold about the world, influence their choice of study topic, the research questions they attempt to answer, the methods they choose and how they interpret the collected data (Wellington *et al.*, 2005). Within the context of this study, these were true and real issues to be acknowledged. It was recognised that my professional experiences and consequent perspectives about the subject matter could bias to some extent the data collection process and interpretation. Moreover, being an insider-researcher, it was acknowledged that my main role within the MAC to give intervention and offer support to autistic people and their families, and being a colleague of the participating professionals, could potentially impact on the data collection process and data analysis of this study. More specifically, there are advantages and disadvantages to being an insider-researcher, that need to be recognised to minimise the cons and maximise the pros. These will be discussed in the following sections.

3.14.1. Advantages of being an insider-researcher

> Insider research is that which is conducted within a social group, organisation or culture of which the researcher is also a member (Greene, 2014, p. 1).

Several scholars have identified various advantages of researching a community of which the researcher possesses a profound insight, claiming that it makes the research process more accessible. For instance, in this study being an insider-researcher provided easier access to the young people's diagnostic reports and progress records. Moreover, the insider-researcher possesses knowledge which takes the outside-researcher a long time to obtain. Smyth and Holian (2008) claim that insider-researchers benefit from knowing the philosophies underpinning the culture they are studying and know the best way of how to communicate with the participants. Similarly, Unluer (2012) maintains that the flow of interaction between an insider-researcher and participants remains natural. Furthermore, the already formed relationships and familiarity encourages participants to be more honest and allows the researcher to evaluate genuineness in the participants' responses (Bonner and Tolhurst, 2002).

Within the context of this study, the participating parents and professionals were likely to be more willing to share their experiences and views with me due to 'an assumption of understanding' (Floyd and Linet, 2012, p. 58). Additionally, the already established relationship with me and having discussed their son's abilities and needs several times, were likely to make parents feel more comfortable to disclose personal thoughts and beliefs about the study topic. Moreover, since I was familiar with the communication style of the young people, I was able to adjust the instructions accordingly thus, making interaction and communication with these participants easier. Furthermore, Floyd and

Linet (2012) argue that an insider-researcher is likely to be more easily accepted by the participants which leads to greater openness with the researcher resulting in potentially more profound data.

Unluer (2012) claims that the insider-researcher benefits from already established respect which makes the participants more willing to facilitate the research process for the researcher. It is believed that due to the participants' respect towards the researcher's dual role of a professional together with their personal interest in the study topic, the participating stakeholders are likely to give importance and value to this study and be more willing to participate. Furthermore, being an insider researcher, was deemed beneficial when researching a topic which could heighten the participants' emotional responses, particularly in the case of the young people and their parents. My dual role of a practitioner who gives regular intervention and has a good rapport with these individual participants, made it possible to monitor their emotional responses and give the necessary support when required both during the data collection process and afterwards.

3.14.2. Disadvantages of being an insider-researcher

While insider-research can generate several advantages for both the researcher and the participants, there are also a number of dilemmas which the insider-researcher should be mindful about (Labaree, 2002). Insider-researchers benefit from an increased sense of trust as participants feel more comfortable and willing to share personal information (Floyd and Linet, 2012; Corbin Dwyer and Buckle, 2009). On the other hand, Mercer (2007) argues that participants may want to preserve the impression that the researcher holds about them and may not be completely honest. Furthermore, being familiar to the culture being studied could decrease the researcher’s level of objectivity, and prior knowledge could lead to incorrect assumptions (Hewitt-Taylor, 2002; De Lyser, 2001). Within this context, throughout the process of choosing the most appropriate research methodology and method for this study, the researcher’s positionality and potential bias were central. Q sort was identified as the most appropriate methodology that could answer the research questions while providing distance between myself and the participants to minimise my influence and allow the subjective viewpoints of participants to surface.

Notwithstanding the level of objectivity that Q methodology affords the researcher, the process of factor extraction and interpretation, as well as the interpretation of the qualitative data gathered from the study, may be influenced by the researcher’s own opinions, beliefs and positionality. Thus, in order to increase the researcher’s level of reflexivity during the process of factor interpretation and data analysis, I became a participant in this study and completed the Q sort exercise. This practice has been adopted by various Q sort researchers (e.g. Milton, 2016; Plummer, 2012). This afforded me the opportunity to record my own subjective viewpoint and reflect on my position in relation to the data as a whole. Such a process does not impact on the responses of the other participants and does not influence the findings, but could be compared in the same way as the viewpoints of the other participants.

Unluer (2012) points out difficulties in creating questions to which the insider-researcher already knows the answers. In this study, this was largely overcome through Q sort methodology. Since the Q sort statements were mainly generated through informal discussions with the participants they were representative of their beliefs and opinions. During the process of choosing and creating the Q sort, I was very vigilant to choose a representative sample of statements expressed by the participants. The creation of the questions for the informal discussion was based on my outlook to the study topic. The in-depth interview questions were generated from the findings of the Q sorts. My interest in exploring the participants’ view enabled me to generate a set of questions that also included questions to which I had my own ‘answers’.

Semi-structured interviews are potentially more prone to insider-researcher bias, as the researcher may make assumptions about the participants’ views and issues and refrain from seeking clarifications. Additionally, the participants may overestimate the information that the researcher could have about their views and experiences and may consequently overlook the importance of sharing certain information. Alternatively, they may not be completely honest about their opinions. In order to overcome these biases as much as possible, I adopted a preventive approach and collected data without prejudice as much as possible. De Lyser (2001) maintains that insider-researchers need to achieve a balance between their insider role and the role of a researcher, which may be difficult to separate sometimes. I tried to minimise this difficulty by explaining to the participants the difference between my dual role and encouraged them to focus on my researcher role during the interview. I emphasised to the participants that I was only interested in their opinions and that there were no right or wrong answers. I also encouraged the participants to share any information which they believed to be relevant even if they thought that I may hold a different view, or was already aware of such information. Corbin Dwyer and Buckle (2009) conclude that:

> …the core ingredient is not insider or outsider but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience (Cobin Dwyer and Buckle, 2009, p. 59).

3.15. Concluding remarks

This Chapter presented detailed information about the three data collection methods used that is, (i) the Q sorts and post-sorting interviews, (ii) the DLS Checklist and the (iii) in-depth semi-structured interviews. It also provided the rationale behind these choices and why such methods were beneficial for this type of study. This chapter presented the ethical considerations and discussed the researcher positionality and potential bias.

The following three chapters will present the findings of this study from the three data collection tools used namely, the Q sorts, the DLS checklist and the in-depth interviews, respectively.

CHAPTER 4

FINDINGS FROM THE Q SORTS

4.1. Introduction

This chapter starts with brief details of the participants and the Q sorts conducted. This is followed by an overview of the process of factor extraction and rotation chosen for factor analysis. The general findings from the Promoters and Barriers Q sort factor analysis are given, in addition to the method for factor interpretation. This is followed by some verbatim quotes from the participants loading on the relevant factors. Consensus and disagreement between factors are presented. Finally, a summary of the main promoters and barriers identified by each group is presented.

4.2 The participants

The participants were 9 young autistic people, their mothers (n= 9), their fathers (n= 7) and 9 professionals, including myself (the researcher), totalling to 34. Participants completed two Q sorts each, one on the Promoters of DLS and another on the Barriers of DLS. Participants were asked to rank 50 statements in each Q sort on a grid from -6 to +6, from least agreed with, to most agreed with. Following each Q sort, participants had a post-sorting interview (see Appendix 9 for the post-sorting questions) about their Q sorting experience and their underlying thoughts and views behind the placement of statements. Quotes from these interviews are included in each Factor interpretation to reveal the participants' rationale.

4.2. Factor analysis in context

The Promoters and Barriers Q sorts of the 34 participants were analysed separately through the PQMethod software. Each Q sort was entered into a computer program, where a numerical value was ascribed to each statement according to its position on the grid. Q sort analysis allows for an intercorrelation to take place, where each of the participants' Q sorts are compared to each other. Centroid Factor analysis (CFA), which is the preferred extraction method for Q methodologists (Watts and Stenner 2012), was chosen to look for repeated patterns in the data. Factor analysis identifies a group of Q sorts that have been sorted in a similar way, thus, identifying a group of participants who share a viewpoint. Through this intercorrelation, a correlation matrix is created from which a number of factors emerge. A number of criteria were used to guide my decision on the number of factors to be extracted and interpreted:

(i) An eigenvalue (EV) – which indicates the statistical strength of a Factor, greater than 1.00 (Brown, 1980)

(ii) A Factor should have at least two Q sorts that load significantly upon it (Watts and Stenner, 2005a)

(iii) A significant Factor loading based on the statistical calculation 2.58 x (1 ÷ √number of statements) (Brown, 1980; Watts and Stenner, 2012). Given that the number of statements was 50 in this study, this was calculated as 0.36. Thus, a Q sort with a Factor loading of 0.36 or above, was considered to be associated with that Factor. The higher the number the stronger the association.

Varimax was used as the process of factor rotation. This choice was guided by my decision to adopt an ‘abductive’ approach; to follow the data and let the participants’ viewpoints take the lead.

> Varimax is an excellent means of revealing the subject matter from viewpoints that almost everybody might recognise and consider to be of importance (Watts and Stenner, 2012, p. 126).

Different factor solutions were extracted starting from a 7 factor solution for both Promoters and Barriers to choose the factor solution that would bring out the best variety of viewpoints.

4.3. General findings from the Q sort factor analysis

Following preliminary interpretations of the factor solutions, a 4-factor solution for the Promoters and a 3-factor solution for the Barriers were considered the most meaningful solutions. Two of the Barriers factors were ‘bipolar’, meaning that each of these viewpoints had two opposing factor arrays. Every factor solution is represented by a factor array, which is ‘a single Q sort configured to represent the viewpoint of a particular factor’ (Watts and Stenner, 2012, p. 140).

4.3.1. Promoters factors

The four Promoters factors together explained 42% of the study variance, with the two dominant factors making up 29% of the variance (Factor 1: 16%; Factor 2: 13%). Factors 1 and 2 had eleven and seven participants respectively, who statistically exemplified these viewpoints. Factor 3 had four exemplifying Q sorts, while Factor 4 had three. In all, there were 25 exemplifying Q sorts, 4 confounded sorts (with statistically significant loadings on two factors) and 5 sorts that did not exemplify (that is, were not associated with) any of the factors. I (ProfF9) loaded significantly on Factor 1, which was the most dominant factor.

Table 9 below shows the participants and their factor loadings for the Promoters of DLS. The calculated statistical significance is 0.36. Every participant was assigned a code: YA: Young Adults; PM: Parent Mother; PF: Parent Father; ProfM: Professional Male; ProfF: Professional Female.

Table 9. Promoters - Four Factor Solution

Participant	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**
1. YA1	0.2020	0.2433	0.4973X	0.1851
2. YA2	-0.1192	0.5538	0.0262	0.4462
3. YA3	0.2396	-0.1030	0.3297	0.0271
4. YA4	-0.0122	-0.0580	0.0384	0.3153
5. YA5	0.1097	0.3060	0.1923	0.3716X
6. YA6	0.2205	-0.2134	-0.0886	0.0890
7. YA7	0.0054	-0.0026	0.0054	0.4917X
8. YA8	-0.0032	-0.1768	0.5604X	0.0838
9. YA9	0.7267X	0.2347	0.1521	-0.2835
10. PM1	0.1849	0.2741	0.5751X	0.2932
11. PM2	0.5528X	0.2067	0.2497	0.0753
12. PM3	0.3213	0.3779	0.0394	0.5118
13. PM4	0.5397X	0.1836	0.2760	0.1211
14. PM5	0.1746	0.5037	0.4713	0.0750
15. PM6	0.5741X	0.0264	0.3379	0.2658
16. PM7	0.3011	0.4723X	0.2874	0.0148
17. PM8	0.2971	0.3477	0.3091	0.3742X
18. PM9	0.3203	0.6941X	0.0830	0.0431
19. PF1	0.0582	0.0565	0.2911	-0.0152
20. PF2	0.4831X	0.2219	0.3239	-0.2547

21. PF3	0.1003	0.5086	0.4418	-0.1008
22. PF4	0.6928X	-0.0678	0.1913	0.0410
23. PF5	0.0922	0.0194	0.4457X	-0.0392
24. PF6	-0.0064	0.2271	0.3386	-0.3526
25. PF7	0.3110	0.6017X	0.1015	0.0828
26. ProfM1	0.6686X	0.3199	0.0451	0.1134
27. ProfM2	0.3139	0.4260X	-0.0216	-0.2157
28. ProfF3	0.3463	0.4279X	-0.1163	-0.0688
29. ProfF4	0.6325X	0.1791	0.0600	0.0166
30. ProfF5	0.2354	0.5540X	0.1609	-0.0392
31. ProfF6	0.5401X	0.2789	0.1018	-0.0074
32. ProfF7	0.6406X	0.2867	-0.0488	0.0898
33. ProfM8	0.1442	0.7899X	-0.1458	0.0812
34. ProfF9	0.7332X	0.2167	0.2879	0.0393
Variance	16%	13%	8%	5%
Eigenvalue	8	6.5	4	2.5
Total variance: 42%				

Gold: Q sorts with a significant loading on a factor

Blue: Confounding Q sort (with a significant loading on two factors)

Pink: Non-significant Q sorts (does not load on any factor)

Table 9 demonstrates that all professionals exemplified Factors 1 and 2, while there was no dominant factor amongst the other groups of participants. The young people exemplified Factors 1, 3 and 4. One young adult had a significant correlation with Factors 2 and 4, while another three young people did not exemplify any factor. However, of these three, participant YA3 had a strong association with Factor 3 (0.3297) and participant YA4 was inclined towards Factor 4 (0.3153). Mothers exemplified all four factors with two mothers loading significantly on two factors (refer to Table 9). Fathers exemplified Factors 1, 2 and 3 and one father loaded significantly on Factors 3 and 4. Another two fathers did not load on any factor with participant PF6 having a strong correlation with Factor 3 (0.3386).

Table 10 shows the extent to which Promoter factors intercorrelate with one another. A degree of overlap can be observed between the different factors, particularly between Factors 1 and 2. However, despite a correlation of 0.53, there is enough to distinguish them from each other, as shown in Section 4.5.

Table 10. Promoters – Correlation between factor scores

	Factor 1	**Factor 2**	**Factor 3**	**Factor 4**
Factor 1	1.0000	0.5271	0.3778	0.2938
Factor 2	0.5271	1.0000	0.2397	0.2938
Factor 3	0.3778	0.2397	1.0000	0.2999
Factor 4	0.2938	0.2938	0.2999	1.0000

4.3.2. Barrier factors

The three Barriers factors explained 26% of the study variance. Factor 1 was the most dominant factor with 13 participants statistically exemplifying this viewpoint. The other two factors were both ‘bipolar’ and had 4 exemplifying Q sorts each. In total there were 21 exemplifying sorts, 2 confounded sorts (with statistically significant loadings on two factors) and 11 sorts that did not exemplify any of the factors. I (ProfF9) loaded significantly on Factor 1, which was the most dominant factor.

Table 11 shows the participants and their factor loadings for the Barriers of DLS. The calculated statistical significance is 0.36.

Table 11. Barriers - Three Factor Solution

Participant	Factor 1	Factor 2	Factor 3
1. YA1	-0.0493	0.1809	0.3385
2. YA2	0.1231	-0.4832	-0.4035
3. YA3	0.1201	0.4294X	-0.0168
4. YA4	0.0373	-0.1770	-0.0556
5. YA5	0.0075	0.4794X	0.1191
6. YA6	-0.0038	0.2767	0.2777
7. YA7	0.4655X	-0.0292	-0.3315
8. YA8	0.1076	0.2551	0.2281
9. YA9	0.5522X	-0.1326	-0.1363
10. PM1	0.4846X	-0.1179	0.0140
11. PM2	0.0224	0.4055	0.7799
12. PM3	0.0012	-0.2001	0.0501
13. PM4	0.2023	0.1193	-0.4301X
14. PM5	0.4681X	0.2943	-0.0884
15. PM6	-0.1336	0.0540	0.5344X
16. PM7	0.1677	-0.0258	0.2792
17. PM8	0.2254	0.1117	-0.1435
18. PM9	0.6305X	0.2371	-0.2976
19. PF1	-0.1839	0.1383	0.4098X
20. PF2	0.4749X	0.1720	-0.1541
21. PF3	0.2904	0.2175	0.0513
22. PF4	0.6265X	-0.0946	0.0625
23. PF5	0.0552	0.2952	0.1363
24. PF6	-0.1182	0.0725	0.6763X
25. PF7	0.6576X	-0.0994	0.0523
26. ProfM1	0.4499X	-0.3011	-0.2502
27. ProfM2	0.1277	-0.4118X	-0.0203
28. ProfF3	0.3730X	-0.1608	-0.1264
29. ProfF4	0.1003	-0.4168X	0.1319
30. ProfF5	0.4858X	0.0041	-0.2995
31. ProfF6	0.2986	-0.0767	0.2062
32. ProfF7	0.4685X	-0.3201	0.0768
33. ProfM8	0.0116	-0.0779	0.3164
34. ProfF9	0.6664X	0.2132	0.1798

Variance	13%	6%	4%
Eigenvalue	6	3	4
Total variance: 26%			

Gold: Q sorts with a significant loading on a factor

Blue: Confounding Q sort (with a significant loading on two factors)

Pink: Non-significant Q sorts (does not load on any factor)

Table 11 shows that professionals exemplified Factors 1 and 2 with Factor 1 being the most dominant. Two professionals did not exemplify any factors, although participant Prof8 had an association with Factor 4 (0.3164). Young people also exemplified Factors 1 and 2, while one loaded significantly on Factors 2 and 3. Four did not exemplify any factor although participant YA1 had a strong association with Factor 3 (0.3385). Both mothers and fathers exemplified Factors 1 and 3 with one mother loading significantly on Factors 2 and 3. Three mothers and two fathers did not exemplify any factor.

Table 12 shows the extent to which the Barrier factors intercorrelate with one another. There are no statistically significant correlations between any of these factor arrays. It is noted that there is a very weak correlation of a 0.03 between Factors 2 and 3, and a -0.08 correlation between Factors 1 and 2. This indicates that these factors have next to nothing in common between them.

Table 12. Barriers – Correlation between factor scores

	Factor 1	**Factor 2**	**Factor 3**
Factor 1	1.0000	-0.0849	-0.2641

Factor 2	-0.0849	1.0000	0.0258
Factor 3	-0.2641	0.0258	1.0000

While section 4.3 gave an illustration of how participants loaded on the different factors, the following sections will explain what participants felt the main promoters and barriers were. A selection of their verbatim comments from the post-sorting interviews just after the Q sorts, will illustrate their views further.

4.4. Factor interpretation system used in this study

In Q methodology, participants rank order a set of items relative to one another. Therefore, a sound factor interpretation should consider, explain and interpret the complete configuration of items captured by each factor array. This entails that each item is to be considered to understand the whole configuration and the inter-relationship of the items. Watts and Stenner (2012, p. 148) argue that: ‘It is the viewpoints themselves, and the genuine desire to understand, that must be foremost throughout the interpretation process.’

For this purpose, the *crib sheet* system, developed by Watts in 2010 (Watts and Stenner, 2012) was chosen as a systematic and consistent method of factor interpretation. This involved working through the factor arrays to identify the following four categories, for each separate factor: (i) the three top ranked statements (+6, +5, +5), (ii) statements ranked higher than other factors, (iii) statements ranked lower than other factors, and (iv) the three bottom ranked statements (-6, -5, -5). The crib sheet for each factor consists of a list of statements that were identified according to these four categories. A detailed crib sheet for each factor can be found in Appendices 13 and 14.

This system allowed for the identification of those items that made the most important contribution within the relevant factor. This system involved what Watts and Stenner (2012, p. 155) describe as ‘the logic of abduction’ which includes going through the items, observing and devising the story each Factor is telling. Throughout this process, I observed the *clue* each item provided according to its ranking, and how items were connected with each other. During the second pass through the factor array, I looked for further items of potential importance that could clarify the account I had interpreted. By actively moving through the grid and reflecting on the potential clue of each item, I was able to build up a narrative for each factor, that could be corroborated by the quotes of participants loading on the relevant factors.

4.4.1. Factor interpretation: Promoters

The following factor narrative accounts were constructed by reference to the rankings and the entire configuration of statements in each factor exemplifying Q sort. The demographic details of the participants who loaded significantly on the relevant factor are given. The number and ranking of each statement that contributed to the overall composition of the narrative accounts are included in brackets. For example, (40: +6) indicates that the statement 40 was ranked at +6 (most agree) within the relevant factor array, and (49: -6) means that statement 49 was ranked at -6 (most disagree). The narrative accounts are supported by quotes of participants who loaded significantly on the particular factor, to give their personal views.

4.4.1.1. Factor 1

Parents should teach DLS despite challenges, while professional support is necessary. Emphasis on the passing of parents is a negative motivator that instils anxiety.

Factor 1 has an eigenvalue of 8.0 and explains 16% of the study variance. Eleven participants were significantly associated with this factor. Of the eleven exemplifying Q sorts for Factor 1, one was an autistic young adult, three were mothers, two were fathers, and five were professionals, including myself.

Table 13. Highest z-scores for Promoters Factor 1

No.	Statement	Z-score
40	…have parents who are determined to teach them DLS despite challenges	2.007
2	…have good professional support	1.755
14	…have parents who are ready to take calculated risks	1.308
33	…have parents who encourage them to help out with everyday DLS	1.287
21	…are surrounded by people who focus on their strengths and abilities	1.147

Table 14. Lowest z-scores for Promoters Factor 1

No.	Statement	Z-score
37	… aspire to be like their non-autistic peers	-1.527
36	… are helped to understand that as parents grow older they will have to depend on them less	-1.736
8	… are concerned about how others perceive them	-1.752
9	… live in families with open communication about the eventual passing of parents and the importance of learning DLS	-1.782
49	…are taught to ask a peer for assistance rather than an adult	-1.901

The participants who represented this viewpoint gave considerable weight to the role of the parents, and took the view that they should teach DLS to their autistic children despite challenges (40: +6). One mother explained:

> Good things don't come for free. If you believe that the child really needs to acquire a skill, you have to persist, despite the challenges and hardships (PM4).

They also believed that if parents were ready to take calculated risks (14: +5), if they encouraged their children to help out with everyday DLS (33: +4), and if they were consistent when teaching them DLS (20: +4), autistic young people were more likely to develop such skills.

The role of good professional support was also considered very important (02: +5). Importance was given mainly to the qualities of the people who support these young adults. They considered it necessary to be surrounded by people who believe in their abilities and skills (21: +4), and that they are taught by people who do not assume that these skills are common sense (35: +3). Clear step-by-step visual instructions were also considered an effective means to learn DLS (03: +2). Having regular opportunities to participate in age-appropriate DLS (39: +3) from a young age (45: +2) was considered more important than having transition planning and support when they reach adulthood (25: -1).

Those aspects given most priority by this viewpoint are summed up in a comment by one of the professionals:

> I believe that support by professionals and parents is essential. Otherwise, it can be counterproductive. They must also be exposed to opportunity to practise, mostly at home (ProfF4).

While participants valued the role of parents and professionals, they did not consider siblings and neurotypical peers influential. Therefore, being encouraged by siblings to learn DLS (47: -4), siblings' involvement in the everyday routine of household chores (11: -3), and peer influence and support to perform DLS independently (10: -3) were not considered effective strategies. Indeed, Factor 1 rated the statement *'…are taught to ask a peer for assistance rather than an adult'* the lowest (49: -6). A mother's reasons for rating these statements very low were:

> Asking peers for help requires making social approaches which may introduce other challenges for autistic children…while siblings and peers may be important in the acquisition of DLS, they are not a determining factor like parents and professionals (PM6).

Living in an inclusive society where people have positive attitudes towards autistic people, was not considered that important to develop DLS (29: 0). Neither was it important how others perceive them (08: -5). A father explained:

> I believe it's more important that they believe in themselves and not try to become someone else. They are better off accepting who they are and not depend on others' opinion (PF2).

The statement about parents growing old and eventually passing away (09: -5; 36: -4), was thought to "create anxiety" and be a "negative motivator", as one father described it (PF4). The professional who had an autistic son, explained that instilling confidence rather than fear was likely to be more effective:

> I feel that extra emphasis on the passing of parents can only instil fear in the individuals who might find it hard to plan long term. Confidence can be acquired through family and professional support (ProfF6).

A mother who gave the lowest ranking to this statement said:

> Teaching an autistic individual through fear and the impending “doom” of losing parents through death will result in an emotional fear-induced shut down, and the whole DLS learning will take on a negative form rather than be a positive calm experience (PM6).

4.4.1.2. Factor 2

Professionals are key stakeholders. Parents’ consistency and reassurance are essential. Generalisation of skills is fundamental.

Factor 2 has an eigenvalue of 6.5 and explains 13% of the study variance. Seven participants were significantly associated with this factor. These included four professionals, two mothers and one father.

Table 15. Highest z-scores for Promoters Factor 2

No.	Statement	Z-score
2	…have good professional support	2.327
20	…have parents who are consistent when teaching them DLS	1.483
38	…are given opportunities to practise learnt skills in different settings and circumstances	1.424
12	…are mentally ready to learn and perform such skill	1.393
7	…have educators who encourage independence	1.256

Table 16. Lowest z-scores for Promoters Factor 2

No	Statement	Z-score
1	…do not like other people to do things for them	-1.321

19	…have a special interest in the area of DLS	-1.411
8	…are concerned about how others perceive them	-1.572
49	…are taught to ask a peer for assistance rather than an adult	-1.946
41	…have sufficient money to support the development of DLS when money is needed	-2.185

Good professional support (02:+6) was highly valued, with this being the most approved (z-score = 2.327). Autistic people need educators who encourage them to be independent (07: +4). Professionals were considered key stakeholders to guide both the young adults and their parents.

Parents were thought to play an important role even if they did not seek to acquire knowledge about autism (43: -2). Families should be open about the eventual passing away of parents, and encourage their autistic young people to carry out basic daily living skills without help (09: +3; 44: +2). The acquisition of DLS could be achieved if parents are consistent when teaching DLS (20: +5), and if they offer their young people a lot of reassurance (24: +4). These could be effective especially if they are given opportunities to practise learnt skills in different settings and circumstances (38: +5).

Participants considered role play (05: 0) and regular observation of others performing DLS (15: +1) as more effective strategies than teaching by repetition (13: -3). However, being mentally ready to learn and perform such skill was thought to be a prerequisite (12: +4). A mother who ranked this statement very high said:

> Unless they are mentally ready for it, they will not succeed because it will be a bigger challenge (PM9).

Being surrounded by calm people who understand autism and do not give up on them (16: +1; 31: +1) is necessary. This should be accompanied by good transition planning and support as they reach adulthood (25: +4).

Having peer influence and support to perform DLS independently, was seen as potentially helpful (10: 0). There was no distinction made between peers and adults in terms of who they should approach for assistance (49: -5). Quotes from participants who rated this statement very low said:

> I believe peers and adults should have equal validity in this statement (ProfF5).

> They should ask for assistance that is available irrespective of whether it is a peer or an adult (PM9).

Other qualities, such as feeling confident to perform such skills (23: -3), having a special interest in the area of DLS (19: -4), and having a desire to become an independent adult were not considered as important in acquiring DLS (46: -4), but rather the result of having achieved such skills:

> At the beginning they might lack confidence. They need guidance to learn these skills, so they will get that confidence (PM9).

Being concerned how others perceive them (08: -5) was viewed as a “barrier that might cause stress” (Participant PM9), rather than a motivator to learn DLS.

Finally, the statement ranked lowest was *'have sufficient money to support the development of DLS when money is needed'* (z-score = -2.185). The following quote reflects others expressed by participants:

> Financial issues should not be considered a barrier to achieving DLS, since most skills may be taught with simple inexpensive means (ProfF5).

4.4.1.3. Factor 3

Collaboration between parents and professionals; both need to be knowledgeable about autism. Young people should have a desire to learn DLS.

Factor 3 has an eigenvalue of 4 and explains 8% of the study variance. Four participants were significantly associated with this factor. These were two young people, a mother and a father.

Table 17. Highest z-scores for Promoters Factor 3

No	Statement	Z-score
50	…have parents and educators who collaborate together	2.358
16	…are guided by people who understand autism	2.137
2	…have good professional support	2.118
46	…have a desire to become an independent adult	1.776
43	…have parents who seek to learn about autism	1.572

Table 18. Lowest z-scores for Promoters Factor 3

No	Statement	Z-score
26	…are taught in environments where they observe and imitate peers performing DLS	-1.300
28	…have a structured routine that they can follow	-1.541

5	…are taught through role play	-1.643
35	…are taught by ppl who don't assume that skills are common sense	-1.749
49	…are taught to ask a peer for assistance rather than an adult	-2.116

The roles of parents and educators were seen as mutually important, with collaboration between the two, being the most essential (50: +6). Being knowledgeable about autism makes both parents and professionals better equipped to guide young people towards independence (43: +4; 16: +5). A young adult explained:

> I feel that it is very important that people understand what it means to live with autism and how we see things, to be able to guide us towards independence…we might not follow the same paths as our peers but we can still get there (YA8).

DLS would be acquired if young people have good professional support and if they are given time to learn at their own pace (16: +5; 48: +4). According to these participants, they do not necessarily need to be surrounded by people who focus on their strengths and abilities (21: -3) or who are aware that such skills are not common sense (35: -5). They felt it was important that parents exposed them to different experiences in life and gave them a lot of reassurance throughout the learning process (06: +3; 24: +3).

The family's beliefs and habits were considered influential. Having siblings involved in the everyday routine of household chores (11: +3) and being helped to understand that as their parents grow old they can depend on them less (36: +2) were seen as potentially motivating forces. It follows that having a desire to become an independent adult may be closely tied to the achievement of DLS (46: +4). Thus, an aspiration to be like their non-autistic peers could be a promoter (37: 0) that may be developed while spending time with them (18: 0). However, observation and imitation of peers performing DLS was not considered as important as other factors in teaching DLS (26: -4).

Step-by-step visual instructions (03: -3), a structured routine to follow (28: -4), and parents' consistency when teaching DLS (20: -3) were not seen as important as other factors. One mother said:

> If they get used to the same routine they'll find any change difficult to adjust to. When he was young he was obsessed with routine and would protest if it changed…but I always tried to help him become more flexible (PM1).

Physical and verbal prompting (32: -2) and role play (05: -5) were also given low rating. Similarly, it was not considered important to encourage learning of age-appropriate DLS from a young age (45: -1). On the other hand, learning by repetition (13: +1) and having the opportunity to receive feedback during the process of learning DLS (42: 0) were viewed more important.

4.4.1.4. Factor 4

Living in an inclusive society and being surrounded by people who believe in them is important. Confidence is the key to the young people's performance.

Factor 4 has an eigenvalue of 2.5 and explains 5% of the study variance. Three participants were significantly associated with this factor. These included two young people and a mother.

Table 19. Highest z-scores for Promoters Factor 4

No	Statement	Z-score
21	…are surrounded by people who focus on their strengths and abilities	1.672
23	…feel confident to do such skills	1.669
31	…are surrounded by calm people who don't give up on them	1.523
41	…have sufficient money to support development of DLS when money is needed	1.451
29	…live in society where people have inclusive and positive attitudes to people with autism	1.311

Table 20. Lowest z-scores for Promoters Factor 4

No	Statement	Z-score
18	…spend time with non-autistic peers	-1.374
8	…are concerned about how others perceive them	-1.672
49	…are taught to ask a peer for assistance rather than an adult	-1.816
14	…have parents who are ready to take calculated risks	-2.174
1	…do not like other people to do things for them	-2.247

Those expressing this view considered the role of those surrounding autistic people as a significantly determining factor. It was seen very important to be surrounded by people who focused on their strengths and abilities, who are calm, and did not give up on them (21: +6; 31: +5). It follows that these characteristics are likely to instil confidence which was considered necessary for young people to perform DLS (23: +5). A young adult explained this link well:

> Confidence is very important to learn and to do things independently…and you gain confidence if you are surrounded by people who believe in you (YA5).

Such thought was extended to the importance of living in an inclusive society, characterised by positive attitudes towards autistic people (29: +4). The support of service providers and local authorities (34: +3) were considered necessary, including having good professional support (02: +3), teaching DLS as part of the school curriculum (17: +1) and providing transition planning and support when they reach adulthood (25: +3). To this end, money was considered important to be able to support the development of DLS (41: +4).

While it was believed that having parents knowledgeable about autism was necessary (43: +4), it was considered less important for parents to expose their young people to different experiences in life and to encourage them to help out with everyday DLS (06: -3; 33: -1; 44: -2). Additionally, young people’s eagerness to help out with everyday chores was not considered as a key effective promoter (04: -3), but having a structured routine could help (28: +1). More so, to have parents who are ready to take calculated risks was not considered high priority, but rather unsafe (14: -5). A young adult explained:

> I believe that people on the spectrum whose parents take risks, even if calculated, can possibly be dangerous for themselves or other people (YA7).

The role of siblings and peers was considered less influential. To have siblings involved in the everyday routine of household chores or to be encouraged by siblings to learn DLS (11: -4; 47: -1) were not rated as highly as others. Neither was it thought to be as beneficial as other factors to spend time with non-autistic peers and to ask a peer for assistance rather than an adult (18: -4; 49: -5).

The statement ranked lowest was *'do not like other people to do things for them'* (z score = -2.25). Participants believed that it was necessary to get help from others. One autistic young person said:

> Help from other people is very important to me as I feel less anxious if I don't know how to do something and ultimately, it helps me to learn more (YA5).

4.5. Comparisons between Promoter Factors 1 and 2

Given that there is a significant correlation between Factors 1 and 2, which are the two most dominant Promoter factors, this section discusses what distinguishes these viewpoints from each other and the potential similarities between them. The following tables demonstrate: (i) which statements are preferred by Factor 1 and not by Factor 2 (Table 21), (ii) which statements are favoured by Factor 2 and not by Factor 1 (Table 22) and, (iii) where there is a level of consensus across statements (Table 23).

Table 21. Descending array of differences between Factor 1 and Factor 2 – statements preferred by F1 and not by F2

Statement	F1 z-score	F2 z-score	Difference
…have a desire to become an independent adult	0.584	-1.233	1.817
…are given time to learn at their own pace	0.780	-1.011	1.791
… have regular opportunity to participate in age-appropriate DLS activities	1.086	-0.545	1.631
…have parents who are determined to teach them DLS despite challenges	2.007	0.552	1.455
… are taught by repetition	0.165	-1.109	1.273
… feel confident to do such skills	0.086	-1.122	1.208
… are given clear step-by-step visual instructions to follow	0.884	-0.323	1.207
… have parents who seek to learn about autism	0.516	-0.677	1.193

… do not like other people to do things for them	-0.227	-1.321	1.094
… have parents who encourage them to help out with everyday DLS	1.287	0.228	1.058
… are taught by people who don't assume that skills are common sense	0.981	0.111	0.869
… have sufficient money to support development of DLS when money is needed	-1.324	-2.185	0.861
… are taught DLS by physical & verbal prompting reducing gradually	0.053	-0.721	0.774
… have a special interest in the area of DLS	-0.644	-1.411	0.767
… are guided by people who understand autism	1.065	0.388	0.677
… learn DLS as part of their school curriculum	-0.401	-0.842	0.441
… are surrounded by calm people who don't give up on them	0.862	0.444	0.417
… have parents who are ready to take calculated risks	1.308	1.145	0.163

Table 21 shows that the main difference between these two viewpoints is that Factor 1 considers young people’s desire to become independent necessary for the development of DLS while Factor 2 does not.

Factor 1 suggests that being given time to learn at their own pace, and having regular opportunity to participate in age-appropriate DLS activities are likely to promote DLS, whereas Factor 2 does not consider these important.

Table 22. Descending array of differences between Factor 1 and Factor 2 – statements preferred by F2 and not by F1

Statement	**F 1 z-score**	**F 2 z-score**	**Difference**
… are given opportunity to practise learnt skills in different settings and circumstances	0.588	1.424	-0.836

… have siblings who support and accompany them when practising in the community	-1.010	-0.165	-0.845
… have peer influence and support to perform DLS independently	-1.077	-0.212	-0.865
… are mentally ready to learn and perform such skill	0.521	1.393	-0.872
… are taught through role play	-0.818	0.102	-0.921
… have siblings involved in everyday routine of household chores	-1.255	-0.317	-0.938
… are taught in environments where they observe and imitate peers performing DLS	-0.624	0.323	-0.947
… have regular opportunities to watch and observe others doing DLS	-0.588	0.501	-1.088
… have educators who encourage independence	0.012	1.256	-1.244
… are helped to understand that as parents grow old they will be able to depend on them less	-1.736	-0.273	-1.463
… have transition planning and support as they reach adulthood	-0.541	1.185	-1.725
… live in families with open communication about the passing of parents and the importance of learning DLS	-1.782	0.973	-2.755

Factor 2 considers living in families with open communication about the eventual passing of parents as a good promoter of DLS while Factor 1 disagrees, with a z-score difference of 2.755. Factor 2 also gives importance to transition planning and support as they reach adulthood while Factor 1 does not.

While Factor 1 prioritises the young people’s desire for independence, Factor 2 focuses more on their awareness for the need for DLS when parents are no longer able to support them. Moreover, Factor 2 gives importance to support in adulthood whereas Factor 1 prioritises opportunities for regular age-appropriate participation in DLS.

Table 23. Descending array of differences between Factor 1 and Factor 2 – statements rated similarly by F2 and not by F1

Statement	**F 1 z-score**	**F 2 z-score**	**Difference**
…are given important roles and chores within family to carry out daily	0.610	0.459	0.150
…have opportunity to receive feedback during process of learning DLS	-0.542	-0.648	0.106
…are encouraged from a young age to do age-app DLS independence	0.704	0.613	0.091
…are willing to help out with everyday chores	0.031	-0.053	0.085
…are taught to ask a peer for assistance rather than an adult	-1.901	-1.946	0.044
…are helped to understand the imp of DLS for independence	0.107	0.063	0.044
…are surrounded by ppl who focus on their strengths and abilities	1.147	1.126	0.021
…have parents who expose them to different experiences in life	0.892	0.872	0.020
…have a structured routine that they can follow	-0.221	-0.089	-0.132
…spend time with non-autistic peers	-1.066	-0.897	-0.169
…are concerned about how others perceive them	-1.752	-1.572	-0.180
…have parents who give them a lot of reassurance	0.807	1.097	-0.290
…have parents who are consistent when teaching them DLS	1.117	1.483	-0.365
…are given support of service providers and local authorities to achieve it	-0.194	0.224	-0.417
…live in society where people have an inclusive and positive attitude towards people with autism	0.168	0.652	-0.484
…are encouraged to carry out basic DLS without help	0.398	0.885	-0.487
…aspire to be like their non-autistic peers	-1.527	-1.030	-0.496
…are encouraged by siblings to learn DLS	-1.479	-0.951	-0.528
…have good professional support	1.755	2.327	-0.572
…have parents and educators who collaborate together	0.187	0.824	-0.637

Table 23 shows statements on which there is a level of agreement between Factors 1 and 2. Both factors gave high importance to good professional support, being surrounded by people who focus on their strengths and abilities, and having parents who are consistent in teaching them DLS. The same positive ranking was given to being encouraged from a young age to do DLS, and being given chores in the family. The same negative ranking was given to having opportunity to receive feedback during the learning process. Both factors *ranked 'helped to understand the importance of DLS'* and *'willing to help out with everyday chores'* neutrally. Moreover, both factors gave similar negative rankings to aspiring to be like their non-autistic peers and spending time with them.

4.6. Consensus and Disagreements between Promoter Factors

Table 24 shows that there were five consensus Promoter statements for this study. It details the z-score loading of these statements for each factor and how they were ranked on a factor array from -6 to +6. The rankings of these statements do not distinguish between the different factors, indicating that these were valued similarly by all the four Promoters factors.

Table 24. Consensus statements (do not distinguish between any pair of factors)

All listed statements are non-significant at P>.01, and those flagged with an * are also non-significant at P>.05

		F1	**F2**	**F3**	**F4**
No.	Statement	Rank z-scr	Rank z-scr	Rank z-scr	Rank z-scr
8*	…are concerned about how others perceive them	-5 -1.75	-5 -1.57	-4 -1.27	-4 -1.67
22*	…are given important roles and chores within the family to carry out daily	1 0.61	1 0.46	1 0.23	1 0.58
24*	…have parents who give them a lot of reassurance	2 0.81	3 1.10	3 0.88	1 0.51
42	…have opportunities to receive feedback during the process of learning DLS	-1 -0.54	-1 -0.65	0 0.08	-1 -0.29
49*	…are taught to ask a peer for assistance rather than an adult	-6 -1.90	-5 -1.95	-6 -2.12	-5 -1.82

The statements that were given a similar positive ranking indicate that all factors agreed that, parents' reassurance is important, and that young people should be given roles and chores within the family, although this was not of key importance to any of the factors. The shared negative rankings suggest that many participants believed that peer assistance and a concern about how others perceive them are not essential for the development of DLS, with all the factors ranking these statements very negatively.

Table 25. Ascending array of disagreement statements across all factors

		F1	F2	F3	F4
No.	**Statement**	**Rank z-scr**	**Rank z-scr**	**Rank z-scr**	**Rank z-scr**
35	…are taught by people who don't assume that skills are common sense	3 0.981	0 0.111	-5 -1.749	2 0.586
46	…have a desire to become an independent adult	1 0.584	-4 -1.233	4 1.776	0 -0.217
20	…have parents who are consistent when teaching them DLS	4 1.117	5 1.483	-3 -1.231	-1 -0.435
14	… have parents who are ready to take calculated risks	5 1.308	3 1.145	1 0.134	-5 -2.174
41	… have sufficient money to support development of DLS when money is needed	-3 -1.324	-6 -2.185	1 0.339	4 1.451

Table 25 shows the five statements which varied most in the ranking they were given by the different factors. The greatest level of disagreement was on whether money is needed to support the development of DLS. This was considered of no importance by Factor 2, was also negatively ranked by Factor 1, but positively ranked by Factors 3 and 4. The need for parents to take calculated risks was considered a priority by Factor 1 and of importance by Factors 2 and 3, but was ranked very negatively by Factor 4. The following quotes show how the views of participants differed about this statement:

> Parents can make or break the process of achieving independence. If they are unable to ease their protective instincts over their children, it may tamper the acquisition of DLS (Prof5, who exemplified F2).

> I don't think it's good for parents to take risks because their children can get hurt or end up in trouble (YA5, who exemplified F4).

To have parents who are consistent when teaching DLS was ranked positively by Factor 1 and 2 and negatively by the others. Statements 46 and 35 also drew a wide variety of responses, ranging between very positive, very negative and neutral.

4.7. Factor interpretation: Barriers

As with the Promoters, the demographic details of the participants who loaded significantly on the relevant factor are given. The rankings of those statements that contributed to the complete narrative accounts are included in brackets. For example, (16: +6) indicates that the statement 16 was ranked at +6 position (most agree) within the relevant factor array, and (12: -6) means that statement 12 was ranked at -6 position (most disagree). The narrative accounts are supported by comments of participants who loaded significantly on the particular factor, to clarify the interpretation and bring out the participants' thoughts and feelings.

4.7.1. Factor 1

Barriers may mostly result from parents' beliefs, attitudes and fears. DLS are not being taught through direct teaching.

Factor 1 has an eigenvalue of 6 and explains 12% of the study variance. Thirteen participants were significantly associated with this factor. There were two young people, three mothers, three fathers and five professionals, including myself.

Table 26. Highest z-scores for Barriers Factor 1

No	Statement	Z-score
16	…have parents who give importance to academic skills rather than DLS	2.086
2	…are not encouraged by parents to perform DLS	1.949
35	…have parents who are scared to enable them to become independent	1.912
8	…are unable to cope when something out of the ordinary routine happens	1.740
10	…have parents who worry about people's reaction and judgment of unusual behaviour in the community	1.364

Table 27. Lowest z-scores for Barriers Factor 1

No	Statement	Z-score
43	…do not take the initiative to perform DLS	-1.358
6	…are clumsy or poorly coordinated	-1.448
47	…do not aspire to live independently	-1.544
28	…spend a lot of their free time on ipads, iphones or gaming	-1.738
12	…have a lot of commitments (work, intervention, sports)	-1.800

The participants who shared this viewpoint put considerable weight on the parents. They took the view that barriers mostly result from parents' beliefs, attitudes and fears. One professional said:

> Parents are crucial in a child's development, and parents' fears many times hinder a child's (and young adult's) independence (ProfF3).

Participants with this viewpoint believed that young people did not lack awareness of risks and consequences of DLS at home or in the community (40: -2; 45:-3). Yet parents may choose a cautious approach and refrain from encouraging their children to perform DLS as they experience fear in enabling them to become independent (02:

+5; 35: +5). Parents' worries about people's reactions and judgements (10: +4) and fear of being bullied or exploited (46: +1) were considered as main obstacles to acquiring community DLS. A young adult said:

> Parents need to take risks and have faith in their children. They should teach them the necessary skills instead of expecting their child to take interest (YA9).

These participants extended this 'parent barrier' beyond fear. Parents may be too busy with other commitments (25: +3). It was also regarded of great hindrance to have parents with low expectations for their young adult (30: +4). Similarly, when parents do not accept their child's condition (20: +3) and if they believe that DLS may still be acquired without training (41: +2) were considered impeding. Thus, there may be no family discussions about the importance of learning DLS (23: 0). A young adult explained:

> I believe that it can be very challenging for people with autism to pursue DLS if they come from families who don't discuss the importance of DLS. Furthermore these people should be encouraged by their parents to do DLS primarily, rather than giving importance to academic skills (YA7).

Participants took the view that the greatest barrier is when parents give importance to academic skills rather than DLS (16: +6) (z score = 2.086). A mother said:

> A lot of parents assume that everything is fine as long as their child is getting good grades at school (PM9).

Similar views were voiced by professionals:

> I think the greatest barrier is that a lot of importance is given to academic skills, and we are thus lacking direct teaching of DLS. I feel that there is this belief that such skills can be achieved automatically (ProfM1).

Young people may be lacking “basic and fundamental” (PF4) opportunities to learn DLS, and are not taught such skills directly (32: +3; 18:+3). Moreover, they are likely to develop dependence on adults who support them (17: +2), especially when they have educators who lack autism knowledge and give too much assistance (38: +1; 04: 0).

While participants believed that anxiety may hinder young people from acquiring DLS (19: +2), they did not think they were comfortable with everything being done for them (14: -2). Neither were autistic young people believed to forget DLS if not done regularly (33: -3). Moreover, taking longer to learn DLS was not considered an obstruction (22: -3), as one mother pointed out:

> No matter how long it takes, with perseverance and encouragement they’ll get there (PM9).

Being clumsy or poorly coordinated (06: -4), and having fine motor difficulties(34: -4), were not considered an important barrier. The idea of getting lost in their own thoughts (26: -2), losing attention on task easily (11: -1) and not having enough patience to learn a new skill (01: -3), was contested. Rather participants thought otherwise:

> Experience has indicated that many autistic adults can indeed be very persistent in learning DLS (ProfM1).

This viewpoint also gave a low ranking to the statement '*Do not take the initiative to perform DLS'* (43: -4). A Speech and Language Pathologist explained:

> The individual's own initiative should not be expected in the beginning, but rather work should be focused to nurture such initiative when the need arises (ProfF5).

Young people's commitments and free time spent on iPads, iPhones and gaming were not seen as a barrier to DLS and were indeed given the lowest rankings (12: -6; 28; -5). Moreover, participants opposed the idea that young people do not aspire to live independently (47: -5) or that one's desire or lack of it is a determining factor:

> The desire and need to acquire independence needs to be nurtured and not assumed to be a deciding factor for the acquisition of DLS (ProfF5).

> From my experience, most young people do aspire to live independently but they are not given enough opportunities and empowerment to voice their wishes. It is almost taken for granted that they have no aspirations, or even worse, their aspirations are put down (ProfF9).

4.7.2. Barriers Factor 2

Factor 2 has four significantly loading participants. It explains 6% of the study variance and has an eigenvalue of 3.

Factor 2 is a 'bipolar' factor where participants loading on this factor expressed opposite viewpoints. Each viewpoint has a factor array that is a 'mirror image' (Watts and Stenner, 2012, p. 165) of the other. Two young people loaded on the positive pole of this factor while two professionals loaded on the reverse pole. Therefore, what the young people view as most hindering to acquire DLS, the professionals consider as least impeding, and vice versa. Therefore, two narrative accounts will be presented for factor 2.

4.7.2.1. Barriers Factor 2+

Fear, anxiety, anger and frustration when we fail at DLS are great barriers. No opportunities to discuss our wishes. Society's negative attitudes are impeding.

Table 28. Highest z-scores for Barriers Factor 2+

No	Statement	Z-score
27	…scared of doing something wrong	2.700
7	… are influenced by negative attitudes from people in society	2.074
13	…experience anger and frustration when they fail to do DLS well	1.804
48	…find it difficult to plan ahead	1.695
31	…find it difficult to understand abstract things	1.627

Table 29. Lowest z-score for Barriers Factor 2+

No	Statement	Z-score
2	…are not encouraged by parents to perform DLS	-1.395
36	…do not feel confident to perform DLS independently	-1.423
20	…have parents who do not accept their child's condition	-1.497
24	…are not interested in performing DLS	-1.817
3	…do not feel the need to learn DLS	-1.901

The young people loading on this factor took the view that the key barriers derive from their own fear of doing something wrong and their experienced anger and frustration when they fail to perform DLS well (27: +6; 13: +5). One young adult explained:

> I feel scared of doing something wrong as it could get me in trouble, especially if I have to fill in some documents like bank papers…and even if I don't get in trouble, my mind keeps on bringing it up and I find it hard to get rid of such thoughts (YA3).

Thoughts and experiences could lead to a lot of anxiety (19:+3) and they may find comfort in having things done for them (14:+2). Participants disagreed with the idea that they are not interested in performing DLS or that they do not feel the need to learn DLS (24: -5; 03: -6), and gave these statements the lowest ranking. They also did not believe that they are not confident enough to perform DLS or that they lack opportunities to learn them (36: -4; 32: -3).

> I enjoy learning many of these skills and I think I am also very good at some, like cleaning the house and doing the laundry (YA3).

The young people believed that their difficulty to plan ahead and to understand abstract things hindered their independence significantly (48: +4; 31: +4). However, they did not agree they found it difficult to transfer taught DLS to everyday situations (50: -2) or to plan and organise steps to carry out DLS (42: -1). They considered their tendency to be clumsy and poorly coordinated (06: +2), to lose their attention on task easily (09:+1), and fine motor skills difficulties (34: 0) as potential barriers. Being unable to cope when something out of the ordinary happens, and a difficulty to adapt to different circumstances, (08: +1; 29: 0) were also regarded as potentially impeding.

Those holding this viewpoint believed that young people are influenced by the negative attitudes of people in society (07: +5). They also live in an age when life is hectic and families lack time to teach DLS (39: +4). Young people may also lack opportunities to discuss their wishes about developing DLS (09: +3). One of the young adults pointed out:

> Sometimes parents let their children do what they want as long as they are quiet because parents would be busy. The children often end up getting lost in their own thoughts…I can relate (YA5).

These participants believed that when parents give more importance to academic skills than DLS (16: +3), they pose a barrier to the development of DLS. These participants disagreed with the idea that parents do not encourage their children to perform DLS (02: -4) or that they do not discuss their importance (23: -3). They also disagreed with the idea that parents may not accept their child's condition (20: -5). A young adult said:

> I believe most parents accept their children's condition, they care for them and do tell them about the importance of learning DLS (YA3).

4.7.2.2. Barriers Factor 2-

The key barriers to DLS arise from the young people's lack of perceived interest and need to perform DLS and their parents' failure to accept their condition and to encourage them to perform DLS.

Factor 2- represents the viewpoint of two professionals, which is a complete reversal of the arrangement of statements characteristic of 2+, as expressed by two young people.

Table 30. Highest z-scores for Barriers Factor 2-

No	Statement	Z-score
3	…do not feel the need to learn DLS	1.901

24	…are not interested in performing DLS	1.817
20	…have parents who do not accept their child's condition	1.497
36	…do not feel confident to perform DLS independently	1.423
2	…are not encouraged by parents to perform DLS	1.395

Table 31. Lowest z-scores for Barriers Factor 2-

No	Statement	Z-score
31	…find it difficult to understand abstract things	-1.627
48	…find it difficult to plan ahead	-1.695
13	…experience anger and frustration when they fail to do DLS well	-1.804
7	… are influenced by negative attitudes from people in society	-2.074
27	…scared of doing something wrong	-2.700

The professionals who shared this viewpoint believed that the key barriers to DLS arise from educators, parents and the young people themselves. A quote from one of the professionals clearly states this:

> Parents, educators and the young people themselves can be the greatest barriers for independent functioning (ProfM2).

According to this viewpoint, the greatest barriers are the young people's lack of perceived need and interest to learn and perform DLS (03:+6; 24:+5), accompanied by a feeling of insecurity to do DLS independently (36: +4). This insecurity is in no way related to a fear of doing something wrong (27: -6). Neither is it generated by the negative attitudes of people in society (07: -5). Moreover, it was not believed that young people experience anger and frustration when they fail to do DLS well (13: -5).

The professionals did not consider the difficulty to understand abstract things (31: -4) or to plan ahead as barriers (48: -4). They also gave a low ranking to the statement *'Experience a lot of anxiety'* (19: -3). Moreover, being clumsy and poorly coordinated (06: -2), losing attention on task (11: -1), and having fine motor skills difficulties (34: 0) were not considered very impeding. However, young people may find it difficult to transfer taught skills to everyday situations (50: +2), to plan and organise steps to carry out DLS (42: +1), and to adapt to different circumstances (29: 0).

Furthermore, parents may fail to accept their child's condition (20: +5). They may not discuss the importance of DLS or encourage them to perform DLS (23: +3; 02: +4). These professionals did not believe that this was due to a hectic lifestyle that families have (39: -4). Neither did they think that parents prioritised academic skills over DLS (16:+3). According to this viewpoint, parents may not worry as much about their young people being bullied or exploited (46: -3). However, they tend to worry more about people's reaction and judgement of their young people's unusual behaviour in the community (10: +1). Thus, young people may lack opportunities to learn DLS (32: +3). Subsequently, they may develop a dependency on those adults who support them (17: +2). This could be more so if they have educators who give too much assistance (04: +2). One of the professionals remarked:

> Overdependency promoted by parents and educators kills the young people's interest (ProfF4).

4.7.3. Barriers Factor 3

Factor 3 has an eigenvalue of 4 and explains 8% of the study variance. Four participants were significantly associated with this factor. These were two mothers and two fathers. Factor 3 is also a bipolar factor. Three participants loaded on the positive pole of this factor while a mother loaded on the reverse pole. Thus, two narrative accounts will be presented for Factor 3.

4.7.3.1. Barriers Factor 3+

Barriers stem from the young people's difficulties in decision-making, organisational and flexibility skills, along with uncertainty about their abilities and a lot of anxiety.

Table 32. Highest z-scores for Barriers Factor 3+

No	Statement	Z-score
37	…find it difficult to take decisions about everyday things	1.797
8	…are unable to cope when something out of ordinary routine happens	1.683
42	…find it difficult to plan and organise steps of carrying out DLS in everyday life	1.354
44	…experience uncertainty and fear about their abilities to do DLS	1.346
50	…find it difficult to transfer taught DLS to everyday situations	1.098

Table 33. Lowest z-scores for Barriers Factor 3+

No	Statement	Z-score
20	…have parents who do not accept their child's condition	-1.679
41	…have parents who believe that without training their son will still be able to develop DLS	-1.771
30	…have parents with low expectations of them	-2.211
15	…meet professionals and educators with low expectations for them	-2.290

16	…have parents who give importance to academic skills rather than DLS	-2.384

Participants loading on this factor took the view that key barriers stem from the young people’s difficulties in decision-making, organisational and flexibility skills. These parents believed that young people have difficulty in planning and organising the steps to carry out DLS in everyday life (42: +5), accompanied by a difficulty to transfer taught skills to daily situations (50: +4). Young people are unable to cope when something out of the ordinary happens (08: +5), as they find it hard to adapt to different circumstances (29: +4). Moreover, they experience a lot of uncertainty and fear about their abilities to do DLS (44: +4), along with a lot of anxiety (19: +3) and lack of confidence (36: +2). A mother who ranked these statements very high remarked:

> Anxiety is like a mental prison. It gets in the way of reality, all new experiences and learning, and therefore everything gets that much harder…same thing with lack of confidence and fear (PM6).

This is likely to make it difficult for young people to take decisions about everyday things (37: +6). This mother continued to observe that: “…the fear, anxiety, lack of self-confidence, and overthinking snowball effect gets in the way of decision-making” (PM6).

Therefore, they do not take the initiative to perform DLS (43: +3) and may not aspire to live independently or feel the need to learn DLS (47: +1; 03: +1). They would need a lot of prompts for reassurance to learn DLS (05: 0) and may take a long time to learn them (22: +1). Young people may also lack awareness of consequences to do household chores independently (40: +1). These participants all of whom were parents, did not believe that parents presented their young people with barriers. To have parents who give importance to academic skills rather than DLS was given the lowest ranking (16: -6) (z-score = -2.384). A father stated his opinion clearly:

> Quite the opposite. Quality of life – physical and mental wellbeing, and finding perhaps a simple uncomplicated life and work balance, and doing what he enjoys, are the best and happiest outcomes (PF6).

They disagreed with the idea that parents believe that without training their young people will still be able to learn DLS (41: -4). To have parents busy with other commitments was not regarded as hindering (25: -4) and the idea that families lack time to teach DLS due to a hectic lifestyle was not considered important (39: -2). Additionally, parents were not thought to have low expectations for their young people (30: -5).

According to these participants, barriers did not arise from parents who are scared to enable their young people’s independence (35: -2) or who worry about their lack of sense of danger (49: -1). Moreover, it was not believed that they lack opportunities to discuss their wishes about DLS (09: -2) or that they are not taught how to do DLS directly (18: -2). Having a poor sense of danger and being scared of doing something wrong were not viewed as a barrier (21: -1; 27: -1). Moreover, these participants did not believe that the young people meet professionals and educators with low expectations of them (15: -5). A mother remarked:

> The professionals we have assisting us feel the opposite and tell him so and gently are challenging him in the right direction (PM6).

4.7.3.2. Factor 3-

Barriers arise from the low expectations of parents, professionals and educators. Parents may be too busy with other commitments and give importance to academic skills rather than DLS

Factor 3- represents the viewpoint of one mother, which is a complete reversal of the view expressed in Factor 3+.

Table 34. Highest z-scores for Barriers Factor 3-

No	Statement	Z-score
16	…have parents who give importance to academic skills rather than DLS	2.384
15	…meet professionals and educators with low expectations for them	2.290
30	…have parents with low expectations of them	2.211
41	…have parents who believe that without training their son will still be able to develop DLS	1.771
20	…have parents who do not accept their child's condition	1.679

Table 35. Lowest z-scores for Barriers Factor 3-

No	Statement	Z-score
50	…find it difficult to transfer taught DLS to everyday situations	-1.098
44	…experience uncertainty and fear about their abilities to do DLS	-1.346
42	…find it difficult to plan and organise steps of carrying out DLS in everyday life	-1.354
8	…are unable to cope when something out of ordinary routine happens	-1.683
37	…find it difficult to take decisions about everyday things	-1.797

This mother believed that the main barriers were the low expectations of parents, professionals and educators (30: +5; 15: +5). Additionally, parents, who are also very busy with other commitments (25: +4), and give importance to academic skills rather than DLS (16: +6). She remarked:

> Many parents give too much importance to academic skills and no DLS will be learnt along the way, and it is the DLS that will see the individual throughout his life (PM4).

4.8. Consensus and Disagreements between Barrier Factors

Table 36 shows that there were five consensus Barriers statements identified. It details the z-score loading of these statements for each factor and how they were ranked on a factor array from -6 to +6. The rankings of these statements do not distinguish between the different factors, indicating that these were valued similarly by the following three Barriers factors.

Table 36. Consensus statements (do not distinguish between any pair of factors)

All listed statements are non-significant at P>.01, and those flagged with an * are also non-significant at P>.05

		F1	**F2+**	**F3+**
No.	**Statement**	**Rank z-scr**	**Rank z-scr**	**Rank z-scr**
4*	…have educators who give too much assistance	0 -0.25	-2 -0.71	-1 -0.28
5*	…need a lot of prompts for reassurance to perform DLS	-1 -0.30	-1 -0.31	0 0.22
19*	…experience a lot of anxiety	2 0.63	3 0.75	3 0.90
21*	… have a poor sense of danger	0 0.02	0 0.03	-1 -0.25
46	… have parents who worry about them being bullied/exploited in the community	1 0.41	3 0.83	3 1.06

The statements that were given a similar positive ranking suggest that all three factors listed in the table above agreed that two main barriers are the young people's anxiety and their parents' fear of their son being bullied or exploited in the community. However, since Factors 2 and 3 are bipolar, Factors 2- and 3- represent a direct opposite viewpoint of that created for the positive ones shown in Table 36. This suggests that statements 19 and 46 were given the same negative ranking of -3 by Factors 2- and 3-, thus indicating a disagreement with the other factors. On the other hand, the need for prompts, educators' excessive assistance and having a poor sense of danger were not considered as key barriers by the factors listed in the table above and were ranked somewhat neutrally or slightly negatively. Factors 2- and 3- ranked these statements slightly positively (+1), with the highest positive ranking of +2 given to statement 4 by Factor 2-. This indicates only a slight disagreement between Factors 2- and 3-, and the factors listed in Table 36.

Table 37. Ascending array of disagreement statements across all factors

		F1	**F2+**	**F2-**	**F3+**	**F3-**
No.	**Statement**	**Rank/ z-score**	**Rank/ z-score**	**Rank/ z-score**	**Rank/ z-score**	**Rank/ z-score**
7	…are influenced by the negative attitudes of people in society	-1 -0.489	5 2.074	-5 -2.074	-3 -0.853	3 0.853
20	…have parents who do not accept their child's condition	3 1.314	-5 -1.497	5 1.497	-4 -1.679	4 1.679
2	…are not encouraged by parents to perform DLS	5 1.949	-4 -1.395	4 1.395	-1 -0.100	1 0.100
30	… have parents with low expectations of them	4 1.329	-3 -1.031	3 1.031	-5 -2.211	5 2.211

16	… have parents who give importance to academic skills rather than DLS	6 2.086	3 0.836	3- -0.836	-6 -2.384	6 2.384

Table 37 shows the five Barriers statements that were ranked most variably by the different factors. Four of these statements focus on parents' attitudes and beliefs. Statement 16 produced the widest variety of responses. The rankings suggest that parents' importance to academic skills rather than DLS was considered a big barrier by Factors 1 and 3-, and impeding by Factor 2+. On the other hand, this statement was given a very negative ranking by Factor 3+ alongside a negative ranking by F2-, indicating that this was not considered a barrier by the participants exemplifying these factors.

Responses to statements 30, 2, and 20 were also varied, indicating conflict across the different factors about barriers arising from parents' level of acceptance of their child's autism, their expectations for their children and how much they encourage independence. These were considered hindering at different rankings by Factors 1, 2- and 3-, while deemed not impeding by Factors 2+ and 3+. Society's negative attitudes were considered a barrier mostly by Factors 2+ and also by Factor 3-, contrasted with the slightly negative ranking of Factor 1, the negative ranking of Factor 3+ and the very negative ranking of Factor 2-.

4.9. Summary of Q sorts key findings

Thirty-four participants from four stakeholder groups, namely young people (n=9), their mothers (n=9), their fathers (n=7) and professionals (n=9) completed two Q sorts, one about the Promoters and another one about the Barriers of DLS. Each Q sort consisted of 50 statements, which participants had to rank order on a grid from -6 to +6.

In all, 7 factors were extracted, four for the Promoters and 3 for the Barriers, two of which were bipolar. For the Promoters Q sort, of the 34 participants, 25 exemplified a factor, while 4 loaded on two factors and 5 did not exemplify any of the factors. For the Barriers, 21 exemplified a factor, 2 loaded on two factors, while 11 participants did not exemplify any of the factors.

4.9.1. Promoters

The four distinct views for the Promoters of DLS were:

Factor 1: Parents should teach DLS despite challenges, while professional support is necessary.

Factor 2: Professionals are key stakeholders. Parents’ consistency and reassurance are essential. Generalisation of skills is fundamental.

Factor 3: Collaboration between parents and professionals is important; both need to be knowledgeable about autism. Young people should have a desire to learn DLS.

Factor 4: Living in an inclusive society and being surrounded by people who believe in them is important. Confidence is the key to the young people's performance.

Factor 1 was the most dominant factor identified by professionals, followed closely by Factor 2. All professionals exemplified either one of these factors. Clearly, professionals valued parents' reassurance and consistency in teaching DLS while acknowledging challenges. They also thought that good professional support was important. Some professionals also gave importance to opportunities that facilitated skill generalisation.

Factor 1 was also the most popular factor among mothers, followed by Factor 2. However, the mother's correlation with these two factors was weaker than that of the professionals. Two other mothers, PM1 and PM8 exemplified Factor 3 and Factor 4 respectively, while PM3 exemplified Factors 3 and 4 and PM5 exemplified Factors 2 and 3. This indicates a wider diversity of views among mothers.

Similarly, fathers as a cohort were not confined to a particular view. Although Factor 1 was preferred by two fathers, a father exemplified Factor 3 and another one Factor 4, PF3 exemplified both Factors 2 and 3, while another two fathers (PF1 and PF6) did not load on any factor.

The most popular views among the young people were Factors 3 and 4. This indicates that young people gave importance primarily to being surrounded by people who understand and believe in them. They also thought that their own desires and confidence play an important role in their learning and performance of DLS. Only one young adult (YA9) exemplified Factor 1. YA2 loaded on both Factors 2 and 4, while three young people did not exemplify any factor.

4.9.2. Barriers

The distinct views for the Barriers of DLS were:

Factor 1: Barriers may mostly result from parents' beliefs, attitudes and fears. DLS are not being taught through direct teaching.

Factor 2+: Young people's fear, anxiety, anger and frustration when they fail at DLS are great barriers. They lack opportunities to discuss their wishes. Society's negative attitudes are impeding.

Factor 2-: The key barriers to DLS arise from the young people's lack of perceived interest and need to perform DLS, and their parents' failure to accept their condition and to encourage them to perform DLS.

Factor 3+: Barriers stem from the young people's difficulties in decision-making, organisational and flexibility skills, along with uncertainty about their abilities and a lot of anxiety.

Factor 3-: Barriers arise from the low expectations of parents, professionals and educators. Parents may be too busy with other commitments and give importance to academic skills rather than DLS.

The most popular view among professionals was Factor 1. These professionals thought that parents' fears and worry about people's judgements and bullying, may discourage them from enabling their son's independence. Two professionals who exemplified Factor 2-, considered the young people's lack of interest in DLS and their parents' lack of encouragement as barriers. Another two professionals (ProfF6 and ProfM8) did not exemplify any factor.

Similar to the professionals, Factor 1 was also the most popular view among mothers and fathers, although less participants from these two groups loaded on this factor. Two fathers and one mother exemplified Factor 3+, and viewed the young people's difficulty to cope with out of the ordinary situations, their lack of confidence and high anxiety as main barriers. One mother thought that low expectations of parents, and educators are main barriers (Factor 3-) while another mother loaded on both Factor 2 and 3+. Three mothers and two fathers did not exemplify any factor.

Factors 1 and 2+ were equally preferred by young people, who thought that the main barriers are their parents' fears, as well as their own, along with high anxiety and society's negative attitudes. One participant loaded on Factors 2- and 3-, while another four young people did not exemplify any factor.

CHAPTER 5

DAILY LIVING SKILLS THAT WERE PRIORITISED BY PARTICIPANTS ON THE DLS CHECKLIST

5.1. Introduction

Thirty-four participants from the four stakeholder groups: autistic young people (n=9), their mothers (n=9), their fathers (n=7) and professionals (n=9) were given a list of 50 DLS (see Appendix 11) before starting the Q sorts. The DLS pertained to personal hygiene and appearance, health care, cooking, housekeeping, caring for clothes, money, budgeting and travelling. Participants were asked to rate each DLS as *high* or *low* priority according to how important they thought each skill was. Following this rating, participants were asked to choose the five *most important* and the five *least important* DLS from the list.

The data were analysed to identify *High Priority* (HP) and *Low Priority* (LP) DLS for the different participant groups. Following this procedure, data were further analysed to reveal any similarities and differences between the four participant groups.

5.2. Consensus across the groups

This section discusses the consensus on HP and LP DLS across the four groups.

5.2.1. Young people’s views on High and Low priority DLS

Table 38 shows that there were four DLS which all nine young people rated as HP.

Table 38. High priority DLS as rated by the young people

1.	Understand the importance of keeping windows and doors locked particularly when not at home and during the night
2.	Acknowledge the importance of personal hygiene and maintaining a neat appearance
3.	Understand the importance of saving and budgeting
4.	Know what to do if he takes a wrong bus or stops at the wrong bus stop

However, the young people's views on LP DLS varied and there were no DLS that were given a *'low priority'* rating by all the young people. There were three DLS rated as LP by at least 5 young people. These were: (i) '*be able to drive own car and go to places'*, (ii) '*know how to handle incidents with other drivers when driving own car'*, and (ii) '*care for minor cut/minor burn'*.

5.2.2. Mothers' views on *High* and *Low* priority DLS

Table 39 shows that there were twelve DLS that were rated HP by all the mothers. Four were related to money and budgeting, three to personal hygiene and appearance, two to health care, and three to safety at home and on the street.

Table 39. High priority DLS rated by the mothers

1.	Shower or bathe regularly
2.	Shave and care for skin
3.	Brush teeth regularly and maintain oral hygiene
4.	Acknowledge the need to see a doctor/therapist
5.	Responds to questions from the doctor or therapist to support them in reaching diagnosis of symptoms
6.	Use kitchen appliances safely
7.	Recognise household dangers
8.	Understand the value of money

9.	Understand safety measures related to credit cards
10.	Make a purchase from shops and calculate the change
11.	Understand the concept and importance of saving and budgeting
12.	Recognise and demonstrate safety rules on the street

There was no consensus among all the mothers on LP DLS. However, many mothers rated DLS related to *caring for clothes* as LP. Seven out of 9 mothers gave low ratings to: *'store dirty clothes in a laundry basket*' and *'fold clothes and put them away'*, while 6 mothers gave a LP rating to: *'follow washing instructions on garments', 'change bed linen regularly and/or according to need', 'iron clothes', 'make a grocery list according to needs',* and *'care for fingernails and toenails'*.

5.2.3. Fathers' views on High and Low priority DLS

As depicted in Table 40, all fathers rated sixteen DLS as HP. Five were related to budgeting and money skills, three to personal hygiene and appearance, two to household and outdoor safety, two to health care, and three to travelling skills.

Table 40. High priority DLS rated by fathers

1.	Shower or bathe regularly
2.	Acknowledge the importance of personal hygiene and of maintaining a neat appearance
3.	Brush teeth regularly and maintain oral hygiene
4.	Recognise household dangers
5.	Use kitchen appliances safely
6.	Keep an appointment at the doctor/dentist/therapist without being reminded
7.	Take own medication appropriately without supervision
8.	Understand the value of money
9.	Understand the difference between necessities and luxuries and spend money accordingly
10.	Understand safety measures related to credit cards

11.	Make a purchase from shops and calculate the change
12.	Understand the concept and importance of saving and budgeting
13.	Know what to do if he takes a wrong bus or stops at the wrong bus stop
14.	Recognise and demonstrate safety rules on the street
15.	Know how to handle incidents with other drivers and traffic accidents when driving own car
16.	Be able to follow traffic and safety rules when driving own car

With regards to LP DLS, there were no DLS that were given a low rating by all the fathers. However, most fathers (5 to 6 out of 7 fathers) rated the following as LP: *‘clean, mop, vacuum, wash the floor to keep the house clean’, ‘use cleaning products accordingly’*, *‘dispose of garbage appropriately’*, *‘be able to drive own car and go to places’, ‘fold clothes and put them away’*, *‘iron clothes’, ‘prepare simple snacks and hot drinks’* and *‘care for fingernails and toenails’*.

5.2.4. Professionals’ views on High and Low priority DLS

All professionals, including myself (ProfF9) gave a HP rating to ten DLS, listed in Table 41. These consisted mainly of personal hygiene (2), household safety (3), health care (2), travelling (2) and money skills (1).

Table 41. Views on High priority DLS by professionals

1.	Shower or bathe regularly
2.	Use kitchen appliances safely
3.	Recognise household dangers
4.	Understand the value of money
5.	Recognise and describe symptoms of common health problems
6.	Use common kitchen tools
7.	Respond to questions from doctor/therapist to support them in reaching a diagnosis

8.	Use public transport to travel to both known and unknown places
9.	Acknowledge the importance of personal hygiene and of maintaining a neat appearance
10.	Know what to do if he takes a wrong bus or stops at the wrong bus stop

Professionals, including myself were the only group that also agreed on two LP DLS which were to: *'iron clothes'* and *'fold clothes and put them away'*.

5.3. Comparison between groups on the *High Priority* DLS

There were a number of DLS on which there was a level of agreement between the different groups, while others were rated as HP by a particular group only.

Table 42. High Priority DLS as rated by the different groups

Domain	DLS	Young people	Mothers	Fathers	Professionals
Personal hygiene and appearance	Shower or bathe regularly		√	√	√
	Shave and care for skin		√		
	Brush teeth regularly and maintain oral hygiene		√	√	
	Acknowledge the importance of personal hygiene and of maintaining a neat appearance	√		√	√
Health care	Recognise and describe symptoms of common health problems				√

	Acknowledge the need to see a doctor/therapist		√		
	Respond to questions from doctor/therapist to support them in reaching a diagnosis		√		√
	Keep an appointment at the doctor/dentist/therapist without being reminded			√	
	Take own medication appropriately without supervision			√	
Money and budgeting skills	Understand the value of money		√	√	√
	Understand safety measures related to credit cards		√	√	
	Make a purchase from shops and calculate change		√	√	
	Understand the concept and importance of budgeting	√	√	√	
	Understand the importance of saving and budgeting			√	

	Understand the differences between necessities and luxuries and spend money accordingly			√	
Safety at home	Recognise household dangers		√	√	√
	Use kitchen appliances safely		√	√	√
	Use common kitchen tools				√
	Understand the importance of keeping windows and doors locked particularly when not at home and during the night	√			
Safety on the street	Recognise and demonstrate safety rules on the street		√	√	
Travelling skills	Use public transport to travel to both known and unknown places				√
	Know what to do if he takes a wrong bus or stops at the wrong bus stop	√		√	√
	Know how to handle incidents with other drivers and traffic			√	

	accidents when driving own car				
	Be able to follow traffic and safety rules when driving own car			√	

As Table 42 indicates, the two groups with the greatest agreement on the HP DLS were the mothers and fathers. Eight DLS were given a HP rating by all the parents. Parents gave key importance primarily to the understanding and management of money. They also valued basic personal hygiene routines and safety at home and on the street. The remaining 3 DLS rated as *HP* by all the mothers (e.g. shave and care for skin), were regarded HP by 6 out of the seven fathers, while another 7 DLS regarded as HP by all the fathers (e.g. take own medication appropriately without supervision), were also valued similarly by 6 to 8 mothers.

While parents gave considerable importance to a variety of *Money and budgeting skills*, professionals and young people rated only one skill as HP within this domain. All groups gave importance to DLS related to household safety. However, while parents and professionals prioritised household dangers, such as those arising from appliances and tools, young people focused on protecting their homes by locking windows and doors. Only parents gave importance to *Safety on the street*. Parents and professionals also gave HP to DLS within the *Health care* domain. All groups except the mothers regarded some *Travelling skills* as HP.

5.4. Comparison between participant groups on *Low priority* DLS

Only professionals agreed as a group on two LP DLS. Within the other groups there were no DLS that were rated as LP by all the participants. However, there were a number of DLS that were regarded as LP by most of the participants within their respective groups. Table 43 shows which DLS were rated LP by most of the participants, and where there is a level of agreement or difference between the different groups.

Table 43. Agreement on Low priority DLS across the different groups

Domain	DLS	Young People	Mothers	Fathers	Professionals
Personal hygiene and appearance	Care for fingernails and toenails		√	√	
Health care	Care for a minor cut/burn	√			
Caring for clothes	Store dirty clothes in a laundry basket		√		√
	Follow washing instructions on garments		√		√
	Fold clothes and put them away		√		√*
	Iron clothes		√	√	√*
	Change bed linen		√		

Housekeeping	Clean, mop, vacuum, wash the floor to keep the house clean			√	
	Dispose of garbage appropriately			√	
	Use cleaning products accordingly			√	√
Cooking skills	Prepare simple snacks and hot drinks			√	
	Make a grocery shopping list according to needs		√		
Travelling skills	Be able to drive his own car and go to places	√		√	
	Handle incidents with drivers and accidents when driving own car	√			

*All professionals rated this DLS as LP

As Table 43 shows, participants' views on LP DLS varied. The two participant groups that agreed mostly were the mothers and the professionals. The shared LP rating was given to *Caring for clothes* skills. Fathers gave least importance to *Housekeeping* skills, while the young people rated skills related to driving their own car as LP.

5.5. The Five *most important* DLS

Participants were asked to choose five DLS from a list of 50 which they believed were the *most important*. This section discusses which DLS were identified by the different groups.

5.5.1. Young people’s views on the *5 most important* DLS

Table 44 shows which DLS were chosen as the *most important* together with the number of young people that chose each skill.

Table 44. Young people’s choice of the *5 most important* DLS

Domain	**DLS**	**No. of Young People**
Personal hygiene and appearance	Shower or bathe regularly	4/9
	Shave and care for skin	2/9
	Care for hair, keeping it clean	3/9
	Wear clothing appropriate to the weather and occasion	2/9
Health care	Acknowledge the need to see a doctor, therapist	2/9
	Keep an appointment at the doctor/dentist/therapist without being reminded	2/9
	Responds to questions from the doctor or therapist to support them in reaching diagnosis of symptoms	2/9
	Care for a minor cut, minor burn	1/9
Safety at home	Understand the importance of keeping windows and doors closed	2/9
	Use kitchen appliances safely	1/9
Housekeeping	Clean, mop, vacuum, wash the floor to keep the house clean	3/9
	Make a grocery shopping list according to needs	1/9

Caring for clothes	Use a washing machine, and dry clothes	2/9
	Identify clothes that need to be washed	2/9
Cooking skills	Follow simple recipes and cooking instructions to cook meals for oneself	1/9
	Recognise spoilage in food	4/9
	Use common kitchen tools (e.g. knives, cheese grater, can opener)	1/9
Money and budgeting skills	Understand the value of money	5/9
	Budget for monthly expenses	2/9
Travelling skills	Be able to drive own car and go to places	2/9
	Be able to follow traffic and safety rules when driving own car	1/9

Personal hygiene and appearance was the young people's most chosen domain. DLS related to *Health care,* and *Money and budgeting skills* were also regarded important. To '*understand the value of money'* was the most chosen DLS, followed by *'shower and bathe regularly'* and *'recognise spoilage in food'*.

5.5.2. Mothers' views on the *5 most important* DLS

Table 45 shows which DLS were identified by mothers as the *most important*, and the number of mothers who chose each skill.

Table 45. Mothers' choice of the 5 most important DLS

Domain	**DLS**	**No. of Mothers**
Personal hygiene and appearance	Shower or bathe regularly	7/9
	Brush teeth regularly and maintain oral hygiene	1/9
Health care	Responds to questions from the doctor or therapist to support them in reaching a diagnosis	2/9
	Acknowledge the need to see a doctor/therapist	1/9
	Contact the doctor/dentist/therapist to make an appointment	1/9
	Recognise and describe symptoms of common health problems	1/9
	Take own medication appropriately without supervision	1/9
Safety at home	Recognise household dangers	5/9
	Understand the importance of keeping windows and doors locked particularly when not at home and during the night	4/9
	Use kitchen appliances safely	2/9
Cooking skills	Follow simple recipes and cooking instructions to cook meals for oneself	2/9
Money skills	Understand the value of money	6/9
	Budget for monthly expenses	3/9
	Understand safety measures related to credit cards	2/9
	Understand the concept and importance of saving and budgeting	1/9
	Make a purchase from shops and calculate the change	1/9

Travelling skills	Be able to drive own car	2/9
	Be able to follow traffic and safety rules when driving own car	1/9
	Know how to handle incidents with other drivers and traffic accidents when driving own car	1/9
	Use public transport to travel to both known and unknown places	1/9

Table 45 shows that *Money skills* was the most chosen domain by mothers. DLS related to *safety at home* were also considered important. The most chosen DLS was *'shower or bathe regularly'* followed by *'understand the value of money'* and *'recognise household dangers'*.

5.5.3. Fathers' views on the 5 most important DLS

Table 46 shows which DLS the fathers thought were the most important.

Table 46. The *5 most important* DLS chosen by fathers

Domain	**DLS**	**No. of Fathers**
Personal hygiene and appearance	Shower or bathe regularly	2/7
	Acknowledge the importance of personal hygiene and of maintaining a neat appearance	1/7
Health care	Responds to questions from the doctor or therapist to support them in reaching a diagnosis	1/7
	Acknowledge the need to see a doctor/therapist	2/7

Safety at home	Recognise household dangers	1/7
	Understand the importance of keeping windows and doors locked particularly when not at home and during the night	1/7
	Use kitchen appliances safely	4/7
Housekeeping skills	Make a grocery shopping list according to needs	1/7
Cooking skills	Follow simple recipes and cooking instructions to cook meals for oneself	1/7
	Use common kitchen tools (e.g. knife, cheese grater, can opener)	1/7
	Acknowledge the importance of proper food handling	1/7
Money skills	Understand the value of money	5/7
	Use a credit card to make purchases and to withdraw money from an ATM	1/7
	Understand safety measures related to credit cards	2/7
	Understand the difference between necessities and luxuries and spend money accordingly	1/7
	Make a purchase from shops and calculate the change	4/7
Travelling skills	Recognise and demonstrate safety rules on the street	3/7
	Be able to follow traffic and safety rules when driving own car	1/7
	Use public transport to travel to both known and unknown places	2/7

As Table 46 shows, similar to the mothers, *Money skills* was the most chosen domain by the fathers. The DLS which was regarded most important was *'understand the value of money'*, followed by *'make a purchase from shops and calculate change'* and *'use kitchen appliances safely'*.

5.5.4. Professionals' views on the *5 most important* DLS

Table 47 shows the professionals' choice of the DLS they consider most important, and the number of professionals who chose each skill.

Table 47. Professionals' choice of the *5 most important* DLS

Domain	**DLS**	**No. of Professionals**
Personal hygiene and appearance	Shower or bathe regularly	6/9 *
	Brush teeth regularly and maintain oral hygiene	1/9
	Care for hair, keeping it clean	1/9
	Care for fingernails and toenails	1/9
	Acknowledge the importance of personal hygiene and of maintaining a neat appearance	4/9
Health care	Recognise and describe symptoms of common health problems	1/9
	Responds to questions from the doctor or therapist to support them in reaching a diagnosis	1/9
	Acknowledge the need to see a doctor/therapist	4/9*
	Take own medication appropriately without supervision	3/9

Safety at home	Recognise household dangers	1/9
	Use kitchen appliances safely	2/9 *
Cooking skills	Follow simple recipes and cooking instructions to cook meals for oneself	1/9
	Prepare simple snacks and hot drinks	4/9
Money skills	Understand the value of money	5/9 *
	Make a purchase from shops and calculate the change	2/9
Travelling skills	Recognise and demonstrate safety rules on the street	4/9 *
	Plan the use of public transport to arrive at a destination on time	3/9
	Use public transport to travel to both known and unknown places	1/9

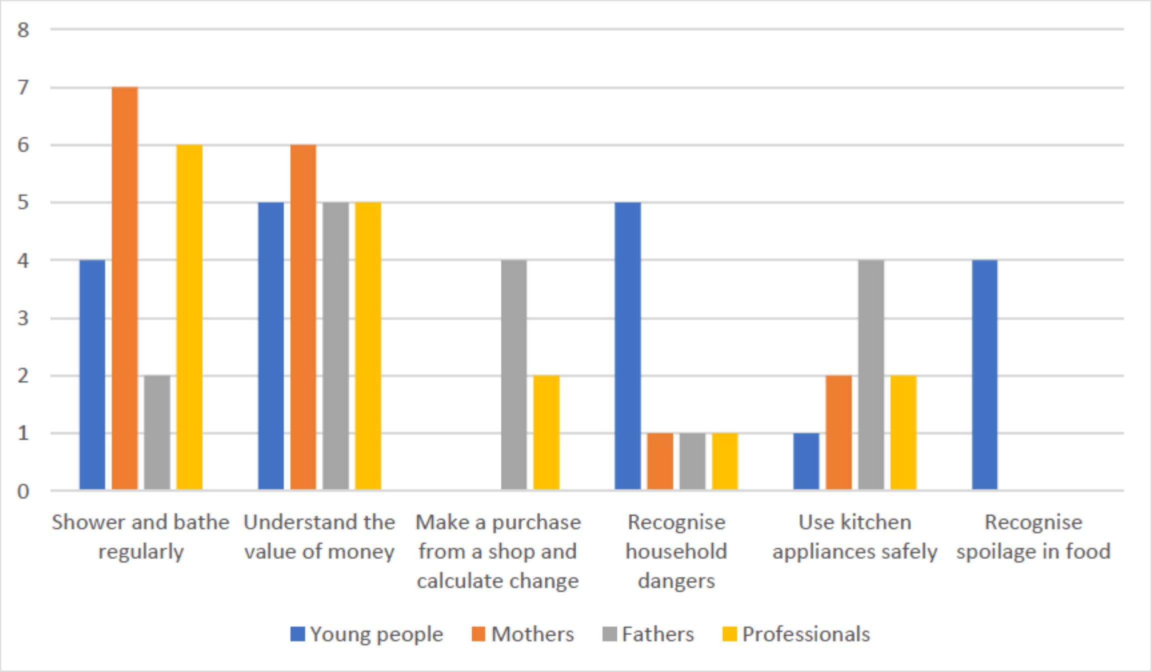
*The 5 DLS chosen by myself as the most important

As Table 47 shows, *Personal hygiene and appearance* was the most chosen domain by the professionals. The DLS *‘shower or bathe regularly’* was thought to be the most important, followed by *‘understand the value of money’*.

5.6. Comparisons between the groups on the *most important* DLS

Figure 1 demonstrates six DLS which were identified as the *most important* by one or more of the groups. It shows how many participants from each group rated these DLS as *most important*.

Figure 1. The 5 most important DLS across participant groups



As depicted in Figure 1 above, the DLS which was rated as most important by more than half of the participants across groups, was to *'understand the value of money'*. This was followed by *'shower or bathe regularly'*, which was given greatest priority by mothers and professionals. To *'recognise household dangers'* was considered *most important* mainly by mothers, while *'recognise spoilage in food'* was chosen as a *most important* DLS by young people only.

5.7 Money and budgeting skills - A major concern for parents

Data from the follow-up in-depth interview support the findings from the DLS checklist that money and budgeting skills are considered a high priority DLS particularly by parents. All four parents interviewed (fathers PF2 and PF3 and mothers PM1 and PM4) emphasised that money skills were a big worry, with one mother insisting: "Money…A big danger! A big headache!" (Participant PM1).

The parents agreed that understanding the concepts of the value of money, money management and budgeting were difficult for their young people. One father explained:

> For him to really capture the concept of the value, the ins and outs of money, the idea of having a bank account…a credit card…it's all too demanding…we're constantly on the guard on what he is spending (Participant PF2).

Parents worry about their young people spending large amounts of money on unnecessary items, or of being tricked by other people due to their naivety. Such fears often result in a lack of opportunities for the young people to practise money skills, such as using their credit cards. One mother admitted:

> I was always afraid to trust him with a card because anyone can trick him really easily (Participant PM4).

Parents' fear was at times transferred to the young people, as the following quotation of a mother confirms:

> I plucked up some courage and asked him to keep his own card but he said he doesn't want it because he doesn't trust himself…I believe it's true he would spend it all (Participant PM1).

This was echoed by one of the professionals who explained that money DLS was not being addressed directly and opportunities to practise money skills were scarce, partly due to parents' fears:

> I don't think it is being addressed…also because of parents' fear...they are scared for example of giving them the credit card because of its consequences (Participant ProfF7).

5.7. The 5 least important DLS

Participants were also asked to choose the five DLS which they thought were *least important*. This section shows the DLS considered least important by each group and the number of participants who chose each skill.

5.7.1. Young people's views on the *5 least important* skills

Table 48 shows the young people's choice of those DLS they thought were the *least important*.

Table 48. Young people's choices of the *5 least important* DLS

Domain	**DLS**	**No. of Young people**
Personal hygiene and appearance	Care for fingernails and toe nails	4/9
	Shave and care for skin	1/9
	Wear clothing appropriate to the weather and occasion	1/9
Health care	Take own medication appropriately without supervision	2/9
	Keep an appointment at the doctor/dentist/therapist without being reminded	2/9
	Care for minor cut/minor burn	2/9
	Recognise and describe symptoms of common health problems	1/9
Housekeeping skills	Dispose of garbage appropriately	2/9
	Make a grocery shopping list according to needs	1/9

	Clean, mop, vacuum, wash the floor to keep the house clean	1/9
	Use cleaning products accordingly	2/9
Caring for clothes	Change bed linen regularly/according to need	2/9
	Iron clothes	2/9
	Follow washing instructions on garments	3/9
	Use a washing machine and dry clothes	1/9
	Fold clothes and put them away	1/9
	Store dirty clothes in a laundry basket	1/9
Cooking skills	Prepare simple snacks and hot drinks	2/9
	Store food in a refrigerator or as needed	2/9
	Follow simple recipes and cooking instructions to cook meals for oneself	2/9
Money skills	Understand the difference between necessities and luxuries and spend money accordingly	1/9
	Budget for monthly expenses	1/9
Travelling skills	Be able to drive own car and go to places	2/9
	Know what to do in case of a car breakdown when driving own car	2/9
	Know how to handle incidents with other drivers and traffic accidents when driving own car	1/9
	Read and understand public transport and timetable schedules	1/9

	Use public transport to travel to both known and unknown places Plan the use of public transport to arrive at a destination on time	1/9 1/9

As Table 48 depicts, young people chose a variety of DLS with little consensus on which DLS were *least important*.

5.7.2. Mothers' views on the 5 least important DLS

Table 49 below shows which DLS were chosen by mothers as *least important* and the number of mothers who chose such skills.

Table 49. Mothers' choices of the 5 least important DLS

Domain	**DLS**	**No. of Mothers**
Personal hygiene and appearance	Care for fingernails and toenails Wear clothing appropriate to weather and occasion	1/9 2/9
Health care	Keep an appointment at the doctor/dentist/therapist without being reminded	1/9
Safety at home	Understand the importance of keeping windows and doors locked particularly when not at home and during the night	1/9
Housekeeping skills	Dispose of garbage appropriately Use cleaning products accordingly	4/9 2/9
Caring for clothes	Change bed linen regularly and/or according to need Fold clothes and put them away	1/9 5/9

	Store dirty clothes in a laundry basket	3/9
	Iron clothes	5/9
	Follow washing instructions on garments	4/9
	Identify clothes that need to be washed	1/9
	Use a washing machine and dry clothes	1/9
Cooking skills	Follow simple recipes and cooking instructions to cook meals for oneself	1/9
	Acknowledge the importance of proper food handling	1/9
Travelling skills	Be able to drive his own car to go to places	3/9
	Be able to follow traffic and safety rules when driving own car	1/9
	Know how to handle incidents with other drivers and traffic accidents when driving own car	2/9
	Know what to do in case of a car breakdown when driving own car	1/9
	Plan the use of public transport to arrive at a destination on time	2/9
	Read and understand public transport timetable schedule	1/9
	Use public transport to travel to both known and unknown places	1/9

As depicted in Table 49, the *Caring for clothes* domain was mostly chosen by mothers as the *least important*, with the DLS *‘fold clothes and put them away’* and *‘iron clothes’* regarded as *least important* by more than half of the mothers. A number of DLS within the *Travelling skills* domain were also identified as least important, although only a small number of mothers chose such skills.

5.7.3. Fathers' views on the 5 least important skills

Table 50 depicts those DLS which fathers consider *least important*, and the number of fathers who made such choices.

Table 50. Fathers' choice of the *5 least important* DLS

Domain	**DLS**	**No. of Fathers**
Personal hygiene and appearance	Care for fingernails and toenails	3/7
	Care for hair, keeping it clean	1/7
Health care	Recognise and describe symptoms of common health problems	1/7
Housekeeping skills	Dispose of garbage appropriately	3/7
	Use cleaning products accordingly	1/7
Caring for clothes	Change bed linen regularly and/or according to need	3/7
	Fold clothes and put them away	5/7
	Store dirty clothes in a laundry basket	3/7
	Iron clothes	3/7
	Follow washing instructions on garments	3/7
	Identify clothes that need to be washed	1/7
Cooking skills	Prepare simple snacks and hot drinks	3/7

	Recognise spoilage in food	1/7
Travelling skills	Be able to drive his own car to go to places Read and understand public transport timetable schedule	3/7 1/7

Table 50 shows that *Caring for clothes* was the most chosen domain for the *least important* DLS. To *'fold clothes and put them away*' was chosen as the least important DLS by the fathers.

5.7.4. Professionals' views on the *5 least important* DLS

Table 51 displays those DLS which professionals chose as the *least important*, and the number of professionals who chose such skills.

Table 51. Professionals' choice of the *5 least important* DLS

Domain	**DLS**	**No. of Pofessionals**
Personal hygiene and appearance	Wear clothes appropriate to weather and occasion	1/9
Housekeeping skillls	Dispose of garbage appropriately Use cleaning products accordingly Clean, mop, vacuum, wash the floor to keep the house clean	4/9 3/9 1/9
Caring for clothes	Follow washing instructions on garments Iron clothes	5/9 * 7/9 *

	Fold clothes and put them away	7/9 *
	Store dirty clothes in a laundry basket	5/9 *
Cooking skills	Follow simple recipes and cooking instructions to cook meals for oneself	1/9
Money skills	Use a credit card to make purchases and to withdraw money from an ATM	1/9
Travelling skills	Be able to drive his own car to go to places	6/9 *
	Be able to follow traffic and safety rules when driving own car	2/9
	Know what to do in case of a car breakdown when driving own car	1/9
	Know how to handle incidents with other drivers and traffic accidents when driving own car	1/9

*The 5 DLS chosen by myself as the least important

As Table 51 shows that, similar to the other groups, professionals chose the *Caring for clothes* domain as the *least important*. To *‘iron clothes’* and *‘fold clothes and put them away’* were the two most chosen *least important* DLS.

5.8. Comparison between the groups on the *least important* DLS

Figure 2 demonstrates five DLS which were identified as the *least important* by one or more of the groups. It shows comparisons between groups and indicates how many participants from each group rated these DLS as *least important*.

Figure 2. The 5 least important DLS across participant groups

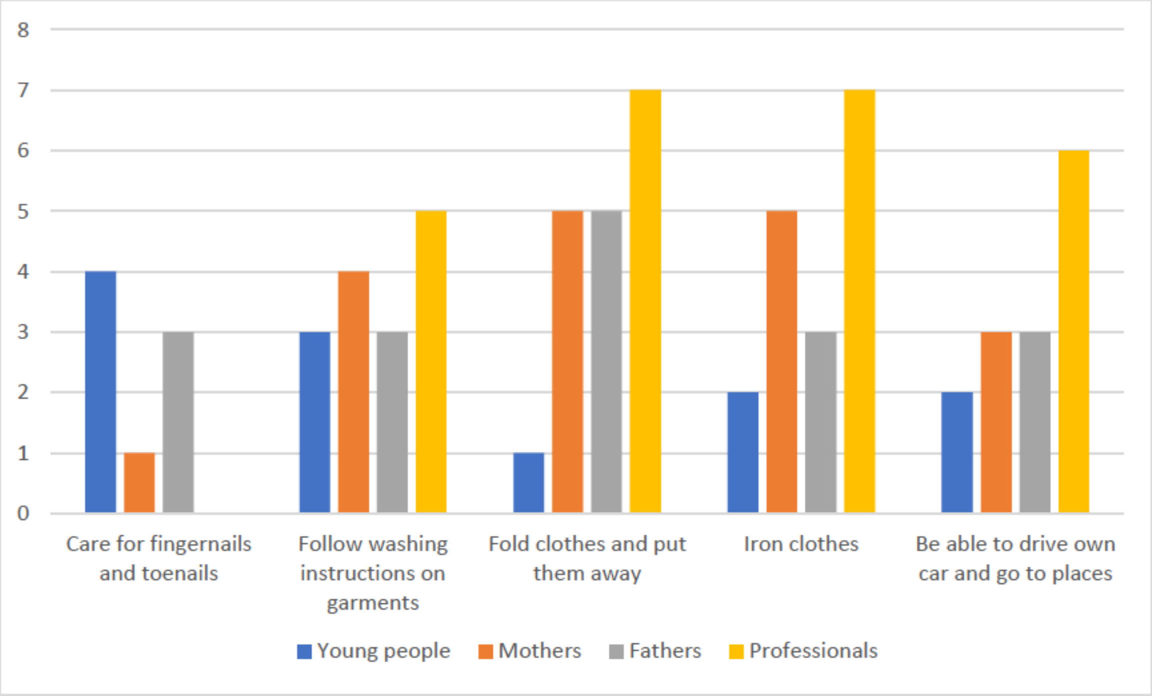


Figure 2 shows that three of the *least important* DLS identified by the different groups belong to the *Caring for clothes* domain. These DLS were considered *least important* by professionals, followed by parents, particularly mothers. Professionals also viewed the skill to *'be able to drive own car and go to places'* as one of the *least important* DLS, while the other groups chose this DLS less. To *'care for fingernails and toenails'* was considered *least important* mainly by the young people, although only four made this choice.

5.9. Summary of the DLS Checklist data - key findings

All participants were given a list of 50 DLS which they had to rate as *high* or *low priority*. Participants within each group agreed on a number of *high priority* DLS. All participants gave importance to personal hygiene and DLS related to safety. Mothers and fathers gave their highest priority to the understanding and management of money. With regards to *low priority* DLS, views were varied within participant groups. Only professionals agreed on two *low priority* DLS as a whole group. Mothers and professionals gave their lowest priority to the *Caring for clothes* domain, while fathers gave their least importance to *housekeeping skills*.

When looking at the 5 most important DLS, the young people's and the professionals' choices were mainly from the *Personal hygiene and appearance* domain while the mothers' and fathers' choices were related mostly to *Money skills*. The DLS that was chosen by the young people and fathers as the most important was *'to understand the value of money'* while mothers and professionals chose *'shower and bathe regularly'*. With regards to the 5 *least important* DLS, all participant groups chose DLS related mostly to the *Caring for clothes* domain.

The next chapter will present the findings from the eight in-depth interviews carried out with two participants from each stakeholder group. Six Barriers and 7 Promoter topics will be discussed from the perspectives of the young people, the mothers, the fathers and the professionals.

CHAPTER 6

FINDINGS FROM THE INTERVIEWS

6.1. Introduction

To obtain a more thorough understanding of the everyday promoters and barriers of DLS and their responses on the Q sort, participants were asked whether they would be willing to participate in an in-depth interview. All 34 participants expressed willingness, and at the end of the Q sort data collection process, 8 participants (2 young people – YA8, YA7; 2 mothers PM1, PM4; 2 fathers PF2, PF3; and 2 professionals ProfF7, ProfM2) were randomly selected to be interviewed. The participants exemplified different factors for the Promoter and Barrier Q sorts (see Table 54).

The semi-structured interview consisted of eight open-ended questions (see Appendix 12). Due to the Covid-19 pandemic, interviews were held online via Skype. All participants agreed to be video recorded and the interviews lasted between 45 minutes and 1 hour. All participants said that they found the interview interesting and useful as a tool to help them reflect on the young people's DLS development in everyday life. Parents in particular were very eager to discuss their worries particularly about money skills and one mother asked whether this was just her son's problem or common for other young people as well. Most of the time participants stayed on topic and did not find it difficult to answer all the interview questions. The interviews resembled to informal discussion with the parents and the professionals, but took a more question and answer format with the young people. Nevertheless, both young people gave thorough information about the questions posed. Overall, it was a very positive experience even for me as all participants seemed to adhere to the idea that I was a researcher for that one hour, and not their practitioner.

Interviews were used as a secondary data collection tool to reinforce the data collected through the Q sorts and post-sorting interviews. The number of participants was kept to a minimum of two from each stakeholder group for two main reasons. Firstly, although all the Q sort participants expressed willingness to take part in the interview, I felt that it would be too demanding on them, particularly those participants who had also taken part in the interview to generate the concourse for the Q sorts. Secondly, it would have also been very time-consuming and demanding on me to transcribe and analyse more interviews. I was aware that the limited number of interviews were very unlikely to represent the views of every young person, parent and professional. However, after having analysed the interviews, from my professional experience, I believe that the data gathered do represent the general views of each stakeholder group.

It is reassuring that the interview data corroborated the data gathered from the Q sorts and the DLS checklist, and the topics that emerged from the in-depth interviews consolidated those that were outlined by the different Factors. Moreover, from my professional knowledge I believe, that the topics that emerged from the interviews do represent the everyday lived experiences of the majority of the families that I support. Another positive characteristic of the interviews was that two of the participants (YA8 and PF3) did not exemplify any of the Barriers factors and therefore, it was unknown which Factor represented their views best. Through the interviews, these two participants were still able to voice their opinions about the topic of DLS.

6.2. Factors that emerged from the Q sort exercise

Throughout this chapter, reference will be made to the Factors and the participants exemplifying them. For ease of access for the reader, the tables below serve as a reminder of the different views that each Factor represents:

Table 52. Promoters Factors

Factor	Participants	Viewpoint
Factor 1	1YA, 3M, 2F, 5 Profs	Parents should teach DLS despite challenges. Professional support is necessary. Emphasis on the death of parents is a negative motivator and instils anxiety
Factor 2	4 Profs, 2M, 1F	Professionals are key stakeholders. Parents' consistency and reassurance are essential. Generalisation of skills is fundamental.
Factor 3	2YA, 1M, 1F	Collaboration between parents and professionals. Both need to be knowledgeable about autism. Young people have a desire to learn DLS. Structured teaching strategies are not effective.
Factor 4	2YA, 1M	Living in an inclusive society surrounded by people who believe in them is important. Confidence is the key to the young people's performance

YA: Young adults; M: Mothers; F: Fathers; Profs: Professionals

Table 53. Barrier Factors

Factor	Participants	Views
Factor 1	2YA, 3M, 3F, 5 Profs	Barriers mostly arise from parents' beliefs, attitudes and fears. DLS are not being taught through direct teaching
Factor 2+	2YA	Fear, anxiety and frustration when we fail at DLS. No opportunities to discuss our wishes. Society's negative attitudes are impeding
Factor 2-	2 Profs	Key barriers arise from the young people's lack of interest and need to perform DLS. Parents do not accept their condition and do not encourage them to do DLS

Factor 3+	1M, 2F	Barriers stem from young people's difficulties in decision-making, organisational and flexibility skills, uncertainty about their abilities and a lot of anxiety
Factor 3-	1M	Barriers arise from low expectations of parents, professionals and educators. Parents may be too busy with commitments and give importance to academic skills rather than DLS

YA: Young adults; M: Mothers; F: Fathers; Profs: Professionals

Table 54. Participants interviewed and their Promoter and Barrier Factors

Participant	**Promoters**	**Barriers**
YA8	F3	Did not exemplify any factor
YA7	F4	F1
PM1	F3	F1
PM4	F1	F3-
PF2	F1	F1
PF3	Confounded – exemplified F2 and F3	Did not exemplify any factor
ProfF7	F1	F1
ProfM2	F2	F2-

6.3. The purpose of the interviews

The analysis of the Q sort and post-sorting interviews suggested topics that were worth exploring in more depth. The questions were developed through an analysis of the DLS checklist and Q sort findings. The interview data was intended to contribute further to the research questions, namely:

(i) Which independent life skills do key stakeholders (i.e. parents, professionals and able young autistic people) believe need to be developed?

(ii) What promotes the development of independent life skills in autistic young people and what are the potential barriers?

(iii) How can one reduce the barriers and promote the development of independent life skills for autistic young people?

6.4. Transcription and analysis of the in-depth interviews

The interviews were transcribed by myself. Doing your own transcribing allows for 'building intimate knowledge of your data' (Bazeley, 2021, p. 101). Since there were only eight interviews, I was able to transcribe every interview, straight after the interview ended. Two interviews were carried out in English and six in Maltese. Those in Maltese were translated during the transcription. Familiarity with the conversation facilitated the transcription process and allowed me to focus on its analysis and interpretation, while being as true as possible to the shared information. Following the transcription process, I went through the transcripts and looked for the views and opinions of the participants to understand their lived experiences. Thereafter, I identified common views and ideas among the participants. Coding of the transcripts was done using Word. Relevant parts of the conversations were highlighted and extracted and put under related headings. During this process it became clear that the views of the mothers and the fathers were very similar. Therefore, I decided to present them together for easier access to the reader.

6.5. Barriers to the achievement of DLS

Following the analysis of the interview data, an inductive approach was used and six main barriers emerged exclusively from the interview data:

1. Past negative experiences instil fear
2. The young people have a negative self-image
3. They get used to being cared for
4. They have no desire to leave their parents' home
5. Parents take a protective role
6. Life has become very hectic

6.5.1. Past negative experiences instil fear

Parents' perspective

All four parents (2 mothers and 2 fathers) recalled a series of negative experiences, including childhood bullying, peer exclusion during adolescence, being reprimanded for repeated mistakes, and not having a proper support system in College.

> …every one of those times starting from primary school, was a series of challenges, of struggles, and struggles and struggles. Obviously as he started to grow up and become a teenager he could look back and all he could see was a trail of failures basically…and disasters (PF2).

Parents felt that these experiences had a negative impact on their children and instilled in them a fear of failing which discouraged them from trying out new things, including DLS. A mother explained how a one-time event changed her son's perception of learning:

> Once a boy called him a freak for having one-to-one lessons with the LSE and he decided…I'm getting extra help because I'm a freak…he then developed a big grudge towards the system… These incidents do have negative effects in their memory and on their future (PM4).

Professionals' perspective

Professionals also acknowledged this fear of trying out new things and of making mistakes, which resulted from Factor 2+ of the Barriers Q sort. However, they attributed it to having been pressured at a young age to learn new skills and keep up with their peers, and perhaps being "scolded for their mistakes rather than praised for trying." (Participant ProfF7). Moreover, professionals believed that the young people experience anxiety and fear when things do not turn out as they would have expected them to:

> I think another factor could be that they would have tried to do something new which would have gone wrong, or the result did not match what they had in mind, and then they would develop this fear of trying out other new things (ProfM2).

Professionals also thought that such fear could be transferred to them through their parents who might be reluctant to encourage them to learn new things. They observed that most young people often reach out for their parents' recognition and approval before they try out new skills. An autism tutor felt:

> You might find a few young people who would still try out new skills to become more independent irrespective of what their parents think, but I don't think it is the majority (ProfM2).

Young people’s perspective

The young people recalled several negative past experiences including bullying, feeling unsuccessful at school and not being understood by peers and teachers. They claimed that these experiences had created feelings of failure and fear, some of which they were still carrying along with them. One of the young people explained:

> They’re like pieces of string tied to your back which in time become tangled and heavier on you (YA7).

They described these experiences as “invisible on the outside but catastrophic on the inside” and like “a volcano which remains dormant and comes back after some time.” They claimed that these experiences often made them scared of facing new challenges in life. One of them described this thought of being attacked by a stranger, which haunts him when he is outside by himself. This he felt, was a result of all the bullying he had been through. Both young people admitted that it was not easy to forget about such experiences because they have “a somewhat obsessive and persistent way of following you forever” (YA7).

6.5.2. The young people have a negative self-image

Parents’ perspective

While focusing on past negative experiences, parents expressed that their young people had developed a negative sense of self. This was primarily associated with failures:

> …the idea of his self-image that he's built throughout the years is one that he cannot achieve…I think the biggest barrier is his conviction that he has failed (PF2).

Uncertainty about their abilities was a view expressed by participants who exemplified Barriers Factor 3+. Both mothers and fathers felt that the autism diagnosis also affected the way their young people perceived themselves. Parents emphasised that they viewed autism as a limitation that makes them "inferior" (PM4) to others. A mother (PM1) explained that although her son had wishes for the future, he tended to think that he cannot become independent because of his autism. This was echoed by a father:

> Many times they would have the skills but because they are very aware of their autism and they carry this baggage along…that they are less able than others…it makes them lack confidence (PF3).

The four mothers and fathers interviewed felt that their sons had not accepted autism as part of who they were and they were reluctant to disclose it to their friends and romantic partners. A father explained that it took his son twenty-seven years to disclose his diagnosis to his group of friends:

> He came home and he was in a sense...relieved...when he spoke to his mother and me…he was almost proud of himself (PF2).

Professionals' perspective

Professionals observed that many young people lacked self-confidence. They pointed to the importance of starting from a young age to teach them that failure is integral to the learning process.

> I feel that a big part of my professional work with these young people is to instil confidence in them to try new things…to empower them (ProfM2).

To prevent the development of a negative self-image, professionals agreed on the importance of rewarding children for trying rather than for succeeding. They also emphasised the importance of presenting fear as a normal feeling when trying out something new, but nonetheless that should not stop them from taking up the challenge. Professionals were also convinced about the necessity to work with parents to motivate their young people to take up challenges and try out new skills.

Young people's perspective

Unlike the parents' beliefs, the two young people did not refer to their autism diagnosis in a negative way. However, they blamed the negative experiences they had been through for their lack of self-confidence. One of the young people described these experiences as "negative energies" inside him which need to be redirected. He explained:

> …when these thoughts come up and become incessant you need to have a professional to help you direct these negative feelings and replace them with something constructive and positive (YA7).

They spend a lot of time thinking before attempting something new. This sense of hesitation delays their motivation to do something and creates in them an *unpleasant* feeling.

6.5.3. They get used to being cared for

Parents' perspective

Consistent with the view of Barriers Factor 2-, the four parents observed that that their young people had got used to being cared for and do not perceive the need to learn DLS and perform them independently. Parents agreed that despite their efforts to involve them in everyday chores and decisions, such as what to cook, their sons leave everything in their hands. One father explained:

> Over the years, he's fallen into a bit of a lifestyle that is convenient and safe and within boundaries...to a certain extent it might have worked in a negative way when it comes to desire… (PF2).

Parents felt discouraged at times by their young people's attitude towards assigned chores and responsibilities, and claimed that they often need to drive them to do them:

> Sometimes it is disheartening because he tries to avoid his responsibilities or gives us a hard time to do them (PF3).

Professionals' perspective

Professionals agreed that years-long habits and routines may be difficult to break. The young people would have got used to everything being done for them. They pointed out that sometimes, their lack of involvement would be a "choice rather than a lack of ability" (ProfF7). Professionals were also convinced about the necessity of the parents' role to encourage independence.

They expressed that quite often parents would also become trapped in the daily routines of doing everything for their young people without realising the "dangers of it"

(ProfM2). This they claimed would result in a lack of desire and motivation in the young people to become independent. Professionals acknowledged the high demands and responsibilities of parents while they emphasised the importance for the young people to be given a role within the family.

Professionals were also critical of the education system which focuses on the wrong definition of inclusion and does not address those skills which would eventually result in more independent adults. The speech therapist argued:

> We are too stuck in a ‘one size fits all’ system…the most important thing is that they are “included” at school, sitting in the classroom with the other children and attending the same lessons…and we miss out on all the other skills they could gain for life… (ProfF7).

Young people’s perspective

The two young people admitted that they had got used to finding things ready for them, such as cooked meals and clean clothes. They also rely on their parents’ guidance when they feel unwell. They claimed that in primary and secondary school they were never given the opportunity to become independent. They described teaching staff as “impatient” (YA8) and as people who offered little help and very few opportunities for independence.

> Elementary and secondary school never gave me the opportunity to try to find a way to independence…it never happened (YA7).

All these they felt had contributed to an established sense of dependency. Nevertheless, the young people still expressed wishes for learning new DLS. They also shared a sense of pride when they talked about their involvement in *‘basic’* family chores such as buying everyday groceries, taking care of their family pets, and doing some gardening.

6.5.4. They have no desire to leave their parents' home

Parents' perspective

While focusing on the comfort their young people get from being cared for, three parents felt that their children had no desire to leave their home. They attributed this to their difficulty to foresee the future and plan ahead. This was a view expressed by those exemplifying Factor 3+, pointing out lack of flexibility and organisational skills as main barriers. A mother explained:

> Sometimes their own condition works against them. He has no vision...it's a status quo…I want to stay here live with you in this house, I'm happy here with my cats, my computer and my games...this is the life he wants to carry on forever (PM4).

Despite worries about when they are no longer able to support their young people, parents still communicated an inner resistance to encourage their sons to live independently away from home. A father explained:

> I can't really see it [moving out of home] happening that soon…he can become very isolated and alone. He can still live at home...there are a lot of adults who still live with their parents. But he will be living in a more independent way (PF2).

Professionals' perspective

Similar to the parents, the two professionals felt that the young people often lacked the ability to envisage their future and the DLS they would need to live independently. The autism tutor shared an observation from his professional experience:

> Most of them find it difficult to have a vision for the years to come...when we discuss it, they either become confused or they repeat things that they would have already been through or would be experiencing at that particular stage of their life (ProfM2).

Professionals were aware that parents worry a lot about what would become of their young people when they passed away. Parents often express their willingness to promote their son's independence. However, professionals observed that very often parents are scared to let go. They maintained that if the parents are not ready, the young people will not feel the need. They agreed that parents should perhaps be the "starting point" (ProfM2). The speech therapist suggested that professionals should help parents understand that:

> Taking small steps would eventually help the young person to acquire certain skills and it would help parents to put their minds at rest that they are equipped and prepared for life (ProfF7).

Young people's perspective

The young people associated leaving the parents' home with being "fed up" (YA7) of living with them. They interpreted one's wish to leave home as a solution to having parents who do not respect their young people's privacy and allow them personal space. Both young adults felt satisfied with their relationship with their parents and did not feel the need to free themselves from them. One of the adults maintained:

> I'm sure there are a lot of autistic people who want to live that way alone…to acquire that freedom to do whatever they want at home, and for them to be their own master…but I feel happy as I am (YA7).

The young people considered going for a holiday with a friend or spending a month or so away from home to experience it. One of the young people admitted that such an experience could "kickstart the idea and desire to live on my own" (YA7). However, he emphasised that it would not indicate that his parents were "bad people" but simply because he would have enjoyed the new experience. It appears that the young people's lack of desire to leave home was more out of respect towards their parents than the other reasons expressed by the parents and professionals. A young adult added:

> I believe that in certain ways autistic people might be repulsed or discouraged if their parents tell them to go out and live on their own (YA8).

6.5.5. Parents take a protective role

Parents' perspective

Parents expressed fear and uncertainty when trying to push their young people into the world, knowing that they are socially vulnerable and not as well skilled as their peers. They worried about the attitudes of other people when their sons are out in the community. They feared that people would pick on them or provoke them to get into a fight.

A difference emerged however, in the way mothers and fathers dealt with this fear. The mothers admitted that they found it very difficult to let go and wanted to keep on protecting them:

> You want to have trust and faith in them but sometimes you can't. I try very hard to encourage him but deep down there is always that fear (PM1).

At times, the mothers made decisions that held their sons back from pursuing new skills that would promote their independence, such as driving a car. Such fear partly originated from worries about getting in trouble with other drivers who would not understand their son. Such decisions however sometimes led to a sense of guilt:

> I decided for him that he would not get a driving license. I am aware that it is my fault that he never learnt how to drive…and you question...was I unjustly scared? (PM4).

Fathers were more inclined to let go and to encourage their young people to take on responsibilities. They stressed the importance of empowering their sons to become more involved in decisions about their own life and to take an active role in the family. One father explained:

> There's a lot of things that us as parents need to learn…for us being our child, we were always there to make sure that he's ok, he's safe, he has everything. But as he gets older he has to understand that he can participate…he has a responsibility…he is the main person (PF2).

Professionals' perspective

Professionals recognised that many parents experienced a lot of fear and lack of trust in their young people's abilities. This often led to *"over-protection"* (ProfM2). They maintained that parents wanted them to be independent but at the same time they did not want them to try and fail.

> I think parents need to be very careful because there is a fine line between guiding and supporting them, and over-protecting them. Sometimes, parents do not realise that they would be keeping their children from developing further (ProfM2).

Professionals also maintained that parents may find it difficult to recognise the long-term effects of doing everything for their children, and they may not know when they should “stop giving in” (ProfF7). Others may hold on to the idea that DLS will eventually be learnt *naturally*. However, the professionals argued that this was not the case for most of the autistic people they support.

Young people’s perspective

The young people agreed that the parents’ attitudes ultimately affected their children’s performance and the level of independence they will manage to achieve. They claimed that when parents are scared and over-protective they would not give their young people the ultimate opportunity to learn and move forward in life.

While they were understanding of parents’ fears, the young people were very explicit in their arguments. They claimed that parents need to work on themselves and on those qualities that would be hindering their children’s independence. Otherwise, their young adults would not be able to improve and move on:

> Parents need to understand that so far it’s not going to work with that mentality. It will hinder their children’s independence…this will be a very heavy bulky barrier (YA7).

6.5.6. Life has become very hectic

Parents' perspective

Parents acknowledged that raising an autistic child in today's busy lifestyle was not easy. They had to attend to their spouse and other children, maintain their job and care for the needs of their autistic child. Parents maintained that sometimes it is even difficult to find time to discuss with their young people their dreams and wishes. This view was also expressed by the young people exemplifying Barriers Factor 2+. A father explained:

> I feel it is easier to keep an appointment than to talk to my son at home. Sometimes you need to treat it as an appointment because life is too hectic (PF3).

Parents agreed that very often it is much easier for them to do everything themselves than insist on their young people to do some chores or learn new DLS. A mother explained that teaching her son DLS from a young age meant less sleep and a lot of persistence and determination:

> I used to wake him up earlier so he has time to dress up by himself...it's true it's not easy to teach them sometimes, but you need to keep on persisting ..at least that's what I believe (PM1).

Professionals' perspective

Professionals acknowledged that families often do not find the right time to discuss important issues like their young people's wishes for the future. They agreed that families generally led very busy lives with both parents working and thus, their routines became a way of life. The autism tutor maintained:

> That is where our professional role comes in...to encourage the young people to discuss their thoughts and wishes about their future with their parents and to help parents understand the importance of such discussions (ProfM2).

Parents often admit with professionals that DLS are *'on their mind'*. However, professionals feel that priorities are often set to accommodate school, parents' careers and household running. DLS often require considerable time and persistence, and are left aside.

> I think DLS are not yet set to be parents' priorities. And I also feel that it's perceived as a race rather than a journey…if they don't succeed straight away then they give up…rather than doing baby steps every day to achieve the big goal (ProfF7).

Young people's perspective

The young people acknowledged the hectic lifestyle that their families live. However, they claimed that this had never come in the way of their parents' dedication to teach them DLS. One of them recalled that his mother insisted on teaching him skills like having a bath, and household and street safety since he was a little boy. He claimed that these were part of his daily routine and he was not even aware that he was learning such important skills for life. He explained:

> I was always aware of these important skills...my mother used to be very careful and persistent about these things. She used to repeat continuously and she still reminds me till this very day before I go out (YA8).

6.6. Promoters

Following the analysis of the data gathered from the eight interviews, seven main Promoter themes emerged:

1. The importance of professional support
2. Instilling desire and self-confidence
3. Sharing their experiences in small groups
4. Giving them small responsibilities
5. Practise DLS away from home
6. The importance of parents' persistence
7. The importance of supporting parents

6.6.1. The importance of professional support

Parents' perspective

Parents were convinced that professional support is a requisite for their young people and themselves. They agreed that there is always a need for that professional to be a *point of reference*, which a father (PF3) described as "an anchor" in the young person's life. They described 'good professional support' as: "…hands-on support…support through listening, teaching, and understanding…" (Participant PM4), and "maintenance sessions that keep him [his son] on track and prevent him from going on a downward spiral" (PF2) .

Parents felt that professional support and their membership at the MAC gave their young people a sense of familiarity and belonging. They described it as a place where they find acceptance and security outside their home and family, and "a motivator in itself…to discover their individual skills and learn how to use them" (PF2).

Parents admitted that professional support had been instrumental for their young people and themselves. Parents felt that they are not alone, and professionals support them when they have to address situations they would be unsure about. Parents agreed that although as their children grow older, the necessity for professional support may become less frequent, the need becomes bigger when it arises because the issues are more challenging. A father concluded:

> I would never think of stopping professional support for him…he would always need that point of reference in his life (PF3).

Professionals' perspective

Professionals acknowledged that professional support is very important. However, they had different ideas to parents about what characterises *good professional support*. Parents focused more on professional support that restores their sons' self-esteem and helps them feel valued. The professionals took different approaches to it. The autism tutor gave a more practical outlook and focused on DLS, while the speech therapist focused on theory and evidence-based practice, which according to her, guide good professional support.

Fuelled by his experience with young people, the autism tutor highlighted important qualities of professionals such as, having a good understanding of autism and how these people learn. He explained the importance of direct teaching and guidance when addressing DLS:

> If you put an autistic person in an independent setting without giving him support and guidance, he would not learn through his own experience…he would need a professional person who has a good understanding of autism to help him achieve such skills (ProfM2).

Young people's perspective

The young people were thankful for always having had professional support. They described good professionals as "patient", "equipped with empathy", "good listeners", and ones who "have good experience in the psychology of humans". One of the young people said:

> The fact that I can open up with a professional who I can confide in and listen to his suggestions and try to follow them, is extremely helpful (Participant YA8).

They felt that professionals provided that niche where they could talk about their experiences in confidentiality and be helped to redirect their negative feelings:

> The way I feel physically, mentally and spiritually makes all the difference…that is vital. We are not machines…we are made of flesh and bone, and have a mind…and these things are fragile and need to be taken care of (Participant YA7).

The young people felt that through professionals they learnt to believe more in themselves as they had come to realise that they are capable of attempting new skills. Similar to the findings of Promoter Factor 3, both young people highlighted the importance of professionals and parents to work together. They claimed that it reassured them that the professionals were people they could trust and it strengthened their support system.

6.6.2. Instilling desire and self-confidence

Parents' perspective

Parents felt that prior to acquiring a desire to learn DLS and become independent, their young people had to attain self-acceptance. Both mothers and fathers agreed that past experiences and fears did not allow their young people to be motivated and feel the desire to learn DLS and achieve independence. Parents highlighted that they had to go through a process that would help them to put the past into perspective and understand that the unpleasant experiences they had been through were not their fault or because others hated them. A father explained:

> I think it's self-understanding…as difficult as the task may be I think it's important to enable them to accept who they are...It will be easier for them then to look into the past and accept it and move towards the future without having to carry all that baggage (PF2).

Parallel to this process, parents believed that opportunities to feel successful were very important to promote their self-esteem. These could be "moments of little achievements such as, having helped someone" (PF2), which are likely to instil in them motivation and desire to attempt new skills and believe that they can be successful in life. Exposing them to different experiences and helping them realise why DLS are important to learn were also believed to contribute to the young people's desire to attempt skills that would promote their independence.

Professionals' perspective

Professionals agreed that the young people's fears need to be addressed before they are able to feel motivated to attempt DLS. They claimed that independence cannot be imposed on the young person but professionals need to:

> …encourage, model, share the benefits of DLS…and when they [young people] are ready help them to take it a step ahead (ProfF7).

They maintained that it is also beneficial to help the young person engage in brainstorming exercises to identify the advantages and disadvantages of learning and performing DLS. Moreover, they need to be given the opportunity to discuss their fears about their future and of living on their own or away from home. Creating opportunities for them to contribute and feel useful may also be effective:

> I think sometimes…to motivate them, a need for them to do certain DLS…for example the laundry, has to be deliberately created and presented to them as their responsibility (ProfM2).

Young people's perspective

The young people shared similar views to those expressed by parents and professionals. They agreed that unless they address their fears and rediscover themselves, their independence would be hindered. They believed that they need to have the courage to seek professional help to rise above their problems and take control over themselves. One of the young people referred to the professionals as their "crutches". Referring back to his analogy of the detrimental impact of past negative experiences feeling like "tangled strips tied to his back", he explained:

> So you need to stretch them out, strip them and work on redirecting them. Only after doing that you can use those strings to tie pieces of wood together to support you in other difficult situations (YA7).

The young people felt that through a lot of encouragement, the professionals had helped them to overcome their fears particularly of doing something wrong. One of the young people explained what helped him most:

> He [the professional] used to tell me you have a good brain...you are able to think…and you know where you want to go. He used to help me believe in myself that I can do it (YA8).

The young people claimed that motivation could also come from watching similar peers performing DLS and succeeding. They explained that this was likely to give them more courage to try as well.

6.6.3. Sharing their experiences in small groups

Parents' perspective

Recognising the limited social life their young people have, and the lack of opportunity to speak about their future wishes, parents believed that sharing their views, thoughts and experiences in small groups would be beneficial. A father explained:

> I think joining small groups…sharing your experience and what you would like to do in your life takes you out of yourself…they may encourage each other (PF2).

Parents believed that being together in a small group is likely to help their young people to feel safe to talk about their fears of doing something wrong and be ridiculed about it. They would thus realise that they are not alone and acquire more confidence in themselves to attempt new DLS. Moreover, such groups could help them to extend themselves to other people.

Professionals' perspective

Professionals were of a similar opinion about the effectives of meeting in small groups. They maintained that the lack of motivation to learn DLS and discuss their wishes could result from never having been asked to talk about it and share their views. They agreed that group sessions allow them the opportunity to brainstorm together on how they imagine their lives to be in a few years' time. Professionals claimed that through such exercises they could become more aware of the importance of learning DLS. Moreover, the autism tutor explained:

> Group sessions and group activities are also a good opportunity to try out new things which they might be able to practise more on their own later on (ProfM2).

Young people's perspective

The young people spoke from their experience of the MAC group sessions they participate in. They claimed that they learn a lot through discussions with their peers and they gain several skills together. One of the young adults explained:

> Sharing thoughts and ideas in group sessions is very helpful…we listen to each other's experiences and professionals understand our needs and guide us further…you feel you are not alone (YA8).

He claimed that before he participated in these groups, he used to keep all the negative emotions bottled up inside him as he felt that he had no one to discuss them with. Group sessions helped him to share his thoughts and experiences and explore his wishes for the future. Both young people felt that attempting DLS as a group during live-in activities and going abroad together, gave them more courage and motivation to face their fears with the support of their peers.

6.6.4. Giving them small responsibilities

Parents’ perspective

Parents agreed that when their young people are given responsibilities, it enhances their confidence and makes them feel useful. Both mothers and fathers suggested that their sons’ weekly professional support at the MAC should be extended to include hands-on involvement in the maintenance and running of the premises, such as painting, tidying up, and doing cleaning chores. They agreed that such contribution and responsibilities would primarily help to “restore their self-esteem” (PF2) and “become more confident” (PM1). Moreover, they would gradually learn new DLS and reinforce others they would have already achieved.

Parents believed that performing such chores as a group is a motivator in itself and would make the experience more meaningful. They felt that this addition to the professional support their young people already receive would help them as parents to alleviate their anxiety and fears related to their sons’ independence:

> …this helps parents to have more faith and trust in them [young people]…and to rest their mind that they can do a number of jobs (PM1).

Professionals' perspective

The theme of giving the young people responsibilities was prevalent mainly among parents. However, professionals also expressed a need to address the area of DLS more regularly as part of the professional support they give. They acknowledged however, that the environment would need to be partly transformed to accommodate such learning:

> Ideally you would have a setup where students can spend some days and follow a DLS programme (ProfM2).

Young people's perspective

Similar to the parents, the young people agreed that hands-on activities are very beneficial for them to learn DLS and become independent. A young person suggested that they have a list of activities to practise such as cooking and cleaning when they attend the MAC. They felt that such activities could instil in them a good sense of self as they would feel useful to others and capable of performing various skills.

One of the young people gave a vivid description of why such activities could be effective for autistic people:

> I like to think that autistic people like me are colourful people who like to see the world in colour. I believe that hands-on activities such as gardening, pottery, working with wood… would really help them and give them more inspiration in their life…and have a more positive outcome (YA7).

6.6.5. Practise DLS away from home

Parents' perspective

Parents believed that the community outings and *live-in* activities organised by the MAC are a very effective means for teaching their young people DLS. Such activities provided them with a glimpse of which skills are necessary to lead an independent life. A father highlighted the importance of becoming aware of daily priorities such as, personal hygiene and keeping the house clean, which they may not appreciate enough unless they spend some days away from home. He emphasised:

> Priorities.. life is based on priorities...this is something I really wish to teach him because I feel it is fundamental. When it comes to everyday life…when there are no deadlines like in College…you need to choose your priorities…and that he still finds difficult to do (PF3).

Parents agreed that despite their efforts to involve them in household chores, the young people tend to rely on them too much. A mother expressed her wish to arrive at a stage when such live-in activities could be carried out with minimal supervision and the young people would be monitored from a distance. This could reduce the tendency to lean on the professionals' help to cook, clean and take decisions.

Professionals' perspective

Professionals acknowledged the effectiveness of community outings and live-in activities. They observed that they give the young people a sense of empowerment and motivation as they realise that they are able to carry out a number of DLS such as cooking, cleaning and the laundry. Professionals claimed that such activities give them the opportunity to observe how the young people cope away from home, and assess their performance to identify areas that need to be further developed. Professionals maintained that such activities could also be beneficial for parents:

> Such activities may help parents to realise that they [young people] managed to survive without them and they may become more motivated themselves to teach them DLS (ProfF7).

Young people’s perspective

The young people claimed that they find live-in activities very beneficial in various ways. They learn time management, how to compromise, care for each other and not think about themselves only, and how to share responsibilities. Moreover, such activities give them the opportunity to practise DLS such as shopping for groceries cooking, and cleaning. Above all, these experiences help them to understand better the importance of DLS and how it actually feels to live away from home.

The young people were enthusiastic about having the opportunity to experience such activities for a longer period of time and to be able to spend some days without relying on the professionals’ help. They admitted that although the professionals hand over all responsibilities to them, knowing that they are within reach sometimes hinders their efforts to do things completely independently:

> Sometimes knowing that the professionals are there we tend to rely on them and ask for example what we should do next…so the next step would be to be supervised from a distance…it would be a good opportunity to practise total independence (YA8).

6.6.6. The importance of parents' persistence

Parents' perspective

Consistent with the view of Promoters Factor 2, parents recognised the importance of their own perseverance. They explained that their young people may be reluctant to attempt something new, scared of doing something wrong, or think that a skill is not important. Parents were aware that they cannot give up on their young people and through repeating and a lot of persistence, their sons managed to achieve a lot of skills. A mother recalled:

> Persistence is very important. For example, he used to ask me what to wear…But I used to insist that he opens the wardrobe, we take out the clothes and he chooses… He used to tell me "I don't know"…but I used to tell him... "it's OK just try!" (PM1).

Parents believed that persistence had to be present from a young age and continued into adulthood. They observed that even at an older age their young adults were able to keep on learning new skills. Moreover, through their persistence many were able to overcome many fears and attempt new DLS. However, one father remarked that with some young people, parents' persistence may come across as pressure and result in a lot of resistance. He therefore suggested "consistent gentle persuasion" (PF2) through discussions that communicate respect towards the young person's intelligence and ideas.

Professionals' perspective

Professionals agreed that parents need to be persistent when it comes to empowering their young adults to perform DLS and become independent. They believed that parents' persistence reinforced the young people's motivation to learn new skills. Moreover, the professionals argued that when the young people observe that their parents are giving up, they would stop trying as well. The autism tutor insisted:

> I think parents need to keep on persisting even when they feel that it is to no avail…and they need to take risks…even when the situation appears to be challenging (ProfM2).

Young people's perspective

The young people appreciated their parents' continuous encouragement to learn new skills and keep on trying. They maintained that as the people who are directly involved in their children's upbringing, parents' perseverance is a key contributor to their success in DLS and their level of independence. They emphasised the importance for parents not to lose heart and to keep on working with their children to teach them different skills. One of the young people expressed a wish for many more autistic children and adults like him:

> I really wish that this would happen…that parents do not lose heart and keep on believing in their children. My mother always kept on believing in me even in challenging situations. She kept on persisting and helping me…and that is how I have achieved so much (YA8).

The young people explained how parents should persist in giving small chores like taking out the garbage and washing their plate after they eat, and taking care of pets and plants. They felt that their mothers' reminders to perform these basic chores helped them to strengthen their skills and become more confident in doing them. The other young adult explained:

> Parents should be involved directly or indirectly as long as they find a way to positively motivate the person to do these basic chores and then take it up a notch and introduce more independence skills (YA7).

6.6.7. The importance of supporting parents

Parents' perspective

Parents acknowledged the importance of having a sound support system when raising an autistic person. One mother emphasised:

> I always looked for professionals who would also support me. It is important to feel that you are not alone…and they help you handle things which you would not know how to address as a parent (PM4).

Parents described the feedback they receive from professionals after every intervention session as “extremely helpful” and “useful”. They maintained that it gives them the opportunity to discuss how to address daily situations and support them in attempting new DLS. Parents also suggested parent support groups. They claimed that meeting up with other parents and discussing the challenges and fears they face about DLS and independence would be supportive and a learning experience in itself.

> Meeting and sharing thoughts with other parents is a big keystone in bringing up these children. It is very helpful when you meet other parents and share experiences together...you feel that you are not alone (PF3).

Professionals' perspective

Professionals recognised the importance of supporting parents throughout their journey with their young people. The autism tutor explained:

> It is important that as professionals we support and encourage parents because sometimes their fears would be unfounded…out of their good will to protect their young person, but they would be keeping them from achieving new skills. Sometimes it takes just one instance for parents to realise that their young people are capable of performing certain skills (ProfM2).

Parent support groups were also believed to be an effective medium of giving parents hope and alleviating their fears about their young person's next step to independence. Professionals maintained that it is often very helpful to make parents aware of other autistic people who were in similar circumstances and they managed to overcome the challenges and move on in life. Such successful stories are likely to instil courage in parents and motivate them to give more importance to DLS. Professionals suggested that such support groups could start from an early age. Meeting families of older children could encourage parents to choose where they want to get and start addressing the area of DLS from a young age.

Moreover, professionals suggested that parents could be present for some DLS workshops with their young people. This could encourage parents to practise the activities at home and help their young people generalise learnt skills to other environments.

Young people's perspective

The young people acknowledged their parents' need for support. They believed that parents need to be knowledgeable about what autistic people experience throughout their lives to be able to understand them and support them. They claimed that professionals are instrumental in helping parents understand their children and give them practical suggestions on how to teach them skills that are important for life. Moreover, they can guide parents on how to identify anxiety and fear in their young people and encourage them to spend more time with them to discuss such worries and support them.

The young people agreed with the parents about the importance of the feedback professionals give parents after every session. They described it as *‘very useful’* because it guides parents about which skills they can reinforce at home. They also suggested parents’ meetings which give them the opportunity to meet other parents and learn from professionals. Such meetings give parents encouragement to empower their children to learn DLS and become independent and to realise that they are not alone.

One of the young people explained how genuine professionals could be *‘role models’* for parents:

> Role models like such professionals are important for families that are afraid and who feel that there’s no hope. We need these friendly faces and we need them with open arms. They can make a big difference (YA7).

6.6.8. Summary of the findings from the interviews

Eight participants from the four stakeholder groups (2 young people, 2 mothers, 2 fathers and 2 professionals) took part in a follow-up in-depth interview. The interviews consisted of eight open-ended questions which were asked to all the participants. The interviews were semi-structured and took the form of a discussion about the topic of DLS, particularly what promotes and what hinders their development. In all, 13 topics emerged from the analysis of the interviews: 6 for the Barriers and 7 for the Promoters. Each topic provided further information that corroborated the Q sort findings and gave relevant and more in-depth answers to each of the three research questions. Moreover, the different world views of the individual stakeholders were brought out very clearly particularly about the Barrier topics.

Negative past experiences such as bullying and being misunderstood during childhood were considered main barriers that resulted in the young people having a negative self-image. The young people and their parents held similar views about the negative effects of experiences such as bullying and harassment, on the young people's fears of trying out new things, including DLS. On the other hand, professionals, while acknowledging the young people's anxiety, they attributed it to within-individual and familial factors such as, fear of things turning out different from expected, and parents' fears transferred to the young people. Unlike the parents and young people interviewed, professionals did not consider societal barriers. Professionals focused on empowering the young people and their parents to accept failure and take up challenges. On the other hand, parents focused on the effects of negative experiences on their sons' acceptance of their autism. Meanwhile, the young people emphasised that their lack of self-confidence was a result of past negative experiences.

According to parents and professionals, difficulties in EF skills resulted in a lack of ability to foresee the future, and thus a lack of desire to leave home. On the other hand the young people felt that a desire to leave home might be a solution to being unhappy. Professionals and parents interviewed, outlined money skills and the ability to prioritise and plan ahead as very important DLS. They believed that the young people needed to practise several DLS on a regular basis and possibly within groups and away from home to acquire more independence. Thus, the importance of professional support with a focus of instilling self-confidence in the young people were outlined as potential ways of minimising the barriers to DLS.

Other barriers outlined revolved around family matters, such as parents being too protective. Parents' over-protectiveness was another barrier perceived from different angles by the participants interviewed. While parents attributed their fears of letting go to societal and systematic barriers, professionals perceived it as the parents' difficulty to recognise the need to 'let go'. Despite the negative experiences the young people had been through, they expressed a wish for their parents to address their fears and encourage their children to be more independent. Parents interviewed put part of the blame on their very hectic lifestyle, while professionals emphasised that DLS were not on the parents' priority list. The young people contradicted both views and expressed an appreciation for their parents' dedication to teach them DLS despite their very busy lives. To counteract such barriers, participants outlined the importance of parents' persistence when addressing DLS, and parental support.

The next chapter will discuss the findings from the three data collection methods used, that is, the Q sorts, the DLS checklist and the in-depth interviews in the light of the studies discussed in the Literature Review chapter.

CHAPTER 7
DISCUSSION OF THE FINDINGS

7.1. Introduction

This chapter will reiterate the main aims and research questions of this study and give a brief reminder of the research methods used to collect the data. The main findings will be discussed in terms of which DLS are considered important by the four groups of participants, and what the potential barriers and promoters of DLS are. Putting the Barriers before the Promoters is intended to give the reader a better understanding of the difficulties encountered before presenting what might be done to alleviate them. The views of the different stakeholders, namely, the autistic young people, their mothers and fathers and the professionals will be compared and contrasted. Further analysis will reflect on the findings of other studies in the literature.

This study used Q methodology to explore the views of autistic young people, their parents and professionals on the promoters and barriers of DLS. A DLS checklist was developed to identify the participants' high and low priority DLS. Moreover, in-depth interviews were used to gather a more comprehensive understanding of the lived experiences of eight of the participants across the different stakeholder groups. The use of Q methodology enabled a systematic approach to understanding the views of the different stakeholders. The post-sorting interview with every participant allowed them to explain why they had decided to sort their statements in the way they did.

It cannot be claimed that the views and experiences gathered through the Q sorts and interviews represent all possible views held by these groups in Malta. Each family and young autistic person is unique. Nevertheless, the findings do report on real life experiences and will serve to guide an understanding of priorities in DLS and their promoters and barriers.

7.1.1. Factors that emerged from the Q sort exercise

Throughout this chapter, reference will be made to the Factors and the participants exemplifying them. For ease of access for the reader, the tables below serve as a reminder of the different views that each Factor represents:

Table 55. Barriers Factors

Factor	**Participants**	**Views**
Factor 1	2YA, 3M, 3F, 5 Profs	Barriers mostly arise from parents' beliefs, attitudes and fears. DLS are not being taught through direct teaching
Factor 2+	2YA	Fear, anxiety and frustration when we fail at DLS. No opportunities to discuss our wishes. Society's negative attitudes are impeding
Factor 2-	2 Profs	Key barriers arise from the young people's lack of interest and need to perform DLS. Parents do not accept their condition and do not encourage them to do DLS
Factor 3+	1M, 2F	Barriers stem from young people's difficulties in decision-making, organisational and flexibility skills, uncertainty about their abilities and a lot of anxiety
Factor 3-	1M	Barriers arise from low expectations of parents, professionals and educators. Parents may be too busy with commitments and give importance to academic skills rather than DLS

YA: Young adults; M: Mothers; F: Fathers; Profs: Professionals

Table 56. Promoters Factors

Factor	Participants	Viewpoint
Factor 1	1YA, 3M, 2F, 5 Profs	Parents should teach DLS despite challenges. Professional support is necessary. Emphasis on the death of parents is a negative motivator and instils anxiety
Factor 2	4 Profs, 2M, 1F	Professionals are key stakeholders. Parents' consistency and reassurance are essential. Generalisation of skills is fundamental.
Factor 3	2YA, 1M, 1F	Collaboration between parents and professionals. Both need to be knowledgeable about autism. Young people have a desire to learn DLS. Structured teaching strategies are not effective.
Factor 4	2YA, 1M	Living in an inclusive society surrounded by people who believe in them is important. Confidence is the key to the young people's performance

YA: Young adults; M: Mothers; F: Fathers; Profs: Professionals

7.2. DLS which stakeholders prioritise

The findings showed that all mothers and fathers agreed that personal hygiene routines including showering regularly, shaving, and brushing teeth are high priority DLS. The professionals also acknowledged the importance of showering regularly but considered household safety as very important as well. The young people agreed on the importance of personal hygiene and a neat appearance, and highlighted the importance of budgeting. However, this was the only group who considered it high priority to keep windows and doors locked, particularly when they are not home and during the night. It is likely that young people feel insecure when they are alone which might be underpinned by negative experiences they have had, as will be detailed in the sections below.

These findings do not match those found in earlier studies. For example, participants with a learning disability in Haigh et al.'s study (2013) mentioned skills like cooking and travelling as highly important. Moreover, a study on adult outcomes (Wittemeyer, *et al.*, 2011) revealed that autistic adults felt that community skills such as shopping, using money, and public transport were very desirable DLS. The findings of the current study were similar with regards to money skills, which were considered one of the most important skills by more than half of the participants (n=21), with parents rating this the most important. In the in-depth interviews, parents reiterated the importance of money and budgeting skills. Their young people tended to spend large amounts of money on unnecessary items such as, more than one mobile phone, and buying more than one take away meal until they spend all the money in their wallet. Parents also worried about their sons being cheated on because they lacked the skills to recognise that others might be tricking them. Professionals agreed that money skills are very important but they argued that these are often not addressed directly by parents due to parents' fear, which is sometimes transferred on to the young people.

In another study by Wang and Berg (2014), autistic participants said that driving a car or riding a scooter was a priority, for bettering their vocational opportunities. However, learning to drive a car was considered low priority by the young people in this current study, possibly because Malta is a very small island, where one can easily use public transport to travel to different destinations in a short time. In addition, Maltese parents generally keep on driving their young people to places until they acquire their driving licence, even when they do not have any special educational needs or learning difficulties. It is therefore considered normal practice for young people in Malta to depend on their parents for travel. However, as a practitioner, I often find that the parents of young autistic people are scared to let them drive. Further research is needed to determine whether learning how to drive a car might have an impact on other areas of independence and autonomy such as, making their own decisions.

7.3. Barriers to developing DLS

The data from this Q sort elicited three distinct views on what constitutes a barrier, two of which are polar opposite. These were analysed together with the post-sorting interviews and the data from the in-depth interviews. Following these analyses, three categories for the Barriers to DLS are:

(i) Executive Functioning (EF) difficulties

(ii) The effect of negative experiences on young autistic people

(iii) Familial and cultural aspects

7.3.1. Executive Functioning difficulties

The findings indicate that a possible barrier lies in one of the core difficulties of autism, that is, their executive function (EF) processes. It is a term that refers to a number of cognitive processes such as, planning and sequencing events, mental flexibility, initiating and inhibiting responses, and controlling impulses (Robinson *et al.*, 2009).

There is a similarity between Barrier Factors 2+ and 3+ consisting of two young people and three parents respectively. The findings demonstrated that a difficulty to plan ahead and organise, the inability to cope with change or something out of the ordinary, and their lack of flexibility were considered main barriers. This was confirmed by the interview data from parents who felt that their sons do not perceive the need to learn DLS due to their difficulty to foresee the future and to plan ahead. Parents also gave practical examples of their sons’ difficulties in controlling their impulses when it comes to shopping. This often left parents with no choice but to control the amount of money their sons were trusted with. The difficulty in prioritising tasks, which is also a sign of an impaired EF (Attwood, 2006) was also highlighted as a drawback to carrying out DLS and being independent.

Viewed from the alternative perspective of Factor 2- (consisting of 2 professionals), although a difficulty to plan ahead was not regarded highly problematic, other EF processes like the planning and organisation of steps to carry out DLS, and the ability to generalise skills, were considered an impediment. Similar to parents, in their interview accounts, professionals confirmed the Q sort findings and claimed that the young people often lacked the ability to envisage the future and the DLS they would need in the coming years. These findings support the results of a longitudinal study by Pugliese et al. (2015) who reported that difficulties in EF processes are a barrier to independence outcomes. Since executive functioning encompasses many essential areas of DLS such as cooking, money handling, self-care and household chores, these findings suggest that further consideration should be given to addressing EF processes from an early age.

As many as 11 (1 YA, 3 M, 2 F, 5 Profs) of the 34 participants, representing Promoter Factor 1, agreed that opportunities to acquire such skills and to participate in DLS should start from a young age. These are in agreement with professionals in other studies (e.g. Wittemeyer *et al.*, 2011) and autistic adults (Grandin and Panek, 2013; Blackburn, 2010). In autism one cannot assume that a skill can be picked up just by watching others. Tasks need to be broken down into concrete steps and practised several times (Sarris, 2014a). However, participants in this study felt that DLS were not given the importance they deserved, and in Barrier Factor 1 (2 YA, 3 M, 3F, 5 Profs), the lack of direct and explicit teaching of DLS was considered to be a main barrier.

Narrative accounts of the professionals and two parents further supported the idea that DLS are generally not set as priorities by parents. Wittemeyer et al. (2011) also found a similar attitude particularly in the childhood years. Instead, parents tend to focus on issues such as behaviour management and academic skills (Sarris, 2014b). Consistently, Barrier Factor 1 identified the importance given to academic skills as a major barrier. Similar to the findings of Wittemeyer et al. (2011), in this study, all interview participants claimed that DLS were also completely overlooked by the school system, with one mother describing schools as “a hopeless case” (PM1). Schools tend to work towards the National Curriculum and often limit the teachers’ flexibility to address DLS. Despite having an Individualised Educational Plan (IEP), the focus is often on fitting these students neatly in the education system rather than adapting the system to accommodate their real and long-term needs. In the Maltese system, the concept of inclusion is often given an opposite definition to that defined by Jordan (2008, p. 13), that ‘to treat people equally we have to treat them differently, not the same.’

7.3.2. The effect of negative experiences on young autistic people

Scholars supporting the nurture position of the *nature-nurture debate*, would argue that human responses, mindset, aspirations, attitudes and expectations are shaped by our experiences. The findings of this study highlighted this view, quite unexpectedly, with as many as six parents (PM1, PM4, PM6, PF1, PF2, PF3) and four young people (YA3, YA5, YA7, YA8) pointing their fingers towards negative childhood experiences as a main reason for difficulties in acquiring DLS and independence later on.

The young people representing Barrier Factor 2+ were afraid of doing something wrong, and negative thoughts and experiences were viewed as the main barriers which caused them a lot of anxiety. Consistently, the parents demonstrating a Barrier F3+ view, recognised that young people experience a lot of uncertainty and fear about their abilities which restricted them from taking the initiative to perform DLS. These findings are in line with those of previous studies (e.g. McCollum, La Vesser and Berg, 2016; Cheak-Zamora, Teti and First, 2015) which also found that autistic youths and adults experience uncertainty, fear and doubt about their abilities to do particular skills independently. What this study further highlights is that some young people and parents believed that such fears are underpinned by past negative experiences. The interview findings corroborated the Q sort results and revealed a number of experiences which participants felt had left a negative impact on them. All four parents and the two young people blamed their fear of failure on childhood bullying and peer exclusion, being reprimanded for mistakes and, feeling unsuccessful and not understood by teachers and peers. These experiences they felt, made them feel scared of facing new challenges in life and discouraged them from trying out new things. These findings support other studies which show that autistic people often develop negative beliefs about themselves (Han et a l., 2021)

Research suggests that the prevalence estimates of bullying for instance, among autistic students is higher than that of NT peers or other special educational needs (SEN) groups (Humphrey and Hebron, 2015). Moreover, various studies indicate that autistic young people have lower participation rates in DLS than NTs (Wang and Berg, 2016) and indeed the lowest rates among other SEN groups (e.g. Anderson *et al.*, 2014; Orsmond *et al.*, 2013; Shattuck *et al.*, 2012). Interestingly, the findings of this study showed a potential association between undesirable experiences and the development of DLS. Similar to the accounts of other autistic adults, such as Clare Sainsbury (2000), participants in this study described the psychological effects of bullying as having a long-lasting, devastating effect on them. Such experiences seem to have led to internalising symptoms such as anxiety and fearfulness in some of the participants. This is in line with findings of other studies whose participants shared how negative experiences had led them to develop negative beliefs about themselves (e.g. Hal et al., 2021; Cage Di Monaco and Newell, 2019). What this study has also revealed is that such experiences and a negative self-worth were withholding the young people from seeking to learn and participate in DLS.

Although the Barrier Q set made 50 possible statement configurations available to the participants, the post-sorting and in-depth interviews shed light on barriers other than those included in the Q sort exercise. This reaffirms that a plethora of other subjective experiences exist and are worthy of note. For instance, this study found that all four parents who were interviewed believed that their young people felt inferior because of their autism. Leedham et al. (2020) found similar attitudes among their participants who felt that they could not integrate autism into their identity. This was also voiced by other parents during the post-sorting interviews. They said that although their sons had wishes for the future, they tended to think that they would not become independent because of their autism. On the other hand, professionals representing Barrier Factor 2- interpreted the young people's hesitation to participate in DLS as a lack of interest to learn, and a result of failing to acknowledge the need for independence. The young people exemplifying Barrier Factor 2+ did not agree with this view. They reiterated that negative experiences affected their self-confidence and consequently they were hesitant before attempting something new, which in turn delayed their motivation.

These young people also admitted that they felt influenced by the negative attitudes of people in society. The same sentiment was expressed by participants in Cardona's (2013) study who described the attitudes of the Maltese population towards disability as a major constraint to their independence. Although this may have been thought to be a Maltese characteristic due to Malta's location, size and the influence of the Catholic Church (Camilleri, 1999; O'Reilly Mizzi, 1994), literature shows that this negative perception and misconceptions about autistic people are a reality in other countries as well (Dickter et al., 2020). This aspect was overlooked by the professionals and parents representing Barrier Factors 2- and 3+. However, participants representing the most dominant Barrier Factor 1 (2 YA, 3 M, 3F, 5 Profs) gave more value to societal barriers and believed that parents' fear and worry about others' judgement was a main barrier.

This finding was supported by the parents' interviews where parents admitted that they felt scared of people's reactions when their sons were alone in the community, and worried about their lack of skills to deal with these. Other studies show that parents express uncertainty about their young people's awareness of consequences and the ability to distinguish between right and wrong (Mitchell, 2012; Saaltink *et al.*, 2012). A study carried out in Canada (Saaltink *et al.*, 2012) found that parents' preoccupation about society's perceptions of their family and young people with ID influenced the extent to which they encouraged their independent functioning. Meanwhile, in this study, the young people of Barrier Factor 2+ were aware of their parents' fears of them being bullied or exploited in the community. The professionals believed that such fear could be transferred through the parents, resulting in the young people's reluctance to learn new skills.

7.3.3. Familial and cultural aspects

This study identified that one of the main barriers concerns familial and cultural aspects to DLS and independence. Thus, in order to better understand this, reference to the Family Systems Theory (FST) and the Maltese culture will be made. The FST is derived from *systems theories* which view objects as interrelated with each other. Through the lens of the general systems theory, the family is viewed as a whole. It is an interactional system made up of family members who are mutually dependent on each other. FST provides an explanation to why family members behave the way they do (Fingerman and Bermann, 2000).

The FST serves as a useful framework to understand the complex interactions between family attitudes, beliefs and mindset, and their impact on DLS and the independence of the young people. The findings of this study showed that one of the main barriers is the parents' tendency to be over-protective of their autistic sons. This was outlined by the most dominant Barrier Factor 1 (2 YA, 3 M, 3F, 5 Profs) and Factor 3- (1 M). These views showed that parents were scared to let go of their young people. This was corroborated by all the interview participants who acknowledged the parents' fear. This is also in line with Grech and Aquilina (2011) who describe Maltese parents as over-protective, especially when their children have a disability.

However, the professionals interviewed had a different understanding of parents' fears, and attributed their *over-protection* to not knowing when to stop giving in. On the other hand, the young people interviewed expressed a need for parents to face their fears and work on those aspects that hindered their independence. This sentiment was also expressed in other studies (Cardona, 2013; Shogren and Broussard, 2011), where young people with ID considered over-protective parenting as a major barrier to their independence. These types of families are what the FST would describe as 'enmeshed', as opposed to 'disengaged' (Minuchin, 1974, in Sturge-Apple, Davies and Cummins, 2010, p. 1320). According to Minuchin (1974), extreme cohesion in families often results in over-protective parents, where independence is less encouraged. In enmeshed families, the individual's identity and behaviours are seen as a reflection of the family rather than a quality of the individual member. This puts more pressure on parents to protect the family's image with society, particularly in a country like Malta where the phenomenon of *honour and shame* is given a lot of importance. Moreover, parents feel pressured by societal barriers, such as misconceptions about autism, harassment and maltreatment of their young people while they are unsupervised in the community.

According to the FST, family characteristics are highly influenced by factors which may be internal to the family such as, family values, or external like cultural and societal expectations (Allen, 1982). Indeed, this study found that parents also worry about others' judgements. Gossip has an influential means of social control in Malta (O'Reilly Mizzi, 1994) and the Maltese give value to having a good name and reputation. Thus, this could be one reason why parents were preoccupied about society's perception of their young adults, and in turn their family, which could be keeping them back from empowering them to learn DLS. It seems that autism is still perceived negatively by many in Malta. This is similar to international studies, even very recent ones which found that stigma remains common (Gillespie-Lynch *et al.*, 2020; Butler and Gillis, 2011) even though attitudes towards autism appear to be improving (White *et al.*, 2019). In fact, in Malta, giving the diagnosis to the young people is often feared by many parents and some professionals. Within some families, a member's autism diagnosis is kept secret from the extended family and friends. The Q sort findings also showed that parents have low expectations of their autistic young adults. This was expressed by the parents in the interviews, who said that they would like to trust their sons more, but fear often takes over as they doubt their abilities to perform certain skills independently. Similarly, Di Gennaro et al. (2014) found that parents of youths with ID did not believe in their youths' abilities and skills to do household chores safely.

Despite parents' worries about when they will be no longer able to support their young people, parents often communicated an inner resistance to encourage their sons to live independently away from home. Bowey, McGlaughin and Saul (2005) state that terms associated with independence may cause parents a lot of anxiety. In fact, Promoter Factor 1 participants did not agree that talking about parents’ death could be a promoter of independence. The parents exemplifying this factor felt strongly that communication about such events would instil in their young people a lot of anxiety and have a rebound effect on their learning of DLS. Bowey and McGlaughin (2005) reported similar findings where caregivers avoided discussions about independent living opportunities. However, the reason they gave was that they did not want their youth with ID to feel unwanted. In this study, a similar thought was expressed by the young people interviewed, who felt that they would ‘insult’ their parents if they showed a desire to leave home. Ros Blackburn, an autistic woman (2010) is in total disagreement with this lack of communication about the death of parents. She admits that although it is not something pleasant to think about, it is wiser to discuss it than to deal with the crisis when it eventually happens.

Literature shows a recurring lack of communication in these families where adults with learning difficulties (LD) do not express their aspirations to do DLS more independently (Bowey and McGlaughin, 2005). Meanwhile some participants in this study believed that parents do not discuss the importance of DLS and do not encourage their young people to perform DLS (Barriers Factor 1 and 2-). This lack of communication very often leads to incorrect opinions and perceptions between parents and their adolescents about each other’s opinions and sentiments towards independence (Cheak-Zamora, Teti and First, 2015). All interviewees agreed that the young people often get used to being cared for and do not show interest in performing DLS. Although some young people may feel comforted by the routine of everything being done for them (Cheak-Zamora, Teti and First, 2015), the young people in this study still expressed a wish to learn DLS and felt a sense of pride when they were given small chores. These views did not seem to be known to their parents and professionals who focused on the young people's lack of interest. Family systems are characterised by roles and rules which are entrenched in the cultural and familial contexts. These are often established through communication processes within the family system (Allen, 1982). Through this framework, there appears to be a difficulty in the communication system both within the family and with *suprasystems* outside the family, that is, the professionals. It is likely that this is another reason why the young people are not involved in DLS within the household.

Bowey and McGlaughin (2005) found that a lack of involvement in family responsibilities of young people with ID impacted on their self-confidence. In this study, the young people's self-confidence had been affected by negative past experiences. Their lack of involvement in family roles and responsibilities could be both a result and a reinforcer to their negative self-image and low self-confidence. This suggests the importance of addressing this aspect, especially since studies show that when young people are not assigned any valued roles and duties at home, their level of happiness is negatively impacted (Haigh *et al.*, 2013).

Another finding of this study showed that parents were often too busy with other commitments (Barrier F1 and F3-) and life was too hectic for them to find time to teach their young people DLS (Barrier F 2+). In the interview, two young people claimed that they lacked the opportunity to discuss their wishes. The parents interviewed confirmed this and admitted that it was also very difficult to find time to practise DLS with their young people. These findings are consistent with those of McDaniel and Pisani (2012) who reported that families find it difficult to achieve a balance between the demands of teaching DLS and the competing needs of other family members.

7.4. Promoters of DLS

The data from the Q sorts elicited four distinct viewpoints about what constitutes the Promoters of DLS for autistic young people. For the purpose of this discussion, these were analysed together with the post-sorting interviews and the 8 in-depth interviews. Three categories were chosen through which the viewpoints of the different stakeholders are compared and contrasted. The chosen categories are consistent with the Q set statements and interview questions. They also provide some relevant answers to the Barriers outlined in the above sections. The three categories for the Promoters of DLS which will be discussed are:

(i) Qualities of the parents
(ii) Qualities of Professionals and significant others
(iii) Strategies to promote the development of DLS

7.4.1. Qualities of the parents

This study found a consensus between Promoter Factors 1, 2, and 3 on the essential role of parents. As many as 22 (3 YA, 5 M, 5 F, 9 Profs) out of the 34 participants rated the various qualities and attitudes of parents as necessary for the development of DLS and independence of their young people. These findings were corroborated by the interview data from all the eight participants. To my knowledge, research in this area is not abundant.

This study found that parents' persistence and perseverance are thought to be of the utmost importance, despite the daily challenges they face. This was echoed by all the participants interviewed across the different stakeholder groups. The young people viewed parents' persistence as a continuous form of encouragement, which is a key contributor to their success and confidence building. They emphasised that parents should not lose heart because that gives them the courage to keep on trying. This is in line with Woodman et al.'s study (2016) who found that autistic young people whose mothers had a positive outlook to life and used praise and positive remarks, had better functional outcomes. The parents and professionals interviewed agreed that persistent parents reinforce the young people's motivation and empower them to overcome their fears and try new skills.

Persistence ties in with another quality highlighted in this study, that is, consistency while teaching DLS. While there is great agreement among participants about the importance of these characteristics, parents admitted that life is very hectic and sometimes it is easier to do DLS themselves than to teach their young people. These findings suggest that parents' commitments could pose a detriment to the importance of consistency and persistence.

Similarly, exposing their young people to different life experiences is bound to be dependent on the time that parents can allocate. However, in line with the Barrier findings of this study, exposure to different learning opportunities is likely to address the difficulty of generalisation as a result of EF difficulties. This study suggested that parents should encourage their children to help out with everyday DLS from a young age, and offer a lot of reassurance. This is in line with other studies (Brannen, Heptinstall and Bhopal, 2000; Brannen, 1995) which point to the significance of children's opportunities within the family to undertake varied responsibilities for everyday chores and life skills to promote autonomy and independence. In their interview accounts, the two young people expressed that being given small chores would strengthen their skills and help them to become more confident. This confirms the findings of other studies (Farlow and Snell, 2006; Sowers and Powers, 1995) which emphasised the importance of daily chores and responsibilities within the family and its effect on the development of self-determination skills. Moreover, involvement in the family routine can enhance the young people's happiness (Haigh *et al.*, 2013).

7.4.1.1. A sound support system for parents

This study found that participants valued parents' knowledge about autism as a medium of more understanding and thus, better guidance about DLS and independence. This was revisited during the interviews with all the participants emphasising the importance of support for parents. Curryer, Stancliffe and Dew (2015) argue that a comprehensive plan to promote the functional independence of people with ID and developmental disorders should include working with families to understand the importance of their role in promoting their young people's life skills. Consistent with the Q sort findings, in the interview accounts, the young people emphasised the importance of professional support for their parents to understand them better and acquire practical suggestions on how to teach them DLS. Parents expressed a similar need for opportunities to discuss daily situations and feel supported in attempting new tasks with their sons. Consistently, professionals highlighted the necessity of supporting parents especially with their fears to help them become less protective. Through the FST framework, where families are understood as systems, the whole family should be the target of intervention rather than the young adult. A change in the behaviour of one member is likely to create a *ripple effect* and the whole family system undergoes a readjustment process (Kerr, 2000). Thus, through support, parents may become less anxious about the letting go of their sons and realise that their young adults are able to learn and perform DLS, which in turn can impact on the young people's motivation and courage to try DLS.

Interestingly, all participants across the different stakeholder groups mentioned *parent support groups* as a medium of intervention that would help parents feel part of a community of parents going through similar challenges. Professionals believed that these groups could alleviate parents' fears, instil courage, and motivate them through success stories. These findings reflect the framework of the FST which points out that when a family member has a condition which necessitates the assistance of outside support services, the family's external boundaries may become more permeable. These would allow more opportunity for sources outside the family to impact on the characteristics of the family system.

7.4.2. Qualities of professionals and significant others

A general consensus seems to hold between all the Promoter Factors in terms of good professional support. However, literature on this topic is scarce. It is therefore difficult to compare the findings of this study to that of others. All participants in this study viewed professional support as detrimental for the development of DLS and independence. In particular, parents described professional support as a prerequisite both for their young people and themselves. An emphasis was made on particular qualities which participants believed professionals need to have to make a positive impact on the wellbeing of the young people. Professionals need to be people who believe in the young people's abilities and skills and offer hands-on support through listening, understanding and teaching.

In the interviews, the young people gave importance to specific qualities such as, being 'patient', 'empathic' and 'good listeners', and 'having experience in the psychology of people'. Such qualities they believed would provide them with opportunities to talk about their negative experiences in confidence. The Danish philosopher Knud Ejler Logstrup (2007, in Gerland, 2013) assigns great importance to trust and empathy in a professional-client relationship. Only through such values can professionals understand the young people's position and attitudes towards life, and guide them forward (Gerland, 2013). In their interviews, professionals acknowledged the importance of such qualities and recognised that an important part of their role is to instil confidence in the young people and to create opportunities for them to feel useful and contribute. This they believed is the first step to help them become mentally ready to attempt new DLS.

In this study, professionals were described as a point of reference for the young people as well as their parents. They help the young people put the past into perspective, address their fears, rediscover themselves and attain self-acceptance, while offering a shoulder for parents when they feel alone and in doubt on how to address particular situations. The young people also emphasised the importance of professionals and parents' collaboration, which helps them build trust in the professionals and strengthens their support system.

Factor 4 took the aspect of important qualities further and emphasised the significance of being surrounded by people who focus on their strengths and abilities. Young people go to school, college or to work and, in such places the attitudes of educators, friends and colleagues also prove to be an important factor. The two young adults and a mother representing this Factor gave a lot of weight to qualities such as being calm and believing in them to instil confidence in the young people. Shogren and Broussard (2011) found that others' negative attitudes and expressed doubt in their abilities, resulted in lack of confidence in their participants with ID.

The ultimate achievement would be to live in an inclusive society where people hold positive attitudes towards autistic people. Research shows that the expectations of significant others are implicated in the young people's wellbeing, developmental course and independent outcomes (Woodman *et al.*, 2016; Test, Smith and Carter, 2014). As discussed previously, the findings of this study implied that a lack of constructive and helpful attitudes from the people who they had met in their lives had impacted greatly on the young people's wellbeing, making it more difficult for them to acquire important DLS for their independence.

7.4.3. Strategies to promote the development of DLS

Damian Milton, an autistic adult and academic confirms that research on interventions often does not focus on the views and wishes of autistic people. A positive characteristic of this study, I believe, is that it listened to the voices of the young people as well as to their parents and professionals in the field.

Views were varied among the different factors as to which interventions and strategies are most effective for the development of DLS. Promoter Factor 1, which is the most dominant view (1 YA, 3M, 2 F, 5 Profs) considered regular opportunities to participate in age-appropriate DLS an effective medium. This is in agreement with the parents' interview accounts who maintained that being given opportunities to feel successful, such as being given a role to help someone, would increase their young people's motivation. This is confirmed by the findings of two studies (Humphrey and Lewis, 2008; Rosetti *et al.*, 2008) which reported that being assigned responsibilities gave the young adults a sense of satisfaction and an aspiration to become more independent. Factor 1 also gave importance to teaching DLS from a young age. This is in line with the educational practitioners' opinion in Wittemeyer, Charman and Cusack's (2011) study who highlighted the importance of teaching simple basic DLS to young children, and gradually building on those skills as the child gets older.

In Factor 2 (4 Profs, 2 M, 1 F) importance was given to role play, and the observation of others. In the interviews, professionals supported this view and maintained that direct guidance and teaching of DLS is necessary. These techniques are similar in principle to video-modelling techniques but instead of using technology they have person-to-person contact. Factor 3 (3 YA, 1 M, 1 F) gave priority to learning through repetition and feedback, and giving the young people time to learn at their own pace, while Factor 4 (2 YA, 1 M) emphasised teaching DLS as part of the school curriculum. All the interview participants complained that schools do not address any DLS. Similarly, Wittemeyer, Charman and Cusack (2011) found that autistic adults were dissatisfied with the school system which had not prepared them for an independent adult life.

While the Promoters Q sort gave the participants a choice of 18 statements related to strategies and techniques that could promote the development of DLS, only the aforementioned were considered good promoters of DLS. For instance, the finding of Promoter Factor 3 (which includes the viewpoints of two young people, one mother and one father), that structured teaching was not considered helpful, is indeed very interesting in this regard. Moreover, the interviews gave rise to other intervention strategies with similarities across participant groups. As a reaction to the identified barriers, and building on to the promoters, the focus of all the interviewees was on strategies that would address fears arising from the past. The findings showed that participants valued intervention sessions with professionals to rediscover themselves, address their problems and to take control over themselves. The young people claimed that professionals’ encouragement was very effective in overcoming their fear of doing something wrong. This would in turn help them to move onto the next step of skill building.

Another type of intervention strategy that was highlighted by all the interview participants was group intervention. The young people claimed that discussions in groups were very effective to talk about negative emotions, share thoughts and experiences and explore future wishes. Professionals agreed that group sessions were beneficial to help the young people imagine together how their lives would be in a few years' time and to become aware of the importance of DLS together. Such discussions could also address EF difficulties such as planning. Moreover, group sessions could serve as brainstorming exercises about the pros and cons of learning DLS and living independently, and include discussions about fears they hold about the future and living alone. Cheak-Zamora, Teti and First (2015) found that those who wished for more independence did not know how to change the situation at home and avoided communicating about it. Group sessions could be a platform for them to communicate their wishes with their peers in a safe environment. Thereafter, professionals could empower them and support them to communicate such wishes to their family.

Research shows that living with parents leads to poorer DLS competence for LD and autistic young people alike (Haigh *et al.*, 2013; Smith, Maenner and Seltzer, 2012). The findings of this study were similar. All participants who were interviewed agreed that community outings and live-ins (when a group of young people live together for a specific time under the supervision of professionals) gave the young people empowerment and motivation to attempt DLS like shopping, cooking, self-care, and to address generalisation of skills in different environments. They also became aware of daily priorities and gave them courage to face their fears. Finally, this study found that hands-on activities, such as helping out at the MAC were very beneficial because they instilled in them a good sense of self and were more meaningful when carried out in a group. This is in line with other studies which show that responsibility for participation in DLS can contribute to the development of choice and decision-making and is likely to promote the individual's self-confidence (Wehmeyer *et al.*, 2004; Sowers and

Powers, 1995). Thus, the present findings suggest that experiencing DLS rather than learning them through traditional means could be more effective for adults' independence.

7.5. A summary of the key points arising from this study

The discussion of the findings started with those DLS which participants thought were of high or low priority. An agreement among participants emerged about the importance of personal hygiene routines and money skills. Parents expressed particular concern about budgeting skills which put a lot of pressure on them as to how much they should allow their young people to be independent in this area. On the other hand, travelling skills and laundry chores were agreed to be the least important DLS among different stakeholders.

The remaining discussion of the findings was two-fold. It highlighted six categories: three elicited from the analysis of the Barriers data, and another three from the Promoters of DLS data. Together, they narrate the participants' stories and bring out their individual world views and voices about their daily experiences of DLS and independence. Executive functioning difficulties, the effects of negative experiences on the young people, and familial and cultural aspects, were the three main Barrier categories. On the other hand, the three Promoter categories were qualities of parents, professionals and significant others, and strategies that promote the development of DLS.

The young people pointed their fingers mainly to societal barriers, claiming that negative past experiences like bullying, had taken away from them the much needed confidence to attempt DLS and to believe in themselves to become independent adults. As a result, they lacked the desire to learn new skills. The young people emphasised the importance of living in an inclusive society surrounded by people who believe in them. This wish is similar to the one expressed by the participants of Lee et al. (2021) who wished to neither be glorified nor misjudged, but accepted for who they are. The young people were critical of structured teaching as an approach to learning, but agreed that exposure to different life experiences, and being given small chores, helped them to become more confident. The young people also valued parents' knowledge and collaboration with professionals. They believed that it enhanced understanding of their difficulties and resulted in more support to help them attempt new skills.

Similarly, some parents agreed that structured teaching was not effective, but could rather make their children less flexible in their approach to life. Parents acknowledged the difficulties in EF which make it difficult for their young people to be flexible and take decisions according to priority on a day-to-day basis. Parents were also concerned about their young people's difficulties to control their impulses especially when it comes to money and prioritising tasks. They called for more direct teaching and practical hands-on training of DLS, and giving the young people small responsibilities that would empower them and instil back in them self-confidence. Anxiety and lack of self-worth and confidence were observed by parents as main difficulties. These were emphasised again in the interviews, whereby parents associated these difficulties with past negative experiences.

Parents still believed in the importance of their persistence despite all these challenges. However, a sense of protection was present among parents. They emphasised that discussions about their eventual passing would instil more anxiety in their young people. In the interviews, a sense of hesitation was communicated by the mothers and fathers, to see their young people walk away from their home and out into the world. This reluctance often surfaced from memories of negative past experiences that their young people had been through, and thoughts about a society that lacks autism knowledge. Parents were aware that their own fears were indeed causing their young people barriers to achieving DLS and independence, and emphasised the importance of professional support for themselves and their young people.

Both the young people and their parents were influenced by society's judgements and negative attitudes and parents felt fearful to let their young people be alone in the community. However, a divergence in the opinions of the professionals interviewed was observed, as they interpreted such hesitation as the young people's lack of interest to learn, and parents' difficulty to realise when they should stop giving in. Most professionals perceived the difficulty to learn DLS and become independent as a familial issue triggered mainly by the parents' beliefs, attitudes and fears. They emphasised that parents should persist and be consistent in teaching their young people DLS, and offer them reassurance, despite the challenges they faced. Moreover, they emphasised that professional support was necessary.

The results and discussion of this study indicate inconsistent communication between the parents, their young people as well as the professionals about the topic of DLS. Such lack of communication resulted in a misunderstanding by both the parents and the professionals, whereas parents undermined their young people’s wishes to learn DLS and professionals misinterpreted it as lack of interest or parents’ over-protection.

Based upon the results and discussion above, there were varied views across factors about effective strategies. The most dominant view was about regular opportunities to participate in age-appropriate DLS from a young age. These would help the young people feel successful and enhance their motivation. Others were role-plays, observation of others, and direct teaching. Participants agreed that DLS should be included in the school curriculum. Moreover, this study emphasised that strategies that would address the young people’s fears arising from the past would help the young people to eventually move on to skill building. Group discussions were seen as a communication platform for the young people to share their past experiences and discuss how their lives could be in a few years’ time.

The next chapter will present the conclusions of this study and practical implications arising from the findings and discussion. It will also outline the limitations of this study and will make recommendations for future research.

CHAPTER 8

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE, AND RESEARCH

8.1. Introduction

This research sought to identify the views of autistic young people, their mothers and fathers, and professionals on the acquisition of Daily Living Skills (DLS) in terms of which DLS they believe need to be developed, and the promoters and barriers to developing such skills.

The study aimed to address the current lack of research on the gap that exists between the verbal and cognitive abilities of autistic young people and their independence skills. It responded to the call from researchers such as Duncan and Bishop (2015, p. 3) who argued that: '…it is critical to gain a clearer understanding of which factors are related to better or worse DLS in children and adolescents with ASD.'

This chapter will present the conclusions of this study, the implications for practice, its limitations and recommendations for future research.

8.2. The sample

The sample consisted of 34 participants, namely 9 autistic young adults, their mothers (n=9), their fathers (n=7), and 9 professionals. The sample was a convenience one. All the young people were members of the Malta Autism Centre (MAC) where I work. They all had good spoken language and cognitive ability, had a full-time or part-time job, or were in College at the time of the study. All the young people were between 16 and 30 years old, and still lived with their parents. All the professionals worked full-time (n=3) or part-time (n=6) at the MAC. Their professions varied. These were namely, 5 autism educators - 3 on a full-time and 2 on a part-time basis, 2 part-time speech and language pathologists, 1 part-time educational psychologist and 1 part-time social worker.

8.3. Research methods

This study used a number of different methods to address the research questions. A DLS checklist was developed by myself through a review of existing DLS checklists. This consisted of 50 DLS from the areas of personal hygiene and appearance, health care, cooking, housekeeping, caring for clothes, money, budgeting and travelling. This was used to identify which DLS participants believed to be high or low priority for independence, and their choice of the five most and five least important DLS were compared.

Q sort methodology (Stephenson, 1935) was used to identify the views of the participants on what helped or hindered the development of DLS. Fifty promoter and 50 barrier statements were created by myself following a systematic review of the literature and 8 informal discussions with 2 participants from each stakeholder group (2 young people, 2 mother, 2 fathers, and 2 professionals). During the Q sorting exercise, the participants were given two separate Q sorts, one for the promoters and another one for the barriers. They were asked to place each statement on a grid from -6 to +6 according to how much they agreed or disagreed with each statement. During this exercise, participants made their decisions by comparing statements with each other and decided which ones represented their views best. This method was used to highlight similarities in opinions about the promoters and barriers of DLS. Following the sorting exercise, participants took part in a brief post-sorting interview to explain their ideas behind their sorting and how they had chosen which statements to sort in the most agree and most disagree positions.

In-depth interviews were carried out with eight participants from the four different groups (2 young people, 2 mothers, 2 fathers, and 2 professionals) after the Q sort data collection was completed. The aim was to elaborate on the data of the Q sorts, and acquire a deeper understanding of the lived experiences of the young people, their parents and professionals.

8.4. Main findings

What the data revealed was that DLS acquisition is not merely about skill building but that many other factors contribute to their acquisition. Among such factors are the young people's Executive Functioning (EF) ability, their experiences since childhood, family and cultural beliefs, including parental attitudes and sources of support, the experience of professionals and strategies used to address DLS. The findings suggest that more communication is needed between the different stakeholders to identify differences in perspectives and to develop a consensus on which DLS to address. The autistic voice needs to be given priority when exploring what interventions and approaches might be useful. Due to their increased chances of experiencing negative incidents such as bullying, there is a need to identify what the young people believe would be helpful to improve their experiences and outlook for life, in terms of independence and mental health. Autistic people should be more involved together with other stakeholders in identifying what research questions need to be addressed, which methods should be used to bring out best their views and experiences and, be involved in follow-up projects to enhance autism practice.

This study differed from others in the literature in that it sought first-hand data from all the key stakeholders - the young people themselves, their mothers and fathers, and professionals, and did not take just one perspective. It was a linked sample in that people in each group lived or worked with the young person in the sample. So it was found that different people often held differing views on what was important and this was bound to affect the success or otherwise of the development of a skill.

8.4.1. The most important Daily Living Skills

The findings of this study highlighted a number of DLS which were identified by all the stakeholders as important, and others that only some participants felt were important. All stakeholders rated as priority personal hygiene, money and budgeting skills, and house hold safety. Road safety was perceived as a priority by mothers and fathers, while the young people and professionals gave importance to the skill of knowing what to do if they take a wrong bus. Personal healthcare was chosen as a priority DLS by all stakeholders except the young people. This could indicate that the young people still felt that their parents are in charge of such matters. In the interviews, the young people showed a sense of dependence on their parents when it came to their health care. Nonetheless, the young people still chose health care as one of the five most important DLS, together with personal hygiene and budgeting. Home safety was a priority for parents, while similar to the young people, professionals chose personal hygiene.

Money and budgeting was a common domain across the four stakeholder groups who chose it as one of the five most important DLS. In particular, all parents showed great concern about money skills.

Turning to low priority DLS, the young people and fathers chose driving their own car and other skills related to this as low priority. Mothers, fathers and professionals agreed that caring for clothes was a low priority and fathers did not give importance to household chores and preparing snacks. Both mothers and fathers gave less importance to caring for fingernails and toenails.

8.4.2. Promoters and Barriers of DLS

The findings of the Q sorts highlighted 7 Factors – four for the Promoters and three for the Barriers. Two of the Barriers factors were bi-polar, that is, a factor array has a positive pole and a completely opposite one, representing two opposing viewpoints.

Professionals and parents gave importance to parents' and professionals' roles in promoting DLS through consistency, reassurance and generalisation of skills. Three out of the nine mothers exemplified other factors indicating a wider diversity of views. Fathers were not confined to a particular view, although most gave importance to parents' and professionals' support. The young people identified collaboration between parents and professionals as a promoter, plus living in an inclusive society and having the self-confidence to attempt and learn DLS

Most of the professionals viewed parents' beliefs, attitudes and fears, and the lack of direct teaching as key barriers. Most mothers and fathers expressed similar views with two fathers and one mother identifying the young people's difficulties in executive functioning skills and anxiety as their main barriers to DLS. The young people, regarded their parents' fears and attitudes, their own anxiety, and society's negative attitudes as most impeding.

8.4.3. Findings from the interviews

Following the analysis of the data gathered from the eight interviews with two stakeholders form each group, six main barrier and seven main promoter themes emerged.

Participants agreed that main barriers to DLS were the result of negative past experiences that the young people had as children and teenagers, such as bullying, feeling different from their peers and being mimicked and excluded. Such experiences very often lead to a negative self-image and anxiety, robbing them of the desire to try new things such as DLS. Parents often took a protective role and carried out most of the DLS for them due to a fear of being ridiculed, and also as a result of a hectic lifestyle that most families had. To some extent, the young people got used to being cared for and showed no desire to leave their parents' home. This is also partly due to a fear of insulting their parents if they communicated a wish to live more independently.

Interview data revealed that these barriers call for good professional support which instils back in the young people confidence and a desire to learn and develop DLS. It was suggested by participants, that intervention should include sharing experiences in small groups, being given regular small responsibilities and opportunities to practice DLS away from home. The importance of parents' persistence was outlined by all participants as well as the necessity for parental support to enable them and empower them to help their young people develop DLS and become more independent.

8.5. Implications for practice

This section presents ways in which the findings can inform practice at centres such as the MAC and in schools, to improve outcomes for autistic people and opportunities for their education and eventual independence. There were seven key implications that emerged. The first was related to those DLS identified as priority or felt to be less important. The other six consisted of three emerging from the Barriers and another three from the Promoters of DLS.

Implications for practice that emerged from the findings of the Barriers of DLS were:

(i) teach EF and DLS directly and from a young age
(ii) acknowledge and address negative past experiences
(iii) treat the family as a *system*, and understand their culture, beliefs and attitudes

Implications for practice that emerged from the findings of the Promoters of DLS were:

(i) embrace autism as part of one’s identity rather than attach negative connotations to it

(ii) involve professionals in teaching DLS

(iii) educate the general public to create a more inclusive and understanding society

Each of these will be discussed in detail in the sections below.

8.5.1. The most important DLS

The different views between the different stakeholders discussed in Section 8.4.1 call for more efforts to build intervention programmes that cater for the individual needs of the autistic young person and their families. A list of questions may be required in the initial stages of intervention to identify priority DLS for the young people and their parents. Professionals may need to adopt the role of guiding the parents and the young people to arrive at a consensus and perhaps help them view the situation more objectively. It is necessary to build a better understanding of any differences and help them navigate through the situation. For instance, as the findings of this study showed, parents may not give importance to caring for fingernails and toenails. Although there may be various other important DLS to focus on, it is essential for parents to understand that dirty nails, apart from being unhygienic may also put people off socially which could be an added disadvantage to their young people.

8.6. Barriers to the acquisition of DLS and implications for practice

A key finding which came out very clearly from this study is that the acquisition of DLS and independence is not just skill-building. Many studies in this area have often set out to measure independence adult outcomes in terms of independent living, leisure activities, and employment (e.g. Wittemeyer, et al., 2011) and to quantify the amount of DLS and level of independence achieved in relation to the participants' verbal and cognitive abilities (e.g. Duncan and Bishop, 2015). Others have focused on the effectiveness of intervention techniques and work systems such as video modelling and structured teaching (e.g. Hume, Plavnick and Odom,2012; Bereznak et al., 2012; Carnahan et al., 2009; Ayres, Mechling and Sansosti, 2013). Such studies provide interesting findings and quantifiable results to the topic of DLS and independence which make researchers and practitioners question 'Why?'. The findings of this study brought out some key answers to this question through the voices of autistic young people, their parents and professionals in the field.

8.6.1. Teach Executive Functioning and DLS directly and from a young age

EF affects planning, sequencing and moving through the stages of a task. So it is important to teach these skills from a young age, through games, for example, that allow an object to represent something else, during imaginary and make-believe play. Play that allows children to make their own play props with objects that are not necessarily related to the game helps children to adjust their ideas and challenge their mental flexibility.

Attwood (2006, p. 236) coined the term ‘executive secretary’ as a technique to address the difficulty in organisation and planning skills. He explains that children and young people need an adult to take the role of an *executive secretary* to use strategies such as time schedules, *to do* lists and colour coding to help them learn and practise EF skills. Although initially, the young adult may depend on these techniques, eventually s/he may learn to do them independently through gradual fading of the adults’ help. For instance, young people at the MAC are trained and guided to set up an ‘after-school’ schedule to learn to manage their time to complete school work and studying and to manage to fit in some time for a hobby. Live-ins (where a small group of young adults live together for some days under the supervision of professionals) serve to practise various EF skills through joint cooking, and doing household chores such as washing the dishes and making a shopping list. Through such hands-on activities, young people are given the opportunity to train themselves on priorities, time management, and planning skills.

This study pointed to the importance of including EF skills and DLS as part of the school curriculum in the students’ IEP. This would allow such skills to be introduced from a young age. Another important factor is the method of teaching used. While research shows that direct and explicit teaching is very effective even with autistic students (Root, 2018; Knight *et al.*, 2011) the findings of this study showed that DLS are not being taught effectively through such an approach. This was emphasised by the participants of Barrier Factor 1 (the most dominant factor). Professionals exemplifying this Factor emphasised in particular that more importance is given to academic skills at a young age and no time is dedicated to teach DLS explicitly and directly.

This calls for EF and DLS to be taught through explicit instruction, which is a structured way of teaching through direct explanation, demonstration and modelling, guided practice, feedback and independent practice (Renard, 2019). An example of this kind of teaching is following a set of visuals or instruction to make a sandwich or cook a simple meal. Such techniques give explicit guidance and reinforce independence in the skill building.

8.6.2. Acknowledge and address negative past experiences

Another important implication derived from the finding that negative past experiences can impact the young people's self-confidence and instil in them a sense of fear, helplessness, negative thoughts, and a fear of failure. Anxiety often made it difficult for them to perform DLS. As a practitioner, it is observed that very often the area of DLS and independence may be viewed as a *cause and effect* phenomenon, where a list of DLS is set as goals and worked on. For example, the skill of *using public transport* would be broken down into a number of steps and the young person would be trained to achieve it. At times, DLS may be perceived in a vacuum, and practitioners may miss out on a very important factor – the context of what these young people have been through. Very often these would be treated separately, and if autistic people are experiencing anxiety, they would be helped to change their way of seeing things and taught techniques such as breathing exercises to control their anxiety. However, this study revealed that DLS and independence should well be perceived in the context of all the experiences that the young people have had since their childhood.

The finding that came out very clearly from this study is that DLS and the eventual independence of autistic people is not simply a matter of learning the skill of driving, cooking, and money handling but there is a very important context that needs to be addressed. This includes how the person perceives himself; societal issues and experiences that would have led him to view himself in a negative light, what are the messages that he is getting from the most important people in his life, such as the parents, school staff and peers, and other professionals; and fears and anxieties related to past experiences.

Therefore, an important aspect of a DLS curriculum which incorporates skill building, needs to address the issue of anxiety first. Professionals and parents need to promote the young people's self-management and self-confidence through empowerment and by adopting an autistic people-centred approach. Measures of their self-esteem and an assessment of their approach to a new task would be helpful in knowing to what extent their fear of failure might affect the acquisition of DLS. The young people need to be helped to manage their anxiety and face their fears, to be able to accomplish DLS and independence. Uncertainties about their abilities often derived from having built along the years, a negative perception of mistakes. Therefore, it is important that the young person's perception is changed to one that understands mistakes and errors as a normal part of life and an opportunity to learn, rather than a failure (Attwood, 2006). Such training also needs to start from a young age. It is beneficial if young children are given opportunities to complete simple tasks that they would have already mastered, independently without adult support. This is likely to help them feel successful and instil in them a sense of confidence from a young age. Such techniques can be used throughout the years as a reminder of their abilities and skills they have already achieved to instil motivation. A tangible record of their achievements using photos and videos stored on a computer or in a file that they can refer to, can be very useful here.

Many of the young people (7 out of 9) had experienced bullying and other research shows there is a higher incidence among autistic people than NTs (Bancroft *et al.*, 2012). The young people and their parents spoke about the effects of bullying and how such experiences created in them a lot of fear.

This can be more likely for students with average cognitive and verbal abilities in mainstream schools (Zablotsky *et al.*, 2014). So, it is recommended that bullying incidents are pre-empted and prevented as much as possible throughout the school years. Autistic students are likely to be exposed to *subtle* bullying due to their social naivety. Thus, it is important that part of their intervention and education focuses on giving them the skills to recognise it and respond to it, and that staff and parents are aware and take appropriate action.

Teaching about bullying should be done directly and explicitly, by familiarising young people about different kinds of bullying and what to do if it happens, including having a point of reference to whom they can report it. Peer-led approaches, such as *buddy systems* (English *et al.*, 1997) and *Circle of Friends* (Schlieder, Maldonado and Baltes, 2014) could be included in the IEP of the autistic student or adopted as a school approach. Addressing bullying requires a whole-school approach including students, teachers, school administration and parents (Gray, 2004). It is necessary that NT students are educated about bullying and aspects related to it such as the *'bystander* *effect'* (Jenkins and Nickerson, 2017), and given clear guidance about what they should do when they experience or witness bullying. On the other hand, school staff should be provided with training on how to supervise, respond and provide the appropriate support and consequences. Thus, such practical barriers could be addressed by providing ongoing and holistic support by practitioners visiting schools and other environments where autistic people spend most of their time.

8.6.3. Treat the family as a *system* and understand their culture, beliefs and attitudes

Another implication identified was the importance of helping young people understand that leaving their parents' home is a normal process which most adults go through. The young people in this study expressed a fear of insulting their parents if they said they wished to live independently away from home. Joint workshops for young people and their parents could be useful to give them the opportunity to discuss together their sentiments and opinions about the matter, in an environment where trained practitioners can support them and follow them up. Discussing the implications of leaving home and the skills required could become an important motivator for the young people. Opportunities for the young people to live away from home, for example, by attending residentials or live-ins (where a small group of young adults live together for some days to practise DLS under the supervision of professionals) could be beneficial. The advantages of such practice are two-fold: they give the young people the opportunity to practise DLS in a safe environment, and they encourage parents to get used to the idea of letting go, and to reassure them that their children are acquiring the skills to live independently, while being supported and monitored.

The findings highlighted that skill building is only one part of the equation, but the development of DLS encompasses other areas that need to be addressed. Within the Family Systems Theory (FST) framework, this study identifies the family as one of the central elements for DLS development. When families are understood as systems, intervention can be planned and offered in a way that it ensures that all family members have a good quality of life and achieve a personal sense of competence. Parental support and training are significant for parents to recognise their important role in promoting their young people’s independence. The findings showed clearly that parents need a lot of support and encouragement from professionals to help them gradually fade out their protection and encourage their young people to take over some responsibilities, especially personal ones such as, choosing what to wear.

Professional support is also required to help parents view autism more positively and to acknowledge their child’s abilities and skills. Throughout the years many parents may have built a negative view of autism. Since childhood, the focus was most probably on what they were not able to do, compared to NT peers and siblings. From a young age, attitudes need to change starting from schools which are often the first place where parents are given the message that their child is not as able as his/her peers, and perhaps will never be. An increase in family involvement in the intervention programme of their young adult is likely to empower parents to believe more in their young adults and address DLS.

A number of participants viewed parents’ fears and attitudes as inadvertently responsible for preventing the development of DLS. Parents often choose a cautious approach because they worry about them being bullied, they are sceptical about people’s reactions and may have low expectations. All interview participants including the mothers and fathers agreed that parents tended to be over-protective. However, over-protectiveness needs to be viewed within the context of systematic barriers, such as stigma, bullying and exclusion, which their sons would have been experiencing along the years. This affects the self-confidence and motivation of the young people, and makes it very difficult for parents to fade out their support and encourage their young people to face life more independently.

Support services for parents are necessary to help them face these daily challenges and fears, and to encourage them to communicate a more positive attitude towards their young people, by transmitting the message that they can trust them to be more independent. If parents are guided and given practical strategies on how to teach their young people DLS, they are more likely to feel confident about their sons’ abilities. Parental training would be a good opportunity to include the importance of such skills by giving parents the understanding of how people learn and how behaviour can be reinforced. It is also necessary to focus on giving parents practical understanding of concepts such as the executive function to help them grasp the importance of generalising their young people’s skills by exposing them to different experiences. Providing parents with a good understanding of the benefits underpinning their young people’s involvement in household chores, such as enhancing their self-esteem and giving them a greater sense of happiness, is also likely to motivate parents further to include their young people in everyday DLS.

8.7. Promoters of DLS and implications for practice arising from them

8.7.1. Autism as part of one's identity

The findings suggested that young autistic people may attach negative connotations to their autism and perceive it as a barrier to their life achievements. In the Q sorts, 2 fathers and a mother believed that young people have a lot of uncertainties about their abilities which creates in them a lot of anxiety and lack of confidence. Moreover, the mothers and fathers interviewed felt that the autism diagnosis had affected the way their young people perceive themselves, often as inferior.

This highlights the importance of giving young people a positive view of autism and help them to compensate for the negative messages they would have received from society. Attwood (2006, p. 23) explains that autistic people who realise that they are somehow different from their peers but whose diagnosis is not explained, may develop 'compensatory thoughts' which can lead to depression and self-blame or an escape into an alternative world. Thus, the importance of helping the young people to understand autism as part of their identity (Brown, 2011; Sainsbury, 2000; Jackson 1992) which will not impede them from becoming independent, but a negative attitude and lack of confidence would.

Thus, the importance of introducing the autism diagnosis in an optimistic way highlighting positive characteristics that are unique to the individual and arising from autism. For example, qualities like attention to detail, a methodical approach, expertise on a topic, and a high level of skill. Further to this, an effective practise at the MAC is giving the young people a responsibility related to their special skills. For instance, the person in charge of the information technology (IT) department at the MAC is an autistic young person who has a very high level of expertise in computers and technology. Such approaches, instil in the young people confidence and an opportunity to be on the contributing end rather than always on the receiving one. This generates a positive attitude even among parents and professionals who are able to witness how a different way of thinking can add value to the world we live in.

Furthermore, the Board of trustees of the MAC engages members who are autistic and receive support from the Centre. This sends out a strong message that their opinion matters because we believe that autistic adults do see gaps in the service that we provide which neurotypical members may be oblivious to. Generation of the idea that everybody is different and the world needs both autistic and non-autistic brains could be used in schools to contribute to a more inclusive society. Schools can provide a platform for autistic children to talk about their autism and to showcase their strengths to their friends and teaching staff.

Group intervention and discussions are also likely to be a good means of belonging for the young people to feel supported and together explore what wishes they have for their future. Hands-on practise as a group may also motivate the young people to take part and practise DLS together.

8.7.2. Involve professionals in teaching DLS

As part of the FST's *suprasystem*, professionals play an important role in the DLS and independence achievements. An important finding was that not all professionals seemed to understand the barriers to the development of DLS. This is of concern as these are professionals with experience of working with autistic people. There is therefore a need for more training for professionals which includes listening to the voices of the young people themselves to acquire a better understanding and a more accurate picture of those factors which impede them from learning DLS.

Peeters and Jordan (1999, p. 14) emphasise that professionals working with autistic people need to be 'qualitatively different'. They further explain that the secret is to be 'bitten by the bug of autism' (Peeters and Jordan, 1999, p. 15). This ties in with the finding of this study about the qualities that young people look for in professionals. This suggests the development of a professional profile for staff to ensure that professionals have qualities such as being empathic, have a listening ear, and offer encouragement. Being attracted by difference (Peeters and Jordan, 1999) is necessary for professionals to be able to appreciate and focus on the strengths and abilities of the young people. It is suggested that professionals are humble and open to listen and learn from the parents and the young people themselves. In this study, some professionals pointed their fingers towards parents for their young people's lack of DLS. Professionals need to be more aware of the societal barriers that create anxiety in the young people and their parents and prevent them from developing DLS and acquiring independence.

Although findings showed that parents may be over-protective at times, the role of professionals is to understand their fears and to guide parents, keeping in mind that although they may not be autism experts, they surely know their children best. Perhaps this calls for a change in the attitude of professionals through training that provides them with more understanding of the real-life experiences of the families they support. An increase in professional involvement through practical training on how to address DLS is also necessary. Listening to the voices of autistic people and the stories of parents, and spending time with them during home visits are likely to help professionals enter the lives of these families. Professionals would be able to understand better the everyday lived experiences of these families, such as how the young people may present with a different attitude when they are at home with their parents than when they are at the MAC.

8.7.3. Educate the general public to create a more inclusive and understanding society

The importance of educating the general public about autistic people cannot be overlooked. However, realistically speaking, it is not possible to bring about a radical change in attitudes in a few years' time. The findings of this study suggested that autism is still not well understood in Malta. Two young people gave a very high ranking to the statement that they feel influenced by the negative attitudes of people in society. This was corroborated by parents interviewed who explained that they worry about people's judgements and attitudes towards their young people when they are out in the community. This impacts on the parents' assurance to encourage their young people to achieve community independence.

Education needs to start from a young age in schools with the aim of having a more autistic conscious and friendly society in the future. Training co-workers and employers could also be beneficial. However, autistic young people and adults are already out in the community where people are not well educated and often have a negative or mimicking attitude towards them. Thus, young people need to be equipped with skills to deal with these circumstances. Intervention needs to include familiarisation with non-verbal mimicry behaviour, training on how to identify that someone is ridiculing them and how to respond. Other techniques such as avoiding to be alone at leisure places or deserted areas especially late at night are also important precautions.

8.8. Study limitations and recommendations for future research

8.8.1. Different analysis of the Q sorts

Through Q sort methodology, this research clearly illustrated the personal constructions of the individual participants and how these are located within the wider social discourse. The analysis highlighted the shared viewpoints of the different stakeholders, at times distinguishing the views of members of a participant group from that of others, for example, the young people's from the parents'. However, most Factors represent the views of a variety of stakeholders, thus showing that some views do not pertain to one stakeholder group in particular, for example to fathers only. These results raise the question as to whether there are any shared views from within each stakeholder group that are not found in the other groups.

Another limitation of this methodology was that the views of those participants who did not exemplify a Factor remained unknown. This is a characteristic of Q methodology which seeks to uncover shared views and opinions of participants, which was one of the aims of this study. However, I was very interested in uncovering the views of all the autistic young people, even those who had diverse viewpoints from the majority of the stakeholders. Given that the voices of the young people are not often included in research, it would have been an added value. In future research I could analyse the Promoter and Barrier Q sorts of all the young people in this study as well the diverse voices of those who did not exemplify a Factor (four for the Promoters and five for the Barriers) to bring out the possible diverse world views of the autistic participants more clearly.

Future research could also replicate this study with the analysis of the Q sorts being performed separately for each group. This would indicate clearly whether there are any major differences between different participant groups. Moreover, it would allow the voices of the different participant groups to speak independently from that of the other stakeholders. Such analysis would also allow a clearer comparison of the resulting factors at a qualitative level. My aim for this study was to bring out the common ideas and thoughts of the participants about promoters and barriers of DLS. Although through such analysis, potential differences were also highlighted, analysing the four data sets (young people, mothers, fathers, professionals) separately could provide clearer links and divergences.

8.8.2. A broader participant group

The participants of this study were all members of, or professionally linked with the MAC. Thus, a shortcoming of this study could have been that the sample was not representative of similar populations in Malta. In addition, all the autistic young people were male and a study on autistic females could have led to different outcomes. It may be that parents have different expectations of daughters than sons. A similar study could include a larger and more diverse population, such as young people who do not receive any intervention or those who receive support from other institutions. Participants in this study could have had skewed viewpoints due to the fact that they attend the MAC and are given regular support. Their parents are open to the idea that their young people need support to acquire those skills that would help them achieve independence, and they try to ensure that they get it. Including families that do not receive autism specific support would be useful.

Other autistic young people whose families keep the diagnosis undisclosed may have different viewpoints on the importance of intervention and support to develop DLS and independence. Contacting other service providers to recruit participants would have made the process much more time consuming, and most probably with a very limited success rate, due to an unfortunate sense of antagonism that often exists between different service providers in Malta, who are seen as competitors. Furthermore, the process of finding and liaising with families who do not receive support from the MAC could have raised ethical difficulties during the research process and after. My professional relationship with the young people and their parents made it possible to monitor and provide them with support if such need was recognised. Moreover, my professional knowledge about the young people’s abilities ensured that they were able to reflect on their life experiences and articulate their responses. This made the study more robust in bringing out the opinions, daily obstacles and promoters of DLS for the young people. Being members of the MAC also made it possible for them to express their wishes and suggest other strategies and forms of intervention that the MAC could offer them to further enhance their DLS.

8.8.3. Inability to generalise the research findings

Q-sort research bridges the gap between qualitative and quantitative methodology, while combining the strengths of both approaches, by bringing out the subjective perspectives of participants through a structured quantitative framework (Stephenson, 1935). In so doing, its aim is to bring out the range and diversity of the expressed views, but makes no estimates about population statistics. Thus, generalisability was not possible in this study. However, while Q methodology limits generalisability, a strength of this approach is that it provides insight into the subjective experience of participants as they apply their own meaning and understanding to the statements and sort the cards accordingly (Brown, 1997). As Stainton Rogers (1995) maintains, Q methodology allows the expression of voices in a unique way as it delves into personal constructions, while it locates them in the wider social discourse, and suites research questions which aim to listen to ‘many voices’, as was the aim of this study.

8.8.4. Being an insider researcher

Being an insider researcher could be viewed '…like wielding a double-edged sword.' (Mercer, 2007, p. 7). Being familiar with the participants and their culture, the insider researcher may be seen as less objective throughout the research process (Hewitt-Taylor, 2002). As an insider researcher I was aware of the potential for informant bias. However, through the choice of Q methodology, I intended to minimise such influence as much as possible. In Q methodology participants 'inject' (Brown, 1997, p. 11) statements with their own understanding and during the analysis, the researcher does not impose the supposed a priori meaning of the statements (Brown, 1997). As an insider researcher, this study gave me the opportunity to make contributions to practice that were informed by my underpinning knowledge of the work at the MAC. The purpose of this study was to bring about actual change in practice and eventually in the lives of autistic people and their families.

Having dual roles as a researcher and practitioner, I learnt how to create a balance between the two, and how these could be separated without neglecting the participants' needs and emotions. My dual role was well explained in the information sheet. However, I also learnt to be very clear and assertive in explaining my dual role, and all participants respected the fact that during the data collection process, I was the researcher. This was particularly important during the interviews, which did not allow as much ethical distance as the Q sorts. In the majority of the interviews I felt that participants had understood well the aim of the interview and were very honest and open with me.

8.8.5. Enquiring about the most and least important DLS

Through the DLS checklist, this study clearly illustrated those DLS which were considered a priority for the different stakeholders, and others which were regarded less important. Initially, my intention was to explore this area through Q sort methodology. It was planned that the 50 DLS would be given to the participants as statements to sort on a grid, as they did for the promoters and barriers of DLS. However, following the pilot study, it was felt that three Q sorts would be too demanding on the participants both mentally and in terms of time required to complete them. Therefore, I decided to do the checklist instead which only required the participants to mark whether they thought the DLS was of high or low priority.

However, I believe that to better understand this aspect of the study and acquire a more accurate picture of the most and least important DLS for the stakeholders and how they may compare or differ between the four groups, further studies could adopt Q sort methodology to study this area more profoundly. Q methodology is likely to bring out more clearly which DLS are considered most and least important and why. It is also likely to highlight the preferences of different participant groups, particularly if these are analysed separately as it has been discussed above.

Recommendations for future research could also include the development of a practical tool to explore the views and priorities that young people and parents have regarding DLS. This could be used during the enrolment process of the MAC and also in the writing of the schools' IEPs to identify those DLS which are important for the individual student and his/her family.

8.8.6. What are the outcomes of autistic young people in relation to DLS?

This research clearly illustrated that DLS need to be taught directly to autistic people rather than learnt incidentally as may be the case for NT children. Further research is needed to determine the relationship between explicit instructions and the development of DLS. More needs to be understood about whether DLS taught in an explicit and direct way are eventually developed and performed by the young people independently, or whether other techniques like video modelling or simply watching a YouTube video is equally or more effective.

This research has also clearly illustrated that the young people in this study were still very much dependent on their parents. It also showed that parents were quite over-protective and the wishes for the young people's future were rarely discussed. Parents were also very strong in their argument that discussions about their eventual death would do more harm and thus, were to be completely avoided. Therefore, this study raises the question of what is actually going on with these young people once their parents are no longer able to care for them and when they eventually pass away. To better understand the implications of these findings, future studies could address this question to find out, how independent young autistic people become in terms of their living arrangements, employment and friendships and the type of support they have needed and valued. This would throw light on what measures need to be taken from a very young age to ensure good outcomes for autistic adults. It is interesting that a recent report by National Statistics UK (2021) revealed that only 22% of autistic people were in employment – the lowest among other special needs groups, and 75% still lived with their parents. Therefore, it could be argued that some of the findings of this study, particularly the young people’s dependence on their parents, may not be specific to Malta only, but rather similar to the UK, and perhaps universal.

Recommendations for future research include developing methods to reach a consensus between the stakeholders on what might be worked on and how; examining how DLS are best taught and developed; and longitudinal studies following up young autistic people into adulthood to find out which DLS they still need support with and from whom, and which skills they can do unaided.

8.9. Final reflections

My motivation for this research came primarily from my role as a practitioner and my inspiration to bring about a change in the lives of autistic young people. I was also driven by my interest to understand what was underpinning the level of independence of these young people who according to their verbal and cognitive abilities could have good levels of independence and good adult outcomes. As a practitioner, I was also inspired to be more effective in my career and ensure that the students who receive intervention from the MAC grow up to have the best quality of life as possible. My responsibility towards the parents and the families of these young people encouraged me further to embark on this research project. When I reflect upon my journey since the beginning of my studies, I feel I have learnt a great deal primarily as a researcher and also as a practitioner. My choice of Q methodology, which was a hard one to make due to my initial lack of familiarity with it, has proved to be a successful one to fulfil my aim of listening to the voices of the young people and their parents, as well as the professionals who work entirely to bring about a positive change in the lives of these families.

Studying the promoters and barriers of DLS was in itself a complex topic. However, I believe that this study has managed to bring clarity and structure to a multi-faceted topic. Moreover, it has given the young people whose voice is often forgotten, an opportunity to use this innovative approach (Q sort) to record their viewpoints about such an important area in their lives, in a holistic and complete manner. Parents and professionals who are the key people in a young person's life, were given the same chance to express their viewpoints and contribute to the entire picture of gathered data on which areas of DLS were most important, and found that the development of DLS does not merely depend on skill building but many other factors come into play. The inclusion of the different stakeholders, has led this study to uncover many facets to the topic of DLS. It has highlighted a much more comprehensive approach to addressing DLS, which not just includes working with the autistic people only, but reaches out to all the people surrounding the education of autistic people from a young age. This is to ensure that all are trained to understand autistic people better by being aware that negative experiences since a very young age such as, bullying and a negative attitude towards these children, can have severe repercussions on their future. Listening directly to the voices of autistic people has taught me that it is not enough to start teaching them basic DLS from a young age, such as opening and closing their lunch box and pulling up their pants, but practitioners like myself need to ensure that throughout this long process, the messages that should be communicated to them need to be positive and clear: *You can do it! It is OK to try and fail! Everybody makes mistakes!* Parents, teachers, peers, as well as autism professionals need more training to understand this scenario and give it the importance it deserves; to view it as a *means to an end*. If the aim is to reach the end of the line with independent autistic adults, it needs to be ensured that the *means* address the confidence of these students and encourage them to be independent. The *means* would definitely need to include better communication processes within families and with professionals and teaching staff. With appropriate input, developed in discussion with professionals, parents and the young people, autistic people are likely to have better outcomes in terms of their independence skills.

Listening to the autistic voices has been particularly enriching to me both as a researcher and a practitioner. Firstly, that each autistic person is an individual, and that needs to be respected and well considered when supporting these people. Also, as it has already been outlined through their viewpoints and vivid descriptions of their experiences, autistic participants have made me understand very well that DLS is not simply about skill building. This means that as practitioners and researchers, we need to listen more to their voices and involve them in research. We also need to help them embrace autism as part of their identity and focus on the whole family and its dynamics. Above all, the general public needs to be continuously educated to create a more inclusive and understanding society.

Finally, I believe that the nature and structure of the study allowed for a good relationship between myself as a researcher and the participants, reducing the power dynamic as much as possible and generating a feeling that their views were sought because they were truly valued and appreciated.

REFERENCES

Abela, A.M. (2000) *Values of women and men in the Maltese Islands – A Comparative European Perspective.* Malta: Union Print Co. Ltd.

Ackerman, N. (1959) ‘Theory of family dynamics’, *Psychoanalysis and the Psychoanalytic Review,* 46 (4), pp. 33–50.

Ahmed, S., Bryant, L., Tizro, Z. and Shickle, D. (2012) ‘Interpretations of informed choice in antenatal screening: A cross-cultural, Q-methodology study’, *Social Science and Medicine,* 74 (7), pp. 997-1004.

Allen, J. (1982) ‘Family systems theory’, in Swanson, K. (ed.) *Understanding families.* Available at: https://dss.mo.gov/cd/info/cwmanual/section7/ch1_33/sec7ch1.htm (Accessed: 16 June, 2016).

Altiere, M. and von Kluge, S. (2009) ‘Family functioning and coping behaviours in parents of children with autism’, *Journal of Child and Family Studies,* 18, pp. 83-92.

Al-Zboon, E. (2016) ‘Kindergarten curriculum for children with hearing impairments: Jordanian teachers' perspectives’, *Deafness and Education International,* 18 (1).

Anderson, K.A., Shattuck, P.T., Cooper, B.P., Roux, A.M., and Wagner, M., (2014) ‘Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder’, *Autism*, 0 (0), pp. 1–9.

Atkinson, J. (1992) *PQ Method 2.0 Manual.* Available at: http://schmolck.userweb.mwn.de/qmethod/ (Accessed: 12 October, 2018).

Attwood, T. (2006) *The complete guide to Asperger's syndrome.* London: Jessica Kingsley Publishers.

Ayres, K., Mechling, L. and Sansosti, F. (2013) 'The use of mobile technologies to assist with life skills/independence of students with moderate/severe intellectual disability and/or autism spectrum disorders: Considerations for the future of school', *Psychology,* 50 (3), pp. 259–279.

Bal, V.H., Kim, S-H., Cheong, D. and Lord, C. (2015) 'Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age', *Autism,* 19 (7), pp. 774-784.

Bancroft, K., Batten, A., Lambert S., and Madders, T. (2012) *The way we are: Autism in 2012.* London: The National Autistic Society.

Bandura, A. (1977) 'Toward a unifying theory of behavioral change', *Psychological Review,* 84, pp. 191–215.

Barnard, J., Harvey, V., Potter, D., and Prior, A., (2001), *Ignored or ineligible? The reality for adults with autism spectrum disorders.* London: The National Autistic Society.

Barnett, F., Horlin, C., Falkmer, O., Siljehav, J., Fristedt, S., Lee, H. Chee, D., Wretstrand, A. and Falkmer, T. (2015) 'Viewpoints of adults with and without Autism Spectrum Disorders on public transport', *Marita Transportation Research Part A,* 80, pp. 163-183.

Barry, J. and Proops, J. (1999) 'Seeking sustainability discourses with Q methodology', *Ecological Economics,* 28 (3), pp. 337–345.

Bashe, P.R. (2011) *The parents' guide to teaching kids with Asperger Syndrome and similar ASDs real-life skills for independence*. New York: Three Rivers Press.

Bazeley, P. (2021) *Qualitative Data Analysis: Practical Strategies* (2nd edn.). Sage.

Beadle-Brown, J., Murphy, G., and Wing, L. (2006) ‘The Camberwell cohort 25 years on: Characteristics and changes in skills over time’, *Journal of Applied Research in Intellectual Disabilities,* 19, pp. 317–329.

Beckert, T.E. (2011) ‘Autonomy and its assessment’, in Levesque, R. J.R. (ed.) *Encyclopaedia of Adolescence.* London UK: Springer.

Bereznak, S., Ayres, K., Mechling, L. and Alexander, J. (2012) ‘Video Self-Prompting and Mobile Technology to Increase Daily Living and Vocational Independence for Students with Autism Spectrum Disorders’. *Journal of Developmental and Physical Disabilities,* 24 (3), pp. 269–285.

Berg, C., McCollum, M., Cho, E., and Jason, D. (2015) ‘Development of the adolescent and young adult activity card sort’, *OTJR: Occupation, Participation and Health* doi:10.1177/1539449215578651.

Berkovits, L. D., Moody, C. T. and Blacher, J. (2020) ‘ “I don’t feel different. But then again, I wouldn’t know what it feels like to be normal” : Perspectives of adolescents with autistic spectrum disorder’, *Journal of Autism and Developmental Disorders,* 50, pp. 831-843.

Bestow, C. (2021) *Late Bloomer: How autism diagnosis changed my life.* London: Hardie Grant Books.

Bhattacherjee, A. (2012) *Social Science Research: Principles, Methods, and Practices.* Textbooks Collection. Book 3.
Available at https://digitalcommons.ucf.edu/oa_textbooks/3.

Billstedt, E., Gillberg, I.C. and Gillberg, C. (2010) ‘Aspects of quality of life in adults diagnosed with autism in childhood’, *Autism* 15 (1), pp. 7-20.

Blackburn, R. (2010) ‘Within and without autism’, *Good Autism Practice,* May, pp. 9–13.

Blaikie, N. and Priest, J. (2017) *Social Research: Paradigms in action.* Cambridge UK: Polity Press.

Blatchford, P., Webster, R. and Russell, A. (2012) *Challenging the Role and Deployment of Teaching Assistants in Mainstream Schools: The Impact on Schools.* University of London: Institute of Education.

Bonner, A., and Tolhurst, G. (2002) ‘Insider-outsider perspectives of participant observation’, *Nurse Researcher,* 9 (4), pp. 7-19.

Borg, S. and Clark, M. (2007) ‘Leisure and Young Married Women in Malta’, *Journal of World Anthropology: Occasional Papers,* 3 (1).

Bowen, M. (1978) *Family therapy in clinical practice.* New York: Aronson.

Bowey, L., and McGlaughlin, A. (2005) ‘Adults with a Learning Disability Living with Elderly Carers Talk about Planning for the Future: Aspirations and Concerns’, *The British Journal of Social Work,* 35 (8), pp. 1377–1392, Available at: https://doi.org/10.1093/bjsw/bch241.

Bowey, L. McGlaughin, A. and Saul, C. (2005) ‘Assessing the barriers to achieving housing choice for adults with a learning disability: The views of family carers and professionals’, *The British Journal of Social Work,* 35 (1), pp. 139 -148.

Boyce, C. and Neale, P. (2006) *Conducting In-Depth Interview: A Guide for Designing and Conducting In-Depth Interviews for Evaluation Input.* Pathfinder International Tool Series, Monitoring and Evaluation-2. Available at: http://www.pathfind.org/site/DocServer/m_e_tool_series_indepth_interviews.pdf?docID=6301.

Brannen, J., (1995) 'Young People and Their Contribution to Household Work', *Sociology,* 29 (2), pp. 317 – 338.

Brannen, J., (1996) 'Discourses of Adolescence: Young People's Independence and Autonomy within Families', in Brannen J. and O'Brien M. (eds) *Children in Families: Research and Policy.* London: Falmer Press, pp.114–130.

Brannen, J., Heptinstall, E. and K. Bhopal, (2000) *Connecting Children: Care and family Life in Later Childhood.* London: Routledge/Falmer.

Brinkmann, S. and Kvale, S. (2015) *Interviews: Learning the craft of qualitative research interviewing* 3rd edn. Sage Publications Ltd: London.

British Educational Research Association: Ethical Guidelines for Educational Research (2018) 4th edn. London: British Educational Research Association. Available at: https://www.bera.ac.uk/researchers-resources/publications/ethical-guidelines-for-educational-research-, (Accessed: 10 January 2019).

Brouwer, M. (1999) 'Q is accounting for tastes', *Journal of Advertising Research,* 39 (2), pp. 35-39.

Brown, L. (2011) *The significance of semantics: Person-first language: Why it matters*. Available at: https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html (Accessed: 10 October 2019).

Brown, S.R. (1980) *Political subjectivity: applications of Q methodology in political science.* New Haven, CT: Yale University Press.

Brown, S.R. (1993) ‘A Primer on Q Methodology’, *Operant Subjectivity,* 16: 91138.

Brown, S.R. (1997) *The History and Principles of Q methodology in Psychology and the Social Sciences.* Kent OH: Department of Political Science Kent State University. Available at: http://facstaff.uww.edu/cottlec/Qarchive/Bps.htm. (Accessed: 16 November 2016).

Brownlow, C., Lawson, W., Pillay, Y., Mahony, J., and Abawi, D. (2021) ‘“Just Ask Me”: The Importance of Respectful Relationships Within Schools’, *Frontiers in Psychology,* 0.

Burt, C. and Stephenson, W. (1939) ‘Alternative views of correlations between persons’, *Psychometrika,* 4 (4), pp. 269 – 281.

Butler R.C. and Gillis J.M. (2011) ‘The impact of labels and behaviors on the stigmatization of adults with Asperger's disorder’, *Journal of Autism Developmental Disorders,* 41(6), pp. 741-749. Doi: 10.1007/s10803-010-1093-9. PMID: 20811769.

Cage, E., Di Monaco, J., and Newell, V. (2019) ‘Understanding, attitudes and dehumanisation towards autistic people’, *Autism,* 23(6), pp. 1373–1383.

Cameron, A. (2014) ‘Stigma, social comparison and self-esteem in transition age adolescent individuals with autistic spectrum disorders and individuals with borderline intellectual disability.’ University of Glasgow. ProQuest Dissertations & Theses Global (Number: 10030148).

Camilleri, J. (1999) ‘Disability: A personal odyssey’, *Disability and Society,* 14 (6), pp. 845–53.

Camilleri, J., and Callus. A., (2001) ‘Out of the cellars. Disability, politics and the struggle for change: The Maltese experience’, in Barton, L. (ed.) *Disability, politics and the struggle for change.* London: David Fulton pp. 79–92.

Cannella-Malone, H. I., Fleming, C., Chung, Y.C., Wheeler, G.M., Basbagill, A.R. and Singh, A.H. (2011) ‘Teaching Daily Living Skills to Seven Individuals With Severe Intellectual Disabilities: A Comparison of Video Prompting to Video Modeling’, *Journal of Positive Behavior Interventions,* 13 (3), pp. 144–153. Doi: 10.1177/1098300710366593.

Cannella-Malone, H., Wheaton, J., Wu, P., Tullis, C. and Park, J. (2012) ‘Comparing the effects of video prompting with and without error correction on skill acquisition for students with intellectual disability’, *Education and Training in Autism and Developmental Disabilities,* 47, pp. 332-344.

Cardona, G. (2013) ‘Overcoming disabling barriers: disability and attitudes to disability within the Maltese context: an insider’s perspective’, *Disability and Society,* 28 (2), pp. 279-284.

Carnahan, C., Hume, K., Clarks, L. and Borders, C. (2009) ‘Using Structured Work Systems to Promote Independence and Engagement for Students with Autism Spectrum Disorders’, *Autism Spectrum Disorders,* 41 (4), pp. 6-14.

Chakrabarti, S. and Fombonne, E. (2001) ‘Pervasive developmental disorders in pre-school children’, *Journal of American Medical Association,* 285, pp. 3093–3099.

Chavez, C. (2008) ‘Conceptualizing from the Inside: Advantages, Complications, and Demands on Insider Positionality’, *The Qualitative Report,* 13 (3), pp. 474-494. Available at: http://nsuworks.nova.edu/tqr/vol13/iss3/9.

Cheak-Zamora, N., Teti, M., and First, J. (2015) '"Transitions are Scary for our Kids, and They're Scary for us": Family Member and Youth Perspectives on the Challenges of Transitioning to Adulthood with Autism', *Journal of Applied Research in Intellectual Disabilities,* 28, pp. 548–560.

Cheak-Zamora, N., Teti, M., and Maurer-Batjer, A. (2016) 'Capturing Experiences of Youth With ASD via Photo Exploration: Challenges and Resources Becoming an Adult', *Journal of Adolescent Research,* 1–29.

Chiang, H.M., Cheung, Y.K., Li, H., and Tsai, L.Y. (2012) 'Factors associated with participation in employment for high school leavers with autism', *Journal of Autism and Developmental Disorders*. Doi:10.1007/s10803-012-1734-2.

Ciantar, M. J. (2018) 'Maltese parents' lived experience of the diagnostic process for autism spectrum conditions (ASC)', University of Malta: Faculty for Social Wellbeing. Available at: https://www.academia.edu/40599455/Maltese_Parents_Lived_Experience_of_The_Diagnostic_Process_for_Autism_Spectrum_Conditions_ASC_. (Accessed: 18 April 2022).

Coogan, J. and Herrington, N. (2011) 'Q methodology: An overview', *Research in Secondary Teacher Education*, 1 (2), pp. 24–28.

Corbin Dwyer, S. and Buckle, J. (2009) 'The space between: On being an insider-outsider in qualitative research', *International Journal of Qualitative Methods,* 8 (1), pp. 54-63.

Cox, N., Reeve, R., Cox, S., and Cox, D. (2012) 'Brief report: Driving and young adults with ASD: Parents' experiences', *Journal of Autism and Developmental Disorders,* 42, pp. 2257-2262.

Cross, R. (2005) ‘Exploring attitudes: the case for Q methodology’, *Health Education Research,* 20 (2), pp. 206-213.

Cuppen, E., Breukers, S., Hisschemoller, M., Bergsma, E., (2010) ‘Q methodology to select participants for a stakeholder dialogue on energy options from biomass in the Netherlands’, *Ecological Economics,* 69, pp. 579-591.

Curryer, B., Stancliffe, R., and Dew, A. (2015) ‘Self-determination: Adults with intellectual disability and their family’, *Journal of Intellectual and Developmental Disability,* 40 (4), pp. 394-399. DOI: 10.3109/13668250.2015.1029883.

Curt, B. (1994) *Textuality and tectonics: Troubling social and psychological science.* Buckingham: Open University Press.

de Graaf, G. and van Exel, J. (2008) ‘Give me a break! Informal caregiver attitudes towards respite care’, *Health Policy* 88 (1), pp. 73-87. Doi: 10.1016/j.healthpol.2008.03.001.

de Graaf, G. and van Exel, J. (2009) ‘Using Q Methodology in administrative ethics’, *Public Integrity,* 11(1), pp. 63-78.

De Lyser, D. (2001). ‘"Do you really live here?" Thoughts on insider research’, *Geographical Review,* 91(1/2), pp. 441-453.

Dennis, K. (1986) ‘Q methodology: Relevance and application to nursing research’, *Advances in Nursing Science,* 8 (3), pp. 6–17.

Dennis, K. (1993) ‘Commentary: looking at reliability and validity through Q-colored glasses’, *Operant Subjectivity,* 16, pp. 37–44.

Dickter, C. L., Burk, J. A., Zeman, J. L. and Taylor, S. C. (2020) ‘Implicit and explicit attitudes towards autistic adults,’ *Autism in Adulthood,* 2:2, pp. 144-151.

DiGennaro Reed, F., Strouse, M., Jenkins, S., Proce, J., Henley, A. and Hirst, J. (2014) ‘Barriers to independent living for individuals with disabilities and seniors,’ *Behaviour Analysis Practice,* 7, pp. 70-77.

Doherty, W.J., Boss, P.G., LaRossa, R., Schumm, W.R., and Steinmetz, S.K. (1993) ‘Family theories and methods: A contextual approach’ in Boss, P.G, Doherty, W.J., LaRossa, R., Schumm, W.R. and Steinmetz, S.K. (eds), *Sourcebook of family theories and methods: A contextual approach.* New York, NY: Plenum Press.

Duncan, A.W. and Bishop, S.L. (2013) ‘Understanding the gap between cognitive abilities and daily living skills in adolescents with autism spectrum disorders with average intelligence’, *Autism,* 0 (0), pp. 1-9.

Douven, I. (2017) ‘A Bayesian perspective on Likert scales and central tendency’, *Psychon Bull Rev*. Available at: https://doi.org/10.3758/s13423-017-1344-2.

Dziopa, F. and Ahern, K. (2011) ‘A Systematic Literature Review of the Applications of Q-Technique and Its Methodology’, *Methodology,* 7 (2), pp. 39-55.

Eaves, L.C. and Ho, H.H. (2008) ‘Young adult outcome of autism spectrum disorders’, *Journal of Autism and Developmental Disorders,* 38 (4), pp. 739–747.

Ellingsen, I, Størksen, I. and Stephens, P. (2009) ‘Q methodology in social work research’, *International Journal of Social Research Methodology,* 13 (5), pp. 395-409.

English, K., Goldstein, H., Shafer, K., and Kaczmarek, L. (1997) ‘Promoting interactions among pre-schoolers with and without disabilities: Effects of a buddy skills-training program’, *Exceptional Children,* 63 (2), pp. 229-243.

Erikson, E. H. (1963) *Childhood and society.* New York: Norton.

European Commission (2011) 'Employment and Unemployment (Labour Force Survey)', Database, Available at: http://epp.eurostat.ec.europa.eu/portal/page/portal/employment_unemployment_lfs/data/database.

Farley, M., McMahon, W., Fombonne, E., Jenson, W., Miller, J., Gardner, M., Block, H., Pingree, C.B., Ritvo, E.R., Ritvo, R.A. and Coon, H. (2009) 'Twenty-year outcome for individuals with autism and average or near-average cognitive abilities', *Autism Research* 2 (2), pp. 109 – 118. Doi: 10.1002/aur.69.

Farrugia, G (2017) 'Overcoming mental health stigma', *The Sunday Times,* 11 June Available at: https://www.timesofmalta.com/articles/view/20170611/health-fitness/Overcoming-mental-health-stigma.650508.

Farlow, L.J., and Snell, M.E. (2006) 'Teaching self-care skills' in Snell, M.E. and Brown, F. (eds) *Instruction of students with severe disabilities*. 6th edn. Upper Saddle River, NJ: Pearson Education Inc. pp. 328–374.

Fingerman, K., and Bermann, E. (2000) 'Applications of family systems theory to the study of adulthood', *International Journal of Aging and Human Development,* 51 (1), pp. 5–29.

Floyd, A. and Linet, A., (2012) 'Researching from within: external and internal ethical engagement', *International Journal of Research and Method in Education,* pp. 1-10.

Foley, S. (2012) 'Reluctant 'Jailors' speak out: parents of adults with Down syndrome living in the parental home on how they negotiate the tension between empowering and protecting their intellectually disabled sons and daughters', *British Journal of*

Learning Disabilities, 41(4), pp. 304 – 311. Available at: https://doi.org/10.1111/j.1468-3156.2012.00758.x.

Fombonne, (2003) 'The prevalence of autism', *Journal of the American Medical Association,* 289, pp. 87-89.

Fontein-Kuipers, J. (2016) 'Development of a Q-set for a Q-Method Study about Midwives' perspectives of Woman-Centered Care', *Health, Education and Care,* 1 (2), pp. 31-36.

Galbin, A. (2014) 'An introduction to social constructionism', *Social Research Reports,* 26, pp. 82-92.

Gallagher, K. and Porock, D. (2010) 'The use of interviews in Q methodology', *Nursing Research,* 59 (4), pp. 295–300.

Gardner, S. and Wolfe, P. (2013) 'Use of Video Modeling and Video Prompting Interventions for Teaching Daily Living Skills to Individuals with Autism Spectrum Disorders: A Review', *Research and Practice for Persons with Severe Disabilities,* 38 (2), pp. 73–87. Doi: 10.2511/027494813807714555.

Garris Christian, L. (2006) 'Understanding families: Applying family systems theory to early childhood practice', *Beyond the Journal: Young children in the web,* Available at: https://www.naeyc.org/files/yc/file/200601/ChristianBTJ.pdf (Accessed: 3 July 2016).

Gatt, S. and Gatt, K. (2006), 'Gender Stereotypes And Education', in Grech, H. *Survey shows big gender gap in home chores*. Available at: http://www.timesofmalta.com/articles/view/20061117/local/survey-shows-big-gender-gap-in-home-chores.35112 on 15/08/2016.

Gergen, K.J. (1985) ‘Theory of the self: Impasse and evolution’, in Berkowitz, L. (ed.) *Advances in experimental social psychology.* New York, Academic Press.

Gerland, G. (2013) *Secrets to success for professionals in the autism field: An insider’s guide to understanding the autism spectrum, the environment and your role.* London: Jessica Kingsley Publishers.

Giangreco, M., and Broer, S. (2005) ‘Questionable utilization of paraprofessionals in inclusive schools: Are we addressing symptoms or causes?’, *Focus on Autism and Other Developmental Disabilities,* 20, pp. 10–26.

Gillespiepie-Lynch, K., Daou, N., Obeid, R., Reardon, S., Khan, S., Goldknopf, E.J. (2020) ‘What contributes to stigma towards autistic university students and students with other diagnoses?’, *Journal of Autism and other Developmental Disorders,* 51, pp. 459–475.

Gini, G. and Pozzoli, T. (2009) ‘Association between bullying and psychosomatic problems: A meta-analysis’, *Pediatrics,* 123, pp. 1059–65.

Gomez de la Cuesta, G. and Michael, C. (2012) *We exist too: Valuing the contribution of siblings – Supporting autism in maturity.* London: The National Autistic Society.

Gotham, K., Marvin, A.R, and Taylor, J.L., Warren, Z., Anderson, C.M., Law, P.A., Law, J. K. and Lipkin, P.H. (2015) ‘Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data’, *Autism,* 19 (7), pp. 794–804.

Grandin, T. and Panek, R. (2013) *The autistic brain: Thinking across the spectrum.* New York: Houghton Mifflin Harcourt.

Gray, C. (2004) ‘Gray’s guide to bullying parts I-III’, *The Morning News 16,* pp. 1–60.

Gray, K.M., Keating, C.M., Taffe, J.R., Brereton, A.V., Stewart, L.E., Reardon, T.C. and Tonge, B.J. (2014) ‘Adult outcomes in autism: Community inclusion and living skills’, *Journal of Developmental Disorders,* 44, pp. 3006–3015.

Grech, S. and Aquilina, B. (2011) ‘The Effects of negative attitudes towards persons with disability’, *The Malta Independent,* 11 May 2011. Available at: http://www.independent.com.mt/articles/2011-05-11/news/the-effect-of-negative-attitudes-towards-persons-with-disability-292143/. (Accessed: 24 July 2016).

Greene, M.J. (2014) ‘On the Inside Looking In: Methodological Insights and Challenges in Conducting Qualitative Insider Research’, *The Qualitative Report,* 19 (29), pp. 1 - 13. Available at: http://nsuworks.nova.edu/tqr/vol19/iss29/3.

Greer R.D., Dudek-Singer, J. and Gautreaux, G. (2006) ‘Observational learning’, *International Journal of Psychology,* 41, pp. 486–499.

Green, S.A. and Carter, A.S. (2014) ‘Predictors and Course of Daily Living Skills Development in Toddlers with Autism Spectrum Disorders’, *Journal of Autism and Developmental Disorders,* 44, p. 256. Doi:10.1007/s10803-011-1275-0.

Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D., Clarke, Z. and Beail, N. (2013) ‘What things make people with a learning disability happy and satisfied with their lives: An inclusive research project’, *Journal of Applied Research in Intellectual Disabilities,* 26, pp. 26-33.

Hammersley, M and Atkinson, P. (1995) *Ethnography principles in practice.* Guildford and Kings Lynn: Routledge.

Han, E., Scior, K., Avramides, K. and Crane, L. (2021) ‘A systematic review on autistic people’s experiences of stigma and coping strategies’, *Autism Research,* 15, pp. 12-26.

Hassan Z.A., Schattner, P., Mazza, D. (2006) ‘Doing A Pilot Study: Why Is It Essential?’, *Malaysian Fam Physician*, 1 (2-3), pp. 70-73.

Hebron, J. and Humphrey, N. (2014) ‘Exposure to bullying among students with autism spectrum conditions: A multi-informant analysis of risk and protective factors’, *Autism,* 18 (6), pp. 618-630.

Held, M.F., Thoma, C.A., and Thomas, K. (2004) ‘The John Jones show: How one teacher facilitated self-determined transition planning for a young man with autism’, *Focus on Autism and Other Developmental Disabilities,* 19, pp. 177-188.

Henniger, N.A. and Taylor, J.L. (2013) ‘Outcomes in adults with autism spectrum disorders: A historical perspective,’ *Autism,* 17, pp. 103-116.

Hewitt-Taylor, J. (2002) ‘Insider knowledge: Issues in insider research’, *Nursing Standard,* 16 (46), pp. 33-35.

Howlin, P., Alcock, J. and Burkin, C. (2005) ‘An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome’, *Autism,* 9 (5), pp. 533–549. Doi: 10.1177/1362361305057871.

Howlin, P., Goode, Hutton, J. and Rutter, M. (2004) ‘Adult outcome for children with autism’, *Journal of Child Psychology and Psychiatry* 45 (2), pp. 212-229. DOI:10.1111/j.1469-7610.2004.00215.x.

Howlin, P. and Moss, P. (2012) ‘Adults with autism spectrum disorders’, *Canadian Journal of Psychiatry,* 57 (5), pp. 275 – 283.

Howlin, P., Moss, P, Savage, S. and Rutter, M, (2013) ‘Social outcomes in mid to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children', *Journal of American Academy of Child and Adolescent Psychiatry,* 52 (6), pp. 572-581.

Hume, K., Boyd, B.A., Hamm, J.V., and Kucharczyk, S. (2014) 'Supporting independence in adolescents on the autism spectrum', *Remedial and Special Education,* 35 (2), pp. 102-113.

Hume, K., Loftin, R. and Lantz, J. (2009) 'Increasing independence in autism spectrum disorders: A review of three focused interventions', *Journal of Autism Developmental Disorders,* 39 (9), pp. 1329-1338. DOI:10.1007/s10803-009-0751-2.

Hume, K. and Odom, S. (2007) 'Effects of an individual work system on the independent functioning of students with autism', *Journal of Autism Developmental Disorders,* 37, pp. 1166-1180.

Hume, K., Plavnick, J., and Odom, S. (2012) 'Promoting task accuracy and independence in students with autism across educational setting through the use of individual work systems', *Journal of Autism and Developmental Disorders,* 42, pp. 2084-2099.

Humphrey, N. and Hebron, J. (2015) 'Bullying of children and adolescents with autism spectrum conditions: a 'state of the field' review', *International Journal of Inclusive Education,* 19 (8), pp. 845-862. DOI: 10.1080/13603116.2014.981602.

Humphrey, N. and Lewis, S. (2008) '"Make me normal": The views and experiences of pupils on the autistic spectrum in mainstream secondary schools', *Autism,* 12, pp. 23-46.

Humphrey, N., Squires, G., Barlow, A., et al. (2010) Achievement for All national evaluation: Interim report. London: Department for Education.

Humphrey, N. and Symes, W. (2010) ‘Perceptions of social support and experiences of bullying among pupils with autism spectrum disorders (ASD) in mainstream secondary schools’, European Journal of Special Needs Education, 25, pp. 77-91.

Hurblutt, K. and Chalmers, L., (2004) ‘Employment and Adults with Asperger syndrome’, *Focus on Autism and other Developmental Disabilities,* 19 (4), pp. 215-222.

NSW Family and Community services (2019) ‘Independent Living Skills: A checklist for young people in care’. Available at: https://www.facs.nsw.gov.au/.

Israel, M. (2015) *Research ethics and integrity for social scientists*. 2nd edn. London: Sage.

Jackson, L. (1992) *Freaks, Geeks and Asperger syndrome: A user guide to adolescence.* UK: Jessica Kingsley.

Järbrink, K. , McCrone, P. , Fombonne, E. , Zandén, H. and Knapp, M. (2007) `Cost-Impact of Young Adults with High-Functioning Autistic Spectrum Disorder', *Research in Developmental Disabilities,* 28 (1), pp. 94-104.

Jasmin, E., Couture, M., McKinley, P., Reid, G., Fombonne, E., and Gisel, E. (2009). ‘Sensori-motor and daily living skills of preschool children with autism spectrum disorders’, *Journal of Autism and Developmental Disorders,* 39, pp. 231-241. Doi:10.1007/ s10803-008-0617-z.

Jenkins, L.N. and Nickerson, A. (2017) ‘Bystander Intervention in Bullying: Role of Social Skills and Gender’, *The Journal of Early Adolescence,* 39 (2), pp. 1-26. DOI:10.1177/0272431617735652.

Jingree, T. and Finlay, W. (2012). ''It's got so politically correct now': Parents' talk about empowering individuals with learning disabilities', *Sociology of Health and Illness,* 34(3), pp. 412-428. https://doi.org/10.1111/j.1467-9566.2011.01378.x.

Johns, R. (2010) *Likert items and scales, Survey Question Bank: Methods Fact Sheet 1.* University of Strathclyde. Available at: https://www.yumpu.com/en/document/read/41477224/likert-items-and-scales-survey-question-bank.

Jordan, R. (2008) 'Autistic Spectrum Disorders: A challenge and a model for inclusion in education', *British Journal of Special Education,* 35 (1), pp. 11-15.

Kanne, S.M., Gerber, A.J., Quirmbach, L.M., Sparrow, S.S., Cicchetti, D.V. and Saulnier, C.A., (2011) 'The role of adaptive behavior in autism spectrum disorders: implications for functional outcome', *Journal of Autism and Developmental Disorders,* 41(8), pp. 1007–1018.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. and Pellicano, E. (2016) 'Which terms should be used to describe autism? Perspectives from the UK autism community', *Autism*, 20 (4), pp. 442-462.

Kerr, M.E. (2000) 'One Family's Story: A Primer on Bowen Theory', *The Bowen Center for the Study of the Family*, Available at: http://www.thebowencenter.org.

Kerr, C., Mcdowell, B. and Mcdonough, S. (2007). 'The relationship between gross motor function and participation restriction in children with cerebral palsy: An exploratory analysis', *Child: Care, Health and Development,* 31(1), pp. 22-27.

Kitzinger, C. (1987) *The Social Construction of Lesbianism.* Bristol: Sage.

Kitzinger, C. (1999) ‘Researching Subjectivity and Diversity’, in Kimmel, E.B. and Crawford, M.E. (eds) *Innovations in Feminist Psychological Research.* Cambridge: Cambridge University Press.

Kitzinger, J. (1994) ‘The methodology of focus groups: the importance of interaction between research participant’, *Sociology of Health,* 16 (1), pp. 103-21.

Kitzinger, J. (1995) ‘Introducing focus groups’*, British Medical Journal,* 311, pp. 299-302.

Klein, W., Graesch, A. and Izquierdo, C. (2009) ‘Children and Chores: A Mixed-Methods Study of Children’s Household Work in Los Angeles Families’, *Anthropology of Work Review,* 30 (3).

Klin A., Saulnier C.A., Sparrow S.S., Cicchetti D.V., Volkmar F.R. and Lord C. (2007) ‘Social and communication abilities and disabilities in higher functioning individuals with autism spectrum disorders: The Vineland and the ADOS’, *Journal of Autism and Developmental Disorders*, 37(4), pp. 748-759.

Knight, V.F., Mckissick, B.R., Spooner, F. and Browder, D.M. (2011) ‘Using Explicit Instruction to Teach Science Descriptors to Students with Autism Spectrum Disorder’, *Journal of Autism and Developmental Disorders*, 42 (3), pp. 378-389. DOI:10.1007/s10803-011-1258-1.

Knud Ejler Logstrup (2007) in Gerland, G. (2013) *Secrets to success for professionals in the autism field: An insider’s guide to understanding the autism spectrum, the environment and your role.* London: Jessica Kingsley Publishers.

Kvale, S. and Flick, U. (eds.) (2008) *Doing Interviews.* CA: Sage.

Labaree, R.V. (2002) ‘The risk of “going observationalist:”: Negotiating the hidden dilemmas of being an insider participant observer’, *Qualitative Research,* 2 (1), pp. 97-122.

Lawson, W. (2011) *The passionate mind: How people with autism learn.* London: Jessica Kingsley Publishers.

Lebowitz, E., Dolberger, D., Nortov, E. and Omer, H. (2012) ‘Parent Training in Nonviolent Resistance for Adult Entitled Dependence’, *Family Process,* 51 (1), pp. 90-106.

Lee, G. K., Curtiss, S. L., Kuo, H. J., Chun, J., Lee, H., and Nimako, D. D. (2022) ‘The Role of Acceptance in the Transition to Adulthood: A Multi-Informant Comparison of Practitioners, Families, and Youth with Autism’, *Journal of Autism and Developmental Disorders,* 52, pp. 1444-1457

Leedham, A., Thompson, A. R., Smith, R., and Freeth, M. (2020) ‘‘I was exhausted trying to figure it out’: The experiences of females receiving an autism diagnosis in middle to late adulthood’, *Autism,* 24(1), pp. 135–146.

Levine, J. M., and Moreland, R. L. (1998). ‘Small groups’ in Gilbert, D., Fiske, S. and Lindzey, G. (eds.) *Handbook of Social Psychology.* 4th edn. Vol. 2. Boston: McGraw-Hill.

Levy, A. and Perry, A. (2011) ‘Outcomes in adolescents and adults with autism: A review of the literature’, *Research in Autism Spectrum Disorders,* 5 (4), pp. 1271-1282.

Lezak, M. D., Howieson, D. B., Bigler, E.D., and Tranel, D. (2012) *Neuropsychological assessment*. 5th edn. New York, NY: Oxford University Press.

Logstrup, K. E. (2007) in Gerland, G. (2013) *Secrets to success for professionals in the autism field: An insider's guide to understanding the autism spectrum, the environment and your role.* London UK: Jessica Kingsley Publishers.

Loomes, R., Hull, L. and Mandy W.P.L. (2017) 'What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis', *Journal of American Academy of Child and Adolescence Psychiatry*, 56 (6), pp. 466-474. Doi: 10.1016/j.jaac.2017.03.013.

MacDuff, G., Krantz, P., and McClannahan, L. (2001) 'Prompts and prompt-fading strategies for people with autism', in Maurice, C., Green, G. and Foxx, R. (eds) *Making a difference: Behavioral intervention for autism.* Austin, TX: Pro-Ed pp. 37-50.

Martinez-Mesa, J., González-Chica, D., Duquia, R., Bonamigo, R. and Bastos, J. (2016) 'Sampling: how to select participants in my research study?', *An Bras Dermatol,* 91 (3), pp. 326-330.

Matthews, N.L., Smith, C.J., Pollard, E., Ober-Reynolds, S., Kirwan, J., and Malligo, A. (2015) 'Adaptive functioning in autism spectrum disorder during the transition to adulthood', *Journal of Autism Developmental Disorders,* 45, pp. 2349-2360.

McCollum, M., La Vesser, P, and Berg, C. (2016) 'Participation in Daily Activities of Young Adults with High Functioning Autism Spectrum Disorder'*, Journal of Autism and Developmental Disorders,* 46 (3), pp. 987-997.

McDaniel, S. and Pisani, A. (2012) 'Family dynamics and caregiving for people with disabilities', in Talley, R. C. and Crews, J. E. (eds) *Multiple Dimensions of Caregiving and Disability, 11 Caregiving: Research, Practice, Policy.* DOI 10.1007/978-1-4614-3384-2_2.

McKenzie, J., Braswell, B., Jelsma, J. and Naidoo, N. (2011) ‘A case for the use of Q-methodology in disability research: Lessons learned from a training workshop’, *Disability and Rehabilitation, Early Online,* pp. 1-8.

McKeown, B. and Thomas, D. (2013). *Q Methodology.* 2nd edn. Newbury Park: Sage Publications.

McLeod, S. A. (2008) *Likert Scale.* Available at: www.simplypsychology.org/likert-scale.html (Accessed: 12 September 2021).

Meng-Chuan, L., Lombardo, M.V. and Baron-Cohen, S. (2014). *Autism. The Lancet,* 383(9920), pp. 896 – 910. Available at: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61539-1/fulltext.

Mercer, J. (2007) ‘The Challenges of Insider Research in Educational Institutions: Wielding a Double-Edged Sword and Resolving Delicate Dilemmas’, *Oxford Review of Education,* 33 (1), pp. 1 - 17. Available at: http://www.jstor.org/stable/4618693 (Accessed: 12 September 2021).

Millberg, A., Liljeroos, M., Wahlberg, R. and Krevers, B. (2020) ‘Sense of support within the family: Cross-sectional study of family members in palliative homecare’, *Palliative Care,* 19 (120), pp. 1-16.

Milton, D. (2016) *Educational discourse and the autistic student: A study using Q-sort methodology.* PhD dissertation. University of Birmingham.

Milton, D. (no date) ‘So what exactly are autism interventions intervening with?’, University of Birmingham. Unpublished essay.

Minuchin, S. (1974) ‘Families and family therapy’, in Sturge-Apple, M.L. Davies P. T. and Cummins E.M. (2010) *Typologies of Family Functioning and Children’s*

Adjustment, Child Development During the Early School Years Cambridge, MA: Harvard University Press. 81 (4), pp. 1320–1335. Doi:10.1111/j.1467-8624.2010.01471.x.

Mitchell, W. (2012) ‘Parents’ accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making’. *Children and Youth Services Review,* 34, pp.1560-1569.

Morris, J. (2003) ‘Barriers to Independent Living: A scoping paper prepared for the Disability Rights Commission’, Available at: http://disability-studies.leeds.ac.uk/files/library/morris-independent-living-scoping-paper-final-edit.pdf.pdf.

Moxnes, H. (2010) ‘Honor and shame’, in Rohrbaugh, R. (ed.) *The social sciences and the New Testament interpretation.* United States of America: Baker Academic Publishers.

Murray, D., Lesser, M., and Lawson, W. (2005) ‘Attention, monotropism and the diagnostic criteria for autism’, *Autism,* 9 (2), pp. 139-156.

Murray, A., Mckenzie, K., Booth, T., and Murray, G. (2013) ‘Estimating the level of functional ability of children identified as likely to have an intellectual disability’, *Research in Developmental Disabilities,* 34 (11), pp. 4009-4016.

Office for National Statistics (2021) *Outcomes for Disabled People in the UK: 2020.* Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020#toc. (Accessed: 16 December 2021).

Nicholas, J. B. (2011) ‘Reliability in Q Methodology: A Case Study’, *The Eastern Education Research Association Annual Conference.* The University of Akron, Ohio.

National Statistics Office - Malta (NSO) (2021) *News Release.* Available at: https://nso.gov.mt/en/News_Releases/Documents/2021/07/News2021_122.pdf (Accessed: 14 July 2021).

Oekel, B. (2009) ‘Q-Methodology and Modern Marketing Research Part I: Fundamentals of the Science of Subjectivity’, Available at: http://davisbrandcapital.com/wp-content/uploads/q_methodology.pdf (Accessed: 8 September 2017).

O’Grady, S. (2015), ‘Too many men still see household chores as women's work’, Available at: http://www.express.co.uk/news/uk/594493/men-women-gender-equality-household-chores-housework. (Accessed: 15 August 2016).

Oliver, M. (1990), *Politics of Disablement*. Hampshire, England: MacMillan International Higher Education.

O’Reilly Mizzi, S. (1994) ‘Gossip: A means of social control’, in Sultana R. and Baldacchino G. (eds.) *Maltese Society: A sociological Inquiry.* Malta: Mireva Publication.

Orsmond G.I., Shattuck P.T., Cooper, B.P., Sterzing P.R., and Anderson K.A. (2013) ‘Social Participation Among Young Adults with an Autism Spectrum Disorder’, *Journal of Autism Developmental Disorder,* 43, pp. 2710-2719.

Otieno, P. (2009) ‘Biblical and Theological Perspectives on Disability: Implications on the Rights of Persons with Disability in Kenya’, *Disability Studies Quarterly,* 29 (4). Available at: http://dsq-sds.org/article/view/988/1164 2/07/17.

Parker, C., Gladman, J. and Drummond, A. (1997) ‘The role of leisure in stroke rehabilitation’, *Disability and Rehabilitation,* 19 (1), pp. 1-5.

Parliament of Malta (2016), *Bill 136 - Persons within the Autism Spectrum (Empowerment).* Available at: http://www.parlament.mt/billdetails?bid=561&legcat=13. (Accessed: 15 August 2016).

Peeters, T., and Jordan, R. (1999) ‘What makes a good practitioner in the field of autism?’, *Good Autism Practice*, April, pp. 85-90.

Pellicano, E., Dinsmore, A., and Charman, T. (2014) ‘What should autism research focus upon? Community views and priorities from the United Kingdom’, *Autism,* pp. 1-15.

Perry, A., Flanagan, H.E., Geier, J.D., and Freeman, N.L. (2009). ‘Brief report: The Vineland Adaptive Behavior Scales in young children with autism spectrum disorders at different cognitive levels’, *Journal of Autism and Developmental Disorders,* 39 (7), pp. 1066-1078. Available at: https://doi.org/10.1007/s10803-009-0704-9.

Pilnick, A., Clegg, J., Murphy, E. and Almack, K. (2010) ‘Questioning the answer: Questioning style, choice and self-determination in interaction with young people with intellectual disabilities’, *Sociology of Health and Illness,* 32 (3), pp. 415-436.

Pinborough-Zimmerman J. and Bakian A.V. (2011) ‘Just under 1% of adults living in the community in England are estimated to have autism spectrum disorders’, *Evidence Based Mental Health* 14 (4), p. 89. Doi: 10.1136/ebmh.2011.100181. PMID: 22009229.

Plavnick, J. B. and Hume, K. (2013) ‘Observational learning by individuals with autism: A review of teaching strategies’, *Autism,* 0 (0), pp. 1-9.

Plummer, C. (2012) 'Who Cares? An Exploration, using Q Methodology, of Young Carers‟ and Professionals‟ Viewpoints', University of Sheffield UK: Department of Educational Studies. Available at: https://etheses.whiterose.ac.uk/2685/2/Who_Cares_Thesis_FINAL.pdf. (Accessed: 20 November 2018)

Powell R.A. and Single H.M. (1996) 'Focus groups', *International Journal of Quality in Health Care,* 8 (5), pp. 499-504.

Prasad, R.S. (2001) 'Development of the HIV/AIDS Q-sort instrument to measure physician attitudes: Clinical research methods', *Family Medicine,* Nov/Dec, pp. 772-778.

Pugliese, C.E., Anthony, L., Strang, J.F., Dudley, K., Wallace, G.L., and Kenworthy, L. (2015) 'Increasing adaptive behaviour skill Deficits from childhood to adolescence in autism spectrum disorder: Role of Executive function', *Journal of Autism Developmental Disorders,* 45, pp. 1579-587.

Renard, L. (2019) 'The direct instruction method: A practical guide to effective teaching', Available at: https://www.bookwidgets.com/blog/2019/03/direct-instruction-a-practical-guide-to-effective-teaching (Accessed:16 November 2021).

Reid, B. and Batten, A. (2006) *B is for Bullied.* London: The National Autistic Society.

Robinson, S., Goddard, L., Dritschel, B., Wisley,M., and Howlin, P., (2009) 'Executive functions in children with autism spectrum disorders', *Brain and Cognition,* 71 (3), pp. 362-368.

Rock, P. (1988) 'Independence: What It Means to Six Disabled People Living in the Community', *Disability, Handicap and Society,* 3:1, pp. 27-35. DOI: 10.1080/02674648866780021.

Rogers, S.R. (1995) ‘Q methodology’, in Smith, J.A., Harre, R. and Van Longenhove, I. (eds), *Rethinking Methods in Psychology*, Sage, London, pp. 178–193.

Root, J. (2018) ‘Effects of explicit instruction on acquisition and generalization of mathematical concepts for a student with autism spectrum disorder’, *Research in Autism Spectrum Disorders* 57, pp. 1-6. DOI:10.1016/j.rasd.2018.09.005.

Rosenthal, M., Wallace, G.L., Lawson, R., Wills, M.C., Dixon, E., Yerys, B.E. and Kenworthy, L. (2013) ‘Impairments in real-world executive function increase from childhood to adolescence in autism spectrum disorders’, *Neuropsychology,* 27, pp. 13-18. Doi:10.1037/a0031299.

Rossetti, Z., Ashby, C., Arndt, K., Chadwick, M., Kasahara, M., and O’Brien, J. (2008) ‘“I like others to not try to fix me”: Agency, independence, and autism’, *Intellectual and Developmental Disabilities,* 46, pp. 364-375.

Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. (2015) ‘National Autism Indicators Report: Transition into Young Adulthood’, Philadelphia, PA: *Life Course Outcomes Research Program,* A.J. Drexel Autism Institute, Drexel University.

Saaltink, R., MacKinnon, G., Owen, F. and Tardif-Williams, C. (2012) ‘Protection, participation and protection through participation: Young people with intellectual disabilities and decision-making in the family context’, *Journal of Intellectual Disability Research,* 56 (1), pp. 1076-1086.

Sainsbury, C. (2000*) Martian in the playground.* London: The Book Factory.

Sameroff, A.J. (1990) ‘Neo-environmental perspectives on developmental theory’, in Hodapp, R.M., Burack, J.A. and Zigler, E. (eds), *Issues in the developmental approach to mental retardation.* Cambridge, MA: Cambridge University Press, pp. 93-113.

Sarris, M. (2014a) ‘Coming of age: Autism and the transition to adulthood’, Available at: https://iancommunity.org/ssc/autism-adaptive-skills (Accessed: 15 January 2016).

Sarris, M. (2014b) ‘Daily living skills: A key to independence for people with autism’, Available at: https://iancommunity.org/ssc/autism-adaptive-skills (Accessed: 15 January 2016).

Sassoon, F. (1920) *The Jewish Encyclopaedia.* London: Funk and Wagnalls Company

Saulnier, C. and Klin, A. (2007) ‘Brief report: Social and communication abilities and disabilities in higher functioning individuals with autism and Asperger syndrome’, *Journal of Autism and Developmental Disorders,* 37, pp. 788-793.

Schlieder, M., Maldonado, N., and Baltes, B. (2014) ‘An investigation of “Circle of Friends” peer-mediated intervention for students with autism’, *Journal of Social Change,* 6 (1), pp. 1 – 14. Available at: http://dx.doi.org/10.5590/JOSC.2014.06.1.04.

Scott M., Falkmer M., Girdler S. and Falkmer, T. (2015) ‘Viewpoints on Factors for Successful Employment for Adults with Autism Spectrum Disorder’, *PLoS ONE,* 10 (10). Doi:10.1371/journal.pone.0139281.

Shattuck, P.T., Narendorf, S., Cooper, B., Sterzing, P.R., Wagner, M., Lounds Taylor, J. (2012) ‘Postsecondary education and employment among youth with an autism spectrum disorder’, *Pediatrics*, Epub May 14, 2012. DOI: 10.1542/peds.2011-2864.

Shuttleworth, M. (2008) ‘Validity and Reliability’, Available at https://explorable.com/validity-and-reliability (Accessed: 5 September, 2017).

Shogren, K. and Broussard, R. (2011) ‘Exploring the perceptions of self-determination of individuals with intellectual disability’, *Intellectual and Developmental Disabilities,* 49 (2), pp. 86-102.

Sieber (1993) ‘The ethics and politics of sensitive research‘, in Renzetti, C. and Lee, R. (eds) *Researching sensitive topics.* London: Sage.

Smith, T. (2001) ‘Discrete trial training in the treatment of autism’, *Focus on Autism and Other Developmental Disabilities,* 16, pp. 86-92.

Smith L.E., Maenner, M.J., and Seltzer, M.M., (2012) ‘Developmental trajectories in adolescents and adults with autism: the case of daily living skills’, *Journal of the American Academy of Child and Adolescent Psychiatry,* 51 (6), pp. 622-631.

Smyth, A. and Holian, R. (2008) ‘Credibility Issues in Research from within Organisations’, in Sikes, P. and Potts, A. (eds) *Researching education from the inside*. New York, NY: Taylor and Francis, pp. 33-47.

Sowers, J., and Powers, L. (1995) ‘Enhancing the participation and independence of students with severe physical and multiple disabilities in performing community activities’, *Mental Retardation,* 33 (4), pp. 209-220.

Sparrow, S., Cicchetti, D. and Balla, D. A. (2005) *Vineland Adaptive Behaviour Scales*. 2nd edn. Minneapolis, MN: NCS Pearson, Inc.

Spiker, M.A., Lin, C.E., Van Dyke, M. and Wood, J.J. (2012) ‘Restricted interest and anxiety in children with autism’, *Autism,* 16, pp. 306-320.

Spiteri, M. (2019) ‘The needs and challenges of adult individuals with severe autism in service provision: A comparative study between parents’ and professionals’ views in Malta’, University of Malta: Health and Social Care Management. Available at: https://www.researchgate.net/publication/340315085. (Accessed: 18 April 2022).

Stainton Rogers, R. (1995) ‘Q methodology’, in Smith, J.A., Harre, R. and Van Longenhove, I. (eds). *Rethinking Methods in Psychology*. London: Sage, pp. 178-193.

Stockard, J., Wood, T.W., Coughlin, C. and Rasplica Khoury, C. (2018) 'The Effectiveness of Direct Instruction Curricula: A Meta-Analysis of a Half Century of Research', *Review of Educational Research* 88 (4), pp. 479-507.

Stenner, P. and Stainton Rogers, R. (2004) 'Q methodology and qualiquantology: The example of discriminating between emotions', in Tod, Z., Nerlich, B., McKeown, S. and Clark, D. (eds). *Mixing methods in psychology*. London: Routledge, p. 6781.

Steinberg, L. (2011) *Adolescence* (9th ed.) New York: The McGraw-Hill Companies, Inc.

Stephenson, W. (1935) 'Technique of factor analysis', *Nature,* 136 (297).

Stephenson, W. (1953) *The study of behaviour: Q technique and its methodology.* Chicago: University of Chicago Press.

Stephenson, W. (1952) 'Q methodology and the projective techniques', *Journal of Clinical Psychology,* 8 (3), pp. 219-229

Stephenson, W. (1983) 'Against Interpretation', *Operant Subjectivity,* 6, pp. 73-103.

Stephenson, W. (2005) 'A sentence from B. F. Skinner', *Operant Subjectivity,* 28 (3/4), pp. 97-115.

Steward, D. and Shamdasani, P. (2015*) Focus groups: Theory and Practice*. 3rd edn. London: Sage.

Stokes, H., Turnbull, M., and Wyn, J. (2013), 'Young people with a disability: Independence and opportunity', *Research report 39, Youth Research Centre*: The University of Melbourne.

Sturge-Apple, M.L., Davies, P.T. and Cummings, E. . (2010) ‘Typologies of family functioning and children's adjustment during the early school years’, *Child development,* 81 (4), pp. 1320–1335. Available at: https://doi.org/10.1111/j.1467-8624.2010.01471.x.

Sutera, S., Pandey, J., Esser, E. L., Rosenthal, M. A., Wilson, L. B., Barton, M., Green, J., Hodgson, S., and Robins, D. L., (2007) ‘Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders’, *Journal of Autism and Developmental Disorders,* 37, pp. 98-107.

Taylor, J.L. and Mailick, M.R. (2014) ‘A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders’, *Developmental Psychology,* 50 (3), pp. 699-708.

Test, D., Smith, L., and Carter, E. (2014) ‘Equipping Youth With Autism Spectrum Disorders for Adulthood: Promoting Rigor, Relevance, and Relationships’, *Remedial and Special Education,* 35, pp. 80-90. Doi:10.1177/0741932513514857.

Treweek, C., Wood, C., Martin, J. and Freeth, M. (2019) ‘Autistic people’s perspectives on stereotypes: An interpretative phenomenological analysis’, *Autism,* 23 (3). pp. 759-769. ISSN 1362-3613

The Jewish Encyclopaedia, Vol. 3 (1920). New York: Fink and Wagnalls.

Thomas, D. and Baas, L. (1992) ‘The issue of generalisation in Q methodology: “reliable schematics” revisited’, *Operant Subjectivity,* 6 (1), pp. 18-36.

United Nations (2006) *Convention on the Rights of People with Disabilities.* Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html.

Unleur, S. (2012) ‘Being an insider researcher while conducting case study research’, *The Qualitative Report,* 17 (58), pp. 1-14.

Valenta, A. and Wigger, U. (1997) ‘Q-methodology: Definition and Application in Health Care Informatics’, *Journal of the American Medical Informatics Association,* 4 (6), pp. 501-510. Available at: https://doi.org/10.1136/jamia.1997.0040501.

Van Bourgondien, M. E., Dawkins, T. and Marcus, L. (2014) ‘Families of adults with autism spectrum disorders’, in Volkmar F. R., Reichow, B. and McPartland, J.C. (eds) *Adolescents and Adults with autism spectrum disorders.* New York: Springer.

Van Exel and de Graaf. G (2005) *Q methodology: A sneak preview.* Available at: www.jobvanexel.nl (Accessed: 12 November 2016).

Van Velsor, P. and Cox, D. (2000) ‘Use of the collaborative drawing technique in school counseling practicum: An illustration of family systems’, *Counselor Education and Supervision,* 40 (2), pp. 141-53.

Wade, L. (2015) ‘Children, chores, and the gender pay gap at home’, Available at: https://thesocietypages.org/socimages/2015/03/16/children-chores-and-the-gender-pay-gap-at-home/ (Accessed: 15 August 2016).

Wagner, M., Cadwallader, T., Garza, N. and Cameto, R. (2004) ‘Social Activities of Youth with Disabilities’, NLTS2 Data Brief. Volume 3, Issue 1. National Center on Secondary Education and Transition, University of Minnesota (NCSET).

Wainscot, J.J., Naylor, P., Sutcliffe, P., Tantam, D. and Williams, J. V. (2008) ‘Relationships with peers and use of the school environment of mainstream secondary school pupils with Asperger Syndrome (high-functioning autism): A case control study’, *International Journal of Psychology and Psychological Theory,* 8, pp. 25-38.

Walonick, D. (1993) ‘General systems theory’, Available at: http://www.statpac.org/walonick/systems-theory.htm (Accessed: 8 September 16).

Walsh, W. M., and Giblin, N. J. (eds.) (1988) *Family counseling in school settings.* Springfield, IL: Thomas.

Wang, H.-Y. and Berg, C. (2014) ‘Participation of Young Adults with High-Functioning Autism in Taiwan: A Pilot Study’, *OTJR: Occupation, Participation and Health,* 34 (1), pp. 41–51. Doi: 10.3928/15394492-20131209-01.

Watts, S. (2009) ‘Social Constructionism Redefined: Human Selectionism and the Objective Reality of Q Methodology’, *Operant Subjectivity,* 32, pp. 29-45.

Watts, S. and Stenner, P. (2005a) ‘Doing Q methodology: Theory, method, and interpretation’, *Qualitative Research in Psychology,* 2, pp. 67-91.

Watts, S. and Stenner, (2005b) ‘The subjective experience of partnership love: A Q methodological Study’, *British Journal of Social Psychology,* 44, pp. 85-107.

Watts, S. and Stenner, P. (2012) *Doing Q methodological research: Theory, method, and interpretation.* London: Sage.

Webster, S., Lewis, J., and Brown, L. (2014) ‘Ethical considerations in ethical research’, in Ritchi, J., Lewis, J., McNaughton Nicholls C., and Ormston, R. (eds.) *Qualitative Research Practice: A guide for social science students and researchers* . 2nd edn*.* London: Sage.

Wehmeyer, M.L. (2003) ‘A functional theory of self-determination: Definition and categorization’, in Wehmeyer, M.L., Abery, B., Mithaug, D.E. and Stancliff, R. (eds.) *Theory in self-determination: Foundations for educational practice.* Springfield, IL: Charles C. Thomas Publishing Company, pp. 174-181.

Wehmeyer, M.L. (1992) ‘Self-determination and the education of students with mental retardation’, *Education and Training in Mental Retardation and Developmental Disabilities*, 27, pp. 302-314.

Wehmeyer, M.L., Field, S., Doren, B., Jones, B., and Mason, C. (2004) ‘Self-determination and student involvement in standards based reform’, *Exceptional Children,* 70, pp. 413-425.

Wellington, J., Bathmaker, A., Hunt, C., McCulloch, G. and Sikes, P. (2005) *Succeeding with your doctorate.* London: Sage Publications Ltd.

Wesley, M. (2013), ‘The Entitled Adult: What Can be Done?’, Available at: http://www.thewesleygroup.com/blog/?p=364 (Accessed: 24 July 2016).

Wiles, R., Crow, G., Heath, S. and Charles, V. (2008) ‘The Management of Confidentiality and Anonymity in Social Research’, *International Journal of Social Research Methodology,* 11 (5), pp. 417-428. DOI: 10.1080/13645570701622231.

White, D., Hillier, A., Frye, A., and Makrez, E. (2019) ‘College students’ knowledge and attitudes towards students on the autism spectrum’, *Journal of Autism and Developmental Disorders,* 49, pp. 2699-2705. Available at: https://doi.org/10.1007/s10803-016-2818-1.

Wittemeyer, K., Charman, T. and Cusack, J., Guldberg, K., Hastings, R., Howlin, P., McNab, N., Parsons, S., Pellicano, L. and Slonims, V. (2011) *Educational provision and outcomes for people on the autism spectrum: Full technical report,* London: Autism Education Trust.

Wolinsky, F., Miller, D., Andresen, E., Malmstrom, T., and Miller, J. (2005). ‘Further Evidence for the Importance of Subclinical Functional Limitation and Subclinical

Disability Assessment in Gerontology and Geriatrics', *The Journals of Gerontology,* 60B(3), pp. S146-151.

Wolke, D. and Lereya, S. T. (2015) 'Long term effects of bullying', *Archives of Disease in Childhood,* 100, pp. 879-885.

Wood, C. and Freeth, M. (2016) 'Students Stereotypes of Autism', *Journal of Educational Issues,* 2 (2), pp. 131-140.

Woodman, A.C., Smith, L.E., Greenberg, J.S., and Mailick, M.R. (2016) 'Contextual Factors Predict Patterns of Change in Functioning over 10 Years Among Adolescents and Adults with Autism Spectrum Disorders', *Journal of Autism Developmental Disorders,* 46, pp. 176-189.

Zabala, A. (2014) 'Qmethod: A package to explore human perspectives using Q methodology', *The R Journal,* 6 (2), pp. 163-173.

Zablotsky, B., Bradshaw, C. P., Anderson, C. M. and Law, P. (2014) 'Risk factors for bullying among children with autism spectrum disorders', *Autism,* 18 (4), pp. 419-427. Doi: 10.1177/1362361313477920.

Zimmer-Gembeck, M.J. and Collins, W.A. (2003) 'Autonomy development during adolescence,' in Adams G.R. and Berzonsky M. (eds) *Blackwell handbook of adolescence. Oxford,* UK: Blackwell pp. 174-204.

APPENDICES

Appendix 1. Confirmation of Ethical Approval

The University of Birmingham

Application for Ethical Review ERN_16-0089

Samantha Waldron [redacted]

Jan 29, 2018, 2:07 PM

to Despina, Glenys, me

Dear Dr Despina Papoudi & Dr Glenys Jones

Re: "What are the views of able young people with autism, their parents and professionals on what needs to be taught in life skills curriculum, and what are the promoters and barriers to achieving such skills?"

Application for Ethical Review ERN_16-0089

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities and Social Sciences Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly bought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review.

It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards,

Ms Sam Waldron

Deputy Research Ethics Officer

Research Support Group

C Block Dome (room 132)

Aston Webb Building

University of Birmingham

Edgbaston B15 2TT

Tel: [redacted]

Email: [redacted]

Web: https://intranet.birmingham.ac.uk/finance/RSS/Research-Support-Group/Research-Ethics/Research-Integrity-at-the-University-of-Birmingham.aspx

Please remember to submit a new Self-Assessment Form for each new project.

Click Ethical Review Process for further details regarding the University's Ethical Review process, or email ethics-queries@contacts.bham.ac.uk with any queries.

Click Research Governance for further details regarding the University's Research Governance and Clinical Trials Insurance processes, or email researchgovernance@contacts.bham.ac.uk with any queries

Appendix 2. Recruitment Letters

Parents

A study to explore the development of life skills in able autistic young people

Dear ________

My name is Yanika Attard and I am currently a PhD student at the University of Birmingham. I am conducting a research study to investigate the functional independence of able autistic young people. This study is being carried out under the supervision of Dr Despina Papoudi [redacted] and Dr Glenys Jones [redacted]

Research Title

What are the main views of able autistic young people, their parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Introduction to my research topic

I have chosen this topic because research on the independent functioning of able autistic persons suggests that although they may have the necessary intellectual and verbal ability to acquire daily living skills (e.g. household chores, money management, keeping safe, independent travel), they often find it difficult to apply such skills without the support of others. Little is known about why there is a gap between the ability of able autistic people to learn life skills and their actual independent functioning in everyday life.

What this study is about

This study aims to get to know the views of able autistic young people, their parents and professionals about (i) those life skills which they consider to be most important, (ii) what difficulties able autistic people encounter in everyday life to acquire such life skills and, (iii) what they believe would help them to acquire such skills to function more independently in life.

Why you are being asked to take part

You have been chosen to take part in this research study as a parent of an able autistic young person. I am interested in your views about those life skills that you believe are most important for your young person and what helps or hinders the development of such skills.

What your participation will involve

Your participation in this study is entirely voluntary. This means that it is up to you to decide whether you would like to participate, and choosing not to participate will not affect your relationship with me or with the Malta Autism Centre. If you choose to participate, you can withdraw from this research up to four weeks after taking part in this study, without giving reasons for your decision.

If you decide to take part in this research, you will be asked to complete an activity called Q sort. Q sort involves reading some statements on cards and sorting them out to show how important you think they are.

For this study, you will be given a list of daily living skills (DLS) and you will be asked to rate each DLS as high or low priority according to how important you believe it is for able autistic young adults. Then you will be asked to complete two Q sort activities: (i) the first one will involve sorting statements about factors that help your autistic son to acquire and perform daily life skills, and (ii) the second Q sort will involve sorting statements about factors that hinder your autistic son from acquiring and performing daily life skills. Q sorts are designed to be simple to complete and you will be provided with instructions to support you throughout the exercise. I will also be available to explain the Q sort procedure.

After completing the Q sort activities, I will ask you a few short questions about your sorting of the statements. The priority DLS checklist, the Q sort activities, and the follow-up questions should take about 1 hour 30 minutes.

At the end of these activities, you will be asked whether you would like to take part in an interview about 3 weeks later to discuss the development of independence skills in more detail.

How the information you give will be used

Your responses will be confidential, and they will only be shared with my doctoral supervisors at the University of Birmingham. Your answers will be stored safely and they will be presented in writing in a thesis together with the responses of the other participants. The written work will be anonymised and no one will be able to identify you or associate your responses with you.

What you will get in return for taking part in this study

If you decide to take part in this study, it is hoped that it will be a positive experience for you. It will give you the opportunity to voice your views and contribute to the identification of important information that would promote the independent functioning of able autistic persons. You will not receive any money or other benefit for taking part.

Thank you for taking the time to read this information. If you would like to take part in this research study please fill in the consent form and return it to me. Once I receive the consent form, I will contact you so that we can arrange to meet at a convenient time and place to complete the DLS checklist, the Q sorts and post-sorting questions.

You can contact me by email if you have any questions about this [redacted]

Best wishes,

Yanika Attard

Professionals

A study to explore the development of life skills in able autistic young people

Dear Professional,

My name is Yanika Attard and I am currently a PhD student at the University of Birmingham. I am conducting a research study to investigate the functional independence of able autistic young people. This study is being carried out under the supervision of Dr Despina Papoudi [redacted] and Dr Glenys Jones [redacted]

Research Title

What are the main views of able autistic young people, parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Introduction to my research topic

I have chosen this topic because research on the independent functioning of able autistic persons suggests that although they may have the necessary intellectual and verbal ability to acquire daily living skills (e.g. household chores, money management, keeping safe, independent travel), they often find it difficult to apply such skills to function independently in life without the support of others. Little is known about why there is a gap between the ability of able autistic people to learn life skills and their actual independent functioning in everyday life.

What this study is about

This study aims to get to know the views of able autistic young people, their parents and professionals about (i) those life skills which they consider to be most important, (ii) what difficulties able autistic people encounter in everyday life to acquire such life skills and, (iii) what they believe would help them to acquire such skills to function more independently in life.

Why you are being asked to take part

You have been chosen to take part in this research study as a professional working with autistic people. I am interested in your views about those life skills which you believe are most important and what helps or hinders the development of such skills in everyday life.

What your participation will involve

Your participation in this study is entirely voluntary. This means that it is up to you to decide whether you would like to participate, and choosing not to participate will not affect your relationship with me or with the Malta Autism Centre. If you choose to participate, you can withdraw from this research up to four weeks after taking part in this study without providing reasons for your decision.

If you decide to take part in this research, you will be asked to complete an activity called Q sort. Q sort involves reading some statements on cards and sorting them out to show how important you think they are.

For this study, you will be given a list of daily living skills (DLS) and you will be asked to rate each DLS as high or low priority according to how important you believe it is for able autistic young adults. Then you will be asked to complete two Q sort activities: (i) the first one will involve sorting statements about factors that help autistic people to acquire and perform daily life skills, and (ii) the second Q sort will involve sorting statements about factors that hinder autistic people from acquiring and performing daily life skills. Q sorts are designed to be simple to complete and you will be provided with instructions to support you throughout the exercise. I will also be available to explain the Q sort procedure.

After completing the Q sort activities, I will ask you a few short questions about your sorting of the statements. The priority DLS checklist, the Q sort activities, and the follow-up questions should take about 1 hour 30 minutes.

At the end of these activities, you will be asked whether you would like to take part in an interview about 3 weeks later to discuss the development of independence skills in more detail.

How the information you give will be used

Your responses will be confidential, and they will only be shared with my doctoral supervisors at the University of Birmingham. Your answers will be stored safely and they will be presented in writing in a thesis together with the responses of the other participants. The written work will be anonymised and no one will be able to identify you or associate your responses with you.

What you will get in return for taking part in this study

If you decide to take part in this study, it is hoped that it will be a positive experience for you. It will give you the opportunity to voice your views and contribute to the identification of important information that would promote the independent functioning of able persons with autism. You will not receive any money or other benefit for taking part.

Thank you for taking the time to read this information. If you would like to take part in this research study please fill in the consent form and return it to me. Once I receive the consent form, I will contact you so that we can arrange to meet at a convenient time and place to complete the DLS checklist, the Q sorts and post-sorting questions.

You can contact me by email if you have any questions about this [redacted]

Best wishes,

Yanika Attard

Young People

A study to explore the development of life skills in able autistic young people

Dear

My name is Yanika Attard and I am currently a PhD student at the University of Birmingham. I am conducting a research study to investigate the functional independence of able young people with autism. This study is being carried out under the supervision of Dr Despina Papoudi [redacted] and Dr Glenys Jones [redacted].

Research Title

What are the main views of able autistic young people, their parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Introduction to my research topic

I have chosen this topic because research on the independent functioning of able autistic people autism suggests that although they may have the necessary intellectual and verbal ability to acquire daily living skills (e.g. household chores, money management, keeping safe, independent travel), they often find it difficult to apply such skills to function independently in life without the support of others. Little is known about why there is a gap between the ability of able autistic people to learn life skills and their actual independent functioning in everyday life.

What this study is about

This study aims to get to know the views of able autistic young people, their parents and professionals about (i) those life skills which they consider to be most important, (ii) what difficulties able autistic people encounter in everyday life to acquire such life skills and, (iii) what they believe would help them to acquire such skills to function more independently in life.

Why you are being asked to take part

You have been chosen to take part in this research study as an able autistic young person. I am interested in your views about those life skills which you believe are most important for you and what helps or hinders you to develop such skills in everyday life.

What your participation will involve

Your participation in this study is entirely voluntary. This means that it is up to you to decide whether you would like to participate, and choosing not to participate will not affect your relationship with me or with the Malta Autism Centre. If you choose to participate, you can withdraw from this research up to four weeks after taking part in this study without providing reasons for your decision.

If you decide to take part in this research study, you will be asked to complete an activity called Q sort. Q sort involves reading some statements on cards and sorting these out to show how important you think they are.

For this study, you will be given a list of daily living skills (DLS) and you will be asked to rate each DLS as high or low priority according to how important you believe it is. Then, you will be asked to complete two Q sort activities: (i) the first one will involve sorting statements about factors that help you to learn and to perform independent life skills, and (ii) the second Q sort will involve sorting statements about factors that hinder you from acquiring and performing daily life skills. Q sorts are designed to be simple to complete and you will be provided with instructions to support you throughout the exercise. I will also be available to explain the Q sort procedure.

After completing the Q sort activities, I will ask you a few short questions about your sorting of the statements. The priority DLS checklist, the Q sort activities and the follow-up questions should take about 1 hour 30 minutes.

At the end of these activities, you will be asked whether you would like to take part in an interview about 3 weeks later to discuss the development of independence skills in more detail.

How the information you give will be used

Your responses will be confidential, and they will only be shared with my doctoral supervisors at the University of Birmingham. Your answers will be stored safely and they will be presented in writing in a thesis together with the responses of the other participants. The written work will be anonymised and no one will be able to identify you or associate your responses with you.

What you will get in return for taking part in this study

If you decide to take part in this study, it is hoped that it will be a positive experience for you. It will give you the opportunity to voice your views and contribute to the identification of important information that would promote the independent functioning of able autistic people. You will not receive any money or other benefit for taking part.

Thank you for taking the time to read this information. If you would like to take part in this research study please fill in the consent form and return it to me. Once I receive the consent form, I will contact you so that we can arrange to meet at a convenient time and place to complete the DLS checklist, the Q sorts and post-sorting questions.

You can contact me by email if you have any questions about this [redacted]

Best wishes,

Yanika Attard

Appendix 3. Study Consent Form

Parents

Research Project Title

What are the main views of able autistic young people, parents and professionals on what needs to be taught in a life skills curriculum, and are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student, School of Education, University of Birmingham, UK).

Email: [redacted]

Research supervisors and contact email:

Dr Despina Papoudi - [redacted]

Dr Glenys Jones - [redacted]

Dear

Thank you for agreeing to take part in this research study. This form gives a description of your involvement in this study and details your rights as a participant.

My understanding as a participant:

Kindly tick the box if you agree with each of the following statements.

I confirm that I have read the participant information sheet and I have understood the aims and purposes of this research ☐

I understand that my participation will include a priority DLS checklist and two Q sorting activities which will involve the sorting of statements on a grid regarding: (i) factors that help able autistic people to acquire independent life skills, and (ii) factors that hinder able autistic people from acquiring daily life skills, and a post-sorting interview ☐

I understand that my participation is voluntary and that I have the right to withdraw from the study up to four weeks after taking part, without having to provide reasons for this, and that such withdrawal would not result in any negative consequences ☐

I understand that my responses will be kept strictly confidential and that my name will not be identifiable in any written work resulting from this research study ☐

I understand that the researcher will be discussing the information collected for this research study with her doctoral supervisors Dr Despina Papoudi [redacted]) and Dr Glenys Jones [redacted], at the University of Birmingham ☐

I understand that the researcher will be accessing assessment data and using test scores of my autistic young adult son for the purpose of this study ☐

I understand that my autistic young adult will be asked to take part in this study and I give my informed consent for him to participate if he agrees and gives his consent to take part ☐

I confirm that I have read and understand the content of the information sheet, and I agree with the above information ☐

I ____ (name in full) am hereby giving my informed consent to participate in this research study.

______________________________ _______________

Participant’s signature Date

Professionals

Research Project Title

What are the main views of able autistic young people, parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student, School of Education, University of Birmingham, UK).

Email: [redacted]

Research supervisors and contact email:

Dr Despina Papoudi - [redacted]

Dr Glenys Jones - [redacted]

Dear

Thank you for agreeing to take part in this research study. This form gives a description of your involvement in this study and details your rights as a participant.

My understanding as a participant:

Kindly tick the box if you agree with each of the following statements.

I confirm that I have read the participant information sheet and I have understood the aims and purposes of this research ☐

I understand that my participation will include a priority DLS checklist and two Q sorting activities which will involve the sorting of statements on a grid regarding: (i) factors that help able autistic people to acquire independent life skills, and (ii) factors that hinder able autistic people from acquiring daily life skills, and a post-sorting interview ☐

I understand that my participation is voluntary and that I have the right to withdraw from the study up to four weeks after taking part, without having to provide reasons for this, and that such withdrawal would not result in any negative consequences ☐

I understand that my responses will be kept strictly confidential and that my name will not be identifiable in any written work resulting from this research study ☐

I understand that the researcher will be discussing the information collected for this research study with her doctoral supervisors Dr Despina Papoudi [redacted] and Dr Glenys Jones [redacted], at the University of Birmingham ☐

I confirm that I have read and understand the content of the information sheet, and I agree with the above information ☐

I ____ (name in full) am hereby giving my informed consent to participate in this research study.

________________________________ ________________

Participant’s signature Date

Young People

Research Project Title

What are the main views of able young autistic people, parents and professionals on what needs to be taught in a life skills curriculum, and are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student, School of Education, University of Birmingham, UK).

Email: [redacted]

Research supervisors and contact email:

Dr Despina Papoudi - [redacted]

Dr Glenys Jones - [redacted]

Dear

Thank you for agreeing to take part in this research study. This form gives a description of your involvement in this study and details your rights as a participant.

My understanding as a participant:

Kindly tick the box if you agree with each of the following statements.

I confirm that I have read the participant information sheet and I have understood the aims and purposes of this research ☐

I understand that my participation will include a priority DLS checklist and two sorting activities which will involve the sorting of statements on a grid regarding: (i) factors that help or hinder able autistic persons to acquire independent life skills, and (ii) factors that hinder autistic persons from acquiring daily life skills, and a post-sorting interview ☐

I understand that my participation is voluntary and that I have the right to withdraw from the study up to four weeks after taking part, without having to provide reasons for this, and that such withdrawal would not result in any negative consequences ☐

I understand that my responses will be kept strictly confidential and that my name will not be identifiable in any written work resulting from this research study ☐

I understand that the researcher will be discussing the information collected for this research study with her doctoral supervisors Dr Despina Papoudi [redacted] and Dr Glenys Jones [redacted] at the University of Birmingham ☐

I confirm that I have read and understand the content of the information sheet, and I agree with the above information ☐

I ____ (name in full) am hereby giving my informed consent to participate in this research study.

_______________________________ ________________

Participant’s signature Date

Appendix 4. Consent Form for the Concourse Discussion

Parents

Research Project Title

What are the main views of able autistic young people, their parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student, School of Education, University of Birmingham, UK).

Email: [redacted]

Research supervisors and contact email:

Dr Despina Papoudi - [redacted]

Dr Glenys Jones - [redacted]

Dear ___________

Firstly, I would like to thank you for agreeing to participate in this research study. To carry out this research, I need to create a number of statements about life skills for all the participants to sort (as described in the information sheet). To ensure that the statements represent the views and perspectives of able autistic people, their parents and professionals working in the field of autism, I need to carry out an informal discussion with eight people from the different groups.

This form gives information about the informal discussion and what your participation will involve, and details your rights as a participant.

Information about the informal discussion

The main purpose of this discussion is to create a number of statements on life skills to include in a sorting exercise.

Your participation is entirely voluntary. You have the right to refrain from participating in this discussion, and it will not affect your participation in the study.

If you decide to take part, we will agree on a meeting time and place that is convenient for you to talk with me as the researcher, using a set of questions, for about one hour. If you do not wish to answer a question during the discussion, you can ask to move on to the next question.

The discussion will be audio-recorded to help me to remember the information you share with me. The recorded information will be strictly confidential and it will be accessible only to me. The recordings will be destroyed after completion of this research study.

The statements will be anonymous and there will be no information that could identify you or associate you with the statement.

My understanding as a participant:

Kindly tick the box if you agree with each of the following statements.

I confirm that I have read the above information and I had the opportunity to ask questions about it ☐

I understand that my participation is voluntary and I have the right to refrain from answering any questions which I may not wish to answer ☐

I understand my right to stop participating in the discussion without having to give reasons for this ☐

I understand that I have the right to withdraw from this discussion up to two weeks after taking part ☐

I understand that the discussion will be audio-recorded but any information I share will be strictly confidential and destroyed at the end of this research study ☐

I understand that parts of my responses may be included in the list of statements for the Q-sort activity, but I will not be named or identified by any of the statements ☐

I confirm that I have read and understand the content of the information sheet, and I am happy to take part in this discussion ☐

I ____ (name in full) am hereby giving my informed consent to participate in this discussion about the life skills of able autistic young people.

______________________________ ________________

Participant’s signature Date

Professionals

Research Project Title

What are the main views of able autistic young people, their parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student, School of Education, University of Birmingham, UK).

Email: [redacted]

Research supervisors and contact email:

Dr Despina Papoudi - [redacted]

Dr Glenys Jones - [redacted]

Dear _______,

Firstly, I would like to thank you for agreeing to participate in this research study. To carry out this research, I need to create a number of statements about life skills for all the participants to sort (as described in the information sheet). To ensure that the statements represent the views and perspectives of able autistic people, their parents and professionals working in the field of autism, I need to carry out an informal discussion with eight people from the different groups.

This form gives information about the interview and what your participation will involve, and details your rights as a participant.

Information about the informal discussion

The main purpose of this discussion is to create a number of statements on life skills to include in a sorting exercise.

Your participation is entirely voluntary. You have the right to refrain from participating in this discussion, and it will not affect your participation in the study.

If you decide to take part, we will agree on a meeting time and place that is convenient for you to talk with me as the researcher, using a set of questions, for about one hour. If you do not wish to answer a question during the discussion, you can ask to move on to the next question.

The discussion will be audio-recorded to help me to remember the information you share with me. The recorded information will be strictly confidential and it will be accessible only to me. The tapes will be destroyed after completion of this research study.

The statements will be anonymous and there will be no information that could identify you or associate you with the statement.

My understanding as a participant

Kindly tick the box if you agree with each of the following statements.

I confirm that I have read the above information and I had the opportunity to ask questions about it ☐

I understand that my participation is voluntary and I have the right to refrain from answering any questions which I may not wish to answer ☐

I understand my right to stop participating in the discussion without having to give reasons for this ☐

I understand that I have the right to withdraw from this discussion up to two weeks after taking part ☐

I understand that the discussion will be audio-recorded but any information I share will be strictly confidential and destroyed at the end of this research study ☐

I understand that parts of my responses may be included in the list of statements for the Q-sort activity, but I will not be named or identified by any of the statements ☐

I confirm that I have read and understand the content of the information sheet, and I am happy to take part in this discussion ☐

I ____ (name in full) am hereby giving my informed consent to participate in this discussion about the life skills of able autistic young people.

______________________________ _______________

Participant’s signature Date

Young People

Research Project Title

What are the main views of able autistic young people, their parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student, School of Education, University of Birmingham, UK).

Email: [redacted]

Research supervisors and contact email:

Dr Despina Papoudi - [redacted]

Dr Glenys Jones - [redacted]

Dear ____________,

Firstly, I would like to thank you for agreeing to participate in this research study. To carry out this research, I need to create a number of statements about life skills for all the participants to sort (as described in the information sheet). To ensure that the statements represent the views and perspectives of able autistic people, their parents and professionals working in the field of autism, I need to carry out an informal discussion with eight people from the different groups.

This form gives information about this discussion and what your participation will involve, and details your rights as a participant.

Information about the informal discussion

The main purpose of this discussion is to create a number of statements on life skills to include in a sorting exercise.

Your participation is entirely voluntary. You have the right to refrain from participating in this discussion, and it will not affect your participation in the study.

If you decide to take part, we will agree on a meeting time and place that is convenient for you to talk with me as the researcher, using a set of questions, for about one hour. If you do not wish to answer a question during the discussion, you can ask to move on to the next question.

The discussion will be audio-recorded to help me to remember the information you share with me. The recorded information will be strictly confidential and it will be accessible only to me. The tapes will be destroyed after completion of this research study.

The statements will be anonymous and there will be no information that could identify you or associate you with the statement.

My understanding as a participant:

Kindly tick the box if you agree with each of the following statements.

I confirm that I have read the above information and I had the opportunity to ask questions about it ☐

I understand that my participation is voluntary and I have the right to refrain from answering any questions which I may not wish to answer ☐

I understand my right to stop participating in the discussion without having to give reasons for this ☐

I understand that I have the right to withdraw from this discussion up to two weeks after taking part ☐

I understand that the discussion will be audio-recorded but any information I share will be strictly confidential and destroyed at the end of this research study ☐

I understand that parts of my responses may be included in the list of statements for the Q-sort activity, but I will not be named or identified by any of the statements ☐

I confirm that I have read and understand the content of the information sheet, and I am happy to take part in this discussion ☐

I ____ (name in full) am hereby giving my informed consent to participate in this discussion about the life skills of able young people with autism.

______________________________ _______________

Participant’s signature Date

Appendix 5. Consent Form for the In-depth Interviews

Research Project Title

What are the views perspectives of able young people with autism, parents and professionals on what needs to be taught in a life skills curriculum, and what are the promoters and barriers to achieving such skills?

Researcher

Yanika Attard (PhD student (2013 – 2019) School of Education, University of Birmingham, UK).

Dear Participant,

Firstly, I would like to thank you for completing the Q-sort activities and for answering the post-sorting questions. Thank you once more for agreeing to be interviewed. This form gives information about the interview and what your participation will involve.

Information about the interview:

The main purpose of the interview is to further explore the topic of independence of able adults with autism. Your participation in this interview is entirely voluntary. You have the right to withdraw from the interview at any point if you wish, and your withdrawal will not alter the study in any way.

If you decide to take part in the interview, we will agree on a meeting time and place that is convenient for you. In light of the COVID-19 pandemic, we will also agree on whether the interview will be carried out face-to-face or remotely. The interview will take about an hour and I will ask you a series of questions. If you do not wish to answer a question during the interview, you may ask me to move on to the next question.

The interview will be audio-recorded so that I do not have to take notes. The recorded information will be strictly confidential and the recorded information will be accessible to me only. Short quotes from the interview may be contained in the written thesis but these will be anonymous. The tapes will be destroyed after completion of this research study.

My understanding as a participant:

I confirm that I have read the above information and I had the opportunity to ask questions about it.

I understand that my participation is voluntary and I have the right to refrain from answering any questions which I may feel uncomfortable to talk about.

I understand my right to stop participating in the interview without having to give reasons for this.

I understand that the interview will be audio-recorded but any information I share will be strictly confidential and destroyed at the end of this research study.

I understand that parts of my responses may be included in the written work of this research study as quotes, and that I will not be named or identified by any written material arising from this study.

I understand that the researcher will be discussing the information collected for this research study with her doctoral supervisors Dr Despina Papoudi and Dr Glenys Jones, at the University of Birmingham.

I confirm that I have read and understand the content of the information sheet, and I agree with the above information.

I ____ (name in full) am hereby giving my informed consent to participate in this interview about the independent functioning of able young people with autism.

______________________________ ______________

Participant’s signature Date

Appendix 6. Questions to guide the discussions to generate the concourse statements

Parents

Priority life skills

1. Which daily living skills (DLS) do you consider most important for your autistic young person to function independently in life?

Teaching/Learning daily life skills

2. Which daily living skills were easier to teach along the years? Why?

3. Which life skills were most difficult to teach? Why?

4. What has helped your young person to learn the acquired daily living skills?

5. Which daily living skills does your young person still find difficult to learn and to perform without the help of others? Why do you think he struggles with these?

Promoters and barriers of daily life skills

6. What motivates you to encourage independent functioning and teach your son DLS? What scares you?

7. Which aspects interfere mostly with the teaching/learning of daily living skills? (e.g. the autism condition; family life; society; family/cultural expectations; sensory issues)

8. How do you think one can overcome such barriers?

9. How much do you encourage your son to perform daily living skills independently in everyday life?

10. How much do you think opinions differ within your family about the independent functioning of your able young person with autism? Who encourages independence most?

<u>Suggestions to promote DLS</u>

11. What are your suggestions to parents of autistic young children in terms of teaching DLS and encouraging independent functioning?

12. What are your suggestions to autism educators in terms of DLS and independent functioning?

13. What should a life skills curriculum for verbal and intellectually able autistic students include?

Professionals

Priority life skills

1. Which daily living skills (DLS) do you consider most important for able autistic young people to function independently in life? Why?

Teaching/Learning daily life skills

2. From your experience which daily living skills do you believe to be easier to teach to able autistic people? Why?

3. Which life skills are most difficult to teach? Why?

4. From your professional experience, what are those factors which help able autistic people to learn the acquired daily living skills?

Promoters and barriers of daily life skills

5. What do you do as a professional to encourage able autistic young people to perform daily living skills independently in everyday life?

6. What motivates you to encourage independent functioning and teach able autistic persons DLS?

7. What are your concerns during the process of teaching and encouraging the independent functioning of such skills?

8. Which aspects interfere mostly with the teaching/learning of daily living skills? (e.g. the autism condition; family life; society; family/cultural expectations; sensory issues)

9. In your opinion, how can one overcome such barriers?

10. How much do you think opinions differ within and between family members about the independent functioning of able young persons with autism?

Suggestions to promote DLS

11. What are your suggestions to parents of autistic young children in terms of teaching DLS and encouraging independent functioning?

12. What are your suggestions to autism educators in terms of DLS and independent functioning?

13. What should a life skills curriculum for verbal and intellectually able autistic students include?

Young people

Priority life skills

1. Which daily living skills do you consider most important for you to function independently in life? Why do you consider these skills important?

Learning daily life skills

2. Make a list of DLS that you are able to do without help. Which of these daily living skills were easier for you to learn along the years? Why?

3. Which DLS were most difficult to learn? Why?

4. What strategies and which persons helped you most to learn the daily living skills that you can do without help nowadays?

5. Which daily living skills do you still find difficult to learn and to perform without the help of others? Why do you think you struggle with these?

Promoters and barriers of daily life skills

6. What motivates you to learn and perform daily living skills independently? What scares you?

7. Mention 3 things that other people have done to help you function more independently.

8. Which factors do you think interfere most with your learning of daily living skills? (e.g. the autism condition; family life; society; family/cultural expectations; sensory)

9. How do you think you can overcome such barriers?

10. Are there any daily living skills which you used to do independently when you were younger, and which you no longer do? What do you think are the reasons for this?

11. How much does your family encourage you to do everyday life skills independently? Who encourages you most and which skills?

12. How much do you think opinions differ between your family members regarding what daily living skills you should learn and perform independently?

13. Did you learn / practise daily living skills when you were in school? What were they?

Suggestions to promote DLS

14. What are your suggestions to parents of young autistic children in terms of teaching DLS and encouraging independent functioning?

Appendix 7. Q sort Statements

Promoter Statements

1. Do not like other people to do things for them
2. Have good professional support
3. Are given clear step-by-step visual instructions to follow
4. Are willing to help out with everyday chores
5. Are taught through role play
6. Have parents who expose them to different experiences in life
7. Have educators who encourage independence
8. Are concerned about how others perceive them
9. Live in families with open communication about the passing of parents and the importance of DLS
10. Have peer influence and support to perform DLS independently
11. Have siblings involved in everyday routine of household chores
12. Are mentally ready to learn and perform such skill
13. Are taught by repetition
14. Have parents who are ready to take calculated risks
15. Have regular opportunities to watch and observe others doing DLS
16. Are guided by people who understand autism
17. Learn DLS as part of their school curriculum
18. Spend time with non-autistic peers
19. Have a special interest in the area of DLS
20. Have parents who are consistent when teaching them DLS

21. Are surrounded by ppl who focus on their strengths and abilities
22. Are given important roles and chores within family to carry out daily
23. Feel confident to do such skills
24. Have parents who give them a lot of reassurance
25. Have transition planning & support as they reach adulthood
26. Are taught in environments where they observe and imitate peers performing DLS
27. Are helped to understand the importance of DLS for independence
28. Have a structured routine that they can follow
29. Live in society where people have inclusive and positive attitudes towards people with autism
30. Have siblings who support and accompany them when practising DLS in the community
31. Are surrounded by calm people who don't give up on them
32. are taught DLS by physical & verbal prompting reducing grad
33. Have parents who encourage them to help out with everyday DLS
34. Are given support of service providers and local authorities to achieve independence
35. Are taught by people who don't assume that skills are common sense
36. Are helped to understand that as parents grow old they can depend on them less
37. Aspire to be like their non-autistic peers
38. Are given opportunities to practise learnt skills in different settings and circumstances

39. Have regular opportunities to participate in age-appropriate DLS activities
40. Have parents who are determined to teach them DLS despite challenges
41. Have sufficient money to support development of DLS when money is needed
42. Have opportunities to receive feedback during the process of learning DLS
43. Have parents who seek to learn about autism
44. Are encouraged to carry out basic DLS without help
45. Are encouraged from a young age to do age-appropriate DLS independently
46. Have a desire to become an independent adult
47. Are encouraged by siblings to learn DLS
48. Are given time to learn at their own pace
49. Are taught to ask a peer for assistance rather than an adult
50. Have parents and educators who collaborate together

Barrier Statements

1. Are not patient enough in learning a new skill
2. Are not encouraged by parents to perform DLS
3. Do not feel the need to learn DLS
4. Have educators who give too much assistance
5. Need a lot of prompts for reassurance to perform DLS
6. Are clumsy or poorly coordinated
7. Are influenced by the negative attitudes from people in society
8. Are unable to cope when something out of the ordinary routine happens
9. Lack opportunities to discuss their wishes about the development of DLS
10. Have parents who worry about people's reaction and & judgment of unusual behaviour in communication
11. Lose their attention on task easily
12. Have a lot of commitments (work, intervention, sports)
13. Experience anger and frustration when they fail to do DLS well
14. Feel comforted with everything being done for them
15. Meet professionals and educators with low expectations for them
16. Have parents who give importance to academic skills rather than DLS
17. Develop dependence on adults who support them
18. Are not taught directly how to do DLS
19. Experience a lot of anxiety
20. Have parents who do not accept their child's condition
21. Have a poor sense of danger
22. Take a long time to learn certain DLS

23. Live in a family which doesn't discuss the importance of learning DLS
24. Are not interested in performing DLS
25. Have parents who are very busy with other commitments
26. Get lost in their own thoughts
27. Scared of doing something wrong
28. Spend a lot of their free time on ipads, iphones or gaming
29. Find it difficult to adapt to different circumstances
30. Have parents with low expectations of them
31. Find it difficult to understand abstract things
32. Lack opportunities to learn DLS
33. Tend to forget a learnt DLS if not done regularly
34. Have fine motor difficulties
35. Have parents who are scared to enable them to become independent
36. Do not feel confident to perform DLS independently
37. Find it difficult to take decisions about everyday things
38. Have educators who lack autism knowledge
39. Live in an age when life is hectic and families lack time to teach DLS
40. Lack awareness of consequences to do household chores independently
41. Have parents who believe that without training their son will still be able to learn DLS
42. Find it difficult to plan and organise steps of carrying out DLS independently
43. Do not take the initiative to perform DLS
44. Experience uncertainty and fear about their abilities to do DLS independently
45. Lack awareness of risks to do DLS in the community independently

46. Have parents who worry about them being bullied/exploited in the community

47. Do not aspire to live independently

48. Find it difficult to plan ahead

49. Have parents who worry about their lack of sense of danger

50. Find it difficult to transfer taught DLS to everyday situations

Appendix 8. Instructions for the Q sort Exercises

Instructions given to participants for the Q sort exercise

Promoters of DLS

The following instructions will guide you throughout the sorting process:

1. You will be given 50 cards, each with a statement on it. Each statement will be about ideas that may promote the development of DLS for able autistic young people. The different statements are an ending to the phrase: '**Autistic young people will be helped to acquire DLS for independent functioning if they…'**. I will be asking you to rank-order these statements according to your point of view about the topic. Each card has a random number on it which will only be used to record your responses at the end of the sorting exercise.

2. There are no right or wrong answers. I am interested in your opinion and point of view about each idea.

3. Read the statements on each card well and sort them into three piles. Firstly, a pile for those statements which you feel you mostly agree with, secondly a pile for those statements which you feel you mostly disagree with, and thirdly a pile for those items which you feel neutral or unsure about. When you have finished this process, count and write down the number of cards in each pile.

4. You will now be given a sheet with a sorting grid. Take the cards from the pile of statements which you feel you agree most with and read them again. Select

one statement which you agree most with and place it in the far right-hand column of the sorting grid. Next, choose the next two statements from the pile, with which you agree most and place them under the second column on the right-hand side. Repeat this procedure with the remaining ‘most agree’ statements moving from the right-hand columns towards the left-hand side of the grid.

5. Placing the items in this category towards the left-hand side does not indicate you do not agree with these but means these items are slightly less important than the one you ranked before it. Items within the same column are of equal ranking, and therefore the position of statements within the same column is irrelevant.

6. Now take the cards from the pile of statements which you feel are least important and read them. Choose one statement with which you disagree most and place it in the far left-hand side column. Follow the same procedure as with the ‘most agree’ pile, this time moving from left to right.

7. Finally, take the remaining pile of cards and read them. Sort them out in the remaining boxes on the grid.

8. When you have sorted out all the cards, go over how you placed them and make any changes that you wish to make.

9. When you think that the sorting grid represents your viewpoint about the topic of promoters of DLS, please write the number at the back of each card on the respective boxes of the sorting grid.

10. When you have finished think about why you have sorted the three statements at the far right and left-hand sides of the sorting grid and answer the post-sorting questions.

Instructions given to participants for the Q sort exercise

Barriers of DLS

The following instructions will guide you throughout the sorting process:

1. You will be given 50 cards, each with a statement on it. Each statement will be about ideas that may hinder the development of DLS for able autistic young people. The different statements are an ending to the phrase: **'Autistic young people have difficulty to achieve DLS for independent functioning because they …'**. I will be asking you to rank-order these statements according to your point of view about the topic. Each card has a random number on it which will only be used to record your responses at the end of the sorting exercise.

2. There are no right or wrong answers. I am interested in your opinion and point of view about each idea.

3. Read the statements on each card well and sort them into three piles. Firstly, a pile for those statements which you feel you mostly agree with, secondly a pile for those statements which you feel you mostly disagree with, and thirdly a pile for those items which you feel neutral or unsure about. When you have finished this process, count and write down the number of cards in each pile.

4. You will now be given a sheet with a sorting grid. Take the cards from the pile of statements which you feel are the most important barriers and read them

again. Select the statement which you agree with most and place it in the far right-hand column of the sorting grid. Next, choose the next two statements from the pile, with which you agree most and place them under the second column on the right-hand side. Repeat this procedure with the remaining important statements moving from the right-hand columns towards the left-hand side of the grid.

5. Placing the items in this category towards the left-hand side does not indicate these are not important barriers but it means that these items are slightly less important than the one you ranked before it. Items within the same column are of equal ranking, and therefore the position of statements within the same column is irrelevant.

6. Now take the cards from the pile of statements which you feel are least important barriers and read them. Choose the statement which you disagree mostly with and place it in the far left-hand side column. Follow the same procedure as with the 'most important' pile, this time moving from left to right.

7. Finally, take the remaining pile of cards and read them. Sort them out in the remaining boxes on the grid.

8. When you have sorted out all the cards, go over how you placed them and make any changes that you wish to make.

9. When you think that the sorting grid represents your viewpoint about the topic of barriers of DLS, please write the number at the back of each card on the respective boxes of the sorting grid.

10. When you have finished think about why you have sorted the three statements at the far right and left-hand sides of the sorting grid and answer the post-sorting questions.

Appendix 9. Post-sorting interview questions

Promoters

1. What was your overall experience of the Q sort activity?

2. State the number of the 3 statements at the far right-hand columns. Why did you rank these three statements as highest in importance?

3. State the number of the 3 statements at the far left-hand columns. Why did you rank these three statements as least important?

4. Is there anything important missing from the Q set?

5. What other statement/s would you add and where would you place these on the grid?

Barriers

1. What was your overall experience of the Q sort activity?

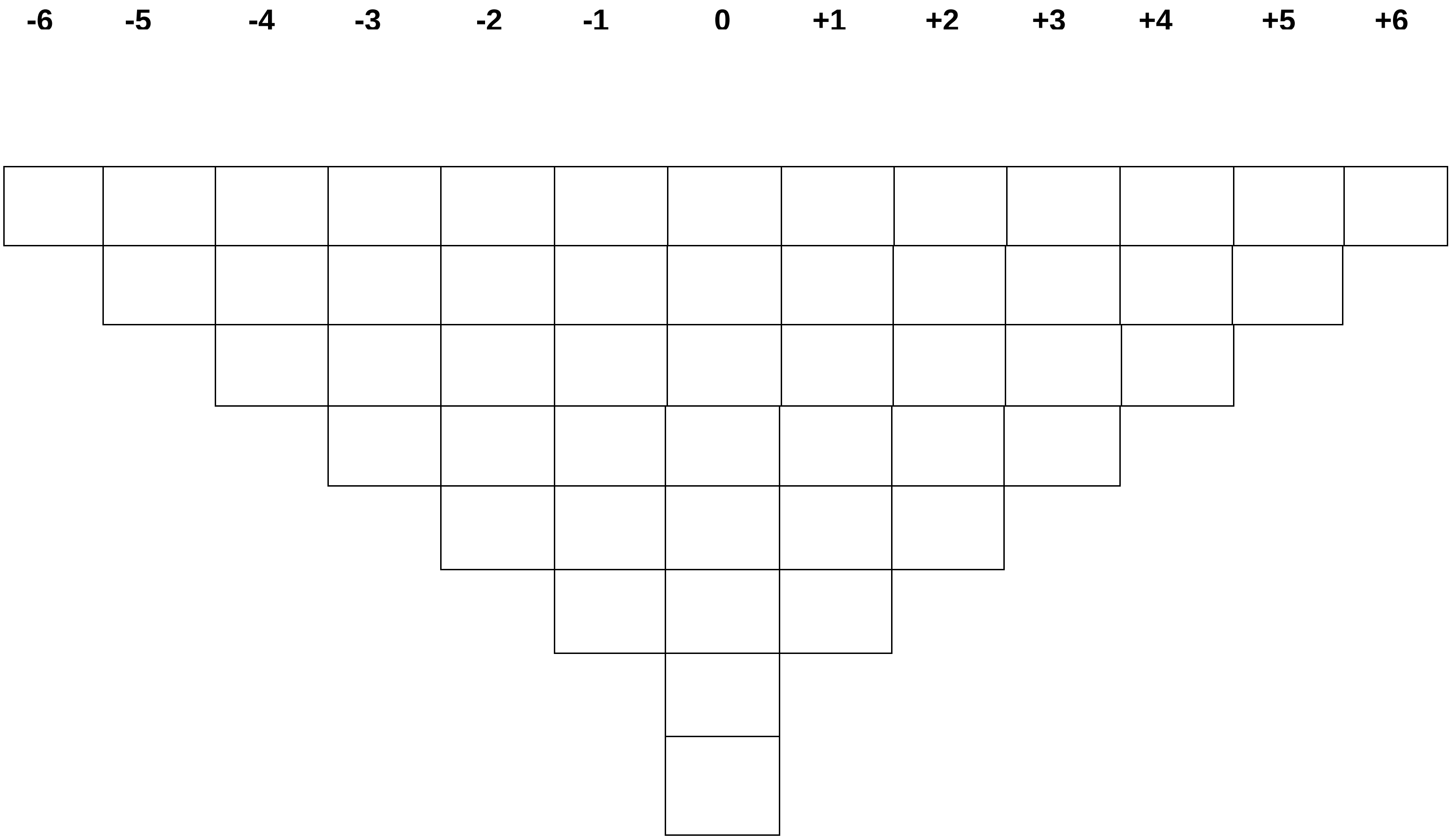
2. State the number of the 3 statements at the far right-hand columns. Why did you rank these <u>three</u> statements as highest in importance?

3. State the number of the 3 statements at the far left-hand columns. Why did you rank these <u>three</u> statements as least important?

4. Is there anything important missing from the Q set?

5. What other statement/s would you add and where would you place these on the grid?

Appendix 10. Q sorting Grid



Appendix 11. Daily Living Skills Checklist

Tick **ONE** box only for each daily living skill (DLS) according to how important you believe that skill is for autistic young people to achieve independence.

Number	**DLS**	**High Priority**	**Low Priority**
1	Shower or bathe regularly		
2	Understand the importance of keeping windows and doors locked particularly when not at home and during the night		
3	Follow washing instructions on garments		
4	Clean, mop, vacuum, wash the floor to keep the house clean		
5	Shave and care for skin		
6	Use a washing machine, and dry clothes		
7	Use kitchen appliances safely (e.g. oven, cooktop, kettle)		
8	Identify clothes that need to be washed		
9	Acknowledge the need to see a doctor, therapist		
10	Recognise household dangers (e.g. in using home appliances, poisonous products)		
11	Understand the value of money		
12	Use cleaning products accordingly		

13	Store dirty clothes in a laundry basket		
14	Recognise and describe symptoms of common health problems (e.g. cold and flu)		
15	Use common kitchen tools (e.g. knives, cheese grater, can opener)		
16	Dispose of garbage appropriately		
17	Understand safety measures related to credit cards (e.g. stores them safely, does not disclose pin numbers)		
18	Change bed linen regularly and/or according to need		
19	Care for hair, keeping it clean		
20	Make a grocery shopping list according to needs		
21	Prepare simple snacks and hot drinks		
22	Be able to drive his own car to go to places		
23	Iron clothes		
24	Follow simple recipes and cooking instructions to cook meals for oneself		
25	Be able to follow traffic and safety rules when driving own car		
26	Care for fingernails and toenails		
27	Keep an appointment at the doctor/dentist/therapist without being reminded		
28	Recognise spoilage in food		

29	Know what to do in case of a car breakdown when driving own car		
30	Make a purchase from shops and calculate the change		
31	Store food in a refrigerator or as needed		
32	Brush teeth regularly and maintain oral hygiene		
33	Responds to questions from the doctor or therapist to support them in reaching diagnosis of symptoms		
34	Know how to handle incidents with other drivers and traffic accidents when driving own car		
35	Acknowledge the importance of proper food handling (e.g. washing hands, keeping raw and cooked food separately)		
36	Use public transport to travel to both known and unknown places		
37	Take own medication appropriately without supervision		
38	Wear clothing appropriate to the weather and occasion		
39	Acknowledge the importance of personal hygiene and of maintaining a neat appearance		
40	Care for a minor cut, minor burn		
41	Budget for monthly expenses		

42	Contact the doctor/dentist/therapist to make an appointment		
43	Fold clothes and put them away		
44	Use a credit card to make purchases and to withdraw money from an ATM		
45	Recognise and demonstrate safety rules on the street		
46	Understand the concept and importance of saving and budgeting		
47	Understand the difference between necessities and luxuries and spend money accordingly		
48	Read and understand public transport timetable schedules		
49	Plan the use of public transport to arrive at a destination on time		
50	Know what to do if he takes a wrong bus or stops at the wrong bus stop		

According to you…

(a) What are the **5 most important** skills from this list?

1.

2.

3.

4.

5.

(b) What are the **5 least important** skills from the list?

1.

2.

3.

4.

5.

Appendix 12. In-depth Interview Questions

Opening comments:

1. Greet the participant

2. Thank the participant for agreeing to take part in this interview, following his/her participation in the Q sort exercises.

3. Remind the participant about the main objective of the interview (to gain their views on which daily living skills (DLS) they believe young autistic people need to develop, what promotes the development of DLS, what are potential barriers and how these can be reduced). and how we might enhance its work in this area

4. Explain the interview process (approximate length of interview, their right to refrain from answering any question, and to withdraw at any time).

5. Assure the participant that information s/he gives will remain confidential.

Key interview questions

1. In the Promoters Q sort, many participants gave ‘good professional support’ a very high ranking.

Can you describe what type of professional support is most helpful in developing DLS?

If we had to do something additional as a Centre to adjust the type of professional support given, what would it be?

2. The Promoters Q sorts showed that an important promoter is the young person's desire to become an independent adult.

   What are your views on this?

   What can be done to instil this aspiration in young people?

3. Another useful strategy identified by the Promoters Q sorts was for parents to be persistent in teaching DLS to their son

   What are your views on this?

   How can we as a Centre support parents to persevere?

4. The Barriers Q sort showed that a key barrier might be the parents' beliefs (eg they may focus on academic skills rather than DLS; may be scared to encourage independence; or may have low expectations for their autistic son).

   What are your views on this?

   What strategies could we adopt as a Centre to address this barrier?

   If we were to do something additional at the Centre to support parents in the development of DLS, what would it be?

5. In the Barriers Q sort, some young people said a fear of doing something wrong or not being able to do something well were barriers

   What are your views on this?

   How might the Centre help young people to be more confident in developing DLS?

6. The Barriers Q sort, some professionals felt the young people's lack of interest to learn DLS was a barrier

   What do you think of this view?

How might the Centre motivate a young person to develop DLS?

7. The Barriers Q sort showed some young people felt they lacked the opportunity to discuss their wishes on DLS.

   What are your views on this?

   How might we increase these opportunities within their families and at the Centre?

8. In the DLS checklist, participants rated the following DLS as High Priority:

(i) Shower/bathe regularly; personal hygiene/neat appearance

(ii) Recognise household dangers

(iii) Safety on the street and public transport

(iv) Money value/budgeting/credit card safety

(v) Recognise health problems and respond to doctor to help in diagnosis

To your knowledge, are these addressed?

at home   YES NO

in school YES NO

by the Centre YES NO

If YES,

Has the work been helpful in addressing these skills YES / NO

If YES – give details of what and where this happened

Thank you very much for your time.

Appendix 13. Promoter Crib Sheets

INTERPRETATION CRIB SHEET

PROMOTER FACTOR 1

Top 3 items (most agree)

40 Have parents who are determined to them DLS despite challenges (+6)

02 Have good professional support (+5)

14 Have parents who are ready to take calculated risks (+5)

Items rated higher than other factors

01 Do not like other people to do things for them (-1)

03 Are given clear step-by-step visual instructions (+2)

33 Have parents who encourage them to help out with everyday DLS (+4)

35 Are taught by people who do not assume that these skills are common sense (+3)

39 Have regular opportunities to participate in age-appropriate DLS (+3)

Items rated lower than other factors

25 Have transition planning and support as they reach adulthood (-1)

29 Live in a society where people have inclusive attitudes towards autistic people (0)

36 Are helped to understand that as parents grow old they can depend on them less (-4)

47 Are encouraged by siblings to learn DLS (-4)

Bottom 3 items (most disagree)

49 Are taught to ask a peer for assistance rather than an adult (-6)

08 Live in families with open communication about the eventual passing of parents and importance of learning DLS (-5)

09 Are concerned about how others perceive them (-5)

Second Pass – other interesting items

20 Have parents who are consistent when teaching them DLS (+4)

10 Have peer influence and support to perform DLS independently (-3)

11 Have siblings involved in everyday routine of household chores (-3)

18 Spend time with non-autistic peers (-3)

21 Are surrounded by people who focus on their strengths and abilities (+4)

INTERPRETATION CRIB SHEET

PROMOTER FACTOR 2

Top 3 items (most agree)

02 Have good professional support (+6)

20 Have parents who are consistent when teaching them DLS (+5)

38 Are given opportunities to practise learnt skills in different settings and circumstances (+5)

Items rated higher than other factors

05 Are taught through role play (0)

10 Have peer influence and support to perform DLS independently (0)

12 Are mentally ready to learn and to perform such skill (+4)

15 Have regular opportunities to watch and observe others doing DLS (+1)

24 Have parents who give them a lot of reassurance (+4)

07 Have educators who encourage independence (+4)

09 Live in families with open communication about the passing away of parents (+3)

Items rated lower than other factors

13 Are taught by repetition (-3)

16 Are guided by people who understand autism (+1)

19 Have a special interest in the area of DLS (-4)

23 Feel confident to do such skills (-3)

31 Are surrounded by calm people who don’t give up on them (+1)

43 Have parents who seek to learn about autism (-2)

46 Have a desire to become an independent adult (-4)

48 Are given time to learn at their own pace (-3)

Bottom 3 items (most disagree)

08 Are concerned about how others perceive them (-5)

41 Have sufficient money to support development of DLS when money is needed (-6)

49 Are taught to ask a peer for assistance rather than an adult (-5)

Second Pass – other interesting items

25 Have transition planning and support as they reach adulthood (+4)

28 Have a structured routine that they can follow (0)

44 Are encouraged to carry out basic DLS without help (+2)

INTERPRETATION CRIB SHEET

PROMOTER FACTOR 3

Top 3 items (most agree)

02 Have good professional support (+5)

16 Are guided by people who understand autism (+5)

50 Have parents and educators who collaborate together (+6)

Items rated higher than other factors

11 Have siblings involved in everyday routine of household chores (+3)

13 Are taught by repetition (+1)

18 Spend time with non-autistic peers (0)

19 Have a special interest in the area of DLS (-1)

36 Are helped to understand that as parents grow old they can depend on them less (+2)

37 Aspire to be like their non-autistic peers (0)

42 Have opportunity to receive feedback during the process of learning DLS (0)

46 Have a desire to become an independent adult (+4)

48 Are given time to learn at their own pace (+4)

Items rated lower than other factors

03 Are given clear step-by-step visual instructions to follow (-3)

12 Are mentally ready to perform such skill (-1)

20 Have parents who are consistent when teaching them DLS (-3)

21 Are surrounded by people who focus on their strengths and abilities (-3)

26 Are taught in environments where they observe and imitate peers performing DLS (-4)

28 Have a structured routine that they can follow (-4)

38 Are given opportunity to practise learnt skills in different settings and circumstances (0)

45 Are encouraged from a young age to do age-appropriate DLS (-1)

Bottom 3 items (most disagree)

05 Are taught through role-play (-5)

35 Are taught by people who don’t assume that skills are common sense (-5)

49 Are taught to ask a peer for assistance rather than an adult (-6)

Second Pass – other interesting items

32 Are taught by physical and verbal prompting (-2)

06 Have parents who expose them to different experiences in life (+3)

24 Have parents who give them a lot of reassurance (+3)

43 Have parents who seek to learn about autism (+4)

INTERPRETATION CRIB SHEET

PROMOTER FACTOR 4

Top 3 items (most agree)

21 Are surrounded by people who focus on their strengths and abilities (+6)

23 Feel confident to do such skills (+5)

31 Are surrounded by calm people who don’t give up on them (+5)

Items rated higher than other factors

17 Learn DLS as part of their school curriculum (+1)

28 Have a structured routine that they can follow (+1)

29 Live in a society where people have inclusive and positive attitudes towards people with autism (+4)

34 Are given support of service providers and local authorities to achieve independence (+3)

41 Have sufficient money to support development of DLS when money is needed (+4)

47 Are encouraged by siblings to learn DLS (-1)

Items rated lower than other factors

02 Have good professional support (+3)

04 Are willing to help out with everyday chores (-3)

06 Have parents who expose them to different experiences in life (-3)

11 Have siblings involved in the everyday household routine of chores (-4)

18 Spend time with non-autistic peers (-4)

24 Have parents who give them a lot of reassurance (+1)

33 Have parents who encourage them to help out with everyday DLS (-1)

39 Have regular opportunities to participate in age-appropriate DLS activities (-2)

40 Have parents who are willing to teach them DLS despite challenges (0)

44 Are encouraged to carry out basic DLS without help (-2)

Bottom 3 items (most disagree)

01 Do not like people to do things for them (-6)

14 Have parents who are ready to take calculated risks (-5)

49 Are taught to ask a peer for assistance rather than an adult (-5)

Second Pass – other interesting items

43 Have parents who seek to learn about autism (+4)

45 Are encouraged from a young age to do age-appropriate DLS (+2)

12 Are mentally ready to learn and perform such skill (+2)

25 Have transition planning and support when they reach adulthood (+3)

Appendix 14. Barrier Crib Sheets

INTERPRETATION CRIB SHEET

BARRIER FACTOR 1

Top 3 items (most agree)

02 Are not encouraged by parents to perform DLS (+5)

16 Have parents who give importance to academic skills rather than DLS

35 Have parents who are scared to enable them to become independent

Items rated higher than other factors

04 Have educators who give too much assistance (0)

10 Have parents who worry about people’s reactions and judgements of unusual behaviour in the community (+4)

17 Develop dependence on adults who support them (+2)

18 Are not taught directly how to do DLS (+3)

20 Have parents who don’t accept their child’s condition (+3)

23 Live in a family which does not discuss the importance of learning DLS (0)

25 Have parents who are busy with other commitments (+3)

30 Have parents who have low expectations of them (+4)

32 Lack opportunities to learn DLS (+3)

38 Have educators who lack autism knowledge (+1)

41 Have parents who believe that without training their son will be able to learn DLS (+2)

Items rated lower than other factors

01 Are not patient enough in learning a new skill (-3)

06 Are clumsy or poorly coordinated (-4)

11 Lose attention on task easily (-1)

14 Feel comforted with everything being done for them (-2)

19 Experience a lot of anxiety (+2)

22 Take a long time to learn DLS (-3)

26 Get lost in their own thoughts (-2)

31 Find it difficult to understand abstract things (-1)

33 Tend to forget a learnt DLS if not done regularly (-3)

34 Have fine motor difficulties (-4)

40 Lack awareness of consequences to do household chores independently (-2)

43 Do not take the initiative to perform DLS (-4)

45 Lack awareness of risks to do DLS in the community independently (-3)

46 Have parents who worry about them being bullied or exploited in the community (+1)

Bottom 3 items (most disagree)

12 Have a lot of commitments (-6)

28 Spend a lot of free time on iPod, iPhone and gaming (-5)

47 Do not aspire to live independently (-5)

Second Pass – other interesting items

48 Find it difficult to plan ahead (-2)

INTERPRETATION CRIB SHEET

BARRIER FACTOR 2+

Top 3 items (most agree)

07 Are influenced by negative attitudes of people in society (+5)

13 Experience anger and frustration when they fail to do DLS well (+5)

27 Scared of doing something wrong (+6)

Items rated higher than other factors

06 Are clumsy and poorly coordinated (+2)

09 Lack opportunities to discuss their wishes about developing DLS (+3)

11 Lose their attention on task easily (+1)

14 Feel comforted with everything being done for them (+2)

31 Find it difficult abstract things (+4)

34 Have fine motor skills difficulties (0)

39 Live in an age when life is hectic and families lack time to teach DLS (+4)

48 Find it difficult to plan ahead (+4)

Items rated lower than other factors

02 Are not encouraged by parents to perform DLS (-4)

04 Have educators who give them too much assistance (-2)

08 Are unable to cope when something out of the ordinary happens (+1)

10 Have parents who worry about people's reaction and judgement of unusual behaviour in the community (-1)

17 Develop dependence on adults who support them (-2)

23 Live in a family who does not discuss the importance of leaning DLS (-3)

29 Find it difficult to adapt to different circumstances (0)

32 Lack opportunities to learn DLS (-3)

36 Do not feel confident to perform DLS independently (-4)

42 Find it difficult to plan and organise steps in carrying out DLS in everyday life (-1)

50 Find it difficult to transfer taught DLS to everyday situations (-2)

Bottom 3 items (most disagree)

03 Do not feel the need to learn DLS (-6)

20 Have parents who do not accept their children’s condition (-5)

24 Are not interesting in performing DLS (-5)

Second Pass – other interesting items

16 Have parents who give importance to academic skills rather than DLS (+3)

19 Experience a lot of anxiety (+3)

46 Have parents who worry about them being bullied or exploited in the community (+3)

INTERPRETATION CRIB SHEET

BARRIER FACTOR 2-

Top 3 items (most agree)

03 Do not feel the need to learn DLS (+6)

20 Have parents who do not accept their children’s condition (+5)

24 Are not interesting in performing DLS (+5)

Items rated higher than other factors

02 Are not encouraged by parents to perform DLS (+4)

04 Have educators who give them too much assistance (+2)

08 Are unable to cope when something out of the ordinary happens (-1)

10 Have parents who worry about people’s reaction and judgement of unusual behaviour in the community (+1)

17 Develop dependence on adults who support them (+2)

23 Live in a family who does not discuss the importance of leaning DLS (+3)

29 Find it difficult to adapt to different circumstances (0)

32 Lack opportunities to learn DLS (+3)

36 Do not feel confident to perform DLS independently (+4)

42 Find it difficult to plan and organise steps in carrying out DLS in everyday life (+1)

50 Find it difficult to transfer taught DLS to everyday situations (+2)

Items rated lower than other factors

06 Are clumsy and poorly coordinated (-2)

09 Lack opportunities to discuss their wishes about developing DLS (-3)

11 Lose their attention on task easily (-1)

14 Feel comforted with everything being done for them (-2)

31 Find it difficult abstract things (-4)

34 Have fine motor skills difficulties (0)

39 Live in an age when life is hectic and families lack time to teach DLS (+4)

48 Find it difficult to plan ahead (+4)

Bottom 3 items (most disagree)

07 Are influenced by negative attitudes of people in society (-5)

13 Experience anger and frustration when they fail to do DLS well (-5)

27 Scared of doing something wrong (-6)

Second Pass – other interesting items

16 Have parents who give importance to academic skills rather than DLS (-3)

19 Experience a lot of anxiety (-3)

46 Have parents who worry about them being bullied or exploited in the community (-3)

INTERPRETATION CRIB SHEET

BARRIER FACTOR 3+

Top 3 items (most agree)

08 Are unable to cope when something out of the ordinary happens (+5)

37 Find it difficult to take decisions about everyday things (+6)

42 Find it difficult to plan and organise steps of carrying out DLS in everyday life (+5)

Items rated higher than other factors

03 DO not feel the need to learn DLS (+1)

05 Need a lot of prompts for reassurance to learn DLS (0)

22 Take a long time to learn DLS (+1)

24 Are not interested in performing DLS (0)

29 Find it difficult to adapt to different circumstances (+4)

36 Do not feel confident to perform DLS independently (+2)

40 Lack awareness of consequences to do household chores independently (+1)

43 Do not take the initiative to perform DLS (+3)

44 Experience uncertainty and fear about their abilities to do DLS (+4)

45 Lack awareness of risks to do DLS in the community independently (+2)

47 Do not aspire to live independently (+1)

50 Find it difficult to transfer taught DLS to everyday situations (+4)

19 Experience a lot of anxiety (+3)

Items rated lower than other factors

07 Are influenced by negative attitudes from people in society (-3)

09 Lack opportunities to discuss wishes about the development of DLS (-2)

18 Are not taught directly how to do DLS (-2)

21 Have a poor sense of danger (-1)

25 Have parents who are very busy with other commitments (-4)

27 Scared of doing something wrong (-1)

35 Have parents who are scared to enable them to become independent (-2)

39 Live in an age when life is hectic and families lack time to teach DLS (-2)

41 Have parents who believe that without training their son will still be able to become independent (-4)

49 Have parents who worry about their lack of sense of danger (-1)

Bottom 3 items (most disagree)

15 Meet professionals and educators with low expectations of them (-5)

16 Have parents who give importance to academic skills rather than DLS (-6)

30 Have parents with low expectations of them (-5)

INTERPRETATION CRIB SHEET

BARRIER FACTOR 3-

Top 3 items (most agree)

15 Meet professionals and educators with low expectations of them (+5)

16 Have parents who give importance to academic skills rather than DLS (+6)

30 Have parents with low expectations of them (+5)

Items rated higher than other factors

07 Are influenced by negative attitudes from people in society (+3)

09 Lack opportunities to discuss wishes about the development of DLS (+2)

18 Are not taught directly how to do DLS (+2)

21 Have a poor sense of danger (+1)

25 Have parents who are very busy with other commitments (+4)

27 Scared of doing something wrong (+1)

35 Have parents who are scared to enable them to become independent (+2)

39 Live in an age when life is hectic and families lack time to teach DLS (+2)

41 Have parents who believe that without training their son will still be able to become independent (+4)

49 Have parents who worry about their lack of sense of danger (+1)

Items rated lower than other factors

03 DO not feel the need to learn DLS (-1)

05 Need a lot of prompts for reassurance to learn DLS (0)

22 Take a long time to learn DLS (-1)

24 Are not interested in performing DLS (0)

29 Find it difficult to adapt to different circumstances (-4)

36 Do not feel confident to perform DLS independently (-2)

40 Lack awareness of consequences to do household chores independently (-1)

43 Do not take the initiative to perform DLS (-3)

44 Experience uncertainty and fear about their abilities to do DLS (-4)

45 Lack awareness of risks to do DLS in the community independently (-2)

47 Do not aspire to live independently (-1)

50 Find it difficult to transfer taught DLS to everyday situations (-4)

19 Experience a lot of anxiety (-3)

Bottom 3 items (most disagree)

08 Are unable to cope when something out of the ordinary happens (-5)

37 Find it difficult to take decisions about everyday things (-6)

42 Find it difficult to plan and organise steps of carrying out DLS in everyday life (-5)

Appendix 15. Sample in-depth interview transcripts with coding

Interview PF2

I think the main barriers..challenges…is the anxiety , the fear of the unknown, the rigidity towards change, also the not understanding the social skills in communicating..these prove to be the main challenges. During covid he had to be admitted to the psychiatric hospital because his state was getting much much worse..it could be a number of issues, it could be the change in medication. Being admitted was a traumatic experience..in hindsight I think it would have been better if he never went. We had to process it with him after. In the long term, it could have been a bit of a wake-up call. This dependency on the parents and professionals maybe he will start to realise that it's not complete, that the major player in a sense it's you..and I say this because X is high functioning..there are certain things and certain skills he can do. What is frustrating is that we can see the potential in him to do certain things because he may not be very academic, he may not be able to sit in an office but he can do various	**Anxiety**

skills…obviously his condition is hindering him..is keeping him back from doing any of them. A lot of time has passed..his concept..the idea of his self-image that he's built throughout the years is one that he cannot achieve..he is more of a failure than a success and this is exactly what is helping with intervention is for him to continue to be reminded that it's not the case. X has the tendency to go on the downward spiral..so these sessions are like maintenance because they constantly keep him on the right kind of track. ***In the Promoters Q sort, many participants gave 'good professional support' a very high ranking. Can you describe what type of professional support is most helpful in developing DLS?*** ***If we had to do something additional as a Centre to adjust the type of professional support given, what would it be?***	**Self-image**
I think having a team of support is important. With MAC he's been coming there for many years so there familiarity it's a place where he finds acceptance and security. His conversations with J are a bit of a more down to earth level. He feels he can speak to him about certain things he feels comfortable about that. But also the fact that he is allowed to	**Professional support**

come there is a of a motivator in itself because he feels part of something and he speaks very proudly of MAC.

He has a social worker who visits him once or twice a month at home to make sure how he's doing, coping and obviously to motivate him to do certain things.

The idea is that there is continuity between all the support he has and all that he's doing.

The Promoters Q sorts showed that an important promoter is the young person's desire to become an independent adult. What are your views on this?

What can be done to instil this aspiration in young people?

One possible thing is that maybe having more regular small group sessions but they have to be that the persons are more or less of the same level and not so overwhelming so big..4 or 5 where they can be open and share and speak about..and then later on maybe to try and motivate him and encourage him if there's a little social thing..join it. And I think X sometimes when he's given a bit of a task.. when he's given a bit of a responsibility, although he may go about it in a long ..it kind of makes him feel a bit sort of happy..and that restores a bit of self-

Giving them small responsibilities

esteem in him. Silly things..for example he was asking his advice about some light fittings..he had his notebook full of notes, he was taking phots of light fittings…and he told me because I’m helping them. These small things can help. ***The Barriers Q sort, some professionals felt the young people’s lack of interest to learn DLS was a barrier. What do you think of this view?*** ***How might the Centre motivate a young person to develop DLS?*** Although on the other hand I have to admit that he is a bit lazy sometimes..that’s another thing sometimes we need to push him, like at home he’s given certain responsibilities that we expect him to do for example to help his mum with certain things to make sure he cleans up in the kitchen..certain responsibilities that would help a bit with independent living like the daily chores of life. Because a lot of these people their experience is that they are being cared for but sometimes especially the ones that are high functioning they would say you know..good..food is always ready for me, either mum or dad will do it. How to get them to own..ownship.	**They get used to being cared for**

The first thing I would need to know is that he has that desire. He needs to discover in himself do I have this desire? Because if he doesn't have the desire nothing that we can do to motivate them will work. He has to want it. But if he's become now over the years..he's fallen into a bit of a lifestyle that is convenient and safe and within boundaries..in a certain extent it might have worked in a negative way when it comes to desire. It might have actually taken away that desire and often he says things like what's the use? Then he has these moments of little achievements when he's helped someone, when he's done this and that. Personally, my main concern would be to see that he has this desire and if in actual fact we discover that his desire is on the very low..then what are his barriers? And I think the biggest barrier is his conviction that he has failed, his fears of what's going to happen to me, he's often worried about me and his mum if we're not around. Also, maybe his image his idea of his image of how others see him. I think this is an important factor..to see first of all..ok let's motivate you..but if you yourself do not have this desire inside you. If I can go over that hurdle first..to get him to realise yes I'd like to do it..that's when the motivation comes in..ok you want to do it..this is how it's done. Often I've wondered about it..MAC has often contacted him to	**Self-image**

join them to do this and that..and I tell him why don't you join..and he says what for?	
Another useful strategy identified by the Promoters Q sorts was for parents to be persistent in teaching DLS to their son. What are your views on this? ***How can we as a Centre support parents to persevere?***	
I think it has to be a balance. Before there was a lot of persistence especially from his mother's side..there was a lot of pushing pushing pushing..but then a lot of the time there is a lot of resistance. I think it's more instead of pressure..because persistence can come across as pressure so especially in his mind it's like I'm being pressured. So instead of maybe the pressure it's more like consistent gentle persuasion. So instead of persistence, it's more gentle persuasion, it's how I see it.	**Parents' persistence**
The Barriers Q sort showed that a key barrier might be the parents' beliefs (e.g. they may focus on academic skills rather than DLS; may be scared to encourage independence; or may have low expectations for their autistic son). What are your views on this?	

Another point that came out with his experience when he was admitted…and this his psychiatrist pointed out ..he said listen ..for a while I feel that both you and his mother need to step a bit aside..step back a bit, he is now 27 and he needs to take a certain amount of responsibility about the way he's living, the possibility of self-harm and stuff like this. The constant or the persistent persuasion needs to be there,the support needs to be there. But we decided to step a little bit back. Whereas before we responded to anything that he wanted..me fixing that appointment and his mother doing this and doing that..now we kind of stepped back a bit. We say listen you keep note of your appointments..you do this and that. At first he found it very difficult..he'd come to me and he'd say is why is mummy ignoring me? And I would say she's not ignoring you..mum is always there if you want her..but what I should have told him was why is mummy not at your back and call. Because there's a lot of things that us as parents need to learn..for us being our child we were always there to make sure that he's ok, he's safe, he has everything When he's very very young it's one thing..an 8, 9, 10 year old..they need that kind of constant support but at his age now I think.. when we started to step back a little bit..so that hopefully he'll start to realise that he'll get the courage, the strength, the realisation like I can't stay depending..as much as I have these issues and as much as I have these problems I	**Parents' fears** **They get used to being cared for**

can't totally depend on for everything on my parents on the professionals. But as he gets older, he has to understand that he can to participate...he has a responsibility…He is the main person. Whatever goes wrong he either lashes out at the professionals, us parents or the medication is wrong..which to a certain extent can be true but we want to reverse this..you're up there with us..what are you doing? How are you participating to do this for yourself..for your own life? When they're young we keep on protecting them and when they're older they have to understand that they can participate they have a responsibility. In X's case it seems that he doesn't have absolutely any desire to leave the house..he's at home..he's comfortable. To us it's very difficult..what level of independence are we talking about? That he lives in an apartment on his own and he takes full control over his life? At this stage it's very difficult..I can't really see that happening that soon because there are certain difficulties that he is still dealing with. But hopefully to move towards more independence, even if he's actually living at home..that he has his own timetable, that he his own part time job, have a lot of a social life..that he can be independent of us. He can still live at home..there are a lot of adults who still live with their parents.	**No desire to leave parents' home**

But he will be living at home but in a different way..in an independent way. At the moment he is living at home in a dependent way. Later on the hope is that he can live at home because we don't want him to be..the other thing is he can become very isolated and alone.	
I'd rather he's in a sense alone at home. At least when he goes out of his room and he come downstairs in the kitchen there's someone..we can have a coffee together..there's always people coming and going here..there's his brother. Him living in a flat on his own it will be worse for him especially since he has the tendency of becoming depressed and over anxious. He might have an issue with one of the neighbours..so that looks far away at the moment.	**Parents' fear**
What strategies could we adopt as a Centre to address this barrier?	
I think joining smaller groups..sharing your experience takes you out of yourself, they may encourage each other.	**Sharing experiences** in **small groups**
Giving them certain small responsibilities maybe..not just their weekly visit and they leave..giving them maybe a responsibility. I can know for example that A will grumble about it if he's told this week we're going to clean the kitchen..this week we're going	**Giving them small responsibilities**

to tidy up the common area..we’re going to clean the centre for example..two of you are going to help wash the floor. That may help a bit I think. And then also what would help I think is to find the time also to ask them the question..what would help you more coming to the centre? He may have ideas or not..but sometimes he comes out with ideas. At first they come across as ‘what is he saying?’ but then thinking about it I say I wasn’t understanding him properly because in actual fact it’s not a bad idea he was right. Coming back to participating at MAC..he also needs to learn about boundaries as well because him having come there for so many years he’s becoming so familiar with the place it’s like his second home. And we’ve told him you have to respect the fact that you are part of that community but you have to respect the boundaries. **The Barriers Q sort showed some young people felt they lacked the opportunity to discuss their wishes on DLS. What are your views on this? How might we increase these opportunities within their families and at the Centre?** Having their voices heard and discussed as equally as ours might probably tun out to be more fruitful because there might be certain things that might be meeting their needs. As long as	**Having their voices heard**

they’re reasonable and acceptable they might be ideas that you say these kind of needs are similar among the persons who come to us.	
In the Barriers Q sort, some young people said a fear of doing something wrong or not being able to do something well were barriers. What are your views on this?	
It is a barrier..the thing is A unfortunately he didn’t have good experiences at school, as a teenager, when he joined a band, when he tried to go to mcast..every one of those times starting from primary school was a serious of challenges, of struggles, and struggles and struggles. Obviously as he started to grow up and become a teenager he could look back and all he could see was a trail of failures basically and disasters whereas we would tell him no A you shouldn’t see it like that..you have your difficulties and challenges but..the fact that he was bullied, the fact that he was excluded in certain things, the fact that he was asked to leave the band, the fact that at mcast there was no system to support people on the spectrum and he was expected to do all the things like others, he couldn’t really communicate well in Maltese. In fact the first year they failed him despite us telling them that this person is vulnerable he needs help, he needs assistance..in fact he only did about 2 years and then he	**Negative past experiences**

quit. So there is this fear of failing yes..that’s why for example there were many times that he felt this anger towards his brother because obviously he could see his brother succeed in everything..university and whatever. Obviously, we always tried to teach him don’t compare yourself to others, the worst thing you could do is compare yourself to others because others don’t have the same difficulties and challenges that you have. But still it’s there. I think..recently..for the first time he was with a group of friends and he told them I am on the autistic spectrum..I have autism..he spoke about it and that was one of the very very first time he did it with others. He came home and he was in a sense..we could sense it my wife and I..relieved..he spoke to us..he was almost proud of himself. I think self-acceptance..one of the things that would help them to achieve is for them to accept who they are..to understand that it’s not their fault. So maybe there can be some healing form the past as they try to put the past in perspective..to understand that..that happened to me not because those people that I was at school with hated me..he used to think that they hated him..it’s not that they hate me..because of your condition you see the world differently so a person that tells you something like this you interpret it in this way. I think it’s self understanding..as difficult as the task may be I think it’s	**Self-image**

important to enable them to accept who they are because that will give them the possibility to cut from the past. I have to understand that I am autistic and that's why I had those experiences. It will be easier for them then to look into the past and accept it and move towards the future without having to carry all that baggage. ***In the DLS checklist, participants rated the following DLS as High Priority:*** ***(i) Shower/bathe regularly; personal hygiene/neat appearance*** ***(ii) Recognise household dangers*** ***(iii) Safety on the street and public transport*** ***(iv) Money value/budgeting/credit card safety*** ***(v) Recognise health problems and respond to doctor to help in diagnosis*** ***To your knowledge, are these addressed?*** I'm not sure if they are being addressed as a priority. Are they just reminders or specifically addressed in acertain way. The financing is important..one of the difficulties he has that he does not seem to have the concept of the value..how to connect with the value of money..the ins and outs of money. Recently,	**Money**

we were discussing this concept of bearing interest on loans..it's amazing but for him to really capture this concept of percentages..for them the idea of having a bank account, a credit card..budgeting..he has no idea on budgeting. We're constantly on guard on what he budgets.	
Safety..I think they're very important because once they become part of their lifestyle and they don't need to be reminded..then these will make the motivational part much much easier. Because imagine we try to motivate them for independence but if they haven't learnt the basic skills properly it's going to be more of a problem. Because the first hurdle that they have to go through is the money issue, the safety issue, the personal hygiene issue..so I think a little bit of more priority on this would be helpful.	
They need to be addressed directly, but there has to be a way where they are addressed directly to him. His level of intelligence is quite high so when he's being told something sometimes he comes back to me and tells me dad you don't need to talk to me like I'm a kid so there's a way that I reminding him of certain things, I have to realise that he's an adult..he's got his intelligence, his difficulties..but certain things I have to ned to tell him as if I am talking to another adult.	**DLS need to be addressed directly**

Getting feedback from them is important because we want them to participate more..what is the scope of them coming every week? how is MAC going to help them in their lives? What should the end result be? The targets achieved? Some may be unseen. You might have a person coming week in week out and you may What see no change at all..but does that mean that the Centre is not being helpful? I don’t think so no..the fact that the person keeps on coming every week..it’s a place for him to come to..to connect..so even indirectly even if there are no significant changes it has value. Then there are those that you can visualise and see positive changes in their attitudes, in their ways..it’s evaluating exactly what is the scope of the Centre? Is it to support the person? Or to support the person and the family? Are you drawing individual targets? You have to adapt according to where they are at.	
Basically MAC as a centre is a place where..at least there’s a place where they can find themselves, to be part of something..to know that they’re not alone..outside their family..their home..there are other people that care..there is hope..there is scope and to find out their individual skills and how they use those skills.	**Professional support**

Interview PM4

In the Promoters Q sort, many participants gave 'good professional support' a very high ranking. ***Can you describe what type of professional support is most helpful in developing DLS?*** ***If we had to do something additional as a Centre to adjust the type of professional support given, what would it be?*** I would describe good professional support as hands-on support…support for listening, teaching, and understanding…for him to be able to speak to someone who can understand him. I always looked for professionals who would also support me. It is important to feel that you are not alone and they help you handle things which you would not know how to address as a parent. I often think if he were to live alone how would he able to do this? Managing money…he definitely does not have an idea…budgeting money is a big problem. I was always afraid to	**Professional support** **Money**

trust him with a card because anyone can trick him really easily. Other life skills like saving, budgeting and spending he still has no idea. One of the problem with money is his naivety…he doesn't question anything. He does not have a vision on how much money is needed to lead a life. Anybody can cheat him at any level at any time. It is a big worry…with every birthday I say another year has gone by and at least he still has us. His first part of his life has been good at least, the rest I don't know. It is a big worry.	**Parents' fear**
The Promoters Q sorts showed that an important promoter is the young person's desire to become an independent adult. What are your views on this? ***What can be done to instil this aspiration in young people?*** If they're laid back they're not going to learn anything and they won't make an effort to retain that knowledge for another time To instil the desire I think it is important that you explain why such skills are important to learn.	**They get used to being** **cared for**

Another useful strategy identified by the Promoters Q sorts was for parents to be persistent in teaching DLS to their son. What are your views on this? As a parent you need to keep on persisting…you can't give up. Sometimes they show you that they can keep on learning…they still learn as adults. You need to keep on persisting and hopefully you find others to support you along the way. Another reason is that I never wanted to look back with regret for not trying. ***How can we as a Centre support parents to persevere?*** It is important for parents to inform themselves and be aware that there are other parents in the same situation. Sharing your experiences with other parents you always learn something from it. Help from school is also very important. Way back when my son was young, teaching staff were still very green…they did not know much about autism.	**Parents' persistence** **Support for parents**

If schools are more aware and knowledgeable it is important because they spend half of their day there.	
The Barriers Q sort showed that a key barrier might be the parents' beliefs (eg they may focus on academic skills rather than DLS; may be scared to encourage independence; or may have low expectations for their autistic son). What are your views on this?	
What strategies could we adopt as a Centre to address this barrier?	
If we were to do something additional at the Centre to support parents in the development of DLS, what would it be?	
There are fears when you're trying to push him into the world to do something..mostly because you know that he is naïve and he has no skills like same aged peers.	**Parents' fear**
For example I decided for him that he would not learn to drive a car. As he grew older and became more aware of his condition I decided I would not go for it. There's too much at stake if it goes wrong..its repercussion could be fatal.	

When it came to crossing the street I used to do it with him and I could observe his growing awareness and judgement. You slowly wean him into it. Same thing with public transport. There would be a lot apprehension but since I had decided that he would not drive a car I knew he would need to travel by bus. I am aware that it is my fault that he never learnt how to drive and you question…was I unjustly scared? If you find support you will be in a position to help him more. But at the same as a parent you need to deal with a lot of other things…your spouse, your other children, work. Parents really need to be careful not to give less attention to the other siblings…because there would be a lot of psychological repercussions. I still feel very guilty for giving so much less attention to my daughter. You need to be aware of it…at the time it goes against your nature...because you feel you need to help the weaker one. ***In the Barriers Q sort, some young people said a fear of doing something wrong or not being able to do something well were barriers. What are your views on this?***	**Life is too hectic**

How might the Centre help young people to be more confident in developing DLS?	
Sometimes I see them as overgrown children…the fear of doing something wrong because someone will scold them. They still want to please..they are aware of their limitations and that they are different from the majority…they are in a minority and they are of a lower level and they know it. They know that there are certain things that they can't do. You need to show them that there are things they can do for their own self-esteem. On a rare occasion they would feel proud of themselves. Otherwise, they would feel inferior or fear getting in trouble for doing something wrong.	**Past negative experiences** **Self-image**
Past experiences like being scolded by parents or teachers for doing something wrong. Once there was a boy who called him a freak for having one to one lessons with the LSE and he developed a big grudge towards the system. If I'm getting extra help it's because I'm a freak. They do have negative effects in their memory and on their future.	**Past negative experiences**
The Barriers Q sort showed some young people felt they lacked the opportunity to discuss their wishes on DLS. ***What are your views on this?*** ***How might we increase these opportunities within their families and at the Centre?***	

They only talk with professionals and their parents. They do not have much of a social life to discuss what they would like to do in life. They're never given a platform.. they don't speak to anyone from anywhere.	**Having their voices heard**
The Barriers Q sort, some professionals felt the young people's lack of interest to learn DLS was a barrier ***What do you think of this view?*** ***How might the Centre motivate a young person to develop DLS?***	
You have to bring things up with him. He has no vision..it's a status quo..i want to stay here live with you in this house, I'm happy here with my cats, my computer and my games..this is the life he's going to carry on forever.	**No desire to leave their parents' home**
If I challenge him what will happen when I get old..he wants to live with his siter but she would not want that at all.	
I am very scared of what will happen when his father and me die. The best of the best is still not enough for me because what I wish for him..to live with his sister…I know that it would not happen.	**Parents' fear**
What makes a person is his everyday home life and if they don't have that…	

Sometimes their own condition works against them because they don't see the need and say I need to pull up my socks and learn how to cook and do other things to be independent. The lack of planning as well..for example I'm hungry and I need to eat something now and they don't know how to plan ahead what they are going to cook. ***In the DLS checklist, participants rated the following DLS as High Priority:*** ***(i) Shower/bathe regularly; personal hygiene/neat appearance*** ***(ii) Recognise household dangers*** ***(iii) Safety on the street and public transport*** ***(iv) Money value/budgeting/credit card safety*** ***(v) Recognise health problems and respond to doctor to help in diagnosis*** ***To your knowledge, are these addressed?*** Personal hygiene is achieved and his love for routine helps him in this regard.	**No desire to leave their parents' home**

Dangerous things..he knows the obvious things but he would not be aware of other subtle and abstract dangers. There can still be threats..if not taught specifically Safety on the street he has no trouble and he is cautious I believe most of these skills need to be taught at home I wish he could have more input and attend more places to learn more skills. Like courses for example on health personal care that for many people are common knowledge but for them it's not. He doesn't speak up when he feels somewhere hurting him. There's so much to teach them//I just wish there would be more places he could go to learn more. I wish there were more opportunities to fill in his life and help him socially.	**DLS need to be taught directly**

Interview YA7

In the Promoters Q sort, many participants gave 'good professional support' a very high ranking. ***Can you describe what type of professional support is most helpful in developing DLS?*** ***If we had to do something additional as a Centre to adjust the type of professional support given, what would it be?*** Professionals should be equipped with empathy…it is very important. They should have good experience in psychology, and also if these people who they themselves had to seek professional help throughout their life. They will find themselves capable of helping them more I believe that for something like that to work, especially for these people who have parents…it would help even more if the parents are in tune and in touch with what is going on between the young person and the professional. That would strengthen the support even more because I come from such family…all I can say is that it makes a difference…a positive difference.	**Professional support**

I think it’s good for parents who are capable of reading, and do the basic research and ask the question what does a child with autism experience throughout his life. Basic research and basic answers are important…they can ask a professional for a brief explanation about what an autistic child goes through so that I can understand him better. Research and curiosity are important.	
I believe that people with autism like myself…I like to think that they are colourful people who like to see the world in colour. I believe that hands-on activities would really help them and give them more inspiration in their life…and have a more positive outcome. You could have pottery, wax melting, working with wood, arts and crafts with plastic, paper mâché to be able to create something artistic. Also music because they will find it important…to me I cannot live without music. Gardening…Planting bulbs, uprooting plants.	**Giving them small responsibilities**
I for one am autistic and I have always had to take medication which helps me to want to do things. The way I feel physically, mentally and spiritually makes all the difference…that is vital. We are not machines…we are made of flesh and bone and have a mind and these things are fragile and need to be taken care of.	**Professional support**

Individuals with autism who have the determination to be independent they do not have to be afraid to seek help from doctors who are qualified in autism.	
If they take a turning for the worse it could hinder their independence. There are many ways how people can receive help and rise above their problems and take control.	
We need help…we need our ‘crutches’ from professionals who really want to help and make a difference in our lives.	
They need to have the courage to want to seek help and not be afraid of doing so. Professionals will train the individual until they can do it on their own. There has to be a healthcare system and a role model.	
The Promoters Q sorts showed that an important promoter is the young person’s desire to become an independent adult. What are your views on this?	
What can be done to instil this aspiration in young people?	
There are those people who are fed up of living with their parents and want their space especially those who have	**No desire to leave their parents’ home**

parents who do not respect their privacy and make decisions for them.

A person like me…well..going on holiday with a friend…to have the freedom to do whatever you like…up to a month…that could be another thing that could kickstart the idea and create the desire to leave on their own…not because they are bad people but because I enjoyed the difference.

The freedom for them to do whatever they want at home, do things of their own choosing, for them to be their own master….I'm sure there are a lot of people with autism who want to live that way.

I think inspiration has to play a role in that…a desire

In some ways that is important. This is a bit of a two-way answer. I believe that in certain ways people with autism might be repulsed or discouraged if their parents tell them to go out and live on their own. Others would want to take the opportunity. To me this is something which would always remain controversial.

I come from a family who do things very flexibly and think outside the box. Life is different shades of grey. A lot of things

are possible but there are autistic people who come from families with low income and have less opportunities. ***Another useful strategy identified by the Promoters Q sorts was for parents to be persistent in teaching DLS to their son. What are your views on this?*** ***How can we as a Centre support parents to persevere?*** Parents shouldn't give up. Siblings can always opt to help. Parents should persist in giving small chores like taking out the trash and rinsing their plate after they eat, taking care of pets, plants...that's what my mum tell me all the time. The basic chores which aren't that hard really/… like brush your teeth well. Parents should be involved directly or indirectly as long as they find a way to positively motivate the person to do these basic things and then take it up a notch and introduce independence skills. Parents should take opportunities that arise for example if there's a supermarket close by you send them to buy the basic things like milk and bread.	**Parents' persistence**

These I would call them not baby steps…toddler steps ***The Barriers Q sort showed that a key barrier might be the parents' beliefs (eg they may focus on academic skills rather than DLS; may be scared to encourage independence; or may have low expectations for their autistic son). What are your views on this?*** ***What strategies could we adopt as a Centre to address this barrier?*** These things would hinder independence. To me number one is stigma…these things can have their drawbacks. Even though the parents feel entitled to be that way…but what is that going to do in the end? It's not going to help a young individual improve. This is about sacrifice..would I change for the sake of my kid or not…or would I want to put my feelings aside and focus on the facts. If you're going to be rigid and stay that way..you need to look at the part that the offspring is not going to improve. So far it's not going to work with that mentality. It will hinder their independence. This will be a very heavy bulky barrier.	**Parents' fear**

If we were to do something additional at the Centre to support parents in the development of DLS, what would it be? Social support from professionals. Sincere family counselling would definitely help. Services from places like MAC… Help them realise that their fears are not real…it's all psychological Professionals at MAC are nice…role models who are patient, empathic, don't shout…role models like that are important for families that are afraid and who feel that there's no hope. We need these friendly faces and we need them with open arms. That can make a difference. I believe we need powerful role models where it's not about the money but about doing the right thing	**Support for parents**
In the Barriers Q sort, some young people said a fear of doing something wrong or not being able to do something well were barriers ***What are your views on this?*** Hesitation…I have experienced it a million times…it's not a good feeling. That's why I spend a lot of time thinking and thinking and thinking. There were times when family members would tell me…stop thinking and just do it. But sometimes you	**Anxiety**

can’t just do it...there are things to take into consideration first and then do them. My father always told me if there’s something you’re about to do especially if it’s risky and costs money and you’re not sure if you should do it …don’t do it. Sometimes you have to do it anyway and take that leap of faith. ***How might the Centre help young people to be more confident in developing DLS?*** If I feel unsure I ask for help…if it’s not at an arm’s reach I pick up the phone and ask questions. It is OK to be afraid but it is also OK to ask questions. No matter how dumb the question is ask it anyway…I’s their problem. At the end even if you make a mistake you can say I did my very best…I asked questions did research…for me asking questions and asking for help is paramount. ***The Barriers Q sort, some professionals felt the young people’s lack of interest to learn DLS was a barrier. What do you think of this view?*** ***How might the Centre motivate a young person to develop DLS?*** This has happened and is still happening with me. These experiences…from the outside they don’t look like much but from the inside they are catastrophic…they have a volcanic	**Past negative experiences**

effect…because the volcano remains dormant and comes back after some time How can I redirect these negative energies. It is not as simple as dropping it on the floor and stepping on it…these things have something like obsessive and persistent way of following you forever…like an old shoelace…it's not a good feeling How can you redirect these feelings…you can write them down in a private diary and discuss them with a professional someone you know would keep it confidential. These experiences should be talked about and expressed. People need to feel safe talking about this knowing that it is going to stay in the tomb. Many people don't feel comfortable talking about these experiences but doing it privately is the best way to go about it. These past experiences need to be redirected. When these thoughts come up and become incessant you need to have a professional to help you direst these negative feelings and replace them with something constructive and positive. It's like pieces of string tied to your back which in time become tangled and heavier on you. So you need to stretch them out strip them and work on redirecting them. Only after doing that you can	

use those strings to tie pieces of wood together to support you in other difficult situations. Many times you're at home and you find things ready…meals cooked. Their clothes are being washed	**No desire to leave their parents' home**
In the DLS checklist, participants rated the following DLS as High Priority: ***(i) Shower/bathe regularly; personal hygiene/neat appearance*** ***(ii) Recognise household dangers*** ***(iii) Safety on the street and public transport*** ***(iv) Money value/budgeting/credit card safety*** ***(v) Recognise health problems and respond to doctor to help in diagnosis***	
To your knowledge, are these addressed? Elementary school and secondary school never gave me the opportunity to become independent…it never happened. I never had the opportunity to try to find a way to independence. People offered me little help…there were very few options…people were impatient. In post-secondary school	**DLS need to be taught directly**

they did help him a lot and gave me a lot of ways to practise my independently at home and come up with ways of managing I had the freedom to explore and to speak more freely without being punished. When I worked in my father’s company I had plenty of opportunity to come up with things myself and my co-workers were very supportive and had good listening skills	

Interview ProfM2

In the Promoters Q sort, many participants gave 'good professional support' a very high ranking. ***Can you describe what type of professional support is most helpful in developing DLS?***	
I think professional support is extremely important. An autistic person needs guidance to do everyday tasks. If you put an autistic person in an independent setting without giving him support he would not learn through his own experience. He would need a professional person who has a good understanding of autism to guide him.	**Professional support**
If we had to do something additional as a Centre to adjust the type of professional support given, what would it be?	
What I feel could be helpful is…there are things which cannot be taught in a session environment. To teach DLS you need to adjust the learning environment to one that is suitable to teach cooking for example.	

Ideally you would have a setup where students can spend some days and follow a DLS programme. ***The Promoters Q sorts showed that an important promoter is the young person's desire to become an independent adult. What are your views on this?*** I think a person's desire is very important. If they have everything done for them at home and they do not have that desire to do something themselves, it would be difficult for them to acquire independence.	**They get used to being cared for**
If a person has a desire to have a job, drive a car…they are more likely to be successful. ***What can be done to instil this aspiration in young people?***	
I think sometimes to motivate them, a need for them to do certain DLS e.g. do the laundry, has to be created for them rather than find everything done for them. They need to have a role in the family. Even for example if someone has a hobby that requires money, it could be a motivator in itself	**Giving them small responsibilities**

to find a small job to earn money for that hobby. Money could be a motivator in itself.	
Another useful strategy identified by the Promoters Q sorts was for parents to be persistent in teaching DLS to their son. What are your views on this?	
I believe parents need to keep on being persistent even when they feel that it is to no avail. I feel that if parents refrain from persisting, the young people's motivation will decrease. Even if parents begin to lose heart and give up and stop persisting, it could be that the young person will stop trying. I think parents need to keep persisting even when they feel that it is to no avail…and they need to take risks..even when the situation appears to be challenging and the young person is persistent in not trying.	**Parents' persistence**
How can we as a Centre support parents to persevere?	
Parent's support meetings are important especially those which expose them to the experiences of other families who have been successful to encourage parents more.	**Support for parents**

I think a lot of parents would appreciate such an initiative and would be willing to participate. ***The Barriers Q sort showed that a key barrier might be the parents' beliefs (eg they may focus on academic skills rather than DLS; may be scared to encourage independence; or may have low expectations for their autistic son). What are your views on this?*** ***What strategies could we adopt as a Centre to address this barrier?*** All in all, parents can be a barrier without even realising it. Parents tend to protect their children and sometimes there is a lot of fear and lack of trust. Sometimes this leads to instil fear in the young people themselves who are scared of trying out new things because they fear the consequences if something does not go well such as what their parents would say. However, there are also parents who are exceptional and allow their young people to be free while providing guidance. I think parents need to be very careful because there is a fine line between guiding and supporting them and overprotecting them. Sometimes, parents would not realise that they would be keeping their children from developing further.	**Parents' fear**

If we were to do something additional at the Centre to support parents in the development of DLS, what would it be?	
One thing which I find works well with parents is when you make parents aware of other autistic people who were in similar circumstances and they managed to overcome the challenges and move on in life. It is important that as professionals we support and encourage parents because sometimes their fears would be unfounded out of their good will to protect their young person, but they would be keeping them from achieving new skills. Sometimes it takes just one instance for parents to realise that their young people are capable of performing certain skills. Then there are parents who would say that they are willing to try but they still keep back out of fear. Sometimes they are scared of what will happen when they pass away, but they do not do anything to address it. Taking small steps would eventually help the young person to acquire certain skills and it would help parents to put their minds at rest that they are equipped to be prepared for life.	**Support for parents**
In the Barriers Q sort, some young people said a fear of doing something wrong or not being able to do	

something well were barriers. What are your views on this? Sometimes the fear could be coming from the parents who would have kept them back from experiencing new situations. If they are things they would have never tried before, it is difficult for the young people if their parents don't support them. You might find a few young people who would still try out new things to become more independent irrespective of what their parents think but I don't think it is the majority. Living with one's parents makes it difficult for young people to take certain initiatives. I think another factor could be that they would have tried to do something new which went wrong, or the result did not match what they had in mind and they would develop this fear of trying other new things. ***How might the Centre help young people to be more confident in developing DLS?*** I feel that a big part of my professional work with these young people is to instil confidence in them to try new things…to empower them and to help them understand that fear is a normal feeling when you are trying out something	**Anxiety** **Professional support**

new but it should not stop us from taking the challenge. It is also important to work with parents to motivate the young people to take up challenges and try out new skills. Group sessions and group activities are a good opportunity to try out new things which they might be able to practise more on their own later on. ***The Barriers Q sort showed some young people felt they lacked the opportunity to discuss their wishes on DLS. What are your views on this?*** It is important to discuss these things with them especially in group settings and encourage them to brainstorm together on how they imagine their life to be in a few years' time. Through such exercises they can become more aware of the importance of learning DLS that they would be needing.	
Most of them find it difficult to have a vision for the years to come..very ..when we discuss it they either become confused or they repeat things that they would have already been through or what they would be experiencing at that particular stage of their life.	**They get used to being cared for**

I feel that sometimes families do not even find the time to discuss with their young people…they would be so busy with their routines. Or it would have become a way of life.	**Life is too hectic**
How might we increase these opportunities within their families and at the Centre?	
That is where our professional role comes in..to encourage the young people to discuss their thoughts and wishes about their future with their parents and to help parents understand the importance of such discussions. Sometimes young people feel scared to discuss their wishes with their parents or that parents do not seem to be interested when they bring it up.	**Professional support**
When you bring it up with parents they often admit that it was on their minds but they would not have addressed it.	
In the DLS checklist, participants rated the following DLS as High Priority: ***(i) Shower/bathe regularly; personal hygiene/neat appearance*** ***(ii) Recognise household dangers*** ***(iii) Safety on the street and public transport*** ***(iv) Money value/budgeting/credit card safety***	

(v) Recognise health problems and respond to doctor to help in diagnosis ***To your knowledge, are these addressed?*** I think when it comes to money skills…we tend to touch on it but do not go into enough detail. Parents may at times lean on professionals to address these skills and they do not trust them with money when it comes to everyday shopping...so they do not get the practise. Sometimes we enter into a vicious circle…parents leave in the professionals' hands and professionals encourage parents to help them practise and I think no one does enough. Parents are often concerned about money because sometimes we think that they would have acquired the skills but they wouldn't have. Sometimes they try and fail and it affects their self-esteem and they wouldn't want to try again.	**Money** **Money**