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Persons with Autism and Persons with ADHD

The need to understand and improve services for families in Malta

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Abstract

Persons diagnosed with autism, or Autism Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD) are often reported to perform significantly low in overall wellbeing when compared to their neurotypical counterparts (van Heijst & Geurts, 2015; Meier et al., 2011). With active participation in society considered to be a key factor surrounding wellbeing (Askari et al., 2015), it comes as no surprise therefore that the reduced levels of involvement reported in areas such as social engagement, education, and leisure may be major contributors to this (Desemo et al, 2016).

Over the years, Malta has made considerable shifts towards the recognition of certain rights when it comes to disability, although negative attitudes still exist, both from the general public, as well as professionals (Cardona, 2013). This study therefore sought to understand the experiences of those living with autism and/or ADHD in the local scenario, looking into how current support structures impact their livelihood. Using a mixed-method approach involving quantitative and qualitative data collection strategies, this study sought to highlight insider voices, attempting to 'take stock' of the status of the evidence base, listening to the voices of those concerned and their experiences with local services and within the wider local community as a whole, identifying any gaps in services or data along the way.

The findings of this study indicate that locally, persons living with autism and/or ADHD, encounter challenges throughout their development from children into adulthood which considerably impact their performance and consequently their wellbeing. A number of areas for development were identified. The services surrounding the attainment of a diagnosis for instance, were found to be typically carried out professionally in the case of those flagged at early years, however, were severely lacking when it came to adults. Moreover, a vast majority (80%) of adult service user participants in the study had received their diagnosis during adulthood, exposing a local picture where diagnoses are not being made early enough, leading to individuals facing foundation schooling and critical years without the necessary support. Although services users who are being diagnosed as adults may have faced a different situation when they were of school age, since these conditions were less known and there was less awareness, nevertheless, caregivers are still reporting that there are instances where they know that there is a condition but find it hard to access a diagnosis as they are told to wait until the child is older. Support services and referrals for treatment offered following diagnosis were also found to be severely lacking, with 91% of service user respondents and

82% of caregiver participants not having received any services or information after receiving their diagnosis. Encouraging achievements within the educational and employment realm were observed, however areas for improvement still remain, with finding indicating this may be more so the case for those living with autism. Levels of dissatisfaction with services were reported across large numbers of participants with the highest ranked dissatisfaction expressed towards how well services were connected amongst each other, followed by access to services following diagnosis. Several lamented long waiting lists, lack of trained professionals and infrequency and inconsistency across public services provided. In addition to this, over 70% of participants reported being dissatisfied with the prospects for lifelong fulfilment, accompanied by concerns about services not catering for different age groups, particularly adolescence and even more so adulthood. These findings were also echoed in data gathered from service providers, who in the larger part, shared that there were waiting lists associated with the provision of their services – in some cases, of even more than 13 months. A review of the services provided amongst participating service providers also reflected the critical reduction in services available for adults when compared to younger ages. Amongst service providers, the largest challenge in offering services both for ASD and ADHD was lack of trained professionals. These include a range of services, such as occupational therapy, speech therapy, behaviour specialists, health and educational services as well as social services, amongst others.

Over the years, valuable developments have been achieved when it comes to Malta catering for the needs of all of its citizens, including those living with ADHD or ASD. The views and experiences discussed in this study have brought several commendations for milestones reached and have also highlighted several others that still need to be worked as a society towards. Ultimately, awareness and understanding across the different strata and branches of society is at the base of making these developments possible. The study concludes with a list of recommendations proposed for the enhanced wellbeing of those living with these conditions and society at large. These include, amongst others, recommendations for policy, such as the creation of a one-stop shop for provision of services, the introduction of quiet rooms in places such as hospitals and schools, the incentivising of youngsters to undertake studies related to disability in order to enrich the local pool of professionals, and the involvement of diagnosed individuals in decision-making processes. Recommendations for further research are also laid out, such as investigating gender differences related to ASD and ADHD, where females are typically underdiagnosed, or further examining the findings of this study by looking into ASD and ADHD separately to bring more insight into, for instance, findings related to the educational and employment attainments for these groups.

1. Introduction

Terminology

In this report, use of the term 'autism' refers to all 'autism spectrum disorders' encompassing autism, Asperger's syndrome, atypical autism (or pervasive developmental disorder not otherwise specified) and other variations on the spectrum. Moreover, this report seeks to make use of identity-first language throughout its discourse when referring to persons living with autism and/or Attention Deficit Hyperactivity Disorder (ADHD), since this is the preferred language of many diagnosed people and their families (Kenny et al., 2016).

This report views disability through the social model, locating impairments not in the individual, as is the approach of the medical model of disability, but within society. Within the social model approach, social barriers are viewed as the factors that constrain the lives of disabled persons (Thomas, 2002). When an individual's participation in society is stopped or hindered, barriers are formed or ignored by society thereby disabling a person from fulfilling their rights and potential. Disability is therefore considered to refer to the hindrances imposed by society, which are distinct from a person's impairment.

Understanding and Improving services for persons with Autism and ADHD in Malta

Autism refers to a neurodevelopmental condition characterised by challenges with communication, behaviour and sensitivity (Roemer, 2021). Autistic individuals often have different ways of learning, interacting with others, or paying attention (Berger & Ingersoll, 2015). Attention Deficit Hyperactivity Disorder (ADHD) is also a neurodevelopmental condition, that is typically associated with inattention, impulsivity and hyperactivity (NCBDDD, 2019). Although different in their origins, these conditions present with both distinct and overlapping (such as issues with executive functioning) expressions and are considered to be two of the most common neurodevelopmental disorders (Erskine et al., 2013). Both conditions bring with them a plethora of diverse needs that can vary from individual to individual, heterogeneous in nature. In both cases too, early diagnosis and prompt subsequent intervention and support play a pivotal role in improving outcomes. Several strategies, including behavioural therapies, occupational and speech therapy, have been found to be beneficial towards improving the wellbeing of diagnosed persons, particularly during early years, but also across later years.

The experiences of autistic people and those which ADHD impact every aspect of their and their family's life, ranging from the social to the economical, from the emotional to the medical. Parents/caregivers of children with autism are often primary care coordinators and shoulder considerable responsibilities (at times left to their own devices) as they navigate the service delivery system. This study will seek to challenge discriminatory and stereotypical discourse in popular language, educational, health and social services which might be blocking the access of persons with autism and/or ADHD to services in Malta. The focus of this study will be to identify not only the needs but also the aspirations and ambitions of autistic people and those with ADHD and seek to conceptualise the experiences of ostracization and community exclusion.

This study therefore aims to engage the national context by attempting to understand the experiences of families and persons with autism and ADHD and how the support structures are operating (if any at all). In terms of the landscape of services currently available, the study will highlight insider voices, by engaging with families' needs, concerns, and aspirations and listening to the persons directly affected with autism and ADHD in order to promote more effective and accessible services.

2. Literature Review

2.1 Autism

What is Autism?

Autism spectrum disorder (ASD) is a term relating to a spectrum of neurodiverse expressions, which include Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (Dawson & Toth, 2015). Early signs of autism include communication difficulties in understanding and using language (Roemer, 2021), variances in the broad domains of social interaction (Berger & Ingersoll, 2015), and behavioural differences, accompanied by the presence of repetitive interests and behaviours (Brereton & Tonge, 2021; Dawson & Toth, 2015). While severe difficulties with social skills and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are core aspects of all ASDs, significant language delays are typically associated with autistic disorder and pervasive developmental disorder not otherwise specified (Plauché Johnson et al., 2007). According to the International Classification of Diseases (ICD-11), (WHO, 2019), ASD is defined as:

> *"Characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities".*

The American Psychiatric Association (Copeland, 2018) similarly states:

> *"Autism spectrum disorder is a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviours. The effects of ASD and the severity of symptoms are different in each person".*

Developmental difficulties and sensory problems accompany autism (Walsh, 2013). Individuals living with autism present along a broad spectrum ranging from requiring high levels of support to considerably lower levels, manifested by traits such as, a level of IQ which could range from severely intellectually impaired to a high IQ level, or a variation in communication skills ranging from non-verbal to a high use of language, with typically eccentric articulation (Volkmar, 2013).

Onset and Prevalence

According to the DSM-5 (APA, 2013), the most obvious signs of autism present before 3 years of age. Research also indicates that signs of autism and related disorders may be identifiable at an earlier age (Charman & Baird, 2002; Charman & Baird, 2000), even as young as 18 months of age (Hyman et al., 2020), pointing out that many children with autism exhibit identifiable difficulties in social interactions as early as their first year of life (Charman & Baird, 2002). Nevertheless, in some instances, signs can develop following toddlerhood, with a halt in acquisition of skills of loss of previously gained skills, with development prior to then occurring typically (WHO, 2019; Copeland, 2018).

Autism is reported to affect 1 in approximately 60-70 children (Brereton & Tonge, 2021; Copeland, 2018) in a consistent manner across races and cultures (Fombonne, 2003), with research pointing at increases in prevalence over the last decade (Wallis, 2021). Recent research in the United States also observed that almost one-quarter of children with documented signs and symptoms of autism were in fact undiagnosed (Wiggins et al., 2020). Autism is reported to be 3 to 4 times more common in males than females, with females manifesting less obvious signs than males (Copeland, 2018). This suggests a genetic role in the inheritance of autism (Plauché Johnson et al., 2007), however the reason for male predominance in autism is not completely understood (Rutter, 2005). In fact, this assumption is at times challenged in research (e.g. Dimech, 2021; Gould & Ashton-Smith, 2011), attributing it to factors such as underdiagnosis due to the milder manifestation of symptoms (Ratto et al., 2018), linking it to the predominance of research includes mostly, and in some cases, exclusively, males (Dimech, 2021; Harrop et al., 2018), or linking it to what is referred to as the 'camouflage hypothesis' whereby females on the spectrum are viewed as able to mask their autistic traits through better management of the rules of social situations (Matheis et al., 2019; Ormond et al., 2018; Beggiato et al., 2017; Dean et al., 2017; Fulton et al., 2017; Wing, 1981a), especially among those without intellectual disability (Ratto et al., 2018).

Comorbidity

Comorbidity, whether directly or indirectly, is common in autism (Hyman et al., 2020; Cawthorpe, 2017; Gillberg & Billstedt, 2000), although it may vary widely in its prevalence (Casanova et al., 2020) and may range from seizures, multisystem disorders, to psychiatric disorders, amongst others (Doshi-Velez et al., 2014). The potential presence of comorbidities may also obscure the clinical presentation of autism (Pisula et al., 2017). Around 70% of autistic people typically meet the diagnostic criteria for at least one other (at times unrecognised) psychiatric conditions that further impairs psychosocial functioning (NICE, 2021b). In autism, comorbidities tend to cluster into different subgroups (Casanova et al., 2020), and frequently manifest in pre-school years (Muratori et al., 2019).

Diagnosis

Early diagnosis and evidenced-based interventions and treatment are an important factor in improving function, outcomes and the quality of life for autistic people and their families (Hyman et al., 2020; Copeland, 2018; European Agency for Special Needs and Inclusive Education, 2017; Mandell et al., 2005; Cooley & McAllister, 2004; Palfrey et al., 2004; Committee on Children with Disabilities, 2001). In later years, the acknowledgement of a diagnosis can also support improved self-awareness, advocacy and better decision-making prospects (Shore, 2004). Nevertheless, children who display only mild traits of autism are easily not identified, often until school age, when differences in social language or personal rigidities affect function (Hyman et al., 2020). This may also be a possible contributing factor towards the underdiagnosing of females, who girls tend to have lesser intensity of symptoms and fewer externalizing behaviours (Hyman et al., 2020; Ratto et al., 2018). The capacity building of professionals working with children during early years, such as nursery staff can therefore help flag early signs of any developmental difficulties (Gray & Tonge, 2005; Steel, 2004).

The clinical picture of autism is a varying one, depending on differences in the severity of autism itself, possible coexisting conditions and the individual's level of cognitive ability (NICEb, 2021b). Although difficulties in the social realm present earlier and may be more specific, these can nevertheless be subtle in nature and easily go by unrecognised by parents or caregivers (Plauché Johnson et al., 2007; Maestro et al., 2006; Mitchell et al., 2006; Zwaigenbaum et al., 2005). Speech delays typically prompt parental concern, with a large part of families seeking professional advice around 15 - 18 months of age (Wiggins et al., 2006; Bhushan Gupta, 2005; Wetherby et al., 2000; Howlin & Asgharian, 1999; Howlin & Moorf, 1997; Mundy & Markus, 1997). Hearing difficulties also often raise concerns, with families reporting what appears to be 'selective' due to children reacting to environmental sounds but not to human voices (Leekam & Lopez, 2000). Paediatricians therefore play an important role in early recognition of autism, being typically the first point of contact for families (Myers et al., 2007; Plauché Johnson et al., 2007; Committee on Children with Disabilities, 2001). It is essential therefore, for paediatricians to be aware of the signs and symptoms of autism and to have a strategy for assessing them. The occurrence of echolalia and at times, hyperlexia (advanced verbal reading skills without corresponding comprehension skills) in children with autism also means that the involvement of a speech-language pathologist (SLP) should be part of the assessment for diagnosis (Plauché Johnson et al., 2007). Such an assessment can inform modes of intervention, bringing insight on the child's abilities, such as whether they are able to follow simple 1-step commands.

Presently, the diagnosis of autism is based on diagnostic dialogues with caregivers (or the adults concerned) assessing an individual's developmental history and behaviours against the criteria laid out in the DSM-5, (APA, 2013), (Info Box 1) and the ICD-11, (WHO, 2019) (Fuentes et al., 2020). Since little is yet known about the biological markers of autism, diagnosis is largely based on behaviours, which so far aren't unequivocally denoted specifically to autism, and no objective measure exists as yet to confirm a diagnosis or allow for earlier detection (Hyman et al., 2020; Walsh et al., 2011). The British National Institute for Health and Care Excellence (NICE) recommends that a multidisciplinary team be involved in the process of recognition, referral and diagnosis of children and young people, including a paediatrician and/or child and adolescent psychiatrist, a speech and language therapist, and a clinical and/or educational psychologist while also having access to an occupational therapist (NICE, 2017).

Initial diagnosis provides individuals as well as their families with a space to make sense and comprehend some of the challenges and experiences they may have been faced with. In this way, it also serves as the foundation to discuss and access services and interventions that can be of support to them. Diagnostic dialogues should be sensitive to the complex difficulties and uncertainties that autism brings with it (Walsh, 2013).

Info Box 1: Parts of the Definitions from the Diagnostic Criteria for ASD according to DSM-5

(APA, 2013; Attwood, 2015)

Persistent Deficits in social communication and social interaction across multiple contexts

- Deficits in social-emotional reciprocity
- Deficits in non-verbal communicative behaviours used for social-interaction *(that is, reading other people's body language, facial expressions, gestures and voice to indicate specific thoughts and feelings)*
- Deficits in developing, maintaining and understanding relationships

Restricted, repetitive patterns of behaviour, interests or activities

- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, or ritualised patterns of behaviour
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper or hypo-reactivity to sensory input *(unusual interest in sensory aspects of the environment)*

Interventions and Treatment

The early years offer a unique opportunity to nurture developmental advances in children (UNESCO, 2009). The European Commission (2008) in fact emphasized the crucial value of interventions at an early stage since learning difficulties are difficult and more costly to rectify at later stages. Early intervention services that provide care, motivation, parental support and access to relevant services, can therefore augment the value of interventions for children with disabilities (UNESCO, 2009). These are also naturally most effective when families are involved, enabling them to explore information about how to optimise a child's potential (European Agency for Special Needs and Inclusive Education, 2017; UNESCO, 2009). Early childhood programmes that provide the necessary individualised support, can lead to more positive transitions and increase the chances for disabled children to participate and flourish in inclusive mainstream educational settings (UNICEF, 2012).

The varying and personal nature of autism means that no single mode of treatment is ever likely to be effective for all individuals and all families (Esbati & Roberts, 2009; Howlin, 1998). Instead, intervention programmes for autistic people "should be based on sound theoretical constructs, rigorous methodologies, and objective scientific evidence of effectiveness" (Hyman et al., 2020, pp. 20), while incorporating the individual's special interests into the intervention plan (Grove et al., 2016). Interventions are typically provided through educational channels, developmental therapy sessions and/or behavioural activities. These can be carried out individually or in a group setting, delivered by a professional or a trainer caregiver/parent, and be held in a school or in a home setting (Smith & Iadarola, 2015; Zwaigenbaum et al., 2015). The age and level of ability of the individual will determine which intervention approach most addresses their strengths and weaknesses (Hyman et al., 2020). Diagnosis is also a key determining factor in the selection of appropriate strategies applied. For instance, researchers such as Szatmari (2000) reports that a subgroup of children living with autism show considerable developments in language, play and social interest between the ages of 4 and 6, which are consistent with the traits of Asperger's syndrome (Macintosh & Dissanayake, 2004; Attwood, 1998; 2000; Gillberg, 1998; Wing, 1981b). In these cases, Attwood (2015) suggests that these children may be diagnosed with high-functioning autism or Asperger's syndrome and therefore proposes that the best treatment plan for them would include strategies and services designed to cater for children with Asperger's syndrome rather than autism disorder. Ultimately, families should be part of the discussion surrounding intervention pathways and should remain involved in educational and therapeutic decisions throughout (Hyman et al., 2020).

> *"Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them. Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle".* (ASAN, 2012, pp. 15)

The care needs of autistic children are significant, and also impact parents or caregivers as well as siblings (Hyman et al., 2020). The diagnosis of a developmental disability is found to be perceived by parents as a lifechanging experience that gives rise to a process of grief and in most cases, eventual resolution and adjustment towards raising a child with an autism (Lilley, 2011; Milshtein et al., 2010; Ryan & Runswick-Cole, 2008; Trute & Hiebert-Murphy, 2002; Bartolo, 2001b). Emotions ranging from sadness, self-blame, despair, devastation and shock to relief at having found an explanation are associated with the communication of a developmental disability such as autism (Landsman, 2005; Midence & O'Neill, 1999). Additionally, stigmatisation arising from society is often found to be not only directed towards the individual with an autism, but also towards parents (Farrugia, 2009; Hutton & Caron, 2005; Gray, 2002, 1993; Schall, 2000), at times even arising from relatives and friends (Hutton & Caron, 2005; Schall, 2000). In the absence of physical differences, the behaviours of autistic children typically differing from social norms, may further exacerbate the occurrence of stigmatisation, leading to parents experiencing feelings of shame and humiliation, together with a sense of exclusion from social events (Farrugia, 2009).

With the value of sibling relationships well established in literature as the longest lasting relationships within a family structure (e.g. Conway & O'Neill, 2004; Seltzer et al., 2005), Rossiter and Sharpe (2001, pp. 81) assert that "the sibling bond is no less enduring nor less influential when one sibling has a disability". Some add however that the kind of disability may impact the nature of sibling relationships, observing for instance, more affectionate ties amongst siblings of children with Down syndrome when compared to autism (Mandleco & Webb, 2015; Hodapp & Urbano, 2007), and fewer positive sibling relationship attitudes in the case of autistic siblings when compared to individuals with intellectual disability (Tomeny et al., 2017). While some attribute these differences to communication difficulties (e.g. Moyson and Roeyers, 2011), literature reviews report mixed results, with, for instance, studies looking into the views of autistic individuals' experience of their sibling relationships, reporting typical sibling relationships (e.g. Petalas et al., 2015). Ultimately, although it appears autism may contribute to unique environmental stressors for siblings (Green, 2013), the "unique characteristics of autism give the siblings' experience a highly personal interpretation" (Moyson and Roeyers, 2011, pp. 41) and may result in both positive and negative outcomes for siblings (Corsano et al., 2017; Ward et al., 2016; Angell et al., 2012; Petalas et al., 2009), in part influenced by factors such as demographical, family and individual variables (Green, 2013). In studies with young Maltese siblings, the same was also reported, with different feelings being exposed by siblings of disabled children (Vella Gera et al., 2021; Vella Gera, 2017). Overall, they highlight the importance of "assisting the Maltese society to eliminate the social and attitudinal barriers towards families of disabled children" (Vella Gera et al., 2021, pp. 77) towards nurturing a more inclusive society.

Researchers report that factors such as social support may improve the wellbeing of families of children with autism (Stuart & McGrew, 2009), together with other aspects such as levels of optimism and parental/caregiver coping styles. The latter have in fact both been linked to greater resilience among families of children with autism (Ekas et al., 2010; Kayfitz et al., 2010). The quality of social support received also plays a part (Altiere & von Kluge, 2008), as does the family's level of satisfaction with it. These have in fact been linked to improved levels of resilience (Fong et al., 2021), physical health (Gallagher & Whiteley, 2012; Lovell et al., 2012), mental health functioning (Khanna et al., 2011; Benson & Karlof, 2009; Bromley et al., 2004), and reduced levels of stress (Ruiz Robledillo et al., 2014; Renty & Roeyers, 2007). Nevertheless, numerous studies have found that families of children with autism tend to experience poorer quality of life (Weiss, 2002), experience higher levels of stress when compared to families of neurotypical children (Gunty, 2021; Davis & Carter, 2008; Hodapp et al., 2003; Kasari & Sigman, 1997), anxiety (Chan et al., 2018), and overall encounter lower levels of social support and friendships (Weiss, 2002). These findings shed light on the value of support networks and the importance of strengthening this aspect – which many affected families identify as a priority (Hodgetts et al., 2015) – when addressing interventions for children with autism. In particular, strengthening informal support also protects families from isolation (Fong et al., 2020; Gray & Holden, 1992).

Support networks surrounding families with children with autism can include aspects of formal and/or informal sources of support. Formal support is typically provided by organisations or agencies, such as educational services, mental health professionals, and respite facilities (McIntyre & Brown, 2018; Bromley et al., 2004; Boyd, 2002). Informal support provision on the other hand, involves a network of support, typically of a social nature, and may include people such as family, friends, other parents of children with disability, amongst others (McIntyre & Brown, 2018). These can both provide valuable support for families of children with autism (e.g. Gouin et al., 2016; Robinson et al., 2016; Barker et al., 2011; Ekas et al., 2010). In this respect, interventions can address this aspect of intervention surrounding autism by including the targeting of families' informal support networks, mobilising families' current social support branches, guiding on how to communicate about autism to contacts and informing on the value of these relationships for family wellbeing. Indeed, research is also showing that even 'virtual' forms of support through social media and online channels too may be a worthwhile source of social support (Dam et al., 2017). In addition, the provision of respite services can also provide valuable support to families, bringing an opportunity to step outside of their caregiving role (Fong et al., 2020). From an administrative perspective, governments must support the wellbeing of families and support their participation in their children's development (European Agency for Special Needs and Inclusive Education, 2017). For instance, governments can address issues such as choices for flexible or part-time jobs, parental leave and supporting mothers to employment (Mistry et al., 2012; Buehler & Marion, 2011).

Autism in Childhood and Early Adolescence

Autistic children universally encounter differences when it comes to social relatedness, that is, the drive to connect with those around them (Rogers & Benneto, 2000). Activities involving joint attention are typically spontaneous in early years, with infants expressing pleasure in sharing an object (or activity) by expressing a smile, looking back and forth between the two, and in later years, using gestures or speech to engage other people's attention (Plauché Johnson et al., 2007). Young autistic children, however, typically do not appear to seek this connectedness and seem to prefer solitary contexts, often not responding to other people's calls for attention, and rarely engaging in eye contact. This behaviour develops further in later years, arising in difficulties during cooperative games and group activities, with these challenges in fundamental social skills building blocks typically resulting in the formation of fewer bonds with friends (Plauché Johnson et al., 2007). Difficulties in joint attention in fact, are reported to be amongst the core characteristics of very young autistic children (Leekam & Ramsden, 2006; MacDonald et al., 2006; Turner et al., 2006; Klin et al., 2005; Wetherby et al., 2004; Charman, 2003; Chawarska et al., 2003; Dawson et al., 2002; Mundy & Markun, 1997), with a response to social stimuli, in particular, orienting towards the calling of one's own name, typically not present (Nadig et al., 2007; Leekam & Ramsden, 2006; MacDonald et al., 2006; Paparella & Kasari, 2004; Mundy et al., 2000; Lord, 1995; Mundy, 1995). Wing and Gould (1979) observed autistic children as appearing to be socially aloof, coming across as

living in a world of their own; passive interactors, not seeking social contact but passively accepting it if offered to them; or, socially active but odd, initiating social interactions however with behaviours that are often viewed as inadequate for its context.

Approximately 25 - 30% of children with autism are reported to make use of a few words during their first months, followed by a cessation in speaking around 15 - 24 months of age (Turner et al., 2006; Werner & Dawson, 2005; Tuchman & Rapin, 1997). The absence of speech, typically from a young age, is in fact also considered to be a hallmark of autism disorder (Hyman et al., 2020), especially when combined with behaviours such as those previously described above; however some children may present with verbal abilities, even if these may not necessarily carry a communicative intent (Plauché Johnson et al., 2007). Some autistic children make use of scripted speech (such as the repetition of excerpts from videos, television or radio programs) however differ from typically developing children in that periods of echolalia may remain present throughout their life. Additionally, their expression of speech comes across as more clearly articulated, of a monotone nature, and/or consisting of longer verbal excerpts of information, such as an entire advertisement, when compared to typically developing children. Children living with Asperger syndrome on the other hand, are often reported to be fluent in speech surrounding topics of interest, however encounter difficulties expressing or recognising feelings (Plauché Johnson et al., 2007).

Autistic children are often reported to express differences when it comes to pretend play. Typically, they engage in what appears to be repetitive play, play involving puzzles or computer games, or sensory-motor activities, such as mouthing, twirling, banging, and manipulating objects in a ritualistic fashion (Plauché Johnson et al., 2007; APA, 1994; 2000). For instance, they will be observed lining up cars instead of pretend-driving them, organising colouring pencils instead of using them to colour, or repetitively stacking blocks in a similar order, with play activities also typically tending to be solitary (Plauché Johnson et al., 2007). Meanwhile, while typically developing children at times form attachments with objects such as stuffed animals or a special blanket, children with autism are reported to express a preference for harder items, such as pens, a torch, or action figures. Children with autism are also often found to favour play involving everyday objects, such as pens, as opposed to toys, with the exception of trains or favourite characters. Puzzles, particularly those involving matching tasks, or computerised puzzle games, are also considered to be common preferences (Wetherby et al., 1998). Because of the social differences associated with autism, children are often reported to struggle in groups games (Arik et al., 2005).

Autistic children sometimes express unusual, stereotypical mannerisms such as hand flapping, finger flicking, rocking, habitual toe walking or twirling (Chawarska & Volkmar, 2005; APA, 1994; 2000), typically appearing after the age of 3 (Stone et al., 1999). An unusual attachment to objects or topics - is often also observed (Twachtman-Cullen, 2000), such as for instance, rather than a desire to play with trains, being overly-interested in train schedules, or knowing a large volume of details about them (Plauché Johnson et al., 2007). These attachments may give rise to forceful resistance when required to transition away from or in instances when routine is changed. These may quickly escalate to periods of undesirable behaviour, potentially including aggression or self-harming behaviours, such as head banging or hand biting (Coury, 2010; Schroeder et al., 2001). Episodes of self-harm may in fact be brought about by instances such as frustration surrounding difficulties communicating, transitions, anxiety in unfamiliar contexts, boredom, depression, tiredness, or pain (Plauché Johnson et al., 2007). These behaviours can greatly impact the child's integration in activities within the community and have also been shown to significantly impact both caregiver stress (McStay et al., 2014; Firth & Dryer, 2013; Khanna et al., 2011) and family functioning (Pozo et al., 2014).

Education

During their school years, autistic learners may face several challenges within their school environment. These could be related to difficulties with communication, socio-emotional difficulties as well as difficulties surrounding rigidity. All of these could act as an increased barrier to students in the classroom while the presence of other comorbidities such as learning difficulties could exacerbate their experience even further. Moreover, several schools encounter difficulties ensuring successful inclusion of autistic children within mainstream settings (Jordan, 2008). Autistic children may struggle to follow the same teaching methods and curriculum as their neurotypical classmates, and activities that may be common practice and straightforward for the latter to handle, may be challenging for a student on the autism spectrum (National Autistic Society, 2016). These include unplanned changes in time-tables or educators, or extended waiting periods (Galea Soler & Pace Gellel, 2018), as well as stimuli such as busy classrooms (Calleja, 2019; Galea Soler & Pace Gellel, 2018) or playground activities (Locke et al., 2017). Readiness for learning and sitting tolerance may also be problematic during younger school age years (Galea Soler & Pace Gellel, 2018). Transitioning to middle and secondary school can be daunting for all students (Zeedyk et al., 2003), and even more so for autistic learners (Makin et al., 2017; Dillon & Underwood, 2012). Instances such as the rapid transitions and physical movements between lessons, increased organisational demands such as use of locker or homework scheduled for different dates or sensory stimuli in noisy hallways can be challenging for a young person on the spectrum. Meanwhile, increasing academic and social demands add to this (Galea Soler & Pace Gellel, 2018). While some autistic people may be verbal, some others may have limited use of speech or be non-verbal, and possibly make use alternative communication strategies such as visual symbols. Nevertheless, both verbal and non-verbal communication can be hard for individuals with autism to comprehend and express, typically having a literal understanding of conversations thereby finding instances such as jokes and sarcasm difficult to grasp (National Autistic Society, 2016). Difficulties understanding abstract language, reduced visual aids and increasing complexities mean that, in the classroom, an autistic learner is likely to encounter difficulties extracting cues from the environment in order to determine what is expected of them (Galea Soler & Pace Gellel, 2018). Additionally, research often identifies the social aspect of an autistic student's mainstream education experience as the most stressful and challenging aspect (Reed et al., 2012; Humphrey & Lewis, 2008). In fact, research indicates that children with neurodevelopmental differences such as autism tend to report higher levels of loneliness and overall have fewer friends as a result of decreased acceptance by their neurotypical peers (Rotheram-Fuller et al., 2010; Bauminger & Kasari, 2000). Chamberlain et al. (2007) who looked into whether inclusive settings were of benefit to autistic children reported that autistic children performed to a lesser degree in the social involvement of the classroom when compared to their neurotypical classmates. Moreover, autistic individuals have been reported to suffer from higher levels of social anxiety when compared to their neurotypical counterparts across their lifespan from childhood, through adolescence to adulthood (Kuusikko et al., 2008; Bellini, 2006; Gillott et al., 2001).

An extensive range of teaching modalities, such as hands-on practise and sensory approaches, can support autistic children with their attainment of different skills (Renzaglia et al., 2003). Specific activities and programmes (e.g. Kohler et al., 2007; Boulware et al., 2006; Kalyva & Avramidis, 2005) presented through early years play sessions have been introduced over the years to support functional outcomes and the development of social competencies such as, toilet training, initiating and maintaining a topic of conversation, turn-taking, eye contact, and openness to peer communication (European Agency for Special Needs and Inclusive Education, 2017). In inclusive settings, autistic children can be supported to interact with their mainstream classmates through buddy systems with the use of these play sessions, which can yield increased inclusion with peers (Meek et al., 2012; Boulware et al., 2006). Social support in the form of peer-based exchanges, such as break-time social skills training groups for instance, can support the development of social networks (Locke et al., 2017). Odom and Wolery (2003) outlined how educators can mediate learners' experiences and provide varying learning opportunities through activity-based interventions, high-probability requests and prompt-fading techniques. Educators play a central role in supporting peer interactions, therefore, it is important that children's social behaviour is monitored (Kwon et al., 2011). Parental involvement in these activities can also further support the development and generalisation of these social skills (Pickles et al., 2016). The participation of parents or caregivers is in fact considered to be essential for successful pre-primary education (European Commission, 2006), and can yield a much stronger impact than working solely with the child (Raver & Childress, 2014). These strategies can also yield benefits on the school as a whole and in turn, society (Denboba et al., 2014; Kwon et al., 2011). Families in fact, are the main context where children learn (Odom & Wolery, 2003) and are considered to be key in the success of classroom inclusion and in educating children to value individual differences (Stivers et al., 2008). This can be further supported by educators who can provide guidance to families about communicating with children about the individual differences (Salend, 2004).

In addition to developmental strategies and programmes, the use of transition processes for children such as those on the spectrum, can ease the stress that some children experience during the transition to primary and secondary school, and support more positive and effective transitions along the years for both families and children (Moore et al., 2013; Malone & Gallagher, 2008). These include, for instance, visits from one setting to new settings (Quintero & McIntyre, 2011), or transition meetings, where parents, professionals and special education co-ordinators share information about the child, such as their areas of strength, needs, goals, learning strategies and recommendations (Villeneuve et al., 2013).

Play and Leisure

Play and leisure are among the main occupations that children participate in (American Occupational Therapy Association, 2014). Amongst other things, they can promote the development social, emotional and life skills (Inclusion, Childhood and Education Ltd, 2003) Not surprisingly, research shows that when it comes to leisure and play, disabled children share similar preferences to their non-disabled counterparts, while the variety of activities, their frequency and their level of social participation can differ between the children (Schreuer et al., 2014; Shimoni et al., 2010; Law et al., 2006). A child with ADHD for instance, would tend to favour physical activities such as cycling, over activities involving rules or long periods of time (Shimoni et al., 2010), while an autistic child would favour activities such as those involving the use of technology or table top games, or more solitary activities such as puzzles, reading, writing or drawing (O'Hagan & Hebron, 2017; Ismael et al., 2015; Watts et al., 2014; Cosbey et al., 2012; Reynolds et al., 2011; Cosbey et al., 2010; Bundy et al., 2007). Although, personal differences in sensory sensitivities can influence children's play preferences, with for instance, a child with a low tactile threshold avoiding sensory-rich activities (Ismael et al., 2015; Reynolds et al., 2011; Hochhauser & Engel-Yeger, 2010). Nonetheless, studies indicate that autistic children tend to participate in fewer leisure activities when compared to their neurotypical counterparts (Askari et al., 2015; Sylvester et al., 2014), with Askari et al. (2015) highlighting this is often the consequence of environmental barriers such as stereotypes and prejudice rather than impairments. This was also echoed in the views of mothers of disabled children who claim that what prevents their children from being fully happy is not in fact a result of impairment, but rather the prejudices arising from society (Dale et al., 2006; Landsman, 2005; Biernat, 2000).

When it comes to participation in recreational activities, autistic youngsters are also typically reported to share most of their leisure activities with family, as opposed to peers (Potvin et al., 2013; Poon, 2011; Raghavendra et al., 2011; Solish et al., 2010; Hilton et al., 2008). Autistic youngsters may find it challenging to participate in leisure activities since these can make them feel unsafe, are often faced by negative attitudes (Brewster & Coleyshaw, 2011), and typically, they tend to prefer playing alone or at home (Hochhouser & Engel-Yeger, 2010). Other significant contributors impacting participation in leisure activities also include insufficient awareness regarding disability amongst leisure coordinators, coaches, caregiver over-protectiveness, academic demands, and financial constraints (Obrusnikova & Cavalier, 2011; Shattuck et al., 2011; Heah et al., 2007).

Accessibility in the context of play environments can be inclusive to all needs, and with support, can enable children to develop successfully through play (Sachs & Vincenta, 2011). For instance, for children with sensory processing sensitives such as autism, sensory, cognitive and auditory features can play a part in the level of participate that an environment promotes (Sachs & Vincenta, 2011). Sachs and Vincenta (2011) for instance, brought forward a 'Sequential Outdoor Learning Environment' concept which encompasses the needs of children with sensory sensitives such as autism within it. This play environment includes the use of a quiet location with minimal distractions from unnecessary stimuli such as airconditioner compressors, the use of non-glare surfaces and calm areas to unwind when a break is needed (Sachs & Vincenta, 2011). On a similar note, in her 'Inclusive Play Spaces For Children Of All Abilities', Standfield (n.d.) added that leisure environments should include sensory experiences that provide tactile, auditory and sensory awareness such as music panels or contrasting colours.

Participation in sports can support wellbeing and a healthy lifestyle through the improvement of physical, social and psychological health (Jowett & Felton, 2013), for both disabled as well as non-disabled persons (Bragaru et al., 2013). Physical activity for disabled persons was traditionally associated with the need to improve the health and function of the impaired body (Aitchison, 2003), however in addition to physical health, participation in sport can improve other facets of wellbeing, such as encouraging independence, reducing anger and tension, aiding with depressive moods, as well as promoting the creation of social contacts thereby preventing social isolation and supporting motivation and personal autonomy (Stephens et al., 2012; Gaskin et al., 2009)

Counselling and Support

In the inevitable face of difficult life experiences, such as for instance grief, researchers highlight that an autistic individual may find it particularly difficult to process and cope, thereby making the provision of effective support essential (Forrester-Jones & Broadhurst, 2007). Nevertheless, autism has proven to be a major challenge for counsellors and professionals in the therapeutic field (Hodge, 2012; Paxton & Estay, 2007). Therapies that are dependent on talking approaches may not be effective with this particular group of clients (Jacobsen, 2003), especially since autistic children typically find it hard to understand or express their emotions or those of others (Bromfield, 2010). Counselling with autistic children or adolescents should be carried out within a consistent, structured setting, based on regular sessions and through the use of varied approaches, such as visuals aids and the alternative of nonverbal therapeutic modalities (Sung et al., 2011). Counselling approaches for autism in fact, should explore active therapeutic techniques, such as play based therapies and the creative arts, in order to promote meaningful contact with these clients (Alvarez & Reid, 1999).

Autism in Adolescence and Adulthood

> *"Autistic adults don't look or act the same as autistic kids. We might learn how to look 'less autistic', or hide parts of ourselves. We learn to act like the non-autistic people around us"* (ASAN, 2020, pp. 12).

Diagnoses of autism in adulthood are more common than is often realised (Rubinstein, 2019). A British survey for instance, found that 71% of participants aged over 55 had received their first diagnosis within the last decade (National Autistic Society, 2012). Individual and environmental factors, combined with lack of awareness may all have contributed to this scenario (Epstein, 2019). In adulthood, a diagnosis typically depends on reports provided by the individual and retrospective reports from parents/caregivers, however by adulthood, individuals often adopt coping strategies that can make it difficult to distinguish between behavioural traits which are characteristic of autism or attributable to other sources (Russ et al., 2020; Epstein, 2019; Rubinstein, 2019). In fact, for every 3 diagnosed cases of autism, Baron-Cohen et al. (2009b) estimate that there are another 2 individuals who have not been diagnosed, although they might require assessment, support, and interventions, and many find that obtaining a diagnosis in adulthood is difficult or not possible (Taylor & Marrable, 2011). Ultimately, a diagnosis, even if in later adulthood years, may enable a new understanding and a sense of belonging, together with institutional recognition and entitlements, and most importantly, appropriate treatment and support (Epstein, 2019). Nevertheless, several adults, albeit experiencing all the core symptoms, do not receive a formal diagnosis (Brugha et al., 2011).

The rates of under-diagnosis or as Epstein (2019) calls it, 'silent integration', pose several questions on the realities of the autism landscape within communities. For instance, Wijngaarden-Cremers et al. (2014) estimated that among follow-up referrals to an addiction unit, out of 118 clients, 8 were previously-undiagnosed autistic adults. Several researchers have in fact reported that risk and protective factors usually surrounding neurotypical individuals occur differently for autistic individuals, linking autism to an increased susceptibility to substance use (e.g. Haasbroek & Morojele, 2021; Ressel et al., 2020; Helverschou et al., 2019, Butwicka et al., 2017; Lever & Geurts, 2016). Meanwhile, Ashworth (2016) reported that the rates of autistic prisoners is 2 to 3 times higher than the rate of neurotypical counterparts. These findings shed light on the fact that sensitivity towards and screening mechanisms for autism still need further investment and development.

Although research focusing on the childhood aspects of autism is more frequent when compared to that addressing experiences faced throughout autistic adolescents and adults (Roche et al., 2021; Epstein, 2019; Nicholas et al., 2017), a number of researchers have looked into the progression of autism along the trajectory of a person's life. Among these, a number have viewed autistic individuals as often not moving into adulthood independently, having social relationships or attaining gainful employment (e.g. Kirby et al., 2016; Magiati et al., 2014; Howlin et al., 2013; Levy & Perry, 2011; Hendricks & Wehman, 2009; Seltzer et al., 2004). Some evidence in fact suggests that a significant proportion of autistic adults across the whole autistic spectrum experience social and economic exclusion (NICE, 2021a). However, a number of autistic adults do in fact successfully attain academic qualifications, participate positively in the world of work, live independently and are healthy participants in social and/or romantic relations (Farley et al., 2009; Eaves & Ho, 2008; Billstedt & Gillberg, 2005). The heterogenous nature of autism, personal variables (Kirby et al., 2016; Magiati et al., 2014; Henninger & Taylor, 2013; Farley et al., 2009; Howlin et al., 2004), environmental factors such as family support, access to interventions and the nature of support services (Holwerda et al., 2012; Levy & Perry, 2011) all play a role in this. Personality is a complex and evolving product of a combination of factors; therefore, is an individual's unique characteristics meet with the appropriate context, a healthy personality may flourish, including for autistic persons. Therefore, while some researchers may have, in its larger part, viewed autism through a lens of impairment, autism "may also be associated with strengths with the potential to leverage improvements in functioning and quality of life" (Scott et al., 2019, pp. 870; de Schipper et al., 2015; Mottron et al., 2009). For instance, amongst other things, researchers have often discussed autistic individuals' strengths in roles requiring systematic information processing or those which involve an element of accuracy, precision and repetition (de Schipper et al., 2016; Baldwin et al., 2014; Walsh et al., 2014). Nevertheless, notwithstanding the growing amounts of literature highlighting the potential strengths that autistic people can bring to the world of work, many, still face barriers and obstacles towards accessing and participating in employment (Howlin & Moss, 2012; Hendricks, 2010; Hurlbutt & Chalmers, 2004). The limited research available that looks into services for autistic adults, also points to the fact that these faces barriers to accessing the services they require (Barnard et al., 2001).

Betz (2001) linked 5 core abilities linked with social and academic success and occupational development: self-esteem and self-efficacy, professional knowledge, setting and formulating goals, planning for the future, and troubleshooting. More recently, Cheak-Zamora et al. (2018) identified 5 themes surround autistic youth's perspectives on transitioning into adulthood. These were difficulty transitioning into adulthood, desires for and problems with relationship

building, feeling different from peers and family, animals as a coping mechanism for negative feelings, and animals as a source of companionship. Support and assistance for individuals in general, as well as those with autism, can improve the trajectory towards adulthood for autistic members of society.

Education

Over recent years, increases have been observed amongst autistic students joining further education following completion of their school years (Lowinger, 2019). Of these however, relatively few are those who successfully complete their post-secondary education (Siew et al., 2017). The experience of transitioning from secondary to post-secondary education on a university or college campus poses numerous challenges for those on the spectrum, and is often reported to be perceived as a time or stress and uncertainty (Gillan & Coughlan, 2010). The social environments of post-secondary educational contexts may pose barriers to optimal participation autistic youngsters individuals (Gurbuz et al., 2019; Kreiger et al., 2012; Robertson, 2010; Stankova & Trajkovski, 2010; Stuart-Hamilton et al., 2009; Beardon & Edmonds, 2007; Hillier et al., 2007), particularly in instances where these contexts do appeal to the individual's skills or interests, or when they are not sensitive to the person's sensory needs (Shogren & Plotner, 2012; Stankova & Trajkovski, 2010). Executive skills expected by post-secondary institutions can also pose challenges for autistic individuals, such as organisation, time-management, processing information and coping with the lack of structure and routine (Jackson et al., 2018; Kuder & Accardo, 2017). Support systems offered in post-secondary institutions are also found to rarely meet the distinctive needs of autistic people (Jackson et al., 2018; Gelbar et al., 2015; McKeon et al., 2013; Taylor & Seltzer, 2011; VanBergeijk et al., 2008).

Educators in post-secondary establishments can support the participation of autistic learners through strategies such as differentiated presentations that can reach a wider pool of students, assigning work based on student strengths, predictable class routines, reminders of upcoming tasks, and the use of visuals and concrete language, amongst others (Gobbo & Shmulsky, 2014; Gurbuz et al., 2019; Zeedyk et al., 2014). Career guidance provided through school years can inform, guide and empower students towards this transition. Especially when it comes to students with intellectual difficulties, adequate support and guidance is critical on the prospects of success and future employment (Winn & Hay, 2009; Azzopardi, 2006; Stodden & Whelley, 2004). Support programmes throughout post-secondary years can also further support successful integration and participation in the college or university experience. These of course, need to be person-centred, sensitive to the challenges and strengths of autistic persons, and also understanding of comorbidities that may accompany autism. Many autistic learners for instance, are reported to face difficulties with issues such as anxiety, depression, loneliness, and more (Anderson et al., 2018; Bennett et al., 2018; Gelbar et al., 2014). In addition to these, several post-secondary educations have come to offer disability services to students (Lowinger, 2019), although these at times tend to offer a homogenous service across disabled students, such as extra time on exams or alternative examinations sites (Kuder & Accardo, 2017), and may not always be catering for the distinctive requirements of autistic learners (Gillespie-Lynch et al., 2017; VanBergeijk et al., 2008). These shortcomings can be further exacerbated by the reluctance amongst autistic individuals not to disclose their disability when commencing post-secondary education as it could set them apart from their neurotypical peers (Gillespie-Lynch et al., 2017; Lei et al., 2018; White et al., 2011; MacLeod & Green, 2009). The use of secondary school peer support for autistic youngsters prior to post-secondary education has also been found to offer positive benefits within the arena of post-secondary experiences (Nicholas et al., 2017). Similarly, peer mentoring interventions along post-secondary years can also be a major source of support for autistic learners (Gunn et al., 2017; Roberts & Birmingham, 2017; Ames et al., 2016), offering individualised, flexible and focused social support (Siew et al., 2017). Literature also suggests that a combination of one-to-one and group-based mentorship can be fruitful to autistic learners (Gillespie-Lynch et al., 2017; Roberts & Birmingham, 2017; Kucharczyk et al., 2015), including a support group of other autistic peers (Hillier et al., 2018), and peer mentors (Barnhill, 2016; Freedman, 2010; MacLeod & Green 2009). Additionally, transition programmes, from early programmes during secondary years, and post-secondary programmes along later years, can further aid towards equipping students with additional tools to face this post-secondary journey (Bennett et al., 2018; Hotez et al., 2018; Lei et al., 2018; Chiang et al., 2012). According to Higgins (2009, as cited in National Disability Authority, 2017, pp. 23-24), good practice during transition needs to include:

- "Full involvement of young people with autism and their families in multiagency transition planning;
- Respect given to the preferences of young people with autism;
- Better information given to families as young people approach transition;
- Better communication between adults and children's services;
- Training in autism for transition staff;
- Attention to the needs of young people with autism who display challenging behaviour;

- Differentiation in assessments between support needs and education needs so that people are not put on academically limited courses due to their communication difficulties";
- Emotional and practical support (Lowinger, 2019);
- Sensitivity towards the distinctive challenges that the individual may face on campus (such as social relations, sensory challenges, and organisational difficulties) (Lowinger, 2019);
- Information about disability services;
- Support self-advocacy skills and identification of strengths (Lei et al., 2018);
- Foster life skills, such as decision-making, self-advocacy skills and considerations around disclosing one's disability (Frank, 2015; Carter et al., 2013).

Supporting autistic people throughout every aspect of post-secondary education, including areas such as learning, socialising, gaining independence and career development, can nurture inclusive educational cultures and environments that can promote the wellbeing of autistic individuals to realise their ambitions, participate fully and fulfil their potential (National Disability Authority, 2017). Good practices to support this include (National Disability Authority, 2017; Barnhill, 2016; Gelbar et al., 2015; SCIE, 2011; Emerson and Robertson, 2009; Emerson et al., 2008):

- Break clubs and youth groups where students can exchange views and extend social connections while demystifying stereotypes surround autism (and disability as a whole);
- Buddy and mentor systems;
- Social skills groups;
- Personalised educational pathways;
- Assigning a key contact person;
- Support with logistical arrangements, such as accessible timetables;
- Staff autism awareness training;
- Transition programmes, including for instance, taster sessions and campus visits;
- Use of technology aids;
- Quiet areas, even during freshers' week;
- The options of alternative teaching methods, such as online lectures, which are a positive development for autistic learners (Lowinger, 2019) or 'low arousal' classrooms;
- Regular meetings with a disability counsellor;
- Information provided in clear and literal language, including in exams; and,
- Access arrangements for coursework and examinations.

On these lines, post-secondary institutions, such as for instance Trinity College Dublin have worked on developing support models for autistic students through their Disability Services and Occupational Therapy Services, with the aim of supporting these students throughout their journey at the college from freshman years to graduation and employment (Trinity College Dublin, 2019). Meanwhile, through collaborations with autism advocacy groups and agencies, others such as Dublin City University have also been working towards creating an autism-friendly campus, that is, a learning environment that is founded on a whole-college inclusive atmosphere and that allows students on the spectrum to fully participate in university life, and subsequently gain employment through initiatives such as autism friendly internships (Dublin City University, 2016).

Employment

> *My mother decided that it was time for me to get a job. I was 15 years old. Soon, the box of fur coats began to full up, and the boss passed by, impressed with the speed of my work. He decided to check the quality. A horrified look grew upon his face, and he began to shout as he turned each garment around and around. "What have you done?", he screamed over and over. "Button-holes in the sleeves, button-holes in the collar, button-holes in the back panel. Get the hell out of here". "Can I have my money?", I asked shyly. "No!" he screamed. "Do you know what you've done? You've caused me thousands of dollars in damage. Get the hell out of here before I kick you out". I hadn't realised the button-holes were meant to go anywhere in particular.* (Excerpt from Donna William's 'Nobody Nowhere', 1991).

Employment can yield considerable positive outcomes on a person's quality of life, supporting stability and independence, maintaining active participation in society, as well as nurturing a sense of dignity and self-sufficiency (Boreham et al., 2016). During emerging adulthood (Arnett, 2006; 2000), it can enable greater autonomy and independence, not only at a financial level but also in terms of identity construction and successful integration into adult life (Vortman-Shoham & Kenny, 2019). Autistic adults however, are often found to encounter difficulties accessing the world of work and securing employment (Howlin & Moss, 2012; Hendricks, 2010; Hurlbutt & Chalmers, 2004). Notwithstanding reports highlighting the valuable contribution that autistic individuals can bring to the labour market, possessing the capabilities companies in fact need (e.g. Annabi et al., 2019) and, for instance, their typical strengths in positions involving systematic information processing, such as careers in computer science (Wei et al., 2013), or involving degrees of accuracy, precision and repetition (de Schipper et al., 2016; Baldwin et al., 2014; Walsh et al., 2014), figures from around the world, highlight the stark reality that autistic individuals are faced with. Employment figures amongst autistic people stand at 42% participation in Australia (Australian Bureau of Statistics, 2010; 2009), while 15% and 21% are employed in full-time positions in the United Kingdom (Mavranezouli et al., 2013; Rosenblatt, 2008), and the United States (Roux et al., 2015; Bureau of Labour Statistics, 2013) respectively. Researchers have often highlighted the value of diversity in the workplace (Wright & Ulrich, 2017; Srikanth et al., 2016), with some reporting that the inclusion of neurodiversity (Austin & Pisano, 2017; Jaarsma & Welin, 2012) can support management towards improved achievements. Moreover, in addition to the lower unemployment figures, reports show that many autistic adults work in positions that stand below their level of qualifications or skill level, in conditions such as reduced working hours and receiving lower average salaries when compared to their peers (Roux et al., 2015; Shattuck et al., 2012; Howlin et al., 2004). At the individual level, low levels of participation in the employment world amongst autistic adults, can negatively impact their socioeconomic status, mental health and overall wellbeing (Fleming et al., 2013; Wanberg, 2012; Gerhardt & Lainer, 2011), and at societal level effectively translate into lost productivity and increased dependency on public funding (Roux et al., 2013; Krieger et al., 2012; Hernandez & McDonald, 2010; Järbrink et al., 2007).

Work environments can prove to be challenging for autistic employees (Nord et al., 2016; Leonard et al., 2010; Müller et al., 2003), together with aspects of employment such as job processes and instructions, and, in particular, interacting with colleagues (Baldwin et al., 2014; Krieger et al., 2012; Müller et al., 2003). Nevertheless, researchers often report that the reduced participation rates amongst autistic individuals, typically stem from environmental factors involving employees' perceptions and attitudes (Ju et al., 2013; Hernandez & McDonald, 2010; Unger, 2002), together with generic job requirements such as teamwork and communication skills, that in truth, may not always be essential for performance in the role (Scott et al., 2015; Strickland et al., 2013; Richards, 2012; Fraser et al., 2011). Awareness amongst employers is also often identified as a critical contributor, highlighting the need for evidence-based strategies to enhance employers' understanding and related actions and supports (Nicholas et al., 2017), together with listening to the voices of autistic adults themselves, since a lack of best practices across diverse sectors often creates a scenario where recommendations for research and practice are often based on only the employers' side of employment in autism (Nicholas et al., 2017).

Replacing perceptions of low potential and capabilities and building instead on individual strengths (Clifton & Harter, 2003) through in person-job-environments (Lorenz & Heinitz, 2014), can provide opportunities for successful performance and participation in the world of work (Lorenz & Heinitz, 2014; Holwerda et al., 2012; Hendricks, 2010; Mawhood & Howlin, 1999). Services addressing employments prospects for autistic people can provide helpful support along this aspect of a person's life, for instance, supported employment programme can reduce barriers to towards this aim (NICE, 2021a; Mawhood & Howlin, 1999). Vocational job banks have also been found to support effective identification of possible job roles that may be suitable for autistic individuals (Nicholas et al., 2017). However, improvements in this area are still often necessary (Anderson et al., 2017; Alverson & Yamamoto, 2016; Nicholas et al., 2014; Lawer et al., 2009), in particular, when it comes to addressing the social aspect of employment and on-the-job training, with services often found to address individual needs with a homogenous approach (Chen et al., 2015; Nicholas et al., 2014; Richards, 2012; Müller et al., 2003). The importance of support being provided within a framework that is understanding of the strengths and capabilities that autistic people can bring along, while being tailored for individual needs therefore is once again brought to the forefront (Chen et al., 2015; Müller et al., 2003). Moreover, some individuals may require support to be sustained instead of only being offered throughout initial employment experiences (Brooke et al., 2018; Nicholas et al., 2017; Schall et al., 2015). The benefits of assistance technology can also be applied to employment support contexts (Nicholas et al., 2017). A variety of digital applications and devices, including tactile prompting, visual and audio guides, and app-aided instruction, amongst others, have been developed along the years to support different objectives for autistic individuals (e.g. Di Gennaro Reed et al., 2011; Hopkins et al., 2011; Goldsmith & LeBlanc, 2004; Parsons, 2006). Strickland et al. (2013) as well as Smith et al. (2014), for instance, developed an internet-based training programmes that combine virtual reality practice environments, aimed at supporting social skills related to employment, such as job interviews. Participants in both studies demonstrated improved interviewing skills. The use of assistive technology for on-the-job training through support such as video modelling and audio cuing are also yielding positive outcomes in the development of employability skills (Allen et al., 2012; 2010a; 2010b; Bennett et al., 2013a; 2013b; Kellems & Morningstar, 2012; Van Laarhovenet al., 2012).

Independence

An important aspect for building of identity is a sense of belonging to and participating in a community (Vortman-Shoham & Kenny, 2019; Terry et al., 2019). People on the spectrum tend to be less outgoing, and with their school years coming to a close, the period of emerging adulthood brings with it a drastic decline in social settings in which they can participate (Taylor et al., 2017; Myers et al., 2015; Orsmond et al., 2013). Understanding the particular challenges that accompany autistic youngsters during these years is therefore essential in guiding support services that can ease this transition (Wehman et al., 2014). The development of social skills for instance, is a primary aspect of successful integration into community life (Carter et al., 2013) and can impact several areas of adult life. However, despite several efforts to provide transition and support programmes, low employment figures and rates of social isolation indicate that improvements in these services at this critical age still need to be developed further (Wehman et al., 2014; Friedman et al., 2013; Orsmond et al., 2013). In order for autistic youngsters to access age-appropriate experiences and develop their personal potential, the options available to their neurotypical peers, should be made available to them too. However, these opportunities, are often found not to meet the distinctive needs to autistic youngsters (Anderson et al., 2018). Additionally, research often indicates barriers towards the development of critical skills due to low personal autonomy and a high involvement of family in their decision-making (Wehman et al., 2014), which in itself, also needs to be addressed within support and transition services provided to these youths (Anderson et al., 2018; Sosnowy et al., 2017). The critical role that identity-building plays during the years of emerging adulthood means that services need to ensure integration into society and the community, while in parallel, also developing links with the local community of other autistic people. This can empower these youngsters, providing role models and key figures, while building pride, resilience and strengthening self-image (Vortman-Shoham & Kenny, 2019).

Amongst activities enjoyed by adolescents, spending time with peers is often considered to be a predominant activity (O'Hagan & Hebron, 2017; Bauminger & Shulman, 2003), however research often points towards a need for more accessible places that can provide opportunities for socialising and communication (e.g. Vassallo et al., 2022). These include outdoor activities such as shopping and eating out, studying with peers, or general opportunities to socialise and mingle. Bauminger and Shulman (2003) add to this observing that the friendships of autistic adolescents differed in number, duration and frequency of meetings when compared to those of neurotypical youths. They reported that autistic youngsters favoured structured activities. When compared to children, research points to the fact that disproportionately little research and relatively few social programs exist for autistic adults (Nicholas et al., 2017). Vassallo et al. (2022) also highlighted the need for more opportunities to socialise, such as library cafés and improved accessible promotion of events and spaces. In their work with 235 autistic adolescents and adults, Orsmond et al. (2013) observed that the larger part of recreational activities that participants enjoyed were typically solitarily in nature, such as walking or exercising. Participants also expressed preference for activities that were planned in advance and included professional or parental facilitation. Rodden (2021) also reported that amongst autistic adults and young adults, preferences tend to include in individual games and sports, such as golf, instead of team activities toward a common goal.

In today's world, the use of screen-based media in establishing and maintaining friendships is understandably gaining interest amongst scientists (e.g. Gray, 2018; Antheunis et al., 2016), and no less when it comes to autistic youths (e.g. Calder et al., 2013; Kuo et al., 2014; 2013; Shattuck et al., 2011). Online channels of communication, such as through social networking sites such as Facebook, WhatsApp and more recently TikTok, amongst others, brought about a new, preferred way of communicating with friends (Gray, 2018). This of course, goes hand in hand with widespread use of devices such as mobile phones, which are considered to be the primary device used by teens for online activity (Lenhart et al., 2015). Although some studies have highlighted the negative impact of this, linking it to depression or cyberbullying (e.g. Hamm et al., 2015), others have pointed out its link to the creation of social connections (e.g. Valkenburg & Peter 2007), claiming it can bring educational and psychological benefits (Greenhow, 2011; Steinfield et al., 2008), including the enhancement of self-esteem and peer relationships (Valkenburg & Peter, 2011). With digital media often found in literature to be amongst the preferred activities of many autistic individuals (e.g. Stiller & Mößle, 2018; MacMullin et al., 2016; Kuo et al., 2013; Nagar et al., 2013; Ploog et al., 2013; Mazurek, et al., 2012; Porayska-Pomsta et al., 2012; Chonchaiya et al., 2011; Orsmond & Kuo, 2011; Mineo et al., 2009; Shane & Albert, 2008), a range of technology-based applications and devices focused on promoting learning, communication, and supporting overall development of independence skills among autistic individuals have emerged over recent years (Shane et al., 2012). For instance, a number of handheld devices such as smartphones and tablets, are being developed to support independence for autistic adolescents through visual aids, behaviour-related prompts and transition steps (Hume et al., 2014; Mechling, Gast & Seid, 2009). Technology-based aids have in fact been found to be able provide support for autistic adolescents in a range of areas and contexts, including learning, staying organised, reducing stress, as well as promoting opportunities for social interaction (Hedges et al., 2017). These

technologies can in fact support autistic youngsters navigate the social and relational difficulties they often face (Bernardini et al., 2014; Gillespie-Lynch et al., 2014; Benford & Standen, 2009), although research in the latter area is limited, with data questioning whether young autistic people may be engaging more in non-social online activities, such as video games, more often than neurotypical others (Mazurek & Wenstrup, 2013; Mazurek et al., 2012; Durkin et al., 2010). The latter has also raised some concerns amongst researchers about the possible excessive use of video games by autistic youngsters, linking it the tendency amongst some autistic individuals to seek restricted and repetitive behaviours (Sundberg, 2018; APA, 2013; Mazurek & Wenstrup, 2013). Nevertheless, virtual environments can offer a unique platform where youngsters, including autistic ones, can interact socially without the stressors of face-to-face interactions (Casey & Evans, 2011; Parsons & Cobb, 2011), with the possibility of networks of online friends (Gallup et al., 2016) and of skills learnt then being generalised to other contexts (Stone et al., 2019; Gallup & Serriani, 2017).

When it comes to having access to a mobile phone, Durkin et al. (2010) found that fewer autistic adolescents (60%) made use of a mobile phone when compared to their neurotypical peers (94%). The use of digital media for social purposes (such as email, social media platforms, SMSs, etc.) by autistic adolescents has also been found to be reduced when compared to neurotypical adolescents (Mazurek & Wenstrup, 2013), with literature suggesting that autistic individuals tend to be significantly older when they start using technology for social activities (MacMullin et al., 2016). In addition to the potential social advantages of online gaming for autistic youth, researchers such as van Schalkwyk et al. (2017) posited that social media platforms can provide a space for social engagement for autistic youngsters, reporting that they could be even positively related to the quality of friendships created. These findings once again highlight the potential benefits in the social realm for autistic adolescents through effective use of digital channels.

Non-formal learning activities and leisure activities such as art, yoga, sailing, activities with animals (pet support, equine activities) can support the development of social skills amongst teenagers, including autistic teenagers. Additionally, the inclusion of autistic teenagers in non-formal learning is even more important as this group is often excluded, and their families often feel marginalised. Although still limited, research is also showing that animals, particularly pet dogs, are providing to be a helpful aid for the overall wellbeing of autistic individuals, showing improvements in combating negative emotions such as stress, anxiety, and depression (Carlisle, 2015; O'Haire, 2013; Smyth & Slevin, 2010; Wells, 2009). Through extensive discussions with 11 autistic 18-23 year olds, Cheak-Zamora et al. (2018) in fact found that most youths used animals as a source of comfort, support, and socialization. Unfortunately, not a lot is known about how interactions with animals can impact facets of autism, such as social interactions in children or youths, with research in this area still requiring further development (Cheak-Zamora et al., 2018).

Relationships and Sexuality

Autism can be a hidden disability since it may not always be immediately clear that a person is on the autism spectrum (CRPD, 2021). Autistic adolescents often experience difficulties in creating and maintaining friendships and social relationships (Sedgewick et al., 2016), although females appeared to have better social skills and were more socially motivated, while males were less concerned with friendships (Head et al., 2014). In adulthood, difficulties may present themselves in varying contexts and to varying degrees, thereby potentially impacting the daily livelihood of autistic individuals, including in contexts such as employment or with friends. For instance, autistic people are often perceived as lacking warmth (Kuriki et al., 2016) and not being able to empathise (McDonald & Messinger, 2012) leading to difficulties with friendships (Jamil et al., 2017) and overall wellbeing (Mehling & Tassé, 2015). Actions considered to be standard in the case of neurotypical people, such as maintaining eye contact, interpreting other people's emotions or their non-verbal communication and social cues, can bring harder to manage for a person on the spectrum. This in turn can lead to regular challenges such as keeping up with a conversation or using inflections that do not reflect feelings, accompanied by a tendency to engage in routine behaviours and possible struggles when changes arise (Rodden, 2021). In the case of females, these may be able to mimic social standards better than some autistic men (Matheis et al., 2019; Ormond et al., 2018; Ratto et al., 2018; Beggiato et al., 2017; Dean et al., 2017; Fulton et al., 2017; Wing, 1981a), possibly displaying a larger range of emotion in her facial expression and tone of voice and "superficially demonstrating better social and emotional skills than males with autism" (Head et al., 2014; pp. 1), although this can be exhausting and stressful (Regan, 2019). Autistic women can also present with an eating disorder, with research indicating that at around 23% of females with eating disorders are on the autism spectrum (Wentz et al., 2005). Some studies have also reported an increased risked of being taken advantage of in relationships for autistic women, which a particular study reporting an increased incidence (9 of 14 participants) of sexual abuse with half of these occurring while in a relationship (Bargiela et al., 2016).

Friendships and social connections play a significant role in a person's life, contributing to happiness and general wellbeing, amongst others (Rowley et al., 2012; Zhou et al., 2012; Myers, 2000). During teenage years they are especially important (Helseth & Misvær, 2010), however the difficulties autistic youth may have with establishing and sustaining friendships may place them at risk of social isolation (APA, 2013; Bauminger, 2002). Bodies of research report high levels of isolation and solitude amongst adolescents and adults with autism, due to their poor-quality connections with others (Mehling & Tassé, 2015; Potter, 2015; Rossetti, 2015; Mazurek, 2014; Müller et al., 2008). This in turn, can contribute to high rates of depression (Lieb & Bohnert, 2017; Mazurek, 2014; Potter, 2014) and anxiety (Mazurek, 2014). Research in fact suggests that autistic people tend to have poor friendships irrespective of their age or ability (Locke et al., 2010) and face additional challenges, both socially and emotionally, not typically experienced by neurotypical counterparts when it comes to social connections (Moss et al., 2017; Mazurek, 2014; Koning & Magill-Evans, 2001). Several assert that autistic people are not able to develop successful connections with others due to their innate preference towards being alone and social and emotional functioning that hinders their ability to initiate and maintain successful friendships (Petrina et al., 2016; Deisinger, 2015; Bauminger & Kasari, 2000). The friendships of autistic individuals are in fact often reported to differ from those of neurotypical persons both in quality and quantity (Lieb & Bohner, 2017; Bauminger et al., 2010). Others researchers however (e.g. VineFoggo & Webster, 2017; Potter, 2015; Humphrey & Lewis, 2008; Carrington & Graham, 2001) revealed that autistic individuals do share a desire to fit in, and a developed understanding of the characteristics of friendships as well as best friend relationships. Nevertheless, autistic adolescents are often reported to feel excluded and to overall establish fewer friendships when compared to neurotypical ones (Calder et al., 2013; Rotheram-Fuller et al., 2010; Bauminger & Kasari, 2000). Bullying is also often reported (e.g. Rowley et al., 2012; Humphrey & Symes, 2010). In their work with autistic girls aged 13-17, VineFoggo and Webster (2017), dispelled stereotypes that individuals on the spectrum cannot develop high quality and meaningful friendships, observing instead that they do engage in quality relationships, while still requiring time to de-stress and pursue their own interests. Similar observations were also shared by other researchers (e.g. O'Hagan & Hebron, 2017; Bauminger et al., 2008a; Bauminger et al., 2008b; Rossetti, 2015; Daniel & Billingsley, 2010), strengthening the importance of understanding the individual experiences when it comes to the formation of relationships for autistic youths. Similar findings were also reported by Micallef (2019) in her work with 5 autistic adolescents aged 19-39 in Malta. Together with other researchers (e.g. Chen et al, 2016; Mazurek, 2014), Micallef (2019) in fact posited that societal perceptions and expectations, and past negative experiences may in fact be influencing autistic individual's self-perceptions and esteem and in doing so, impacting their fluency with social connections, rather than an innate inability to maintain friendships.

Developing intimate relationships and sexual maturity are major themes faced by individuals during the years of transition from adolescence into adulthood and along their adult years. In the case of people with intellectual disabilities however, sexuality is often faced with social barriers surrounding stereotypes and misconceptions, leaving people with intellectual disability hindered when it comes to exploring and developing their sexuality (Azzopardi Lane & Callus, 2014; Fitzgerald & Withers 2013). Factors such as reduced involvement in employment and further education may impact this facet of an autistic person's trajectory since these provide opportunities to expand social networks (Hancock et al., 2019; Shattuck et al., 2012; Stokes et al., 2007). Moreover, the perceptions of caregivers, service providers and the general public towards the sexual development of people with intellectual disabilities in fact tends to be rooted in prejudice and anxieties, leading to negative and prohibiting approaches (Bernert & Ogletree, 2013; Evans et al., 2009; Garbutt, 2008). In fact, although in society, women are typically faced with expectations to bear children, disabled women are often excluded from fulfilling traditionally female roles such as that of motherhood, with termination or the alternative of renouncing the child being brought up (Gould & Dodd 2014; Edmonds 2000). Moreover, mothers more than fathers, in particular those with intellectual disability, often face criticism about their parenting abilities (Blum, 2007; McConnell & Llewellyn, 2002; Read, 2000). Nevertheless, research often reports that individuals with autism express a clear desire for affective, romantic, and sexual relationships (e.g. Strunz et al., 2017; Dewinter et al., 2015; Byers et al., 2013a; Hellemans et al., 2007), observing that autistic people share similar levels of interest in developing relationships as their neurotypical counterparts, however they are more limited in opportunities to meet potential partners (Hancock et al., 2019) and often encounter difficulties exploring the experience of being in a relationship (Byers et al., 2013b).

Reported to experience overall greater initial dating anxiety than neurotypical peers (Hancock et al., 2019), even when involved in romantic relationships, autistic people tend to encounter difficulties such as communicating emotions, differences in sensory experiences, the interpretation of the partner's actions (Mendes, 2015; Attwood, 2006; McIlwee Myers, 2006), as well as overall anxiety about relationships (Roth & Gillis, 2015). Research in fact highlights higher levels of social anxiety and concern surrounding the ability to establish and maintain future relationships among autistic people (Hancock et al., 2019; Roth & Gillis, 2015; Mehzabin and Stokes, 2011; Kuusikko et al., 2008). In their work with a group of 460 international young adults, of which 233 were living with autism, Hancock et al. (2019) found that interactions with peers play a role in improving relationship outcomes, more so than general social functioning. Relationship difficulties were in fact reported to be partially mediated by peer social engagement. Interestingly however, it was observed that autistic people typically learn less about romantic relationships from peers when compared to their counterparts (Hancock et al., 2019; Stokes et al., 2007). Factors such as having fewer peers, being perceived as asexual thereby having peers not discuss romantic relationships with them, or having fewer social engagements, which are opportunities to practice interacting with others, can also play a role in the anxieties and abilities surrounding establishing and sustaining a relationship (Hancock et al., 2019). These findings highlight the value that engagement with peers can provide for informal learning and increasing confidence in interacting with other, including when it comes to sexual and romantic functioning from as a composite of relationship functioning.

Disabled people have sexual desires as much as any other person (Gil-Llario et al., 2018; Borawska-Charko et al., 2016). This is also the case for autistic people (Byers et al., 2013b; Dewinter et al., 2015; Gilmour et al., 2011). Often however, the progress of their sexual life is reported to be intertwined with unfounded stereotypes and social misconceptions that can hinder their development in this realm. Considered by many as being incapable to make their own decisions when it comes to sexuality (Murphy & Young, 2005; Swango-Wilson, 2009), the sexual expression of disabled persons is often found to be hindered, encountering several barriers in its expression (Franco et al., 2012; Olavarrieta et al., 2013). In particular, this is often the case for those whose sexual lives are dictated by caregivers or the support system surrounding them (Wilson & Frawley, 2016; Azzopardi-Lane, 2017), with literature noting that caregivers might underestimate the development of their offspring's sexuality (Dewinter et al., 2016).

Researchers have pointed out that adults with intellectual disabilities for instance, are often less knowledgeable when it comes to sexuality (Mehzabin & Stokes, 2011; Isler et al., 2009; Siebelink et al., 2006), are surrounded by with negative attitudes towards it (Bernert & Ogletree, 2013) and are also prone to increased incidences of sexual abuse (Schaafsma et al., 2013; Brown-Lavoie et al., 2014; Liou 2014). In parallel however, some researchers also report that autistic males are found to seek sexual acts as frequently as their neurotypical counterparts (Dewinter et al. 2015; Gilmour et al., 2011), even though studies with young autistic adults report that most sexual education is more often from television and online than social or formal paths (Brown-Lavoie et al., 2014). Education in sexuality provides a platform for emerging adults, including those with disabilities, to develop and establish their sexual identify and relationships while also providing knowledge on sexual health needs and ways to protect themselves (Isler et al., 2009). However, while there is an understanding on the modus operandi when it comes to sexual education amongst neurotypical individuals, research related to sexual education for neurodiverse people is still at early stages, finding itself on the researchers' map over the last 2 decades years (Conahan et al., 1993; Guldin, 2000; Drummond & Brotman, 2014), and typically focusing on protection (Yau et al., 2009), personal space and hygiene (Ballan 2012; Holmes & Himle, 2014). The heterogenous nature of autism and ADHD could mean that alternative routes for providing adequate sexual education for neurodiverse persons might be necessary (Hannah & Stagg, 2016; Sullivan & Caterino, 2008). Moreover, service providers are also often found to lack proper knowledge and training in relation to support the sexual development of persons with disability (Lafferty et al., 2012), with researchers highlighting for the need for service providers to have clear policies in place addressing sexual education and supported parenthood (Azzopardi-Lane, 2021; Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014).

Of particular concern is the fact that research indicates that autistic people may be more inclined to take part in unsafe or inappropriate sexual behaviour when compared to their neurotypical counterparts, pointing at interactions with the sex industry and higher rates of sexual victimisation (Eastgate et at. 2012; Stokes & Kaur, 2005; Nixon et al., 2017; Hartmann et al., 2019). These findings make the need for a thorough understanding of sexual knowledge, experiences, challenges and aspirations of autistic people and their caregivers ever more necessary. In addition to this, with research looking into the sexual development of disabled persons being so limited, an even bigger lacuna exists when it comes to sexual and gender diversity for persons with disabilities. (Puar, 2015; Eckstrand et al., 2016; Wilson et al., 2018; Dinwoodie et al., 2020). With researchers pointing out, for instance, that autistic people are "7.59 times more likely to express gender variance" (Strang et al., 2014, pp. 1525), and that compared to around 8% of neurotypical people (Twenge et al., 2016), approximately 42–69% of autistic people identify as LGBTIQ+ (Byers et al., 2012; George & Stokes, 2018), the need to further explore the intersection of gender identity, sexuality, and disability becomes even more critical (Cain & Velasco, 2021).

Ageing

Research addressing late adulthood and aging in autism is very recent and remarkably limited especially when compared to childhood and even adolescence (Roestorf et al., 2019; Wright et al., 2019; Wallace et al., 2016; Happé & Charlton, 2011). Nonetheless, a rapidly growing elderly population, with the earlier cohorts of children first diagnosed with autism now well in middle aged or older (D'Astous et al., 2016), combined with advanced in adulthood diagnoses of autism, are in time, giving rise to a new social and financial scenario in society in the autism realm (Happé & Charlton, 2011; Piven et al., 2011). The ageing population is typically found to be particularly vulnerable to both social isolation and loneliness. This as a result of a combination of factors, such as loss of loved ones, decreased physical dexterity or reduced income. These factors can significantly wellbeing in late adulthood, and are often linked with issues such as depression (Liu et al., 2014; Isaac et al., 2009), disability (Lund et al., 2010), increased mortality risk (Shiovitz-Ezra, 2010), and difficulties in cognition (Shankar et al., 2013; Tun et al., 2013). Surveys carried out in the UK reported that amongst autistic adults aged over 65 and who live independently, family was the main source of support for almost half the group while and only 8% had received their support from professionals (Rosenblatt, 2008). More recently, a similar survey also reported that among autistic adults aged over 55, almost three quarters of participants only had 3 or fewer friends, while 65% reported family members / caregivers were their main friends (Bancroft et al., 2012). These findings highlight the increasing risks of isolation, loneliness and depression amongst the ageing group (Happé & Charlton, 2011). With social difficulties and fewer, shorter friendships often linked to autism in adolescence (e.g. Wainer et al., 2013), increased levels of loneliness and social isolation come as no surprise among the autistic population (Jobe & White, 2007). Whether these persist into adult is still unclear. Autistic adults are also often reported to be more like to develop comorbid mental health issues such as depression and anxiety (Croen et al., 2015; Ingersoll et al., 2011), while are likely to continue into old age (Wallace et al., 2016), although research in this area is still limited. The need for further research and understanding, followed by support and services that catering for autistic people as they age is becoming ever more apparent (Wallace et al., 2016; Happé & Charlton, 2011; Wick & Zanni, 2009).

2.2 Attention Deficit Hyperactivity Disorder (ADHD)

What is ADHD?

ADHD is one of the most common childhood developmental conditions (Polanczyk and Rohde, 2007). The majority of children who live with ADHD tend to have a close relative that is also affected by the condition (Wheeler, 2010). ADHD is normally diagnosed in childhood, and children who are living with the condition often have various symptoms, such as inattention, impulsivity and hyperactivity (NCBDDD, 2019). Following an analysis and review of over 170 studies, Thomas et. al (2015) concluded that ADHD affects around 7.2% of children worldwide, while Thapar and Cooper (2016) also added that boys are three times more likely to be diagnosed with ADHD. Although ADHD is one of the most common reasons why a child is referred to mental health services, as a condition it is still under-recognised in both children and adults (Camilleri & Makhoul, 2013).

A child that is living with ADHD is often easily distracted, disorganised and has difficulty to maintain focus. These symptoms are not related to a lack of understanding or disobedience, but are directly connected to their diagnosis (NIMH, 2019). ADHD also frequently occurs with comorbidities, such as learning, sensory or behavioural disorders, anxiety, depression, and even autism spectrum disorder (Akmatov et al., 2019; Reale et al., 2017). With ADHD the cardinal indicators are: excessive risk-taking, high rate of activity, anti-social behaviour and under-developed adaptive behaviour that is commonly associated with inattention (Carr. A, 2016). The symptoms that are prevalent in children with ADHD can have a negative effect on their behaviour at home and at school, and around 80% of children with ADHD may continue to live with some of these symptoms well into their adolescence and adulthood (Sushevska et al., 2011).

Diagnosis

According to the DSM-5 (APA 2013) criteria, in order to make a diagnosis for ADHD, there must be "*persistent impaired behaviour for a minimum of 6 months that exceeds what is expected for an individual's developmental level and is characterized by at least 6 of 9 inattentive and/ or 6 of 9 hyperactive-impulsive symptoms*". (McGough, 2014, p. 28). If the person is 17 years of age or older, 5 out of 9 symptoms are enough for a diagnosis. McGough goes on to say that symptoms must be apparent before 12 years of age, and they must occur in different settings. It is also vital that the symptoms are not caused by another condition and that they cause a meaningful impairment in the person's everyday life.

In assessing whether a child has ADHD, it is imperative to obtain a reliable account of their behaviour, both at school and at home. A psychometric assessment of the child's intelligence, language and attainments is also important, due to the fact that many children with ADHD also have co-morbid neurodevelopmental disorders and learning difficulties (Carr, 2016). While ADHD is more commonly and easily diagnosed in childhood, it continues into adulthood. Children do not outgrow ADHD, but the diagnostic criteria may lessen in adulthood. This reduction in criteria is an important aspect of diagnosis in adults, as with the most common symptoms like hyperactivity and impulsivity becoming less prominent, making a diagnosis may become more difficult. (Camilleri & Makhoul, 2013).

Society needs to work on the social stigma which is still attached to the ADHD condition. Persons having ADHD are still at high risk of being stigmatised and discriminated against due to the public's concept about what ADHD entails. ADHD behaviour is often generally viewed as immature or socially inappropriate, with the result that the affected individual is considered as unable to fit in within society (Mueller et al, 2012). This stigma can become a risk factor which might affect adherence to treatment, aggravation of symptoms and mental well-being of persons having ADHD (Mueller et al., 2012). People need to understand that children with ADHD and their families have very real challenges and that the behaviour of these children is not down to bad parenting (Alexa, 2017). Misconceptions about the condition and its treatment by authorities and the general public only makes life harder for persons living with ADHD and their families (Muller et al., 2012).

How does it affect the life course?

Mueller et al. (2012) discuss how society still lacks knowledge about ADHD, and how people who have the condition can be perceived as a threat, invoking the fear of the unknown (Mueller et al, 2012). As a condition, ADHD affects the daily life of those living with it, as well as their families and peers. ADHD can impact a person's behaviour, their academic performance and their relationships (Sushevska et al., 2011). It is also a trigger for parenting stress in those parents whose children live with the condition. The degree of intensity of the symptoms in the children also reflects the level of parenting stress, which in turn can decrease the quality of life for the family (Miranda et al., 2015). Additionally, given the hereditary nature of ADHD, it is possible that families may be dealing with the condition in more than one person. Studies have shown that children of parents living with ADHD have a prevalence of 57% and direct relatives of a child with ADHD can be 4-5 times more likely to have ADHD (Sushevska et al. 2011).

Treatment

> *"In the treatment of ADHD, physicians focus on a reduction of core symptoms to acceptable levels for adequate behavioural, social, and academic performance. Initial treatment of ADHD is thus not a simple process of prescribing medication and titrating to a specific level or delivering a fixed number of psychosocial interventions"* (Hwang, 2021, p. 16).

ADHD is normally treated with medication, but it may also be accompanied by psychosocial interventions, including training for organisational skills and behavioural interventions (Wolraich et al., 2019). Psychosocial interventions may also consist of education sessions for parents and teachers, behavioural programmes for the classroom, and periodic relief with specially trained people (Carr, 2016). This combination of treatment has produced optimal results in the treatment of ADHD (The MTA Cooperative Group, 1999) and produces the most improvement in children (Morris & Thompson, 2016).

Generally, people with ADHD are treated in the community and supported by their primary care givers (Bussing et al., 1998; Rappley, 1995). Most physicians focus their treatment of ADHD on the reduction of the main symptoms. This enables the person to have adequate performance in different areas of their life, including socially and academically (Hwang, 2021). The medication provided to people with ADHD helps to control their impulsivity and hyperactivity, while also improving their concentration and helping them control their behaviour (Morris & Thompson, 2016).

Although approximately 80% of children living with ADHD receive medication to help control their symptoms, misperceptions and prejudice with regard to ADHD medication are still an issue. These prejudices can lead to the children being non-compliant with their drug treatment and unwilling to disclose their use of medication (Toplak et al., 2008). The APA 2001 Convention dedicated several sessions to the controversial subject of ADHD medication in children. It was contended that professionals tend to over-diagnose and overmedicate children with ADHD. On the other hand, ADHD medications can be a child's best chance at a normal everyday life. The majority of the discussions agreed that the best route for the children is for them to have measured combination treatments (O'Connor, 2001).

To date, there is still a negative stigma about the treatment of ADHD, with society still looking upon parents as if they were not disciplining their child, while at the same time stigmatising the child who is not behaving in conformity with the norm. Despite the fact that studies on the effects of stigma and prejudice against people living with a mental disorder are on the increase, it seems that these effects are highly under-investigated in the area of ADHD. This is unexpected, given that having ADHD makes a person more prone to eliciting negative stigma from the public. In the few studies that were held to see how the public reacted towards individuals with ADHD, participants discredited their counterparts' behaviour and quoted their symptoms as being childish and socially inappropriate (Mueller et al., 2012).

In their article, Camilleri & Makhoul (2013) expressed the belief that ADHD must be managed by a specialist, who should advise the child and the parents; as well as inform all relevant stakeholders, including the school and the family doctor about the condition. The article shows clear preference for parent training when it comes to pre-school children; the authors believe that medication should only be introduced when parent training has not produced the desired results. Medication can also be supported by behavioural therapy, and studies have shown that through this treatment, children or youth with ADHD might show a keener interest in their parents' advice when it comes to friendships and how to improve their behaviour around their peers (Mikami, 2010). The Malta Medical Journal concurs with these studies and goes on to say that:

> *"When using CBT and/or social skills training for the child or young person in conjunction with a parent training/education programme, particular emphasis should be given to targeting a range of areas, including social skills with peers, problem solving, self-control, listening skills and dealing with and expressing feelings. Active learning strategies should be used, and rewards given for achieving key elements of learning. For older adolescents with ADHD, individual psychological interventions (such as CBT or social skills training) are advised as they are more effective and acceptable than group parent training/education programmes or group CBT and/or social skills training"* (Camilleri & Makhoul, 2013).

Overall, treatment of ADHD should be multi-modal and should include "psychoeducation; medication; family intervention to promote rule-following at home; school intervention focusing on the management of school-based learning difficulties and conduct problems; child-focused social skills training; and dietary assessment and intervention" (Carr, 2016, p. 386).

Treatment of ADHD in adults can be somewhat different in its implementation. While children are brought in for treatment by their parents, adults usually choose or agree to go for treatment themselves. Adults usually seek treatment for problems that affect their daily lives and are also the ones reporting on the progress made with the medication. Behavioural treatment can be more complicated in the treatment of adults, since using rewards and consequences may not work as well for adults. Overall, it is important to note that many adults with ADHD are caring for others, instead of being cared for, as is the case with children. They may seek treatment in order to increase their well-being and to reduce the impact that their difficulties may have on their partners and children. (Weiss et al., 2004).

ADHD in Childhood

Education

Young children with ADHD experience various difficulties in their educational life, among which are low grades, poor performance, challenging behaviour, a lack of interpersonal skills, impaired reading skills, language and mathematical difficulties, and aggression at school. All of these difficulties may produce a negative impact on the child's educational achievements over a period of time (Stalkova et al, 2013; Rogers et al, 2015; Ercan et al., 2014; Simms et al., 2013). As Carr (2016) states:

> *Attentional difficulties may lead to poor attainment in school. Impulsivity and aggression may lead to difficulties making and maintaining appropriate peer relationships and developing a supportive peer group. Inattention, impulsivity and over-activity make it difficult for youngsters with these attributes to conform to parental expectations, and so children with ADHD often become embroiled in chronic conflictual relationships with their parents" (Carr, 2016, p. 366).*

The symptoms and deficits resulting from ADHD that young children may suffer from impact their daily lives. Several studies report that children with ADHD face challenges in participating in school activities, difficulties in paying attention in class and the possibility of inappropriate behavioural and learning responses (Shimizu et al, 2014; Cosbey et al, 2010; Ghanizadeh, 2011; Kofler et al., 2011). These symptoms can also give rise to many academic and educational challenges, which in some cases can also lead to expulsion from school due to behavioural problems (Daley & Birchwood, 2010). Children with ADHD also tend to create classroom management problems for their teachers and they often require a diversion from routine teaching methods (Carr. A, 2016). Additionally, children displaying symptoms of inattention and disorganisation become predisposed to academic problems and neglect from their peers, while those displaying hyperactivity and impulsivity could have a greater tendency to be aggressive and be rejected by their peers (Matthews et al., 2014).

Relationships

In the course of their daily lives, children with ADHD symptoms often experience relationship difficulties at school and at home, with their parents, teachers and peers. Their impulsivity makes it difficult for them to wait their turn during games and other activities, which can make them poor playmates and lead to conflictual relationships with their peers (Carr. A, 2016). The way these children behave can make them more prone to be rejected by their peers (Hoza et al, 2005; Pelham and Bender, 1982); a rejection that can occur within hours of meeting new classmates (Erhardt and Hinshaw, 1994; Hodgens et al. 2000).

Children living with ADHD can also suffer from poor communication skills, which in turn affects their social functioning with family members and friends. Their limitations (especially if partnered with other disorders), may keep them from developing positive interactions and may result in stressful relationships and a lack of friendships (Da Fonseca et al., 2009; Marton et al., 2015; Mikami, 2010).

ADHD in Adolescence and Adulthood

While ADHD is most commonly diagnosed in childhood, it might also continue into the adolescent years and adulthood (NCBDD, 2019). In about two thirds of children with ADHD, the main symptoms persist into adolescence, and for some, may even stay with them well into adulthood. Adolescents that are impulsive may be more prone to excessive risk-taking, which may have a number of consequences, including drug-taking, injuries and dropping out of school. These risks also carry long-term effects which can later affect relationships, employment and health.

Adults are more likely to be hindered by poor concentration and a consequent low self-esteem. They tend to prefer exciting and risky jobs and they also have a tendency to have frequent job changes. On a personal level, adults with ADHD often have difficulty with organisational skills, poor planning and may also suffer from unstable relationships (Camilleri & Makhoul, 2013). A third of persons with ADHD "develop significant anti-social behavioural problems in adolescence, including conduct disorder and substance misuse" and for many of them, these problems will persist into adulthood, potentially leading to criminality (Carr. A, 2016, p. 366).

Education

Various studies have focused on students with ADHD and the restricted environment with which they are faced in classrooms or lecture halls. Gwernan-Jones et al. (2016) underscore that this type of environment may trigger and even worsen the student's symptoms, with the added consequence of damage to their self-esteem, their academic achievements and the relationships with their peers. The tendency of students with ADHD to be inattentive and impulsive may be conceived as rudeness, self-centredness or irresponsibility by other students. This may lead to social isolation and may have an impact on the ADHD student's ability to learn and interact (CHADD, 2019).

Adolescents with ADHD face a number of challenges and barriers in the educational field. Time management, planning their work, task completion, difficulty in focusing and sustaining attention, inhibitions, procrastination and cognitive flexibility are among some of the obstacles they may face (Barkley & Murphy, 2011; Weyandt & DuPaul, 2008). Yet, minor adjustments which may be easily provided by the educational institution, such as extra time and being given short breaks, may be of great benefit to these students and may help make up for their cognitive deficits (Barkley, 2016).

An increased support system in the educational establishment may help students who are already struggling with their grades. At University level, the struggle continues to increase, due to greater expectations and the fact that students no longer have the support structure they might have grown used to (Canu et al., 2020). A study conducted by Parker et al. (2013) concluded that students with ADHD who received support from their lecturers were shown to have improved in their study skills, self-discipline and ability to formulate and achieve long-term goals. This support also helped the students to be in better control of their behaviour and emotions.

Employment

The reality is that ADHD is still perceived as a childhood condition, with preconceived ideas of how children with ADHD behave. This can result in a disregard of adults with ADHD, and the way ADHD affects people's relationships and employment (Adamou et al., 2013).

A survey undertaken by the World Health Organisation in 2008 concluded that 3.5% of persons in employment are affected by ADHD. On average, these employees had around 8.4 extra sick days per year, combined with reduced work quality. The study reports that while a proportion of these workers were being treated for comorbidities, only a small minority received treatment for ADHD, in spite of the evidence that such treatment would improve their level of functioning. This low treatment rate could be related to the availability of cost-effective therapies and would provide for an interesting study on workplace screening and treatment programs (de Graaf R., 2008).

This neglect of the condition in adulthood may have contributed to the employment sector overlooking the barriers and occupational difficulties that are faced by people with ADHD (Adamou et al., 2013). While it has been said that adequate and stimulant treatment of ADHD in childhood created the strongest pathway to employment in adulthood; adjustments to accommodate the particular needs of people with ADHD without restricting them purely to "clock time" instead of specific outcomes, would provide this cohort with a better outcome in the employment arena (Halmoy, 2009).

However, research acknowledges that persons with ADHD can also turn the condition into a benefit. Recent studies have given particular importance to some ADHD symptoms which can be a positive attribute in the workplace, such as creativity, resilience, vision and innovative ideas. Persons with ADHD can also be good candidates for self-employment, as this will allow them to focus on their creative side and make good use of their positive attributes. Prominent people such as the founders of IKEA and the Virgin Group have publicly declared that their ADHD symptoms were the driving force behind their decision to start their own business (Verheul et al., 2016).

While individuals with ADHD have plenty of disadvantages in the workplace, they can also be hyper-focused in those areas which incentivise them. An employer who is aware of this potential can easily harness this workaholic trait as a positive aspect of that particular employee and maximise it, while maintaining the right balance to avoid a possible burnout (Adamou et al., 2013).

Relationships

Teenagers with ADHD often struggle when it comes to relationships and are more susceptible to bullying. They tend to have fewer friends and to face more social rejection than teenagers who do not have ADHD (Vella, 2020). They also tend to develop and sustain friendships with peers who also have ADHD or any other social difficulties (Blachman & Hinshaw, 2002). When compared to teenagers who do not have ADHD, their behaviour comes out as less social, and this may in turn produce less stable relationships and more rejection by their peers (Ma et al., 2017).

Adolescents who are living with ADHD also face challenges related to their behaviour, emotions and academic achievements (Hurley, 2019). These challenges may manifest as weak self-regulation, together with extreme emotions such as rage, frustration, hostility and lack of empathy (Wehmeier et al, 2010). These challenges put them at an increased risk of conflicts with their friends, families and partners (Mikami, 2010); and they can also face rejection, bullying and harassment from their peers (Hoza, 2007). On the other hand, Maynard (2017) gives a different perspective and explains that while few friends understand their peers who have ADHD, they empathise with them and try to support them without being judgemental about their condition.

Adults and adolescents on the ADHD spectrum tend to prefer the company of their family, mainly due to a feeling of security and openness, but also because they feel understood, accepted and loved as they are (Halberg et al., 2010). This contrasts with the inevitable conflicts that teenagers have at home, including contradictory interactions with their parents (Johnston & Chronis-Tuscano, 2015). Unfortunately, family-based interventions with adolescents are not as effective as they are in children and pre-adolescents, and statistics show positive results in only one third of the adolescents (Carr. A, 2016).

Adolescents with ADHD, who live with their symptoms on a daily basis, often use social media as a tool to develop their identity in a group, to sustain friendships and to get help for their condition (Vann, 2013). They are also very attracted to video games, since they do not require a long attention span and include teams of people playing remotely, thus allowing for online social interactions (Ehrenfeld, 2018).

For an adult diagnosis of ADHD, the symptoms needed are often the ones that create problems in intimate relationships. A relationship where one person has ADHD and the other does not can be a frustrating experience, with the couple living with the disruptive symptoms that are typical of the condition, such as impulsivity, attention, lack of inhibitions, self-regulation and management of emotions. These symptoms may make conventional approaches to relationship problems close to impossible. Therapy may lead to boredom, restlessness and lack of interest from the person with ADHD, while the other person may feel discouraged and might also note that progress is very slow or even regress (Maucieri & Carlson, 2013) .

ADHD can hinder a relationship or marriage because the person experiencing symptoms can be distracted, impulsive or even fail to meet their responsibilities towards their partners (Robin & Payson, 2002). In a study comparing spouses of people with ADHD to spouses of non-ADHD adults, Ben-Naim et al. (2017) found that spouses of people with ADHD had lower intimacy and experienced less marital satisfaction. Overall, life with a person who has ADHD is challenging, and the symptoms can have negative effects on the person experiencing them, as well as the spouse, who has to deal with them on a daily basis, or other persons who have close relationships with persons with ADHD.

The above section has given an overview of ADHD, its diagnosis and treatment, how it affects the person's daily life at different stages, as well as the effects on the family and friends of persons living with ADHD. The outline aims to give a background of the subject in order to enable better understanding of the methodology used and the results achieved at the end of the study. The ultimate aim of the study is to see what is lacking in terms of services for persons living with ADHD in Malta, so that the shortages may be addressed, and services improved.

2.3 The Maltese Context

Until a few decades ago, disability in Malta was often considered to be taboo, shunned by society and avoided in public discourse (Callus, 2018; Bartolo, 2017; Gonzi, 1955). More recently, the concept of disability found itself intertwined in charitable or religious contexts, particularly following the setting up of the 'House of Providence' by the Catholic church in 1965 (Borg & Camilleri, 2009). Society for instance, sometimes referred to disabled individuals as 'angels' (Callus, 2013) or as objects of charity (Callus, 2018; Camilleri & Callus, 2001). This view of disability easily led to stigma, ostracism, and discrimination, typically driving society towards distancing itself from disabled persons (Bartolo, 2017; Bartolo, 2010; Camilleri & Callus, 2001). While changes have been occurring along the years, Malta's National Autism Strategy published in 2021 maintained that "Maltese society still maintains a strong culture of shame [...that...] hurts persons on the autism spectrum and their families " (Government of Malta, 2021c, pp. 9).

Callus et al. (2019) also observed that many people with intellectual disability in Malta tend to lead structured lives which, in itself, creates a barrier towards developing their potential and making choices about one's own life. Overprotection is in fact often reported in literature from Malta to be a common culprit. Its effects were identified in employment, leisure activities, relationships, and use of public transport, money, and mobile phones (Callus et al., 2019; Callus, 2013). Families are often considered to be the amongst the most influential contributors in the development of self-determination, independence and overall wellbeing (Cardona, 2013). Overprotection however, while often being associated to parents and caregivers, is also be created by society, through patronising attitudes such as addressing adults like they were children or, for instance, communicating with the person accompanying them instead of addressing them directly (Callus & Bonello, 2017).

The power dynamics present between service provider/caregiver and an individual play a significant role in the lives of a person, including those with disability, potentially disempowering them or increasing their level of dependence on others (Buhagiar, 2019; MacFarlane, 1994). Continued levels of overprotection can significantly alter opportunities for any child, including those with intellectual disability; it can impact the development of abilities and the fulfilling of their potential, particularly learning to do so on their own terms (Callus et al., 2019) and risks undermining their level of self-confidence in the process (Munro et al., 2016). Moreover, parents are often the ones at the forefront when it comes to campaigning for the rights of disabled people (Garland, 2015; Azzopardi, 2009; Camilleri & Callus 2001). Socially constructed influences such as the perception of disabled individuals as perpetual children, may act as barriers to individuals becoming self-advocates and further exacerbated these obstacles towards independence and autonomy (Callus, 2013). Research in fact, indicates that the views of disabled students for instance, can be significant contributors in the planning of areas such as inclusive education (Moore, 2000), thereby also challenging myths that students are not capable of deciding what is best for them (Barnes & Sheldon, 2007).

Over the years, Malta made a shift towards recognition of certain rights when it came to disability, although negative attitudes still exist, both from the general public, as well as professionals (Cardona, 2013). For instance, stereotyped portrayals typically related to charity campaigns still tend to present disabled people as charity objects and vulnerable individuals (Borg & Camilleri, 2009). The reduced levels of inclusion and involvement of disabled persons in the disability arena could be partially responsible for the perpetuation of this (Callus, 2014; Azzopardi, 2009). Azzopardi (2009)'s work in fact, brought forward the concept of organisations not 'for' but 'of' persons with disability, highlighting the importance of self-advocacy and empowerment amongst disabled individuals. Additionally, Xerri (2017) also highlighted a lack of coordination between government and NGOs surrounding disability services in Malta.

Childhood and Early Adolescence

With the adoption of the Universal Declaration of Human Rights (UDHR) in 1948 and the United Nation's Convention of the Rights of Persons with Disabilities (UNCRPD) in 2006, the rights and freedoms of disabled persons have been well established as guiding factor in nations' direction of practices. The UDHR formed a critical juncture in international, European Union (EU) and national policy, paving the way for integration and inclusion to become guiding principles in most countries (Roleska et al., 2018; van Kessel et al., 2019a; van Kessel et al, 2019b). Education systems, for instance, vastly came to reflect these through addressing the right to education for all children, the right to have special educational needs (SEN) adequately addressed, and the foundations of inclusive education (van Kessel et al., 2020). Malta was amongst the first members of the United Nations (UN) to sign the UNCRPD in 2007, then ratified in 2013 (European Agency for Special Needs and Inclusive Education, 2014). The development of Malta's education policy consequently, is reported to follow international guidelines, in particular when it comes to inclusive education and the allocation of resources to cater for SEN, with the nation establishing (or recommending) specific tools and requirements to address these issues (van Kessel et al., 2020).

To date, Malta's approach towards addressing the needs of disabled children followed two main pathways: one that addressed their needs within the education system, and a second more general approach addressing the overall empowerment of disabled people. Within the education system, Malta's Education Act (Legislation Malta, 1988) including its subsequent amendments, committed its educational services to delivering an environment where all children were provided with an education, while providing "resources required for inclusive and special educational programmes and for other schemes related to individual educational needs" (pp. 8). The Act brought forward a definition of SEN as a minor who "has special difficulties of a physical, sensory, intellectual or psychological nature" (pp. 26), and also catered for children who would benefit more from alternative education through the establishment of resource centres "whose specialised role will include provision for children with individual educational needs who would benefit more from being in such centres than in mainstream schools" (pp. 26). The services of resource centres were previously already being offered in Malta as 'special schools', however in 2009 they were reformed into resource centres, with one catering for primary years, two for secondary schooling and one for young adults, with each of these forming part of a college with the aim of offering services to mainstream schools, as well as providing full-time education for a small number of learners with complex needs (Ministry for Education, Culture, Youth and Sport, 2009). A number of other reforms in education have also been implemented along the years (Cutajar, 2007). On the other hand, the Equal Opportunities (Persons with Disabilities) Act (Legislation Malta, 2000) also provided guidelines on the provision of the rights of disabled people, including early intervention, employment, education and access, as well as "raising awareness and fostering respect for the rights and dignity of persons with disabilities" (pp. 20), amongst others. Overall, it served as an exercise to steer the nation away from the concept of disability as charity, channelling this into the empowerment of individuals with disabilities.

In 2000, Malta's Ministry of Education's Ministerial Committee on Inclusive Education published its Inclusive Education Policy for Students with Disabilities (Ministry of Education, 2000). This document presented the procedure to be adopted when catering for learners with SEN through an individual education plan (IEP) and brought about the statementing system for identification of students with SEN. Later in 2018, a web-based Provision Map Tool further developed the IEP process. This tool was in fact specifically developed for the Maltese context and made it possible for educators to create learners' IEPs, tracking their progress over time, while making it possible for these to be recorded and transition across institutions as students' progress from primary to secondary or other schools. Callus and Farrugia (2016) however observed that while students should officially participate in instances such as the drafting of their own IEP (Ministry of Education, 2000), they were in fact rarely being extended the opportunity to voice their views, with Psaila (2017) commenting that the social standing of professionals tended towards shutting down the disabled child's voice. Bajada (2019) too reported that during IEP discussions the adults' discourses tended to view students through a lens of impairments, and against the understanding that educators and parents knew what was best for the disabled child. These approach and discourses have the power to unconsciously silence the voices of these pupils (Psaila, 2017), disempowering them, hindering their self-confidence and self-advocacy skills, and in time, increasing their level of dependence on others (Buhagiar, 2019; MacFarlane, 1994). Research consistently reiterates the value of disabled children's rights such as participation in decisions regarding their health, education, home life and relationships (e.g. Calleja et al., 2017; Callus and Farrugia, 2016; Cefai & Cooper, 2010).

In 2002, guidelines for examination arrangements for learners with particular requirements were also issued (Ministry of Education, 2002). These were later amended in 2007 and have been regularly updated since then (European Agency for Special Needs and Inclusive Education, 2020). Amongst others, the arrangements include flexible time and break

arrangements, and/or the use of a prompter for examinations, highlighting that students should be allotted the same person as much as possible during examinations, especially in the case of autistic students. The Inclusive Education Policy for Students with Disabilities (2000) also brought about the 'statementing' process. The statementing of a student is carried out through a multidisciplinary assessment, while a Statementing Moderating Panel (SMP) gives its recommendations on any support and provisions required. This statementing process was reviewed in 2005 in the Inclusive and Special Education Review (Spiteri et al., 2005), then making recommendations for training and support for class teachers as well as specialist teachers. In 2007, the Student Services Department was established, followed in 2008 by the appointment of Service Managers responsible for the Inclusive Education Section, Special Education and Resource Centres and Psycho-Social Service (van Kessel et al., 2020). In 2012, Malta's National Curriculum Framework for All (NCF) (MEDE, 2012) was published, aiming to empower learners towards achieving their full potential and promoting progress for all learners. It also served as an important tool in catering for inclusion and provided more flexible and diverse educational pathways for all learners. A report on the reaction of the Malta Union of Teachers (Malta Union of Teachers, 2011) however, reported that the NCF did not take into account the wider definition of inclusion. Nevertheless, inclusive education remained a guiding factor in Malta's education system (van Kessel et al., 2020). Later in 2016, the My journey: Achieving through different paths - Equitable Quality Education for All (MEDE, 2016) document addressing secondary schools was also published, founded in the UNESCO Sustainable Development Goal 4 and seeking to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.

In 2019, the Ministry for Education and Employment (MEDE) published its Policy on Inclusive Education in Schools: Route to Quality Inclusion (MEDE, 2019b). This document was developed within the context of the Framework for the Education Strategy for Malta 2014-2024 (MEDE, 2014a), the principles of the National Inclusive Education Framework (MEDE, 2019b) and the values highlighted in the Respect for All Framework (MEDE, 2014b). It sought to bring clarity around the concept of inclusion to support the delivery of the principles of inclusion and diversity previously established by the NCF (MEDE, 2012), promoting equitable access to learning for all learners' diversity and viewing individual differences as opportunities for enriching learning (UNESCO, 2005). More recently, Malta's National Reform Programme 2020 (Ministry for Finance and Financial Services, 2020) stated that educators were being provided with training in techniques to improve front-line and professional services surrounding issues regarding disability, while intense training specific to autism was provided to 50 educators, aiming to provide educational services that cater for the specific needs of students towards their holistic development. In February 2020, the then Education Minister stated that autism-friendly environments were being introduced across 17 primary and 6 secondary public schools (Sansone, 2020).

Meanwhile, the Ministries of Education and Health also provide the services of educational and clinical psychologists as well as other professionals. Educational psychologists work with assigned colleges of students as part of the School Psychological Services (SPS) team within the National School Support Services (Government of Malta, 2020a), while the Ministry of Health provides the services of clinical psychologists, paediatricians, speech-language pathologists and other professionals at the Child Development Assessment Unit (CDAU) (Government of Malta, 2021a). Early Childhood Intervention Services for children experiencing difficulties or experiencing delays in developmental milestones in the first five years (0-5) of life are also offered within the National School Support Services aiming to promote early identification and provide families with a support system (Government of Malta, 2020b; Government of Malta, 2017). Additional support initiatives include benefits and services that are extended to individuals and families, such as (Government of Malta, 2021b):

- a Disabled Child Allowance in addition to Children's Allowance (Government of Malta, 2021b; Ministry for Finance and Financial Services, 2020);
- income tax reductions in relation to support services (e.g. LSE);
- an EU Disability Card (SID-EU Card) by Malta's Commission for the Right of Persons with Disability (CRPD) in order to help disabled individuals play an active role in society through free public transport and through assistance in applying for services within Government departments or private establishments (CRPD, n.d.);
- financial assistance to improve the accessibility of one's residence and promote independence;
- a blue badge parking card;
- financial support to purchase equipment that can support a more independent life;
- services of a social worker;
- workshops and support groups to support families offered by Aġenzija Sapport Social Work Services;
- workshops for siblings of disabled persons offered by Aġenzija Sapport Social Work Services.

Around 4 percent of children in Malta are reported to have a disability (National Statistics Office, 2014). Between 2011 and 2012, the number of statemented students on the islands was reported to be 2,572 (European Agency for Development in Special Needs Education,

2012). Of these, more than 2,500 attended mainstream education, meaning that the percentage of students attending resource centres or special units was just over 0.1%, placing Malta amongst the EU countries with the lowest rates when it comes to the segregated placement of learners with individual educational needs (European Agency for Special Needs and Inclusive Education, 2014; van Kessel et al., 2020). Some (e.g. Tanti Burlo', 2010; Bartolo, 2003) however questioned whether students are simply being integrated in mainstream schooling in the name of inclusion, pointing out that while mainstreaming focuses on fitting students into regular schools, inclusion involves "fitting regular schools to the needs of all students" (Bartolo, 2001a, pp. 66). Callus and Farrugia (2016) also pointed to the fact that the relationship between disabled and non-disabled students typically did not appear to follow the friendship pattern observed among non-disabled counterparts, but tended to be established on an approach of care. Bajada (2019) also observed that during group or social activities at school, it was the Learning Support Educators (LSEs) who tended to select their students' buddies. The role of LSEs is in fact controversial in research, since it may create a barrier to a child's inclusion in the context of a classroom, or may on the other hand, provide opportunities and interaction (European Agency for Special Needs and Inclusive Education, 2017; Webster et al., 2011). Some researchers advise for their role to include working with the classroom as a whole, as opposed to solely with statemented learners (e.g. Marchesi et al., 2009) while responding to the specific needs of the children present, such as those on the spectrum (Stahmer & Ingersoll, 2004). In her work seeking the views of 3 7-11 year olds with neurodevelopmental conditions, including autism, Bartoli (2017) reported that social and systemic barriers largely impacted their level of participation in school and leisure contexts. She observed that positive social attitudes facilitated inclusion levels, while less favourable attitudes and reduced social acceptance negatively impacted their experience. These findings were echoed by Cini (2017) who also observed that attitudes of other parents present in play environments act as barriers when it comes to access to leisure activities. Cremona (2019) added that educators have a strategic role that can promote disability awareness and encourage positive social interactions through contact, which can improve the meaning children associate with disability.

Adolescence and Adulthood

In Malta, the Foundation for Information Technology Accessibility (FITA) is the main coordinator for accessibility with information communications technology. The Foundation assists disabled when it comes to assistive technology that can support or improve the individual's quality of life and also provides guidance to private and public organisations in information technology accessibility in order to support to disabled individuals in overcoming or removing barriers to education and employment through ICT. Overall, FITA seeks to promote equal opportunities for all through ICT (FITA, 2020).

In 2015, Richmond Foundation launched their Mental Health First Aid course in Malta. The course aims to provide skills needed to provide the assistance and guidance that can support people facing mental health problems. The Foundation also seeks to train educators, scout leaders, sports coaches, and youth workers, amongst others, while also providing specialised courses for youths and teens (Richmond Foundation, n.a.).

Education

> *Inclusion "needs to be viewed as a process located within the cultures, policies and practices of a whole school and community"* (Azzopardi, 2006, pp. 11).

Following the completion of secondary education, transitioning to post-secondary education can prove to be challenging for any student (Gillan & Coughlan, 2010). The quality of guidance offered to students during their secondary years in preparation for their transition to post-secondary education, particularly in the case of students with intellectual difficulties therefore, is essential and can determine the degree of success experienced in post-secondary education and future employment prospects (Winn & Hay, 2009; Azzopardi, 2006; Stodden & Whelley, 2004). Effective transition programmes can further aid in this journey, and should be student-centred, help the student to develop key skills such as self-determination and self-advocacy, and include training in daily living and social skills (Mula Falzon (2012). In her work on transitions from secondary school to post-secondary education, Mula Falzon (2012) reports that learners as well as parents experience feelings of fear, worry, a degree of overprotectiveness and a sense of helplessness, highlighting the importance of cooperation between the different professionals involved (INCOs, guidance teachers, college career advisors, teachers and LSEs). Pleven and Callus (2017) too report challenges encountered by students with intellectual disability during this transition such as bullying and difficulties with content. Once again, the need for support was emphasized in order to bridge the transition to post-secondary life, accompanied by disability awareness training for post-secondary students, as well as the teaching of basic skills such as use of public transport and self-advocacy skills.

In 2007, the Malta Council for Science and Technology (MCAST) launched its Pathway to Independent Living Programme (The Malta Independent, 2007) as part of an EU-funded project (European Network on Inclusive Education & Disability, n.d.). This programme was specifically designed for people with intellectual difficulties and aimed to support the development of independent living skills, with a particular emphasis on those related to employment (European Network on Inclusive Education & Disability, n.d.). The original version of the programme was 2 years long, however this was later modified to 1 year (The Malta Independent, 2007). The programme offered students practical placements in various work environments, aiming to provide hands-on learning in all subjects (Malta College of Arts, Science & Technology, 2013 as cited in Pleven & Callus, 2017). The entry requirements to the course included a school leaving certificate, literacy and numeracy skills and "the ability to tolerate both classroom and community learning environment" amongst others (European Network on Inclusive Education & Disability, n.d). In 2013, Malta's Institute of Tourism Studies (ITS) offered its Key Skills for Independent Living course (ITS, 2013). Once again, this programme was designed for people with intellectual disability and aimed to consolidate core competencies while introduce basic skills related to food and beverage and housekeeping duties, together with essential life skills for independent living (ITS 2013). A current search for information regarding these programmes yielded limited results, even through MCAST's and ITS's channels, indicating the programmes may have been terminated.

In 2018, the University of Malta published an updated version of its Access Arrangements, recognising the barriers that disabled persons face, in multiple domains, contexts, environments and interactions, and aiming to ensure that student independence was promoted through the necessary access arrangements for courses programs and assessments in order to participate fully in university life (University of Malta, 2018). The document acknowledges that "students with autism may have difficulties with university coursework and examinations because of one or more of the following factors: they feel anxious, they have difficulties with communication and social interaction and may misinterpret instructions; they have unusual sensory reactions and may not cope well with, for instance, strip lighting, noise, strong smells, lecturer or invigilator walking about or a large exam hall; and they have difficulty staying 'on task'" (University of Malta, 2018, pp. 30). Access arrangements for students on the spectrum include clear instructions, sensitivity with potential difficulties surrounding group assignments, reduction of unnecessary stimuli during lectures, flexible time and break arrangements, alternative examination venues, or other access arrangements as may be necessary (University of Malta, 2018). Students with ADHD are also recognised as potentially encountering difficulties when it comes to sustaining attention, regulating motor activity, and managing behavioural impulses. Access arrangements extended to such learners include flexible time and break arrangements during examinations, alternative examination venues to reduce distractions, or other access arrangements as necessary (University of Malta, 2018). Similarly, in 2019, the University also published its Guidelines to MATSEC Examinations Access Arrangements (University of Malta, 2019). These provided the possibility of similar access arrangements, together with the inclusion of the option of a prompter for students at Secondary Education Certificate level examinations (University of Malta, 2019).

MCAST also provides access arrangements, such as a reader and flexible time, through its Inclusive Education Unit. The unit also provides other support such as orientation tours, particularly for students with anxiety, autism or orientation-related needs, and peer preparation sessions amongst others (MCAST, 2021) in order to ensuring that reasonable arrangements are in place, through a flexible and tailored approach based on the needs of the individual learner (MCAST, 2020).

Employment

> *"While most people take their right to work for granted, this is not so simple for persons with a disability. Rather, persons with disability continue to be denied the opportunity and right to work and engage in quality employment. This has proven to be very frustrating and disheartening for disabled people who are able to work but continue to be discriminated against. Malta has very low unemployment rates compared to Europe, but also one of the lowest employability rates for persons with disabilities."* Commissioner for the Rights of Persons with Disability (Pace Gasan, 2020)

Malta's first legislation to address disability came about in the Persons with Disability (Employment) Act in 1969 (Legislation Malta, 1969). It focused mainly on employment, introducing items such as the registry of employees with disabilities, as well as the concept of vocational guidance services and vocational training courses to support the employment of disabled individuals, while also condemning discrimination on the basis of disability. The Act also introduced a 2% quota for companies with more than 20 employees, however this was not enforced for several decades.

The Equal Opportunities (Persons with Disabilities) Act (Legislation Malta, 2000), in addition to providing guidelines on the provision of the rights of disabled children, such as early intervention and education, also addresses the rights of disabled individuals in contexts such as employment. According to the Act, employers are, amongst others, prevented from discriminating persons with disability in regard to:

- procedures relative to applications for employment;
- the hiring, promotion or dismissal of employees;
- employees' compensation;
- job training; and
- any other conditions and privileges related to employment.

Later amendments further address discrimination on the basis of disability and include, for instance, discrimination through failure to provide reasonable accommodation and to provide information about it. A few years later, the Office of the Prime Minister published its Equality Policy for the Public Service as a guide for public service administration (Public Administration HR Office, 2013; Office of the Prime Minister, 2021) in which it included special arrangements for the recruitment of persons with disability.

In 2014, MEDE published its National Employment policy (MEDE, 2014c) which included a chapter dedicated specifically to persons with disability and proposed measures targeting the employment of disabled people including social cooperatives, supported employment, and sheltered work. That same year Malta's National Policy on the Rights of Persons with Disability was also published, aiming for disabled individuals to be treated at par with their non-disabled counterparts (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014). It presented principles and measures to address a number of aspects, including amongst others:

- the right to a dignified life;
- education;
- employment;
- independent living;
- residential homes, community and rehabilitation centres;
- culture, sports, art and leisure;
- sexuality and parenthood; and
- families of persons with disability.

A year later, a consultation document for a National Disability Strategy was published (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015) and included, amongst others, schemes to support disability groups in providing disability awareness training, and logistical support to non-governmental/voluntary organisations (NGOs) involved in disability rights activism. It also set out a number of recommendations, including some related to education, such as the development of IEPs, as well as employment, such as the provision of disability awareness training for employers (Bezzina, 2019b).

In the National Budget for 2015, the Maltese Government announced a series of measures aimed at further promoting the employment of disabled persons. Amongst these, were (Farrugia, 2015):

- National insurance exemption for employed disabled persons;
- Tax credit of up to €4,500 for each disabled person in employment;
- Enforcement of the 2% quota, which denotes that for employers hiring more than 20 employees, at least 2% of the workforce must be persons with a disability. While the clause already previously stood, it was not enforceable and was typically kept in the closet by most employers and policy makers (Scicluna, 2014). Following this legal amendment, companies became obliged to pay an annual contribution of €2,400 for every person with a disability that should be in the company's employment (up to a maximum of €10,000). Moreover, Government committed any funds collected for use in supporting more persons with disabilities in finding their ways into employment through the Lino Spiteri Foundation (Jobsplus, 2021a; CRPD, 2020; Farrugia, 2015).

Following the 2015 National Budget in fact, the Lino Spiteri Foundation was established, aiming to improve the inclusion of vulnerable individuals into gainful employment through the empowerment of the individuals themselves, as well as their employers (Jobsplus 2021b). In 2016, a Memorandum of Understanding was also signed between Jobsplus (the former Employment and Training Corporation), the Malta Employers' Association and the Malta Chamber of Commerce, Enterprise and Industry with the aim of further strengthening these efforts towards favouring the employment of disabled persons (Jobsplus, 2021a). Additionally Jobsplus offers supported and sheltered employment opportunities and also provides guidance for entrepreneurs with disabilities (CRPD, 2020). That same year, employers reported that while people with physical disabilities were generally perceived to be in a better position to fully participate in the workforce, fully integrating people with intellectual disabilities,

autism and mental health disabilities was still found to be challenging (Business Leaders Malta, 2015).

Malta's Commission for the Right of Persons with Disability (CRPD) (the former National Commission for Persons with Disability [KNPD]) which was established in 1987, advocates for the protection of the rights of persons with disabilities. It provides advice – including to employers – about access arrangements, promotes equal opportunities (CRPD, 2021) and is also assigned the responsibility of investigating cases of alleged discrimination on the basis of disability (CRPD, 2020). In 2013, the Commission published a set of key implementation priorities based on the UNCRPD (2006). It also launched the provision of community-based day services to individuals who are not in employment, as well as a disability allowance to all individuals with disabilities, regardless of their earnings or hours worked (CRPD, 2020). In 2021, the Commission published an Employer's Guidelines document addressing disability and employment in Malta seeking to provide support to employment systems and raise awareness around the rights of disabled persons in the employment sphere (CRPD, 2021). The document provides information about disabilities and what can be offered at the workplace as well as guidance on how to interact with different individuals, it lists sources of support and presents the legal framework surround the subject. The Commission also offers Disability Equality Training to public and private organisations, which it developed in collaboration with the Department of Disability Studies at the University of Malta.

This Department of Disability Studies (previously known as the Disability Studies Unit), which was established in 2012, is committed to providing students and future professionals with theoretical and experiential perspectives of what it means to live with a disability and involves disabled people to deliver the lectures (University of Malta, n.d. a). The Department offers study units and Master's level courses in Disability studies, as well as offering continuous professional development opportunities for all those interested addressing topics such as sexuality and disability, hidden disabilities, and representation of disability (University of Malta, n.d. b).

A number of services and measures are likewise offered to individuals with disabilities to complement the existing legislation and policies. These include (Government of Malta, 2021b):

- an EU Disability Card (SID-EU Card) offering free public transport and assistance in applying for services (CRPD, n.d.);
- financial assistance to improve the accessibility of one's residence or to convert part of one's premises in order to make independent or semi-independent living close to

the family possible (Ministry for Finance, 2018; Ministry for Finance and Financial Services, 2020);

- registration tax and road licence exemptions on the vehicles;
- a blue badge parking card;
- subsidies on individualised transport services to go to work, post-secondary education institutions, or attend sports activities;
- advice, information, and training in order to achieve, regain or maintain independence, such as adaptive driving support, offered by the Sonia Tanti Independent Living Centre, which is part of CRPD;
- financial support to purchase equipment that can support a more independent life;
- entry into the Jobsplus Register for Persons with Disability for individuals that although fit for employment, require guidance and assistance to engage in employment which is most suitable to their current physical/mental health condition.

A recent study involving 336 disabled participants commissioned by CRPD (CRPD, 2020), reported that 61% of participants were in employment, whilst 28% used to work however were unemployed at the time of the study. 11% had never been in employment. The study observed that participants with mental health issues were more likely to be unemployed (25% of the unemployed participants compared to 12% of the employed individuals), while those with higher levels of education were reported to be more likely to be in employment. While most respondents expressed a positive opinion about employment, with the majority reporting high level of job satisfaction, the report highlighted that the larger part of respondents were in the lower paid job categories of typically up to €800 a month, with only 15% and 10% being employed as professionals or in managerial roles respectively. Callus and Bonello (2017) had also previously reported a shift in employment opportunities for disabled people, moving from what typically used to be factory-work to more opportunities in offices and the tourism sector. Nevertheless, CRPD (2020)'s research raised questions about opportunities for career progression amongst disabled individuals, observing that 38.5% of participants had changed roles within a company however still remaining within the same grade, while 14% even reported previously having jobs at a higher grade with the same employer. In fact, only 38.5% reported an improvement to a higher grade. Feedback from employers also indicated that they perceived career progression to be more attainable for employees with physical impairment but less so for those who have an intellectual impairment. Callus and Bonello (2017, pp. 12) observed that "employers do not know that an intellectually disabled person has the potential to advance at their place of employment, or else employers may not know how to adapt the workplace to cater for the disabled employee's needs, or how to provide the disabled person with training to help them cope with different work". Disabled job seekers often face stigma, discrimination and negative attitudes by employers Bonello (2015), as well as a lack of disability awareness by recruiters (Zammit, 2017).

CRPD (2020) also reported that while results varied, individuals who participated in employment training schemes were more likely to receive a job offer, adding that some participants considered job coaching to be amongst the most beneficial initiatives to help find or retain a job, followed by training. The report observed that there may be limited awareness amongst respondents regarding employment agencies for persons with disabilities. In fact, among those employed, 20% considered Jobsplus schemes to be helpful in finding employment, while less than 10% recognised the Lino Spiteri Foundation in this respect. Moreover, it was observed that family connections were perceived by participants to be as effective as dedicated employment agencies in aiding disabled individuals to attain employment.

- **61% feel fulfilled doing other activities**
- **Tiredness**
- **47.5% Severe impairment or serious illness**
- **42% need flexible work arrangements and have not found an employer who is willing to provide them**
- **32% do not have any means of transport to get to work**
- **32% do not believe they would be able to have a well-paid job**
- **25% do not have the necessary assistance to prepare to go to work**
- **24% attended interviews in the past but were never selected**
- **21% have parents who do not want them to work**
- **20% spent a year looking for work but have never been called for an interview**

Info Box 2: Environmental causes for which unemployed disabled persons were not considering looking for employment (Source: CRPD, 2020)

As had also previously been observed by Callus and Bonello (2017), CRPD (2020) reported that most employed participants expressed positive interactions with superiors and colleagues at their place of work. A common difficulty encountered however was the ability to drive to work, followed by the awareness of one's rights as a disabled person. Moreover, amongst those who had previously been employment but were not employed at the time of the study, almost a quarter reported having experienced some form of disability-related issues with colleagues, while more than 30% considered their previous employment to be boring. Interestingly, amongst those unemployed, 34% prefer to remain so, with feeling fulfilled doing other activities being the most common reason, followed by tiredness (see Info Box 2 above). Meanwhile, with interactions with others being their main motivator, 41.5% expressed the desire to find employment and were willing to undertake employed-related training.

From interviews with employers carried out as part of the study, it emerged that almost three quarters of employers interviewed provided in-house training opportunities for disabled employees, while more than half of them provided initial and ongoing support. Nevertheless, over 60% had never offered a work placement or training scheme opportunity to persons with disabilities. More than half the employers interviewed expressed that individuals with disabilities were reluctant to share information about their disability, which may be contributing to the reduced chances of finding employment. This was also echoed in comments by the Malta Employer's association (Maltatoday, 2014) and also impacted companies' legal obligation to reach the 2% quota if disabled employees did not wish to officially register with Jobsplus as persons with disabilities. Notwithstanding satisfaction being expressed amongst those making use of services such as the Lino Spiteri Foundation, more than half the group of employers felt that the current level of assistance being provided was insufficient to tackle issues related to the employment of persons with disabilities. Overall, employers felt that there was not enough awareness and technical assistance for them when it came to employing disabled individuals.

Findings from Axisa (2018)'s work with ten Maltese employers also revealed that these felt that the 2% quota was still a grey area, with many unanswered questions, mixed feelings and misconceptions surrounding disability in employment. Axisa (2018) also observed that several of the private sector employers did not have a policy addressing disability, while participants also expressed that although financial support and that of job coaches is available, this is often brief and not sufficient. Resounding throughout findings from different viewpoints of the disability sphere, Axisa (2018), together with several others (such as Bonello, 2015; Camilleri, 2010) reports the need for improved support, awareness and education on disability issues amongst employers. On a similar note as Axisa (2018), Attard (2017) also proposes government should focus on incentivising disability in employment rather than penalising employers for not conforming to legislation.

Independence

> *"The image of a caged bird who knows how to fly and wishes to fly but unfortunately remains locked in its cage" (Callus et al., 2019, pp. 14).*

While Article 19(a) of the UNCRPD (2006) stipulates that intellectually disabled adults have a right to residential services in order to lead a more independent life, in Malta people with intellectual disability tend to reside with their parents indefinitely (Callus & Bonello, 2017), and subsequently move to an institution or, in fewer cases, to a residential community setting (Azzopardi Lane et al., 2014). Several researchers looking into the Maltese context however have reported the dissatisfaction amongst persons with intellectual disabilities surrounding the notion of having to live in an institution if their parents or main source of support were no longer available (Azzopardi Lane, 2017; Debattista, 2015; Azzopardi Lane & Callus, 2014). In his Budget Speech 2018, the Minister for Finance pledged to open more residential homes for people with intellectual disabilities and challenging behaviour and persons on the autism spectrum (Scicluna, 2017), however while the number of residential services within the community is gradually increasing (Bezzina, 2019a; The Malta Independent, 2018a; Sansone, 2015), the need for more community-based services still exists (Bezzina, 2019a), and opportunities for supported community living still remains one of the major barriers to the self-sufficiency of persons with learning disability in Malta (Callus & Bonello, 2017).

"Many people with intellectual disability do not tend to have much say over how and with whom they spend their leisure time" (Callus et al., 2019, pp. 8). Often, they tend to go out and socialise mostly with their family, because they don't typically have friends they can go out with (Callus et al., 2019; Callus & Bonello, 2017). As young adolescents in school, disabled people would typically be accompanied by their mother to any social events (Bajada, 2019). This tendency was found to be even more common in the island of Gozo where living in one's comfort-zone was the norm (Callus & Bonello, 2017). Arising from a protective need to keep their young safe however, this easily results in individuals sitting through events that might not be of particular interest to them, such as bingo or ballroom dancing. Moreover, Callus and Bonello (2017) reported that people with an intellectual disability were amongst those least accepted in society. Overall, it was observed that other than running and errand or going to Church, few intellectually disabled people had the opportunity to go out on their own, or with whomever they choose to (Callus et al., 2019; Callus & Bonello, 2017), pointing out however differences based on the abilities and different needs of support between one person and another (Callus & Bonello, 2017). Also, although some attend day centres, for those who wish to participate in mainstream experiences, these can still be restrictive, while activities organised by NGos were found to supportive of a more active life (Callus et al., 2019).

In its Partnership Agreement 2014-2020, the Maltese Government highlighted its commitment towards actively integrating disabled people into society, with the aim of promoting independent living and empowerment through a network of community-based services (Office of the Deputy Prime Minister, 2014). Meanwhile, Malta's National Policy on the Rights of Persons with Disability (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014) further defined this, outlining the need for community residences, while committing to ongoing disability rights training to staff working in independent living programmes. This was shortly followed by the development of National Standards for Residential Services for Persons with Disability (Working Group of the National Standards for Persons with Disabilities, 2014), with related guidelines and support to service providers later published by the Social Care Standards Authority (SCSA) in 2019 (SCSA, 2019a; SCSA, 2019b). Meanwhile, the Personal Assistant Fund was also launched in 2016, catering mainly for live in carers (Aġenzija Sapport, n.d. a) and in 2018, Malta's National Reform Programme committed to developing the nation's first 10 residential community homes as well as provide financial aid and technical support to disabled persons to adapt their homes in order to enhance their independent living (Ministry for Finance, 2018). Malta's National Reform Programme 2020 also saw the launch a new project to provide additional residential home for adults with disability (Ministry for Finance and Financial Services, 2020). Currently, Aġenzija Sapport acts as the national agency providing services for persons with disability and their families. Amongst their services, the Agency offers community services such as personal assistance to promote independent living (Aġenzija Sapport, n.d. b), and also manages a number of apartments/houses around Malta and Gozo that offer "a family home environment for persons with disability who for some reason cannot continue living with their family" (Aġenzija Sapport, n.d. c; Inspire, 2019).

Aġenzija Żgħażagħ carries out work with local youths and amongst its objectives, seeks to facilitate links between young people and their communities. In this way, young people build bridges and open up spaces within society (Aġenzija Żgħażagħ, 2021a). This is achieved through initiatives such as youth cafes, youth hubs and other initiatives in areas frequented by youths. Youth workers from the South Youth Service region have also worked with young people to develop and implement an initiative with residents at a service that offers residence and independent living apartments for disabled individuals and works towards enhancing the quality of life of persons with a disability. The project brought 6 young people from the South

Youth Service Youth Cafe together with 20 residents to engage and get to know each other. Meanwhile, a local NGO, Opening Doors was established aiming at providing artistic opportunities in theatre, dance and music, for adults with intellectual disabilities. The organisation promotes creative processes and artistic skill through engaging participants in the creative process thereby facilitating the creation of their own work and aesthetic, while empowering them to take ownership of their work (Opening Doors Association, n.d.). Baldacchino (2016) observed how the approach undertaken by the association, challenged misconceptions, stereotypes and attitudes surrounding learning disabilities through the active participation process and through the presence of disabled people in performance.

In terms of financial independence, Callus and Bonello (2017) observed that while some individuals with intellectual disability did make use of money on their own, these were few in number, with parents managing their finances in most instances. In fact, they observed that only a few of the participants were able to shop on their own and check for the right change. Callus et al. (2019) also pointed out that disability pension cheques are at times written out in the parents' name, which means they cannot be cashed by the receiving individual him/herself.

Owning and having access to a personal mobile phone, considered nowadays to be standard practice by most in Malta, is observed to be different too when it comes to people with intellectual disabilities. Individuals who normally only go out with their families were observed to typically not own a mobile phone, whereas in the case of those who go out with people other than their family, tend to own a mobile phones as a means for family members or caregivers to keep track of them, rather than as a means of communication with their peers (Callus et al., 2019).

Relationships and Sexuality

In their research looking into the impact of overprotectiveness on people with intellectual disability in Malta, Callus et al. (2019) observed that out of 17 participants, only 3 were in a romantic relationship with a partner, adding that they were still not able to meet up with them as much as they would like to. Often founded in attitudes of overprotection, stripping people with intellectual disability of their developmental rights, as is sexuality, can very often result in isolation, poor social skills and lack of adequate knowledge about sexuality and relationships (Callus et al., 2019). Additionally, research in Malta indicates that among parents and service providers, considerable conflict exists between religion and the sexuality of persons with disability, amongst other culturally-related issues (Azzopardi Lane, 2011). Parents and service providers typically felt they should be involved in the relationship when it comes to disabled persons and tended to favour platonic relationships as opposed to intimate and sexual ones (Azzopardi Lane, 2011). Societal perceptions and attitudes towards the sexuality of people with disabilities can create restrictions in the sexual options faced by these individuals (Azzopardi Lane et al., 2019; Azzopardi Lane, 2017; Debattista, 2015; Azzopardi Lane & Callus, 2014). Callus and Bonello (2017, pp. 45) in fact reported that in Malta "some parents even put up resistance to sex education because they find it difficult that their children may be talking about the subject". When it comes to females, gender appears to play an additional disabling barrier (Farrugia, 2019). While Azzopardi Lane (2011) observed that the majority of parents did not wish for their disabled sons or daughters to have children of their own, females were often perceived as being increasingly vulnerable and at an increased risk of being abused (Azzopardi Lane et al., 2019), with parents being less willing to let daughters get involved in relationships than sons (Azzopardi Lane, 2011). Azzopardi Lane and Callus (2016, pp. 31) in fact state that "social factors impinge on the experiences of women with disability who become mothers to a greater extent than impairment-related factors". In addition to the opportunity to reside in an independent setting therefore, services can support disabled individuals towards developing self-advocacy skills and autonomy, including those surrounding sexuality and intimacy (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015). In this way, individuals can continue to be empowered to develop and exercise their rights while also dispelling stereotypes about their inability to do things (Azzopardi-Lane and Callus, 2014).

Article 23 of the UNCRPD (2006) outlines the rights of persons with disability to explore and express their sexuality. Malta's National Policy on the Rights of Persons with Disability (2014) also reflects this and includes measures to ensure access to comprehensive sex education, supported living services for couples with disability, assistance for disabled parents, as well as the training of service providers and sexual health professionals on disability issues. In 2013, the Directorate for Quality and Standards in Education (within MEDE) published a set of Guidelines on Sexuality and Relationships Education in Maltese Schools. These aimed to pave the way for a clearer direction for educators when it came to discussing sexuality in schools and provided a framework for the development and delivery of an effective and comprehensive sexuality and relationships education (Camilleri, 2013), however place responsibility on LSEs and INCOs rather than the primary educator such as PSD teachers. The Department of Disability Studies at the University of Malta also offers a study unit addressing sexuality and disability, which is also offered as a Continuous Professional Development (CPD) course on a yearly basis. SCSA's Social Regulatory Standards published in 2019 concerning respite and residential services for disabled persons also acknowledged importance of sexuality, guiding service providers to support their clients when it comes to establishing and maintaining relationships (SCSA, 2019b).

2.4 Autism in Malta

The reported increase in the incidence of autism gave rise to a national legislation that catered exclusively for persons with autism in Malta (Ministry for Justice, Culture and Local Government, 2016). In 2016 in fact, Malta enacted its Persons within the Autism Spectrum (Empowerment) Act, seeking to empower persons on the spectrum by providing for their improved living conditions and wellbeing and supporting their participation and inclusion in society. The Autism Advisory Council was also set up under this legislation, aiming to develop an Autism Support State Plan addressing issues such as early diagnosis and intervention, education, and professional development, amongst others (Ministry for Justice, Culture and Local Government, 2016). The Autism Advisory Council was given its mandate on World Autism Day in 2018 (Government of Malta, 2021c).

More recently, in 2021 Malta's National Autism Strategy 2021-2030 was published, following a number of outreach events with service providers, educational institutions and members of society as well as international platforms involved in the autism sphere (Government of Malta, 2021c). Focusing on the social and empowerment aspects of autism, the strategy committed to developing autism awareness campaigns that included the direct involvement of autistic persons and those around them. Awareness and information campaigns outlined also include the delivery of training across educational, health and social care sectors, providing training and awareness initiatives for persons on the autism spectrum and their families, supporting persons and informal caregivers, as well as the general public, through local councils, and social and cultural groups. Aiming for inclusion to become a natural part of Maltese society, the strategy plans for access to extra-curricular activities, buildings, public offices and open spaces to be welcoming for everyone, while also promoting alternative communication routes and the use of augmentative and alternative communication (AAC) devices (Government of Malta, 2021c).

The document outlines commitments across several life areas including:

- **Early Identification and Intervention**, proposing a holistic reform of current structures and human resources addressing early identification and intervention in order to provide a multi-disciplinary, person-centred approach, informed by evidence-based practice across a person's lifespan;
- **Education**, seeking to meet the educational needs of students on the spectrum through the training of professionals, autism awareness amongst students, as well as the strengthening of current practices and policies such as the SMP, the National Inclusion Policy, and autism-specific toolkits, while extending IEPs also to students in tertiary education. The strategy also caters for the provision of career guidance services, internships and work placement schemes, transition planning, and support classrooms or units for autistic learners, within mainstream education.
- **Employment**, where awareness building and training on autism at the workplace are proposed, together with the strengthening of pre-employment training, job placements, job coaching and mentoring services. The encouragement for firms to operate in autism-friendly manners is also brought forward, supported by guidance, financial incentives and human resources, highlighting the role of trade unions as drivers for promoting equality and non-discrimination for autistic persons in all areas related to employment and industrial relations;
- **Advocacy, self-advocacy and outreach**, aiming to promote empowerment and "enable persons on the autism spectrum to coordinate and direct their efforts at the national level, as agents for change, including through the formation of self-advocacy organisations led by them" (pp. 34). Initiatives such as the development of working groups for parents and siblings of autistic persons are also brought forward, together with dialogue channels with regional councils and NGOs, as well as educational establishments to encourage participation, empowerment and advocacy as part of school curricula and entities' agendas alongside autism awareness; and
- **Autism and adulthood**, where the need to cater for autism in adulthood is highlighted, bringing about a commitment to work with this age-group through the understanding of their needs and challenges alongside awareness-building and the provision of training across sectors. The value of age-appropriate sex education and the right to explore and express one's sexuality are also discussed, concluding with the need to explore challenges surrounding autism and ageing in order to start working towards addressing these.

> *"As parents-to-be, we dreamt of things for our new born babies like everyone else would. Just because our children are different and might not reach the dreams that you have originally set, does not mean that we cannot dream. Today I dream and pray that my son is happy, healthy, understood, appreciated, not judged, loved, independent, and always seen as the uniquely beautiful human being that I was gifted with"* Parent and APA-M Board Member (Brincat, n.d.)

In their recent review of autism and SEN policies in small EU states such as Malta, van Kessel et al. (2020) found that Malta was the only country amongst those reviewed to have adopted policy exclusively targeting the inclusion of autistic children in the education system, which aimed at fully integrating autistic people in society. The nation also implemented services specifically aimed at supporting educators and parents or caregivers in addressing the needs of autistic children, as well as an autism-specific screening and diagnostic programme for children from 18 months of age. Since the earliest symptoms of autism have been reported to start manifesting between as early as 6 – 12 months of age (Lai et al., 2014), this screening programme can support for early identification and intervention.

In Malta, the diagnosis of a child with autism is in fact carried out by a national early screening programme for autism (Government of Malta, 2016b), involving a multidisciplinary team of professionals, including psychiatrists, psychologists and paediatricians. This screening process starts is done through the use of M-CHAT-R – a short questionnaire carried out with parents or caregivers. It provides an indication of any risks relating to autism, making it possible for early flagging of any possible developmental or learning difficulties, so that children can be supported before reaching their kindergarten years (Government of Malta, 2016b). Professionals such as educational psychologists from SPS, and the CDAU team, together with any independent professionals, are involved with identifying and diagnosing of autism in children and young people, and together with auxiliary services are subsequently involved in intervention programmes and support to these individuals and their families (Zammit, 2018). In her work with 8 mothers of autistic children and young adolescents in Malta, Cassar (2014) reported that a number of mothers felt very dissatisfied with the diagnostic process surrounding their son's autism, highlighting a lack of an empathic approach and of information and guidance regarding the condition. These findings bring the need for professionals' awareness and sensitivity to the forefront (Cassar, 2014; Bartolo, 2001b). Moreover, mothers were observed to experience an ongoing struggle handling their son's autism, further highlighting the need for professional support addressing parental wellbeing as well as the importance of support groups that allow parents to connect, share information and provide overall support (Cassar, 2014).

Cultural influences can impact the manifestation of symptoms (Daley, 2002) as well as the diagnostic and treatment pathways surrounding autism (Sadaf et al., 2018). For instance, Coonrod and Stone (2004) observed that American parents tend to become concerned when language delays arise, while on the other hand, Daley (2004) and Daley et al. (2005) reported that Indian parents tend to be more concerned when social difficulties start presenting. The use of culturally-sensitive diagnostic and screening measures can therefore play an important role in addressing early assessment and interventions of autistic children. In the UK for example, NICE publishes guidelines for diagnostic and treatment protocols. Malta currently does not publish official protocols of its own when it comes to the diagnostic and treatment pathways of autism. There is also no assessment tool that has been standardised for the Maltese population. Professionals make use of a range of tools and resources typically standardised for British and American populations together with consultations with those involved in the child's life (Zammit, 2018). In their 2020 audit of the special needs and inclusive education scenario in Malta in fact, van Kessel et al. reported that "national policy for special needs and inclusive education is not adequately tailored to the Maltese context" (pp. 41) and is described by some as being a replica of UK's policies or 'borrowed' guidelines from other countries.

In its educational system, Malta addresses autism within its Inclusive Education Policy (Ministry of Education, 2000) and through an Autism Spectrum Support Service that specifically tailors for children with autism (Government of Malta, 2016a; Spiteri et al., 2005). Recognizing every student as an individual and aiming to maximize their potential (Government of Malta, 2016a), these efforts seek to empower educators and caregivers to support the educational, behavioural and social development of autistic children through supported learning experiences maximizing on students' abilities (Government of Malta, 2016b). In 2018, the Autism Spectrum Support Service published an Autism Toolkit for Mainstream Schools in Malta (Galea Soler & Pace Gellel, 2018), providing practical strategies for educators. The Access to Communication and Technology Unit (ACTU) also provides services to students with communication difficulties who require augmentative and alternative communication and/or assistive technology to access the curriculum (Government of Malta, n.d.). Technology and screen-based media have often been reported in research to provide appealing support tools for autistic children (e.g. MacMullin et al., 2016; Nagar et al., 2013; Ploog et al., 2013; Mazurek, et al., 2012; Porayska-Pomsta et al., 2012; Chonchaiya et al., 2011; Mineo et al., 2009; Shane & Albert, 2008), even at pre-school age (Agius & Vance, 2016). The assistive technology support provided by ACTU incudes "a broad range of devices, technical aids and strategies, which can help solve problems encountered by children with disabilities in everyday life, education, pre-vocational or social situations. Augmentative and alternative communication includes a range of strategies which can be used to support expressive and receptive communication difficulties" (Government of Malta, n.d.). Additionally, a number of institutions and NGOs also provide services and support to autistic individuals and their families Malta. These include The Inspire Foundation, who offer a Structured Training and Education Programme, 'STEP' as specialised programme for children on the autism spectrum through a multi-disciplinary team including speech and language pathologists, occupational therapists, physiotherapists and psychologists (Inspire, 2018), the Equal Partners Foundation, the Eden Foundation, the Malta Autism Centre (Malta Council for the Voluntary Sector, n.d.), HandinHand Malta, the Karl Vella Foundation, the Service Dog Malta Foundation, the National Parents' Society of Persons with a Disability and the Autism Parents Association (APA-M) Malta, amongst others.

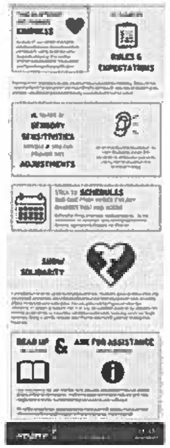


Figure 2.4 – Autism Awareness Infographic (Source: INSPIRE, n.d.)

Mata's low rates of segregated placement for learners with individual educational needs (van Kessel et al., 2020), means that the majority of students living with autism attend mainstream educational settings (Zammit, 2018; European Agency for Special Needs and Inclusive Education, 2014), while being provided with the support of LSEs (Sciberras, 2019). Nevertheless, little is known about whether adequate support structures for learning and participation are in place (Kurth et al., 2015; Sciberras, 2019). Calleja (2019, pp. 71) for instance noted that "children are included depending on their ability to adapt and keep up with the curriculum and not the other way round", while Callus and Farrugia (2013, pp. 35) commented that when it comes to autistic children, these are included in mainstream education depending on the "goodwill and commitment of their educators" and that especially when it comes to instances of challenging behaviour, these children are typically not fully included in the educational system in Malta.

Although there are public services and a number of private providers and NGOs working for autism, no official data is available regarding exact prevalence of autism in Malta (Mubashir et al., 2020; Zammit, 2018; Sciberras, 2019). While the EU estimate is reported to be approximately 1 in every 100 individuals (Baird et al., 2006), a 2014 audit reported a 60% increase in the number of children referred for support in relation to autism and attention difficulties between 2008 and 2012 (European Agency for Special Needs and Inclusive Education, 2014). Tanti Burlo' (2016) also estimated a prevalence of autism of 1 in every 52 births, pointing out that figures from the SMP indicate that the number could be greater than that. Meanwhile, Prisms Malta who coordinate a project advocating for autism friendly spaces (see Section 2.3.3.1) claim that there are 7,700 people with autism in Malta, and a consequent approximate 27,800 immediate family members who are affected (Prisms Malta, 2020a).

When it comes to counselling support available to young autistic people in Malta, it has been observed in local research that counsellors may tend to avoid disabled clients (Camilleri Zahra, 2014; Perera Vega, 2014). This highlights the need for further awareness and training addressing autism and disability among Maltese counsellors. Meanwhile, Bugeja (2014) observed that counselling with autistic clients should value differences and serve as a tool to develop client self-advocacy skills.

Autism in Adolescence and Adulthood in Malta

For adults there is no clear pathway for getting a diagnosis of autism. One way of getting a diagnosis is through a referral from a GP to discuss it with a psychiatrist or clinical psychologist. Limited awareness and diagnostics over recent decades means that many adults would not have been diagnosed as children. However, some adults with autism may not have the insight or skills to seek a diagnosis, may have developed coping mechanisms, or may feel that a diagnosis will not make any difference to their lives. Malta follows the NICE (NICE, 2021a) guidelines when it comes to the diagnosis of autism in adulthood. These are based on current evidence-based strategies for diagnosis and treatment (Wilson et al., 2014). They thereby lay forward recommendations on approaching diagnosis in adulthood through a comprehensive assessment, and, amongst others, specify that all staff members involved in the diagnosis process, have a thorough understanding of autism, its development, its impact on personal, social, educational, and occupational functioning, as well as the impact of the social and physical environment on the individual concerned (Pilling et al., 2012).

Amongst the diagnostic references, the guidelines outline issues in adulthood such as recurring difficulties in social exchanges or social communication, rigidity in behaviours, resistance to change, or restricted interests (NICE, 2021a). These traits would be accompanied by difficulties within the employment or educational sphere, challenges establishing or maintaining social relationships, the presence of other mental health issues or learning disability, or a history of a neurodevelopmental condition (for instance, ADHD) or mental disorder (NICE, 2021a). In its guidelines to carry out an assessment for the diagnosis of autism, a review of early developmental milestones, any behavioural difficulties, functioning skills at home, in education, or in employment, the presence of any physical, mental, neurodevelopmental, or neurological issues, communication skills and any sensory sensitivities and attention to detail are also reviewed. These are carried out though a diagnostic discussion accompanied by direct observation (NICE, 2021a). In the absence of an intellectual disability, the following assessment tools are proposed: the Ritvo Autism Asperger Diagnostic Scale – Revised (Ritvo et al., 2011), the Adult Asperger Assessment (Baron-Cohen et al., 2005), the Asperger Syndrome Diagnostic Interview (Gillberg et al., 2001), the ADOS-G (Lord et al., 2000), and the ADI-R (Lord et al., 1994). In cases of a concurrent intellectual disability, recommendations are made to use the ADOS-G (Lord et al., 2000) and ADI-R (Lord et al., 1994). The guidelines also propose the use of a formal assessment tool to organise the assessment of complex presentations, such as the Diagnostic Interview for Social and Communication Disorders (DISCO, Wing et al., 2002), ADOS-G (Lord et al., 2000), or ADI-R (Lord et al., 1994). The guidelines also make recommendations regarding pharmacological and psychological interventions, together with recommendations for service design that can support the development of specialist adult autism services (Wilson et al., 2014). Overall, these guidelines propose a structure, evidence-based, diagnostic approach that is carried out respectfully, while fostering the individual's independence, such as through allowing them to choose whether to involve family members and encouraging participation in self-help or support groups amongst possible interventions (Wilson et al., 2014).

Echoing findings from other researchers (e.g. VineFoggo & Webster, 2017; Potter, 2015), in her work with 5 autistic adolescents in Malta, Micallef (2019) observed that even though participants had typically experienced difficulties initiating or maintaining friendships, particularly within a group setting, they all valued friendships and expressed satisfaction when this was reciprocated, while at the same time, still also maintaining solitary pastimes. Most participants also expressed a desire to have an intimate relationship. Micallef (2019) in fact posits whether the partiality for aloneness is in fact rooted in past unsuccessful attempts to initiate and maintain successful friendships as a result of societal barriers. Micallef (2019) in fact also observed that the participants' identity and self-image was largely influenced by their friends' and society's perceptions of autism, viewing themselves as sick or deficient on account of others seeing them solely based on the characteristics that make them "autistic". She claims that "the lived experiences of the individuals with autism changes according to the way they are with others and more importantly the way that others are with them" (pp. 51). While being aware of their rights of being equal, participants in fact expressed acceptance of being treated as less and inferior to others in society. This, in turn, could easily lead them to believe they were less valued amongst friends and consequently lead them to withdraw from fully participating in society for fear of rejection. Dissatisfaction with friendships has often been reported in research with autistic people (e.g. O'Hagan & Hebron, 2017; Calder et al., 2013), and was observed with local participants in Micallef (2019)'s work too. Micallef (2019) suggests that these could be a consequence of the sense of feeling less worthy when compared to their neuro-typical peers, rather than a direct result of the autism diagnosis and an innate inability for successful relationships.

Zammit (2018) looked into the use of use screen-based media amongst a group of 24 autistic and 24 neurotypical adolescents in Malta. She observed a higher use of screen-based media to connect with familiar people and for leisure and academic activities amongst neurotypical adolescents, when compared to the autistic group. Nevertheless, she also reported that autistic adolescents preferred to make use of screen-based media independently rather than being accompanied, while both groups of adolescents favoured face-to-face communication rather than online interactions. An element of protectiveness also emerged, with parental perceptions surrounding screen-media mostly focused on risk and safety.

Numerous studies have often reported negative attitudes surrounding autistic people as a consequence of their social skills and particular behaviour (Someki et al., 2018; Fondelli & Rober, 2017; Payne & Wood, 2016; Swaim & Morgan, 2001). Notwithstanding the rising prevalence of autism in Malta and the daily presence of autistic students in mainstream schools, research indicates that simply being exposed to a person or people on the spectrum does not necessarily lead to an accepting approach and contact is not sufficient to overcome stereotypes and develop attitudes of acceptance, inclusion and friendship (Bonnici & Bartolo, 2021; Borg, 2009; Dimech, 2007). Pijl (2007) in fact points out that when disabled children are just physically included in school, and not given opportunities to participate and given equal opportunities as their peers through adequate support, friendships are not formed. People's perceptions of autistic individuals are typically founded in knowledge (Griffin et al., 2012; Nevill & White, 2011) and experience (Dillenburger et al., 2013) that these have with autistic people. Healthy interactions and exchanges have the potential to mould viewpoints and attitudes (Sammut, et al., 2012). This means that experiencing meaningful exchanges with autistic individuals can lead to the development of understanding and acceptance (Bonnici & Bartolo, 2021). Schools for instance, where inclusive practices provide learners with the opportunity to engage in meaningful, social interactions with diverse students, as well as other contexts in everyday society, can act as a catalyst for the development of a clear conceptualisation of autism, and to develop the necessary skills to interact with a diverse population. Educators can facilitate this inclusive approach by nurturing interactions amongst diverse students, including autistics learners, while openly addressing behavioural differences and modelling appropriate social responses (Bonnici & Bartolo, 2021). Schools have "the potential to equip neurotypicals with appropriate images of the strengths as well as weaknesses of persons with autism and with confidence in positive social interaction with them, paving the way for the younger generation to form an ideology that denotes equal status and acceptance" (Bonnici & Bartolo, 2021, pp. 18), thereby altering society's discriminatory attitudes. Supporting society, within different contexts, to engage and interact with autistic individuals, while openly discussing the motives behind behaviours that may come across as unusual, could further contribute towards this aim and foster inclusion and acceptance.

In 2013, the Ministry of Education in collaboration with the Malta Marigold Foundation launched a School Playground Initiative aimed at autistic children. This initiative provided safe playgrounds during the Summer months across a number of schools in Malta and Gozo where autistic children and their families can spend some peaceful time (APA, 2019a). In 2017, De

Martino brought forward a virtual experience designed to create a sensorial approach towards developing empathy and understanding around autism, particularly in the context of a classroom. Based on her belief that "despite teacher training, teachers as well as learners go to class largely unprepared for the arrival of an autistic classmate because they cannot fully visualise the experience that a person with that condition lives through" (De Martino, 2017, pp. v), through the use of a virtual reality application, De Martino's application allowed users to walk through the experience of an autistic child in a classroom and experience their perceptions such as sights, sounds, actions and interactions (De Martino, 2017; De Martino et al., 2016). That same year, the St Jeanne Antide Foundation (SJAF), in collaboration with APA-M launched its Social Integration Programme for Teens – 'SIPT'. SJAF is a local NGO that provides professional support services to very vulnerable individuals and families (SJAF, 2021). The programme provided aimed to support the development of community skills and provided fortnightly activities for young autistic adolescents (APA-M, n.d. a). It sought to empower autistic youths to participate in programs that would support their integration in society and develop their skills to be active participants in the community, while bridging the gap for these youths through outings and sessions held in-house and in the community (APA, 2019b). In 2018, Malta's International Airport (MIA) lit its facade in blue to honour World Autism Awareness week, and in doing so also launched a pilot programme that included initiatives aimed at easing the way to the aircraft for autistic individuals by providing additional assistance. This included pre-available visual guides, fast-check security screening, an identifier tag to alert staff members that an individual may need more time to process information and some additional help in preparing for check-in and security screening, access to quiet designated spaces and, in collaboration with Inspire, providing sensitivity training sessions for its members of staff (MIA, 2021; The Malta Independent, 2018b).

In 2019, Aġenzija Żgħażagħ, with the involvement of CRPD, launched an Autism Friendly Spaces project, aiming to promote a more accessible society and participation in social activities of young people on the autism spectrum. The project is being coordinated by Prisms Malta, a local youth workers NGO that caters for young people (Prisms Malta, 2020b) and involves a collaboration between Malta, North Macedonia, Spain and Belgium. It includes the direct involvement of 240 young autistic people, with an extended outreach claimed to include 8,000 people with 32,000 family members in Malta (Aġenzija Żgħażagħ, 2021b). Amongst its objectives, the project seeks to improve accessibility to public and private spaces through a Certification System and an app indicating these locations, improve awareness through nationwide campaigns, as well as the provision of online modules to strengthen the competences of educators and youth workers in order to better cater for young autistic people.

This initiative also includes a pilot youth hub designed specifically for autistic adolescents that will be facilitated by youth workers and led by youth with autism. At the time of writing, this project is still being executed and should be finalised in May 2022 (Aġenzija Żgħażagħ, 2021b; Autism Europe, n.d.).

As part of the project, Prisms are cooperating with several national and international stakeholders towards creating a positive change in the Maltese community, through awareness campaigns as well as providing guidance, training and consultations to better cater for autistic people (Prisms Malta, 2020a; Valyou, 2019). In 2019 in fact, a local chain of supermarkets was the first to launch a pilot weekly 'quiet hour' for autism shopping (Valyou, 2019). The chain supermarkets committed to reduce noise and lighting during these weekly hours, through modifications such as turning off of music and cash register and scanner sounds, minimising of PA announcements, the removal of roll cages, reduced trolley and basket clashing sounds and having prepared items at point such as the deli counter in order to minimise sounds.

> *"We are investing in training our team members to increase their understanding of sensory overload and how to best respond to the needs of our customers. Although we have modified some of the physical and sensory stimulators in the supermarkets, we also hope to achieve a 'no-judgement' shopping space for people and families on the spectrum, where customers will feel comfortable and welcome"* (Dalli Mintoff, General Manager, Valyou Supermarket, Mellieħa)

Similarly, other local spaces are also following suit. Initiatives to improve accessibility or created adaptions for regular periods of times in order to address the needs of autistic people are emerging. In 2019, a local chain of cinemas and entertainment complexes also launched their monthly sensory friendly screenings in collaboration with APA-M (Eden Cinemas, 2019). Claiming to be "all in the same boat", the complex provides trained staff, softer lighting, no ambient music and lower screening volume, earlier screenings to give access to the site at quieter hours, advanced booking to reduce queuing, pre-popped popcorn to reduce audio and visual stimuli, minimal decorations, manual checking of tickets to remove beeping electronic devices, flexibility with seating, no advertising prior to the movie, refunds if a child changes their mind and does not wish to enter the theatre, as well allowing for own food and drink of choice to be brought from home (APA-M, 2021; 89.7 Bay, 2020). That same year, Malta's first autism-friendly museum was also launched (Borg, 2019). Stating that accessibility should not relate only to physical terms, this initiative saw the Mdina Cathedral Museum improve accessibility for people on the spectrum. This was done through preparatory information and a visual guide provided beforehand to help plan their visit, the option to have a practice run prior to the visit, extended opening hours on particular days to make the site available during quieter hours, resources to aid them during their visit such as a multisensory map pointing out areas which may have higher sensory stimuli and noise-cancelling headphones, access to a 'safe room' for anyone who may need some quiet time, as well trained museum employees and management (Mdina Metropolitan Museum, n.d.); Borg, 2019; Times of Malta, 2019).

In July 2020, a local interactive science centre also launched their autism friendly hours. They provided ambient adjustments through lower volume and softer lighting of attractions in order to allow neurodiverse adults and children to experience the space. A social story was also drawn up by the science centre to aid autistic children prepare for their visit, while fidget toys, ear defenders, weighted blankets and access to a quiet family room is were also made available (Esplora 2020a; DOI, 2019). This initiative is still being carried out by the centre every two months and includes a map highlighting noisy exhibits for those who may wish to avoid them, a trained team and autism friendly workshops and science shows (APA-M, 2021; Esplora, 2021a). The centre also offers subsidized entrance fees for disabled individuals aiming to facilitate their right to education and leisure experiences as members of society. It also committed to providing experiences and activities at their attractions that are aimed at individuals with intellectual disabilities, while developing further joint activities in collaboration with CRPD (Esplora, 2021b). During the same year, the centre also set up a multisensory room through an agreement between a local bank and MCAST (Bank of Valletta, 2020). More recently, in 2021, other similar autism friendly initiatives are coming about, such as the autism and ADHD friendly hour at a local waterpark (APA-M, 2021).

At the start of World Autism Month, Malta's Marigold Foundation holds a symbolic gathering together with APA-M outside Mdina Gate (Times of Malta, 2020). Similarly, the Foundation collaborates with the international autism advocacy group AutismSpeaks (APA-M, n.d. b) and a number of local landmarks are lit up blue to raise awareness about autism (Times of Malta, 2020; APA-M, n.d. b). These initiatives have also started to appear in other contexts. For instance, a local group of companies promoted awareness by dressing in blue throughout Autism Awareness Month, aiming for "greater acceptance and understanding" (Atlast Group, 2017). In 2021, Malta Public Transport announced that they were collaborating with the Malta Trust Foundation and that funds generating from children's public transport traveller cards were going to be used to purchase equipment aimed at aiding autistic children (TVM, 2021).

2.5 ADHD in Malta

In Malta, it was observed that 5.4% of children are living with ADHD (Camilleri et al., 2017), with the incidence of diagnosis reporting to have increased over the last twenty years and alongside this, observing an increase of people who were started on Ritalin treatment (Galea et al., 2014). In 2019, Role et al. also added that socioeconomic status may to play a role in the incidence of ADHD and observed higher rates of ADHD present in the Northern and Southern harbour districts, areas typically associated with low socioeconomic status.

A psychologist or psychiatrist are involved in the diagnosis of ADHD in Mata. Normally, this is carried out following a referral by a doctor, educational institution or after having being referred by the parents/guardians or the person themselves in the case of adults. According to Saliba et al. (2018), assessment for ADHD diagnosis typically takes place at CDAU and is compiled with the involvement of a multidisciplinary team. They reported that following this assessment, children are subsequently transferred to the care of CYPS for additional assessments and the provision of support measures and treatment. Saliba et al. (2018) in fact observed that this could be cause for unnecessary delays and challenges for the children and their families, pointing out inadequate client to staff ratios and the no set treatment protocols, as well as waiting periods as factors that could be impacting the efficiency of practices being implemented.

In addition to public and private channels of support and treatment, a local NGO, ADHD Malta is also present in the local scenario. The group organises regular meetings for families of diagnosed individuals and for adults with ADHD (ADHD Malta, 2020). ADHD Malta was established in 1996 by a group of parents of ADHD adolescents as a result of a need for more information and support locally. The NGO is a member of ADHD Europe and the Malta Heath Network (ADHD Malta, 2019a). It offers parenting-skills courses providing techniques for families of people living with ADHD as well as ADHD Coaching courses that focus on communication, challenges and strengths, and different strategies to use, both for professionals working with people with ADHD as well as for adults with ADHD. The organisation also works on creating awareness and providing resources and support to families locally.

3. Methodology

This section presents a discussion on the tools and approaches applied towards understanding and gathering data regarding the experiences of people living with autism and ADHD and their families. These methods were undertaken with the objective of gaining a comprehensive understanding of the state of play of experiences and services within the local scenario.

Rationale and Research Agenda

This study sought to understand the experiences of autistic persons and those living with Attention Deficit Hyperactivity Disorder (ADHD), as well as families within the local context, looking into how current support structures impact their livelihood. In terms of the landscape of services currently available, this project sought to highlight insider voices, by engaging with the needs, concerns, and aspirations of the families concerned, while ensuring it gave a voice and listened to persons who were diagnosed themselves in order to promote more effective and accessible channels of support.

The way in which autism and ADHD are expressed will vary across individuals and during different age brackets. In this respect, any person living with these conditions may change over time as they mature and their skills may develop in response to environmental demands and interventions, and in the context of co-existing conditions (NICE, 2021b). This means that for the purposes of this study, autism and ADHD constitutes a heterogenous group of people in different age groups, which may have different needs and experiences. The transitions from childhood into adolescent years towards subsequent adulthood bring with them several evolving developmental changes and challenges. In this report, the lifespan is being subdivided into further distinct developmental stages: childhood and early adolescence, and adolescence (referring to late adolescence) and adulthood. This report therefore attempts to 'take stock' of the status of the evidence base, listening to the voices of those concerned and their experiences with local services and within the wider local community as a whole, identifying any gaps in services or data along the way.

This project aims to:

- Establish the demographic dispersal of people in Malta with autism and ADHD;
- Explore available public, private, and NGO-led services catering for these individuals;
- Engage with families and concerned individuals to discover their experiences of persons with Autism and AD(H)D as they navigate through services;
- Develop relevant policy and action actions in the light of current and agreed disability related policies;
- Locate experiences of discrimination surrounding the experiences of persons on the spectrum or with ADHD.

Research Approach

The above-mentioned objectives shall be attained through a mixed research design, comprising:

(i) A literature review of international research relating to autism across the lifespan;

(ii) A review of local literature in relation to autism across different aspects of life;

(iii) Demographic data extraction

(iv) Stakeholders' feedback about the state of play of autistic people's needs vis-a-vis the services offered to them. These include experts in the field, related NGOs, and specialist therapeutic services, amongst others;

(v) The voices of autistic people regarding their experience in the local context

(vi) The views of family members of autistic people.

Following a review of international findings, available local data was reviewed to sketch a picture of the current state of play surrounding autism in Malta, while bringing to light any gaps in data within the local context. The findings of these reviews informed the research approach undertaken for this report.

Literature Review

Systematic literature reviews provide an opportunity to collate literature addressing a specific subject in a structured manner thereby providing insight towards the topic in question. A literature review was conducted as a first step in order to frame the approach undertaken for the purposes of this study and gather an understanding of current research on the concepts of autism and ADHD. Local projects and student dissertations, together with related research projects by University of Malta academics can serve as a valuable source of information on various aspects of the experiences of autistic people and their families. Although sample sizes tend to be small, they give a snapshot on selected issues of concern. A number of local research projects and dissertations were therefore also identified through the University of Malta Library portal HyDi, and Institutional Repository, OAR@UM. These included searches from using key search terms such as 'autism', 'ASD', 'autistic people', 'people with autism' and respective searches related to ADHD. Other literature reviewed included research projects carried out by CRPD as well as academic staff and students at the Department of Disability Studies at the University of Malta, together with references in dissertations reviewed. The dissertations included for the purposes of the review were those focused on the topic of autism, ADHD and, where relevant, disability, in the Maltese context as a main topic, giving importance to the most significant findings and recommendations brought forward. Where significant, the sample size was also referenced.

Data Collection Strategy

Following ethical clearance by the Social Wellbeing's Faculty Research Ethics Committee at the University of Malta, the following data collection approach was implemented. A multifaceted research approach was applied for the collection of data from various sources, in order to present a richer and fuller picture, and allow for the shortfalls inherent in any one type of data to be compensated for by other means of data collection (Wilson, 2014). Data triangulation also allows for better validity and reliability of results, especially in cases where questionnaires are used but stratified sampling is not used, as in this study (Nayak & Narayan, 2019). Informed consent was obtained prior to participation in throughout this exercise.

Informed consent, Confidentiality and Anonymity

All participants throughout the data collection exercise were required to be over 18 years of age. The research participants involved in this study were informed in advance about the detailed purpose and aims of the research, as well as what would be expected from them. This was presented to them in writing prior to completion of the questionnaire (see Appendices A, B, C and D) and through an information letter (Appendices E and F) in the case of interview participants. Written consent was requested from interview participants prior to participation in the interviews (Appendices G and H). Voluntary participation in the project was guaranteed.

Meanwhile, interview participants could withdraw from the research at any stage until not later than one month from the date of the interview, while questionnaire participants could withdraw their participation at any point prior to submitting the questionnaire. Participants were informed that their data would be coded and pseudonymised for use throughout the study and that no identifying details (names, emails or IP address) will be noted, ensuring their responses cannot be identified. Ethical clearance was sought and given by the University of Malta's Research Ethics Committee prior to commencement of the data collection exercise.

Quantitative

Service provider questionnaires were disseminated between July and August 2022 while service user questionnaires were disseminated between August and September 2022. This was carried out largely via email across professionals in the field through a series of institutions and organisations in the sector that were identified by a Technical Advisory Committee assigned to this project and was also advertised on the Faculty for Social Wellbeing's social media channels online in order to attract the participation of various professional service providers in the sector. Meanwhile, participation of service users was also invited through the involvement of local NGOs representing autistic people and persons with ADHD that acted as gatekeepers for the purposes of this study, as well as through professionals and service providers in the field and the Faculty for Social Wellbeing's social media channels and word of mouth.

Professional and Service Provider Questionnaire

An online consultation exercise was undertaken through establishing two GoogleForm questionnaires through which feedback could be gathered across interested parties. These questionnaires (Appendix A and B) were disseminated across service providers that cater locally for persons with autism and/or ADHD respectively. Participation in the questionnaires was on a voluntary basis and required 10-15 minutes to complete. A total of 25 and 33 complete questionnaires were submitted for ADHD and autism service providers respectively. The questionnaire focused on gathering the views and experiences of service providers that offer services in Malta. Participants were offered the opportunity of completing the questionnaire electronically following a link online and were also offered the opportunity to request a printed copy. No direct benefits were extended to participants who chose to complete the questionnaire, other than to help better the experiences of autistic individuals and persons with ADHD with local services offered to them.

Service User Questionnaire

A questionnaire was also disseminated across service users. This refers to both caregivers of persons making use of services (Appendix C), or the services users themselves (Appendix D). In the case of caregivers who cared for more than one diagnosed person, these were asked to complete the questionnaire in relation to one individual and were offered the opportunity to complete the survey once again for a second diagnosed person they act as caregiver should they wish. Once again, participation in the questionnaire was on a voluntary basis and in this case, required 5-10 minutes to complete. A total of 163 caregiver questionnaires and 9 service user completed questionnaires were submitted. This exercise sought to bring insight into the lived experiences of persons with autism and ADHD in order to identify their needs but also their aspiration and ambitions. Participants were offered the opportunity of completing the questionnaire electronically following a link online and were also offered the opportunity to request a printed copy. No direct benefits were extended to participants who chose to complete the questionnaire other than contributing to the purposes of the study.

Qualitative

Recruitment of participants and the qualitative interviewing process for this research was carried out between July and August 2022. This was done through the involvement of local NGOs representing autistic people and persons with ADHD that acted as gatekeepers for the purposes of this study, as well as the Faculty for Social Wellbeing social media channels and word of mouth. Gatekeepers were provided with material to facilitate their dissemination efforts and ensure a consistent, clear message across outreach efforts. Informed consent was obtained prior to participation in the interviews (see Appendices G and H).

Interviews with Caregivers and Service Users

Data for this study was collected through 12 in-depth interviews. Of these, 6 were focused on autism, with 3 being carried out with caregivers of persons living with autism and another 3 being carried out directly with persons living with autism. The caregivers were parents of males aged 11, 13 and 15. The autistic adults were females. Another 6 interviews were focus on ADHD, with 3 carried out with caregivers and another 3 carried out directly with persons living with ADHD. Of these, 1 service user participant was living with both autism and ADHD; whilst 1 caregiver cared for a child who was living with both autism and ADHD, and another cared for a child who was living with ADHD and mild intellectual disability. The aim of participation in the interviews was to help contribute to a better understanding of the experiences of persons with autism and ADHD within the local context.

In-depth qualitative interviews can yield in-depth views of the issues under investigation through thematic analysis (Clarke & Braun, 2017). Participation in the interviewing process was entirely voluntary and did not entail any known risks. Nevertheless, participants were extended a list of support services that could assist them should they feel the need for support in relation to the topics discussed during the interview. Participants were informed beforehand about what their participation would involve and written consent was sought from them prior to the interview. This part of the data collection exercise was carried out through one-time interviews that were held online via Zoom where participants were asked to discuss their views regarding their / their offspring's experience and aspirations as a person living with autism and/or ADHD. Participants were assured that any personally-identifiable details will not be used in the study or disseminated in any way and that following the interviews, the researchers will transcribe and code the data gathered where any data will be pseudonymised so their identification will remain confidential.

The interviewing tool adopted was a structured interview (Appendices I, J, K and L). This research tool organised the interview into a number of sections, such as the participants' experience with their diagnosis process, accessing services and coordination across these, examining patterns of recent service use, and current top 5 services needed, as well identifying participants' ambitions for the national landscape. The inclusion of caregivers as well as direct service users allows for a comparison of perspectives on service needs across these different age groups and perspectives. These are critically important to consider for the development of clinical interventions, policy and programs for autistic individuals of all ages, together with their families/caregivers. During each interview attention was given to ensuring that the participants felt comfortable and secure enough to share details of their experience in the agreed interview format. The interviews were all conducted in English and/or Maltese based on participants' preferences. All interviews were audio recorded and transcribed for subsequent thematic analysis.

Data analysis strategy

The data analysis followed a number of steps (Braun and Clarke, 2006):

- Familiarisation;
- Coding;
- Generating themes;
- Reviewing themes;
- Defining and naming themes

The data analysis process used a systematic coding strategy designed to identify and classify themes and concepts that emerged from the qualitative data collected. This rigorous process of analysis protects against researcher bias while attaining detail and consistency. Credibility is crucial to establishing trustworthiness in qualitative research through a faithful representation of the data. A few credibility strategies were therefore adopted. The first concerned the use of a skilled and experienced interviewer. Secondly, a systematic set of procedures to analyse the transcript data was adopted. The process was also subjected to expert review through regular exchanges and consultations where the transcripts, along with the emerging codes, were discussed among the research team. This validation process increases the rigour of the findings of the study and strengthens the trustworthiness, accuracy and validity of the results by confirming the participants' intended meanings.

4. Research Findings - The experience of autism and ADHD in Malta

This chapter will bring together the findings from data collection exercises carried out for the purposes of this research project. The findings exposed through the research questionnaires distributed across service providers and service users are presented, observing trends emerging from the data gathered. These findings from the questionnaires will then be further developed through a discussion that reviews these in relation to data collected from the interviews carried out through the qualitative branch of this study carried out with direct service users and caregivers of service users.

4.1 Findings from the Quantitative Data

4.1.1 Service Users' views on the services for persons with Autism and/or ADHD

This research study undertook as part of the objectives, to examine the lived experiences of service users. Congruent to the service user experience, for this particular population, is that of caregivers for persons with autism and/or ADHD, i.e., those who provide care for underage persons or those who are unable to express themselves.

Findings from the Service User Questionnaire

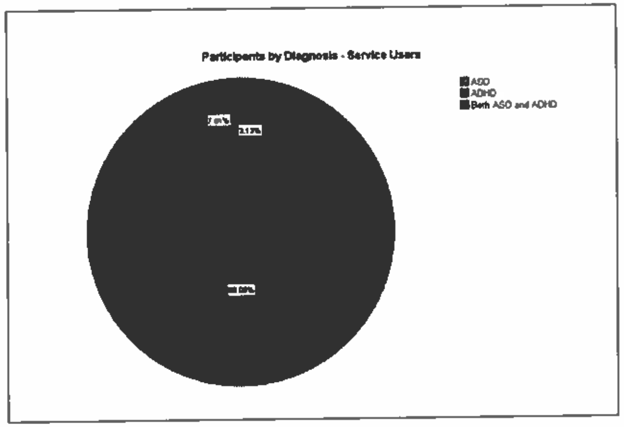
This section will examine the data collected from the responses to the Service User questionnaire for persons with autism and/or ADHD. Based on the literature, other studies and consultation with experts, the questionnaire asked service users demographic questions such as age, gender, district, level of education, employment status, household composition, their experience with their condition as well as their experience with accessing services and barriers to services.

In all, 64 valid responses were received from Service Users having autism, ADHD or a combined diagnosis of autism and ADHD. The majority of respondents have a diagnosis of ADHD (89.06%, *n*=57), while only 3.1% of respondents (*n*=2) have a diagnosis of autism. A further 7.87% have a combined diagnosis of both autism and ADHD. The greater prevalence of responses from persons having a diagnosis of ADHD does not necessarily reflect the distribution within the population as this was a random sample and is not indicative of numbers within the general population. Responses from persons living with autism are better reflected in the Caregiver Questionnaire, which will be discussed below in Section 4.1.2.

Table 4.1.1 – Service Users: Respondent by Diagnosis

Distribution of Sample by Diagnosis		
Diagnosis	**Frequency**	**Percent**
ASD	2	3.1
ADHD	57	89.1
Both ASD and ADHD	5	7.8
Total	**64**	**100.0**

Figure 4.1.1 – Number of Respondents by Diagnosis

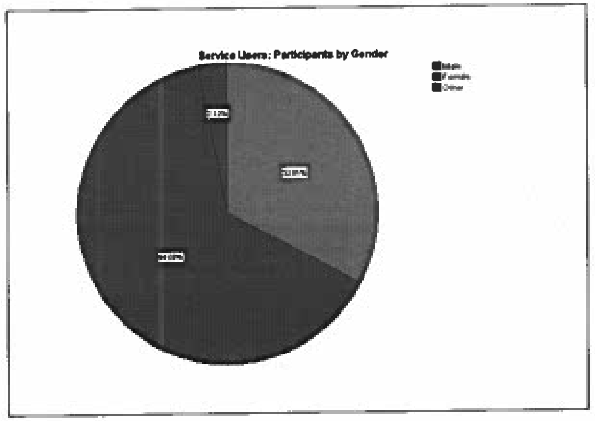


64.1% (*n*=42) of respondents were female, while 32.8% were male (*n*=21), and another 3.1% (*n*=2) reported their gender as 'other'. Table 4.1.2 refers. Research shows that autism affects males more than females, possibly by as much as a difference of 4:1 (Halladay et al., 2015). However, with ADHD, although underdiagnosis could be due to the milder manifestation of symptoms in females (Ratto et al., 2018). Mowlem et al., (2019) report that with ADHD, females are also less diagnosed than males, with a ratio of 2:1 to 10:1, but that for this condition the gender difference in diagnosis is due to differences in how ADHD manifests in females as opposed to males, and to diagnostic criteria that do not always take these differences into account. Within this cohort, respondents were overwhelmingly female. This does not necessarily mean that females are more affected than males by these conditions, but it does show that females as well as males are affected. The finding that females have responded more readily to the questionnaire than males is also in line with the findings of Smith (2008), whose research, in a study examining factors influencing responses to surveys, confirmed that females tend to reply in greater numbers to questionnaires and surveys.

Table 4.1.2 – Service Users: Participants by Gender

Service Users - Distribution by Gender		
Gender	**Frequency**	**Percent**
Male	21	32.8
Female	41	64.1
Other	2	3.1
Total	**64**	**100.0**

Figure 4.1.2 – Service Users: Participants by Gender



Regarding age group of respondents, the majority of respondents, 39.1% (*n*=25) were aged 26-35, followed by 25% of respondents (n=16) who were aged 36-45, while a further 21.9% (*n*=14), were aged 18-25. A cumulative 12.5% (*n*=8) were aged 46 to 65, while the remaining 1.6% (*n*=1) did not reply to this question (Table and Figure 4.1.3).

Table 4.1.3 – Service Users: Participants by Age Group

Service Users - Distribution by Age		
Age Group	**Frequency**	**Percent**
No Reply Given (NRG)	1	1.6
18-25	14	21.9
26-35	25	39.1
36-45	16	25.0
46-55	5	7.8
56-65	3	4.7
Total	**64**	**100.0**

Figure 4.1.3 – Participants by Age Group

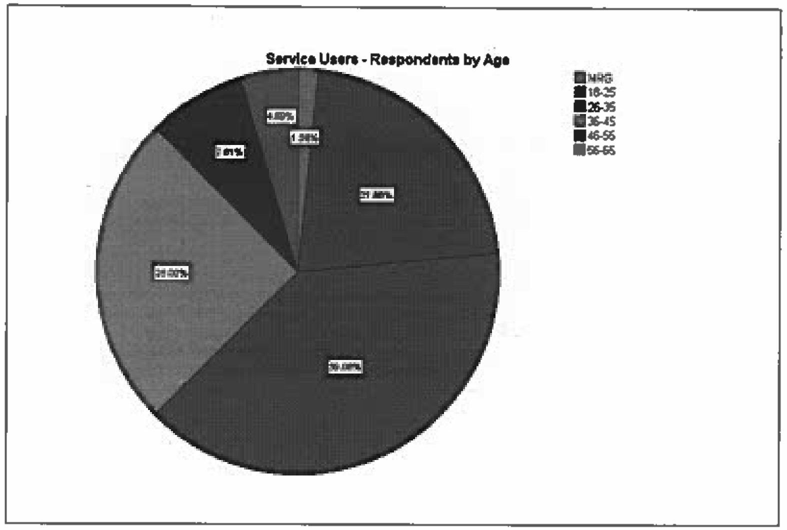


Table 4.1.4 – Service Users: Distribution of Sample Population by Gender and Age Group

Distribution of Population by Age and Gender								
Age Group	**Gender**							
	Male		**Female**		**Other**		**Total**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
No Reply Given	0	0	1	1.6	0	0	1	1.6
18-25	6	9.4	7	10.9	1	1.6	14	21.9
26-35	4	6.3	20	31.3	1	1.6	25	39.2
36-45	8	12.5	8	12.5	0	0	16	25.0
46-55	1	1.6	4	6.3	0	0	5	7.9
56-65	2	3.1	1	1.6	0	0	3	4.7
Total	21	32.9	41	64.2	2	3.2	64	100.3*

* This figure is not an exact 100 because of rounding up of percentages

An examination of the gender of respondents compared to their age group shows that the majority of respondents were aged 18 to 45, while responses for those aged over 56 years of age were lowest. For all the age groups, females responded in greater numbers than males, except for the age group 36-45, where the split between male and female respondents was equal, at 12.5% each. A Pearson's Chi square test was performed, but no significant association was found for age and gender, as the p-value was greater than the 0.05 level of significance.

Regarding the geographical distribution of service users who replied to the questionnaire (see Table 4.1.5 and Figure 4.1.4), the greatest number of respondents live in the Northern Harbour region (32.8%), followed by the Northern region (25%). As expected, with 4.7%, Gozo and Comino had a smaller distribution, which compares to the population share of persons living in Gozo and Comino. Figure 4.1.5 refers. Figure 4.1.5 shows that the district share of persons who responded to the questionnaire is roughly comparable to the share of population living in the district, meaning that although the questionnaire responses are not representative of the population, replies do show trends within the sample population and can be indicative of trends within the geographical spread.

Table 4.1.5 – Service Users: Participants by District

Service Users - Distribution by District		
District	**Frequency**	**Percent**
Gozo and Comino	3	4.7
Northern Harbour	21	32.8
Southern Harbour	8	12.5
South Eastern	9	14.1
Western	7	10.9
Northern	16	25.0
Total	**64**	**100.0**

Figure 4.1.4 – Service Users: Participants by District

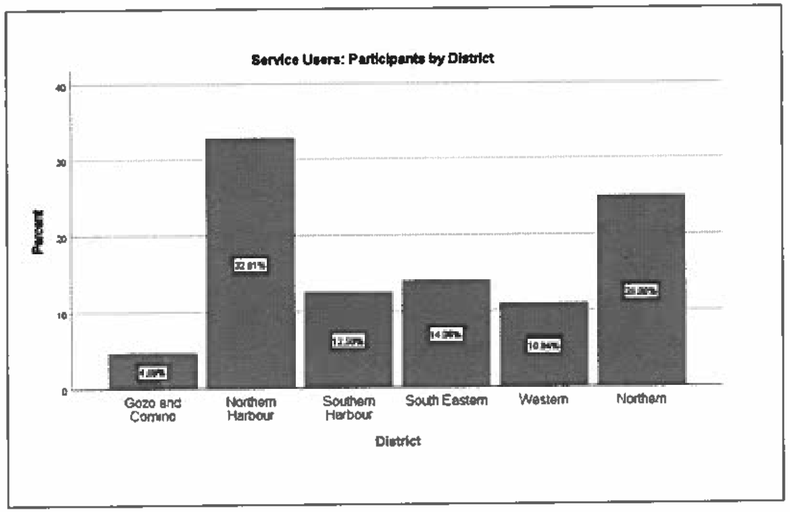


Figure 4.1.5 – Service Users: Comparison of District Distribution - Sample vs Population

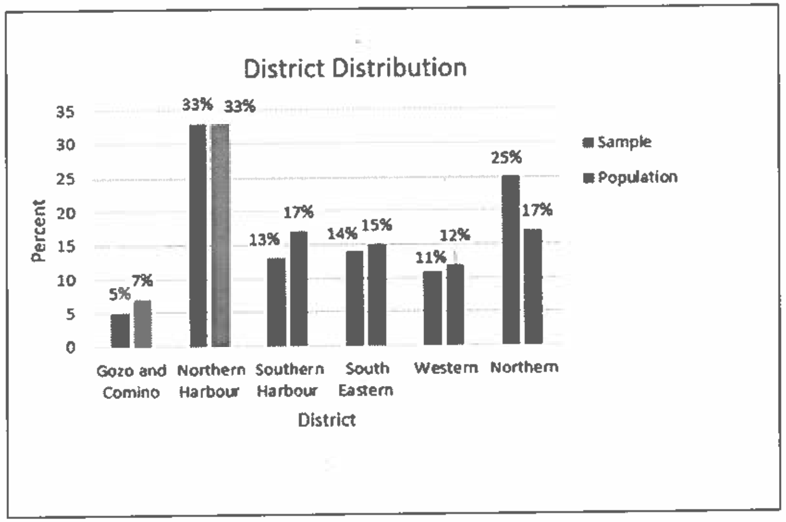


Table 4.1.6 – Service Users: Participants by Level of Education

Service Users - Education Level Distribution		
Level of Education	**Frequency**	**Percent**
Primary Level	9	14.1
Secondary Level	4	6.3
Post-Secondary/ Vocational Level	14	21.9
Tertiary Level	24	37.5
Post Graduate Level	13	20.3
Total	**64**	**100.0**

Over half of respondents to the Service user questionnaire have obtained a high level of education, with 57.8% (*n*=37) having obtained a degree, of which 20% (*n*=13) have a post-graduate degree, and a further 22% having attained at least post-secondary/vocational education. Table and Figure 4.1.6 refer.

Figure 4.1.6 – Service Users: Participants by Level of Education

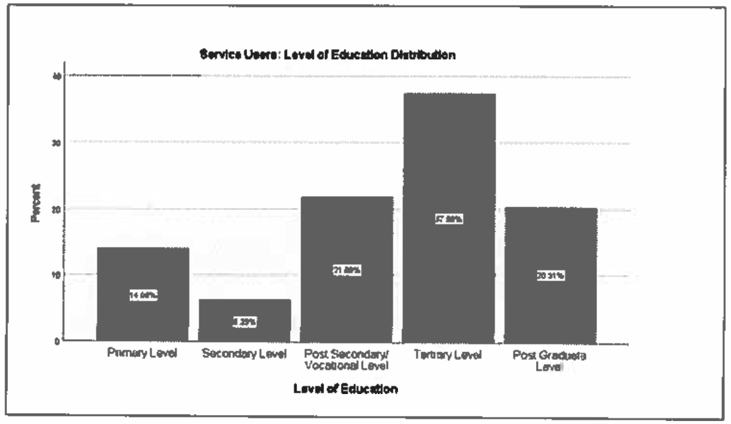


Table and Figure 4.1.7, below, show the sample distribution by employment status. This shows that the majority of respondents are in full-time employment, with a cumulative 15.6% who replied unemployed or other to this question. Meanwhile, Table and Figure 4.1.8 illustrate the household status distribution of the sample.

Table 4.1.7 – Service Users: Participants by Employment Status

Employment Status Distribution		
Employment Status	**Frequency**	**Percent**
Self-employed	11	17.2
Full-time Employment	31	48.4
Part-time Employment	8	12.5
Casual Employment	3	4.7
Unemployed	7	10.9
Retired	1	1.6
Other	3	4.7
Total	**64**	**100.0**

Figure 4.1.7 – Service Users: Participants by Employment Status

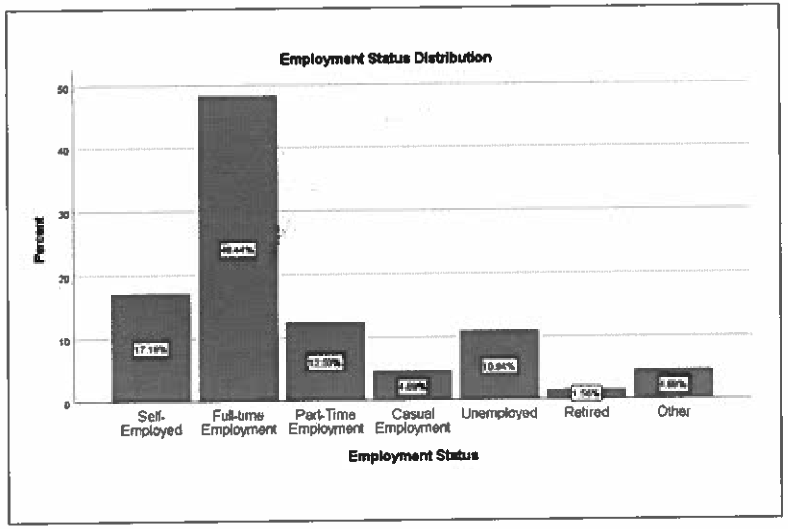


Table 4.1.8 – Service Users: Participants by Household Status

Household Status Distribution		
Household Status	**Frequency**	**Percent**
No Reply Given	10	15.6
Family with 2 parents	23	35.9
Family with 1 parent	7	10.9
Parent and step-parent household	1	1.6
Living Independently	9	14.1
Live independently with another adult or own family	14	21.9
Total	**64**	**100.0**

Figure 4.1.8 – Service Users: Participants by Household Status

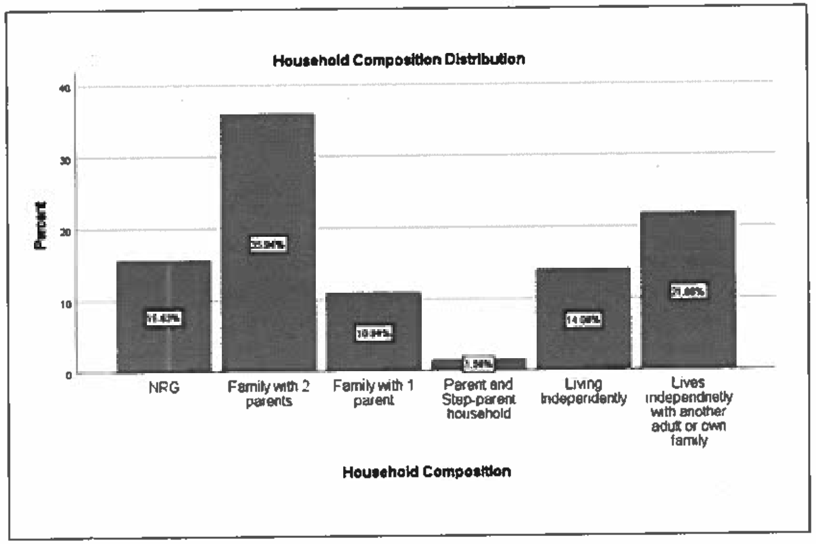
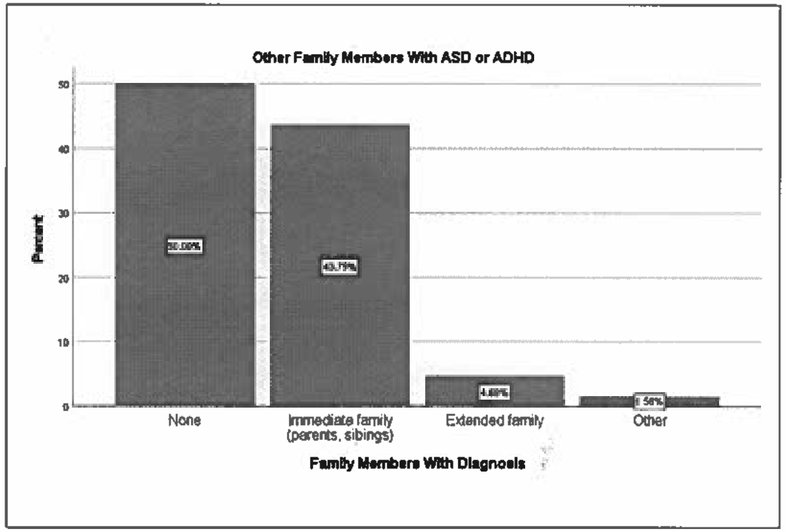


Table and Figure 4.1.9, below illustrate participants who have other family members with an autism or ADHD diagnosis. These visual representations illustrate that half of respondents have immediate, extended or other family members who have also received a diagnosis of autism and/or ADHD. 88% of those who replied that they have family members with a diagnosis, i.e. the vast majority, are immediate family members. Keeping in mind that the majority of persons answering this questionnaire have a diagnosis of ADHD, this is in line with findings in ADHD research (Miller et al., 2018; Ramaswami & Geschwind, 2018) outlining that there is a genetic component to these conditions, particularly ADHD.

Table 4.1.9 – Service Users: Participants with Other Family Members Having ASD or ADHD Diagnosis

Distribution by Other Family Diagnoses		
Family Member	**Frequency**	**Percent**
None	32	50.0
Immediate Family	28	43.8
Extended Family	3	4.7
Other	1	1.6
Total	**64**	**100.0**

Figure 4.1.9 – Service Users: Participants with Other Family Members Having ASD or ADHD Diagnosis



As mentioned in the literature review in Chapter Two, the age of diagnosis is extremely important for persons with autism and/or ADHD, as early diagnosis and intervention are widely considered to lead to better outcomes (Gabbay-Dizdar et al., 2022; Miller et al., 2018; van 't Hof et al., 2021). Table and Figure 4.1.10, below, show the age at diagnosis distribution of the sample. This illustrates that the age group with the greatest number of diagnoses was ages of 31-64 years of age (45.3%, *n*=29), which indicates that a number of diagnoses are happening in adulthood and later adulthood, that is, after the age of 17 years. Table and Figure 4.1.11 present a visual representation of the sample distribution of age at diagnosis and age.

An examination of association for diagnosis and age at diagnosis reveals that these two factors are significantly associated for this cohort, as the Pearson's Chi-square test returned a p-vale of 0.002. However, despite the fact that the literature shows that females tend to be diagnosed later or not at all, gender was not found to be significantly related to age at diagnosis, as a Pearson's Chi-square test testing for significant association between these two factors returned a p-vale greater than the 0.05 level of significance. Table and Figure 4.1.12, below, present the sample distribution of age diagnosis by gender.

Table 4.1.10 – Service Users: Participants by Age at Diagnosis

Age at Diagnosis Distribution		
Age at Diagnosis	**Frequency**	**Percent**
0 to 5	3	4.7
6 to 11	5	7.8
12 to 16	5	7.8
17 to 24	10	15.6
25 to 30	12	18.8
31 to 64	29	45.3
Total	**64**	**100.0**

Figure 4.1.10 – Service Users: Participants by Age at Diagnosis

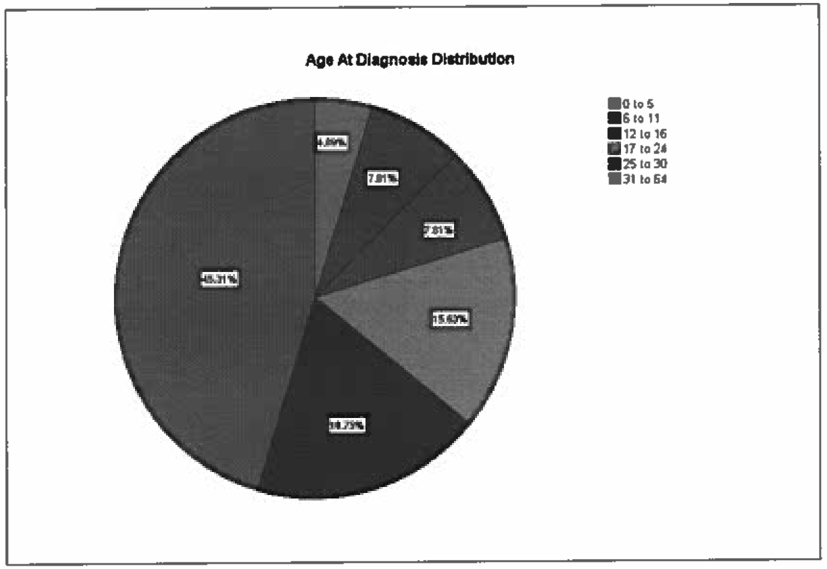


Table 4.1.11 – Service Users: Distribution of Sample by Diagnosis and Age at Diagnosis

Diagnosis by Age at Diagnosis Distribution														
Diagnosis	**Age at Diagnosis**												**Total**	
	0 to 5		**6 to 11**		**12 to 16**		**17 to 24**		**25 to 30**		**31 to 64**			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
ASD	1	1.6	0	0.0	0	0.0	1	1.6	0	0.0	0	0.0	2	3.1
ADHD	0	0.0	5	7.8	5	7.8	9	14.1	10	15.6	28	43.8	57	89.1
BOTH	2	3.1	0	0.0	0	0.0	0	0.0	2	3.1	1	1.6	5	7.8
Total	3	4.7	5	7.8	5	7.8	10	15.6	12	18.1	29	45.3	64	100

Figure 4.1.11 – Service Users: Distribution of Sample by Age at Diagnosis and Age

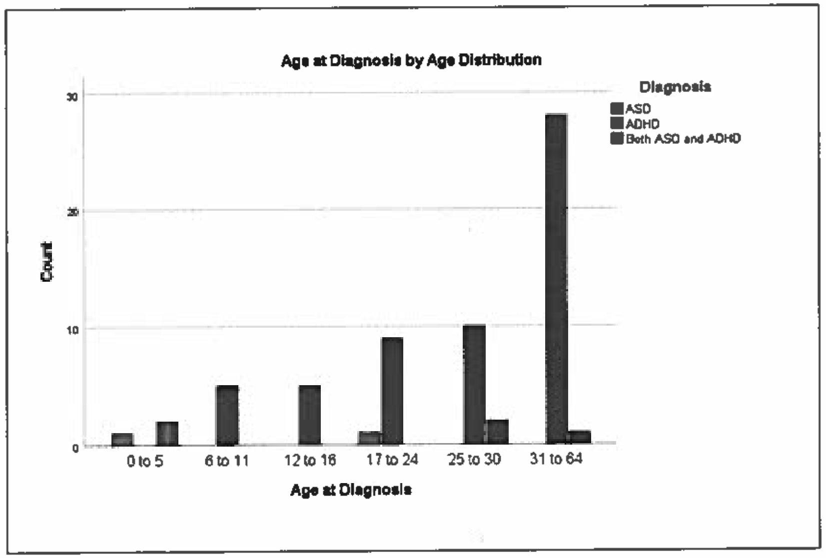
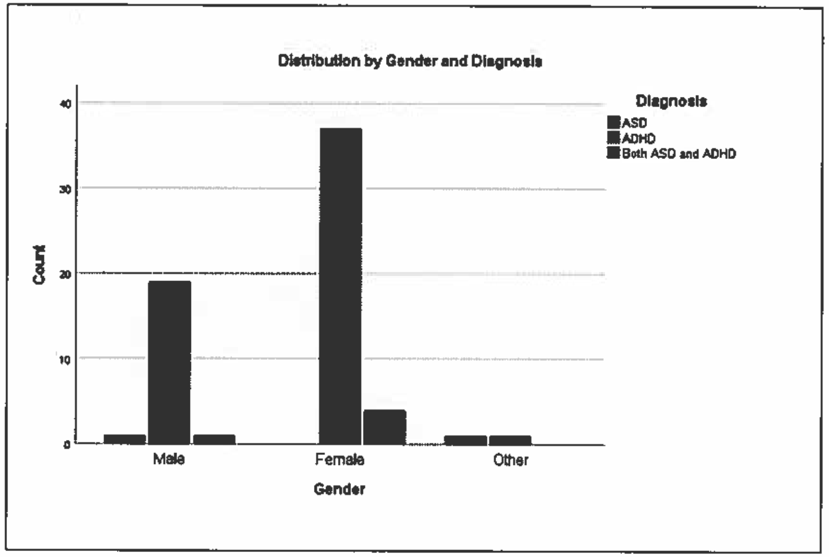


Table 4.1.12 – Service User: Distribution of Sample by Gender and Diagnosis

Distribution by Gender and Diagnosis								
Diagnosis	**Gender**						**Total**	
	Male		**Female**		**Other**			
	No.	%	No.	%	No.		No.	%
ASD	1	1.6	0	0.0	1	1.6	2	3.1
ADHD	19	29.7	37	57.8	1	1.6	57	89.1
BOTH	1	1.6	4	6.3	0	0.0	5	7.8
Total	21	32.8	41	64.1	2	3.1	64	100

Figure 4.1.12 – Service User: Distribution of Sample by Gender and Diagnosis



The questionnaire also asked respondents to rank their satisfaction with the diagnosis process, accessing service once the diagnosis was received, and with how the services were linked together. Replies were ranged on a likers scale and ranged from Least Satisfied, Nor Satisfied, Neither Satisfied nor Dissatisfied, Satisfied, through to Very Satisfied.

A relatively large number of respondents (44%, *n*=28) reported being satisfied or very satisfied with the diagnostic process, while 30% reported being Least Satisfied or Not Satisfied with the process. Table and Figure 4.1.13 refer. However, when it came to expressing satisfaction with access to services post-diagnosis, the majority (61%, *n*=39) replied least satisfied or not satisfied while only 25% (*n*=16) replied that they were satisfied or very satisfied. Table and Figure 4.1.14 refer. Similarly, when asked for their views on how services are linked, 63% (*n*=40) expressed themselves to be either least satisfied or not satisfied, with only 16% replying that they were satisfied or very satisfied. Table and Figure 4.1.15 refer.

Table 4.1.13 – Service User: Distribution of Satisfaction level with Diagnosis Process

Satisfaction Level with Diagnosis Process		
Satisfaction Level	**N**	**%**
Least satisfied	3	4.7
Not Satisfied	16	25.0
Neither Satisfied nor Dissatisfied	17	26.6
Satisfied	18	28.1
Very Satisfied	10	15.6
Total	**64**	**100**

Figure 4.1.13 – Service User: Distribution of Satisfaction level with Diagnosis Process

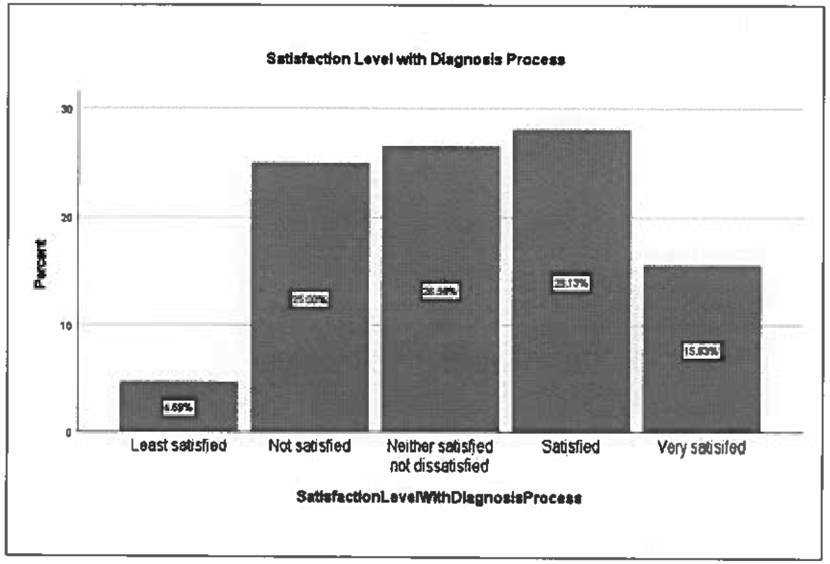


Table 4.1.14 – Service User: Distribution of Satisfaction level with Accessing Services After Diagnosis

Satisfaction Distribution with Access to Services post-Diagnosis		
Level of Satisfaction	**N**	**%**
Least Satisfied	22	34.4
Not Satisfied	17	26.6
Neither Satisfied nor Dissatisfied	9	14.1
Satisfied	11	17.2
Very Satisfied	5	7.8
Total	**64**	**100**

Figure 4.1.14 – Service User: Distribution of Satisfaction level with Accessing Services After Diagnosis

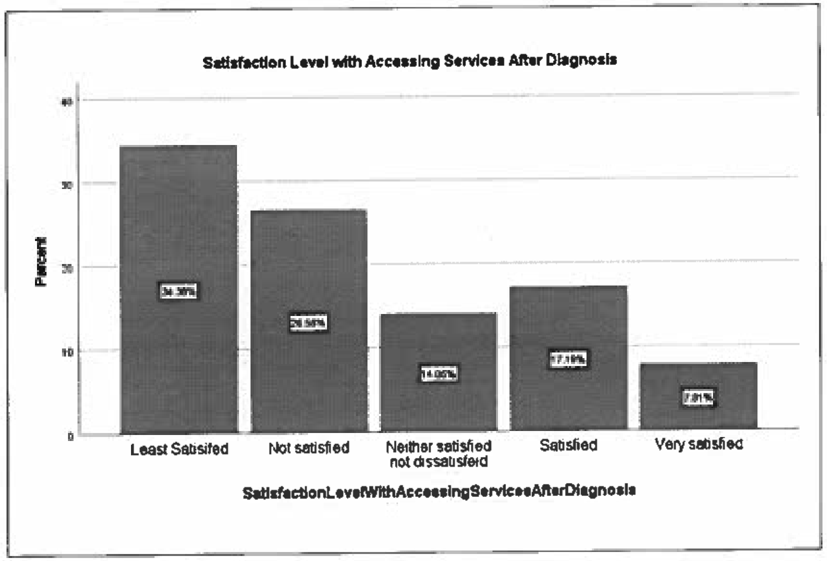
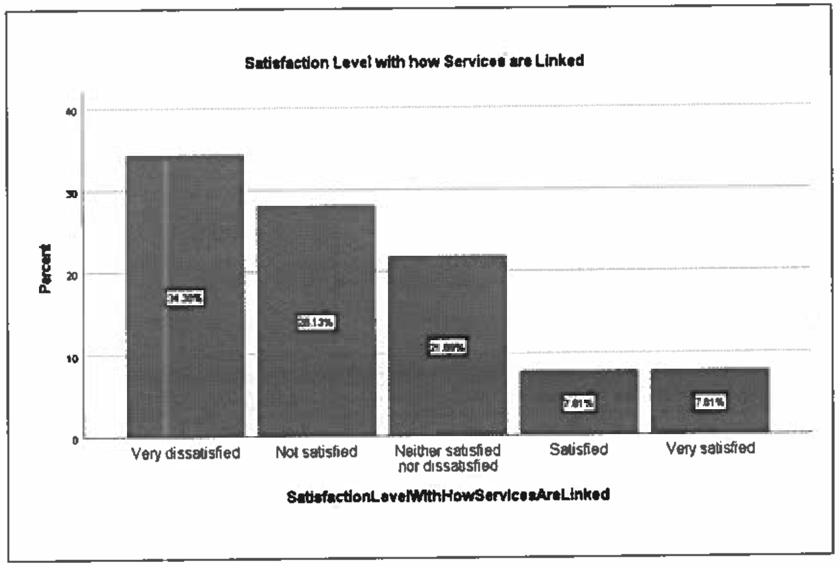


Table 4.1.15 – Service User: Distribution of Satisfaction level with How Services are Linked

Distribution of Satisfaction with how Services are Linked		
Level of Satisfaction	**N**	**%**
Very dissatisfied	22	34.4
Not satisfied	18	28.1
Neither satisfied nor dissatisfied	14	21.9
Satisfied	5	7.8
Very satisfied	5	7.8
Total	**64**	**100**

Figure 4.1.15 – Service User: Distribution of Satisfaction level with How Services are Linked



Additionally, when asked whether they had received any information or support services after receiving their diagnosis, 91% of respondents replied that they had not received any services or information, while 6% stated that they received counselling/family support and a further 3% said that they received other services – mainly caregiver training. Table 4.1.16 refers.

Table 4.1.16 – Service User: Distribution of Support or Information Received after Diagnosis

Information or Support Received after Diagnosis		
Type of Service Received	**N**	**%**
None	58	90.6
Family support/ Counselling	4	6.3
Other	2	3.1
Total	**64**	**100**

When asked what services they received in the last six months, 58% of respondents replied that they had not received any services, while 11% replied that they had received medication and another 11% replied that they had received counselling. All other services received a less than 3% reply. Table 4.1.17 and Figure 4.1.16 refer. The responses for Services received in the last six months were tested for significant association with gender and age group, however no significant associations were found as the Pearson's Chi-square test returned a p-value greater than the 0.05 level of significance. When asked to indicate their level of satisfaction with these services, 50% of respondents reported that they were Least Satisfied or Not Satisfied, while 27% reported being Satisfied or Very Satisfied. Table 4.1.18 and Figure 4.1.17 refer.

Table 4.1.17 – Service User: Distribution of Services Received in the last Six Months

Education, Health, Social or Support Services Received in last Six Months		
Services Received	**N**	**%**
None	37	57.8
Educational - exam support only*	1	1.6*
Medication	7	10.9
None	1	1.6
Other	4	6.3
Psychiatrist	2	3.1
Psychiatrist and OT	1	1.6
Psychiatrist, psychologist, and education support	1	1.6
Social and health	1	1.6
Therapy and medication	1	1.6
Therapy/ Counselling	7	10.9
Therapy/ Counselling and Psychiatrist	1	1.6
Total	**64**	**100.2****

*The figure for Education Services and exam support does not include support given to school- aged children, as they were not respondents in this survey.

**The total is larger than 100 due to rounding up of figures.

Figure 4.1.16 – Service User: Distribution of Services Received in the last Six Months

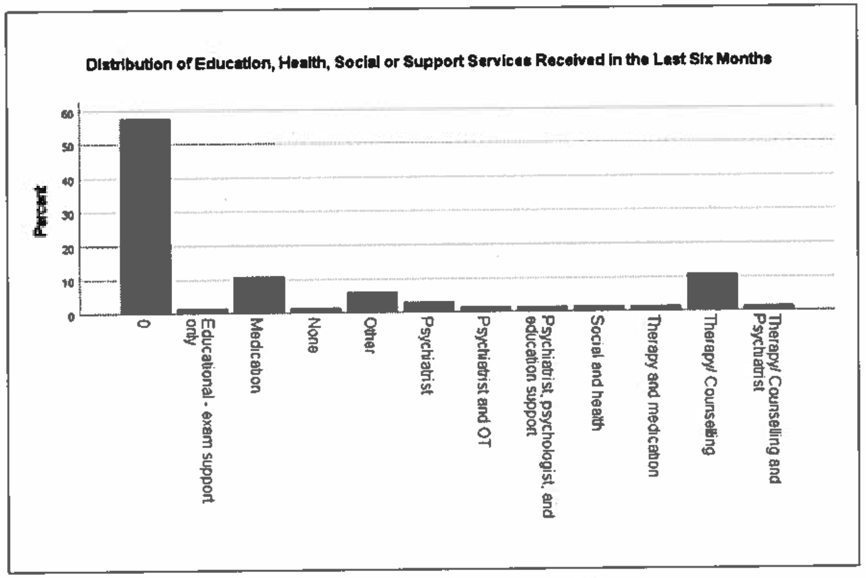
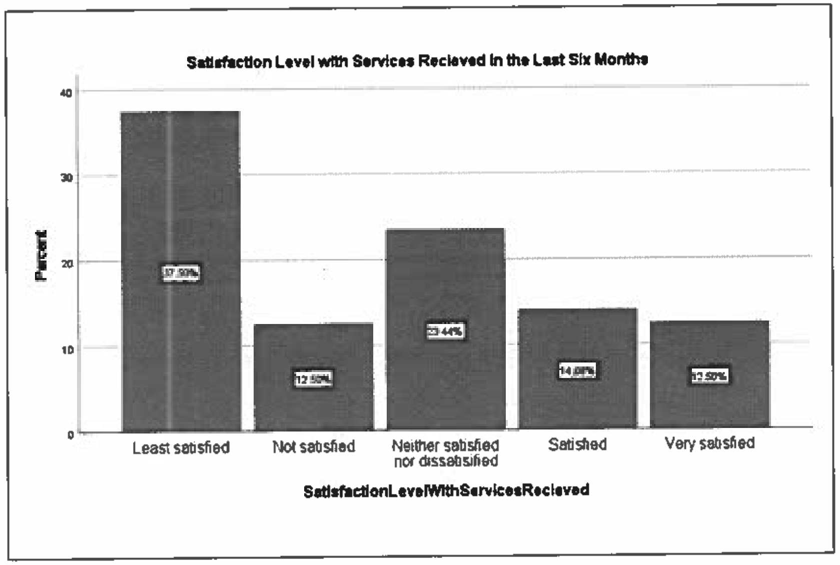


Table 4.1.18 – Service User: Distribution of Satisfaction with Services Received in the last Six Months

Satisfaction Level with Services Received in last Six Months		
Satisfaction Level	N	%
Least satisfied	24	37.5
Not satisfied	8	12.5
Neither satisfied nor dissatisfied	15	23.4
Satisfied	9	14.1
Very satisfied	8	12.5
Total	**64**	**100**

Figure 4.1.17 – Service User: Distribution of Satisfaction with Services Received in the last Six Months

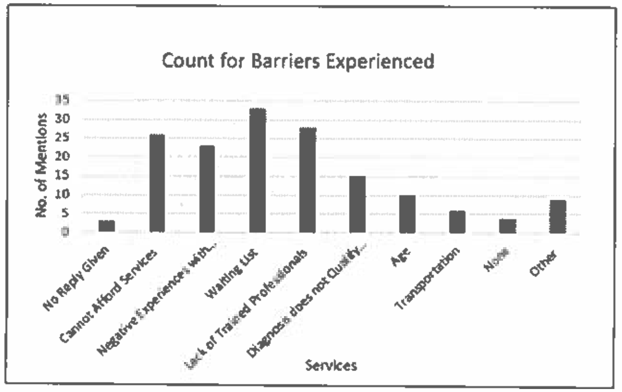


When asked what barriers they experience in accessing services, the barriers that received most mentions from respondents were: 'Waiting list to access services' (33 mentions), followed by 'Lack of trained professionals' (28 mentions), after which 'Cannot afford services' was mentioned, with 26 mentions, followed by 'Negative experiences with professionals' with 23 mentions. Table 4.1.19 and Figure 4.1.18 refer.

Table 4.1.19 – Service User: Distribution of Barriers Experienced in Accessing Services

Barriers Experienced by Service Users	**Number of Times Mentioned**
No Reply Given	3
Cannot Afford Services	26
Negative Experiences with Professionals	23
Waiting List	33
Lack of Trained Professionals	28
Diagnosis does not Qualify for Services/ Even with Diagnosis Deemed Ineligible for Services	15
Age	10
Transportation	6
None	4
Other	9

Figure 4.1.18 – Service User: Distribution of Barriers Experienced in Accessing Services

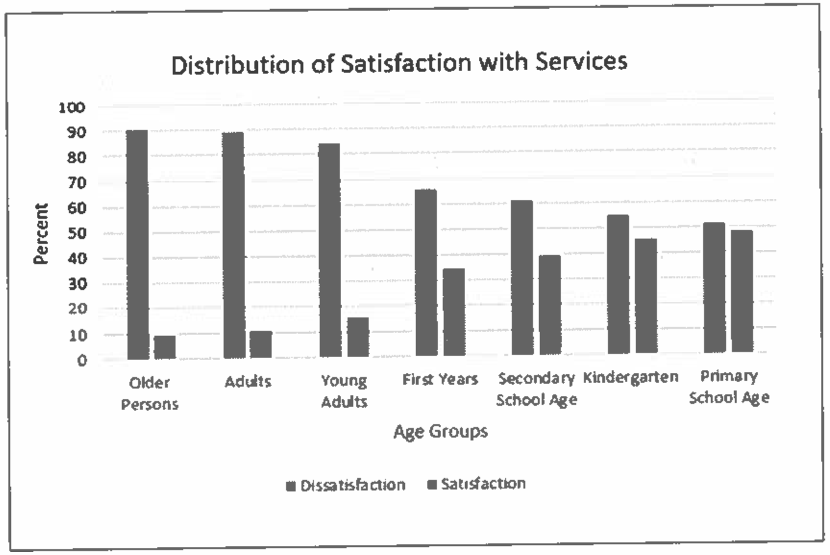


Respondents were also asked whether they were satisfied with the services provided across the life course, with the ages being grouped into First Years (0-3), Kindergarten (3-4), Primary School Age (5-10), Secondary School Age (11-16), Young Adults (16-24), Adults (25-64) and Older Persons (65 years and over). Respondents were dissatisfied with services across all age groups, however the school years seem to be better served, with higher overall respondent satisfaction, while the ages of young adults, adulthood and older years received increasingly low satisfaction ratings.

Table 4.1.20 – Service User: Distribution of Satisfaction with Services by Age Group

Satisfaction with ASD and ADHD Services by Age Group Distribution				
	Satisfaction			
	Yes		**No**	
Age Groups	**Number**	**%**	**Number**	**%**
First Years: 0-3 years	22	34.4	42	65.6
Kindergarten: 3-4 years	29	45.3	35	54.7
Primary School Age: 5-10 years	31	48.4	33	51.6
Secondary School Age: 11-16 years	25	39.1	39	60.9
Young Adults: 16-24 years	10	15.6	54	84.4
Adults: 25-64 years	7	10.9	57	89.1
Older Persons: 65 years and over	6	9.4	58	90.6

Figure 4.1.19 – Service User: Distribution of Satisfaction with Services by Age Group

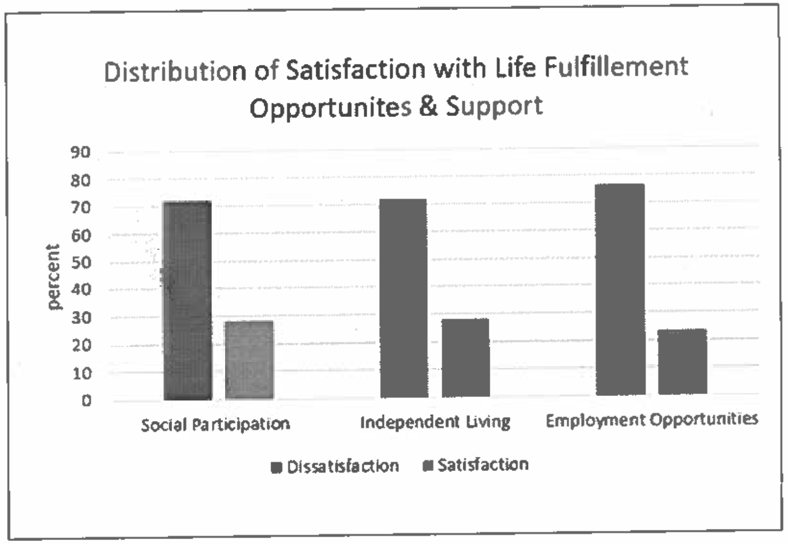


When asked whether they were satisfied with the support and opportunities for life fulfilment in the categories of Social Participation, Independent Living and Employment Opportunities, over 70% of respondents replied that they were not satisfied in all categories, with dissatisfaction with employment opportunities for persons with autism and/or ADHD being highest at 77%. Table 4.1.21 and Figure 4.1.20 refer.

Table 4.1.21 – Service User: Distribution of Satisfaction with Support and Opportunities for Persons with ASD and ADHD

Satisfaction with Support & Opportunities for Life Fulfilment Distribution				
	Satisfaction			
	Yes		**No**	
Category	**Number**	**%**	**Number**	**%**
Social Participation	18	28.1	46	71.9
Independent Living	18	28.1	46	71.9
Employment Opportunities	15	23.4	49	76.6

Figure 4.1.20 – Service User: Distribution of Satisfaction with Support and Opportunities for Persons with ASD and ADHD



4.1.2 Caregivers' views on the services for persons with Autism and/or ADHD

As well as examining experiences of service users, this study surveyed the experiences and views of caregivers of persons with Autism Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD). For the purposes of this research, caregivers refers to those who look after persons who are living with autism and/or ADHD. Similarly to service users, caregivers have extensive day-to-day experience of how services are provided and delivered, as they live the experience of the condition together with the person they are caring for.

Findings from the Caregiver Questionnaire

The caregiver questionnaire asked largely the same questions as the service user questionnaire but solicited replies from the point of view of the caregiver rather than first hand user experiences. Thus, this study tool also asked for user demographic data such as age, gender, district, level of education, employment stats, household composition of the person with the diagnosis; as well as questions pertaining to the experiences of the person in their care, of their condition, services and barriers to services.

163 valid responses were received from caregivers caring for person with autism, ADHD or a combination of both. 50% had a diagnosis of autism, 30% had a diagnosis of ADHD, while a further 20% had a diagnosis of both autism and ADHD combined (Table 4.1.22 and Figure 4.1.21 refer). Of these, 74% were male, 23% were female and an additional 3% either gave no reply or preferred not to state their gender (Table 4.1.23 and Figure 4.1.22 refer).

Table 4.1.22 – Caregiver Distribution by Diagnosis of Person Cared For

Type of Diagnosis of Person Cared For

Diagnosis	**No.**	**%**
ASD	82	50.3%
ADHD	49	30.1%
Both Combined	32	19.6%
Total	**163**	**100%**

Table 4.1.23 – Caregiver Distribution by Gender of Person Cared For

Gender of Person Diagnosed

Gender	**No.**	**%**
Male	120	73.6%
Female	38	23.3%
Other/ Prefer not to say	3	1.8%
No reply given	2	1.2%
Total	**163**	**100%**

Figure 4.1.21 – Caregiver Distribution by Diagnosis of Person Cared For

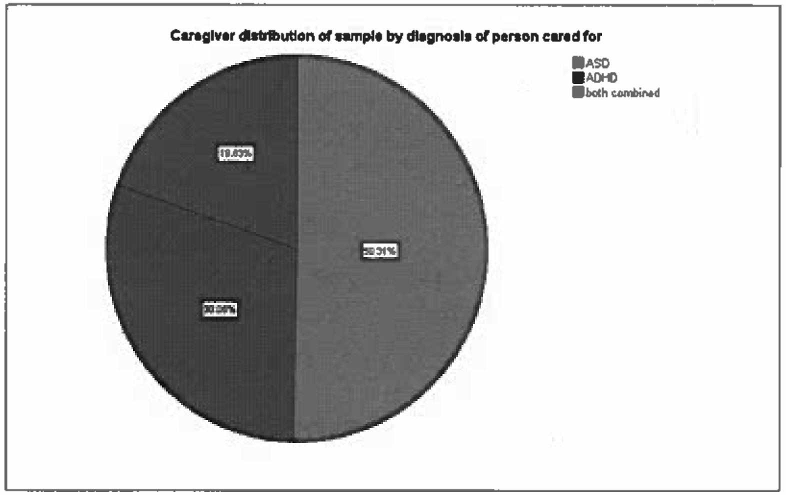


Figure 4.1.22 – Caregiver Distribution by Gender of Person Cared For

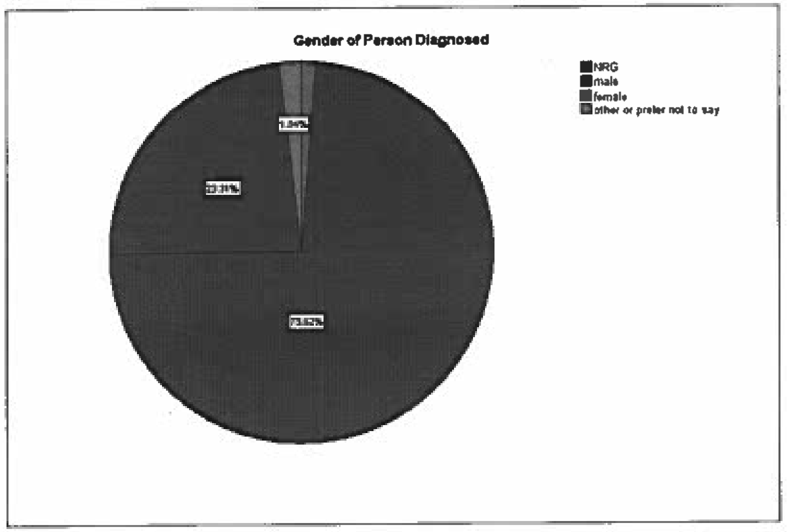
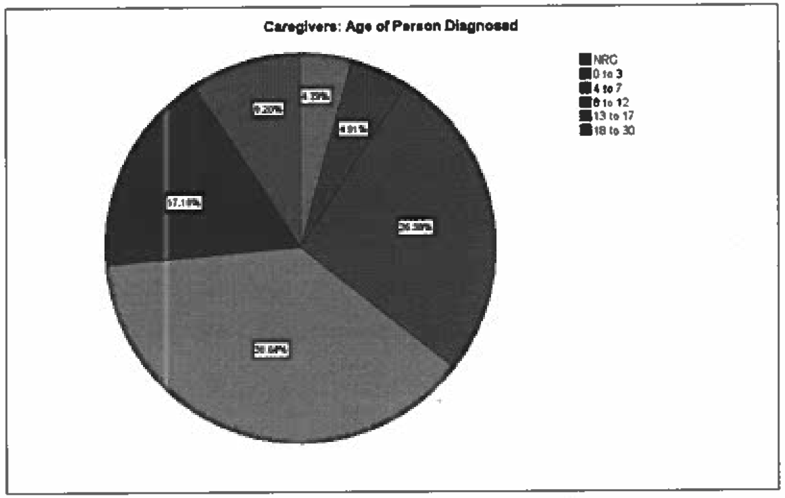


Table 4.1.24 – Caregiver Distribution by Age of Person Cared For

Age of Person Diagnosed

Age	No.	%
NRG	7	4.3%
0 to 3	8	4.9%
4 to 7	43	26.4%
8 to 12	62	38.0%
13 to 17	28	17.2%
18 to 30	15	9.2%
Total	**163**	**100%**

Figure 4.1.23 – Caregiver Distribution by Age of Person Cared For



Regarding the ages of the persons cared for by the caregiver respondents, the majority were minors (86.5%), with 38% who were aged 8 to 12 years (*n*=62) and 26.4% aged 4 to 7 years (*n*=43), while an added 17.2% (*n*=28) were aged 13-17 years and 4.9% (*n*=8) were aged 0-3 years. 9.2% (*n*=15) were aged 18-30 years and a further 4.3% chose not to reply to this question. Table 4.1.24 and Figure 4.1.23 refer.

Interestingly, examining the sample of persons cared for by diagnosis and gender (see Table 4.1.25 and Figure 4.1.24), it becomes evident that while there is a considerable gap between genders for persons with a diagnosis of autism, this narrows considerably for those with an ADHD diagnosis. This tends to support the literature, which shows that whilst there is still considerable debate as to whether autism is gendered (Lai et al., 2015) – and a number of studies assert that it is more prevalent in males (Baron-Cohen et al., 2011; Hull et al., 2020; Loomes et al., 2017), regarding ADHD, recent research has asserted that ADHD is not gendered and that it affects females equally as males, it is the diagnostic processes that need to improve (García, 2019; Lynch & Davison, 2022). This in turn leads to the supposition that ADHD remains underdiagnosed in females, and that similarly, autism is possibly also underdiagnosed in females. However, for this sample the association between gender and diagnosis was not found to be statistically significant as a Chi square test returned a value above the 0.05 level of significance.

Table 4.1.25 – Distribution of Person Cared for by Diagnosis and Gender

Diagnosis by Gender of Diagnosed Person

Gender	ASD		ADHD		Both combined		Total	
	No.	%	No.	%	No.	%	No.	%
No reply Given	0	0.0	2	1.2	0	0.0	2	1.2
Male	65	39.9	32	19.6	23	14.1	120	73.6
Female	16	9.8	14	8.6	8	4.9	38	23.3
Other/Prefer not to say	1	0.6	1	0.6	1	0.6	3	1.8
Total	**82**	**50.3**	**49**	**30.1**	**32**	**19.6**	**163**	**100**

Figure 4.1.24 – Distribution of Person Cared for by Diagnosis and Gender

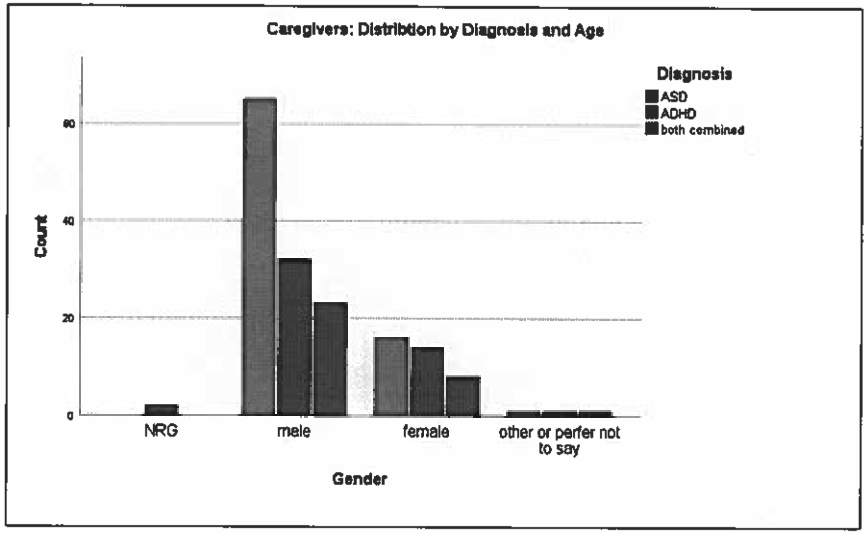
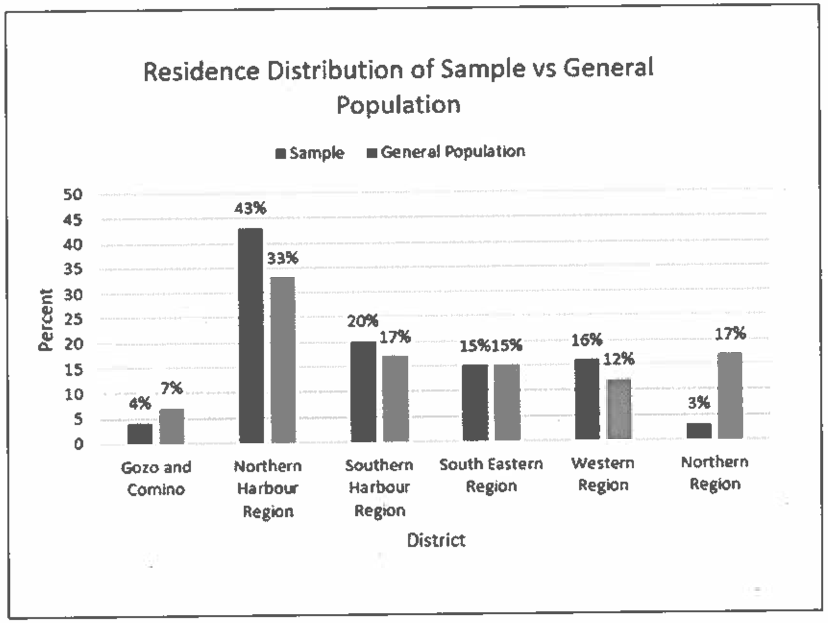


Table 4.1.26 – Distribution of Person Cared for by Region of Residence

Residence of Diagnosed Person by District

Region	No.	%
Gozo and Comino	6	3.7%
Northern Harbour Region	70	42.9%
Southern Harbour Region	33	20.2%
South Eastern Region	24	14.7%
Western Region	26	16.0%
Northern Region	4	2.5%
Total	163	100 %

Figure 4.1.25 – District distribution of sample vs District Distribution of General Population



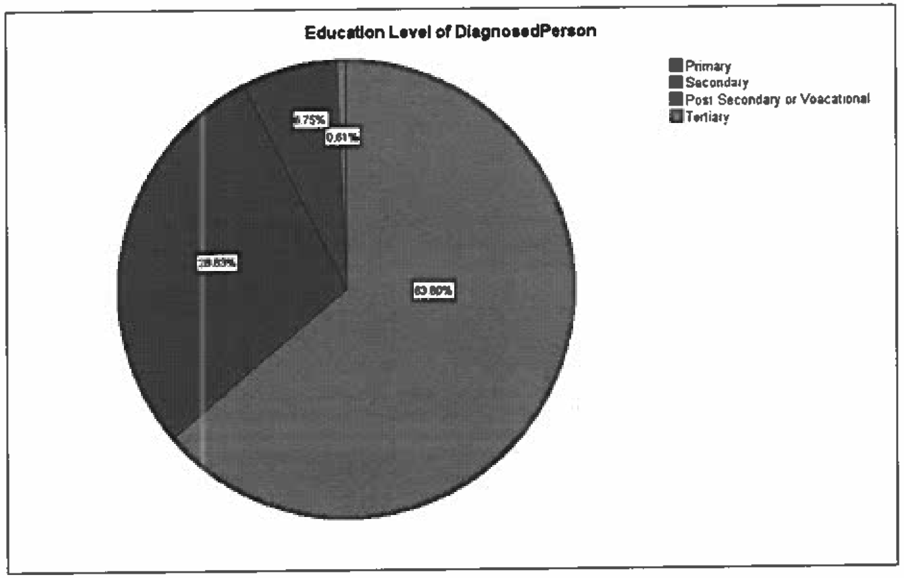
Although the sample is not representative of the general population, by and large the sample district distribution is similar to that of the general population. There are two notable discrepancies – the Northern Harbour Region, where there is a large difference of 10% between the percentage of person within the studied cohort (that is, persons cared for by the caregiver respondents) and the percentage share of the general population who live the region. On the other hand, the sample distribution share for persons living in the Northern Region is far lower than the population share. The reasons for this are unknown but could well reflect a general trend in the geographical distribution of person with neurodevelopmental disorders. Similar findings were also discussed by Rolé et al. (2019) who observed that the incidence of ADHD was higher in the Northern and Southern Harbour areas. Table 4.1.26 and Figure 4.1.25 refer.

Table 4.1.27 – Distribution of Person Cared for by Level of Education

Education Level of Diagnosed Person

Level of Education	No.	%
Primary	104	63.8%
Secondary	47	28.8%
Post-Secondary or Vocational	11	6.7%
Tertiary	1	0.6%
Total	**163**	**100 %**

Figure 4.1.26 – Distribution of Person Cared for by Level of Education



Within the cohort under examination, only 0.6% attained a university degree, while the majority (92%) are in primary or secondary education. This is to be expected within this cohort as the majority, as shown above, are minors (86.5%), therefore not of university age. In fact, this association was not found to be statistically significant. See Table 4.1.27 and Figure 4.1.26.

Examining level of education against age, this study shows that within this cohort there are 1.8% (n=3) of 13 to 17-year olds and 1.2% (n=2) of 18 to 30-year olds who are still in primary school, making a total of almost 3% of respondents who are above primary school age but whose level of schooling remains at the most basic level. Additionally, a further 3.1% of 18 to 30-year olds, i.e. adults, with a highest level of education listed as secondary school level. Given the vast importance that education and the attainment of proficiency in reading, writing and numeracy in achieving life fulfilment (Spengler et al., 2018), these figures highlight that more effort needs to be made to assist neurodivergent persons to attain a good level of education. Table 4.1.27 and Figure 4.1.26 refer.

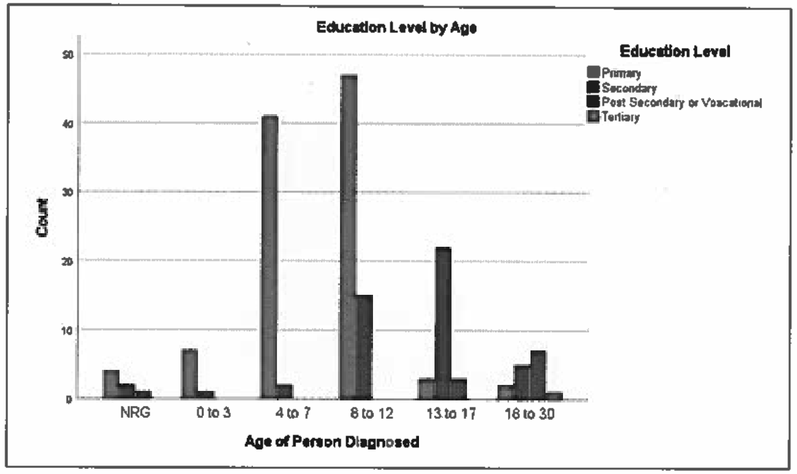
Table 4.1.28 – Distribution of Level of Education by Age

Distribution of Education Level of Diagnosed Person by Age Group										
Age	**Primary**		**Secondary**		**Post-Secondary or Vocational**		**Tertiary**		**Total**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
NRG	4	2.5%	2	1.2%	1	0.6%	0	0.0 %	7	4.3%
0 to 3	7	4.3%	1*	0.6%*	0	0.0%	0	0.0 %	8	4.9%
4 to 7	41	25.2%	2*	1.2%*	0	0.0%	0	0.0 %	43	26.4%
8 to 12	47	28.8%	15	9.2%	0	0.0%	0	0.0 %	62	38.0%
13 to 17	3	1.8%	22	13.5%	3	1.8%	0	0.0 %	28	17.2%
18 to 30	2	1.2%	5	3.1%	7	4.3%	1	0.6%	15	9.2%
Total	**104**	**63.8%**	**47**	**28.8%**	**11**	**6.1%**	**1**	**0.6%**	**163**	**99.3 %****

*These replies were probably entered in error by the respondents, however, were preserved in order not to compromise the integrity of the questionnaire, especially as they have no bearing on the overall results, but only on the level of education.

**This figure does not equal an exact 100 because of rounding up.

Figure 4.1.27 – Distribution of Level of Education by Age



Regarding employment of the cohort, since most of the persons cared for are minors and not of employment age, examination of this factor is not really relevant to this discussion. Table 4.1.29 below refers.

Table 4.1.29 – Distribution of Person Cared for by Employment

Employment of Diagnosed Person

Employment Status	No.	%
Self employed	**1**	**0.6%**
Full time employment	**6**	**3.7%**
Part-time employment	**1**	**0.6%**
Casual employment	**1**	**0.6%**
Unemployed	**27**	**16.6%**
Other	**127**	**77.9%**
Total	**163**	**100 %**

The majority of person cared for by the respondents come from two-parent households (71%, n=116), with 14% coming for one-parent families, 1.8% living with a parent and stepparent and 0.6% having separated parents holding two separate households, a further 12.9% chose to not to respond to this question.

Table 4.1.30 – Distribution of Household Composition for Person Cared for

Household Composition of Person Cared For

	No.	%
No reply given	21	12.9%
Family with 2 parents	116	71.2%
Family with 1 parent	22	13.5%
Parent and stepparent	3	1.8%
2 households of separated parents	1	0.6%
Total	**163**	**100 %**

A cross tabulation of household composition by diagnosis revealed that 38.7% (n=63) of persons with autism, 21.5% (n=35) of persons with ADHD, and 11% (n=18) of persons with a combined autism and ADHD diagnosis, live in a two-parent household. 8% (n=13) of persons with a diagnosis of autism and 3.1% (n=5) and 2.4% (n=4) live in a one-parent household, while no persons with autism or combined autism and ADHD live in a household composed of either parent and step-parent, or 2 households of 2 separated parents, as opposed to 1.2% (n=2) of persons with ADHD. However, 12.9% of respondents, (3.7% with autism, 4.3% with ADHD and 4.9% with a Combined diagnosis) did not reply to this question. Table 4.1.31 and Figure 4.1.30 refer.

Figure 4.1.28 – Distribution of Household Composition for Person Cared for

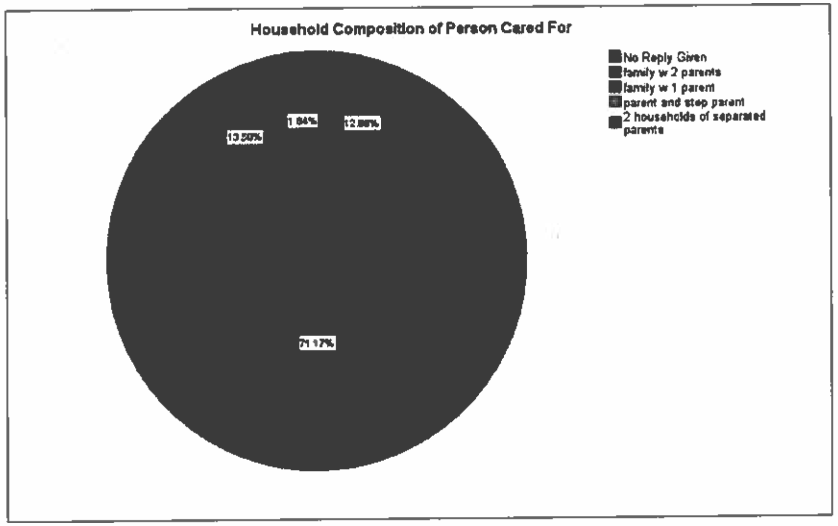


Figure 4.1.29 – Bar Graph of Distribution of Household Composition for Person Cared for

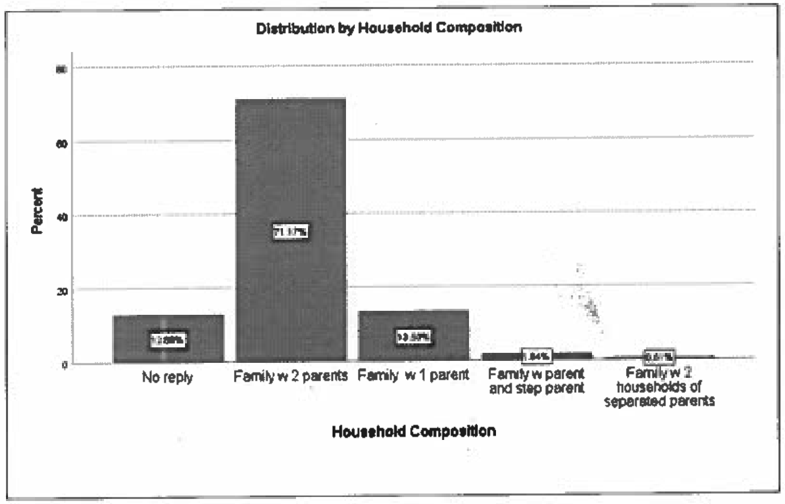
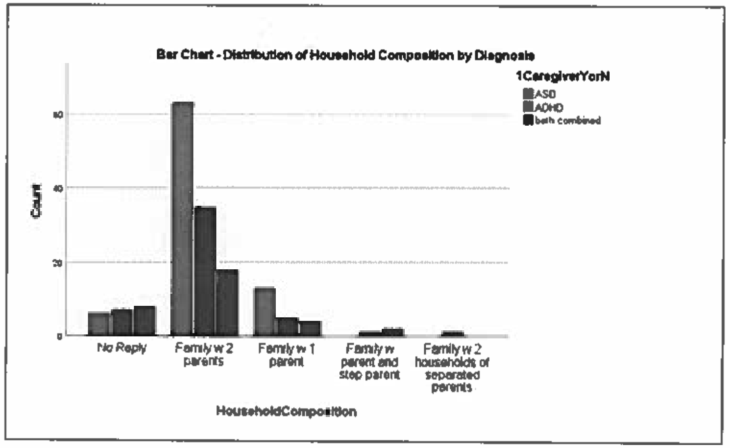


Table 4.1.31 – Distribution of Household Composition for Person Cared for by Diagnosis

Distribution of Household Composition by Diagnosis								
	Diagnosis							
Household Composition	**ASD**		**ADHD**		**Both combined**		**Total**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
No reply Given	6	3.7%	7	4.3%	8	4.9%	21	12.9%
Family w 2 parents	63	38.7%	35	21.5%	18	11.0%	116	71.2%
Family w 1 parent	13	8.0%	5	3.1%	4	2.4%	22	13.5%
Family w parent and stepparent	0	0.0%	1	0.6%	2	1.2%	3	1.8%
Family w 2 households of separated parents	0	0.0%	1	0.6%	0	0.0%	1	0.6%
Total	**82**	**50.4%**	**49**	**30.1%**	**32**	**19.5%**	**163**	**100.0%**

Figure 4.1.30 – Distribution of Household Composition for Person Cared for by Diagnosis



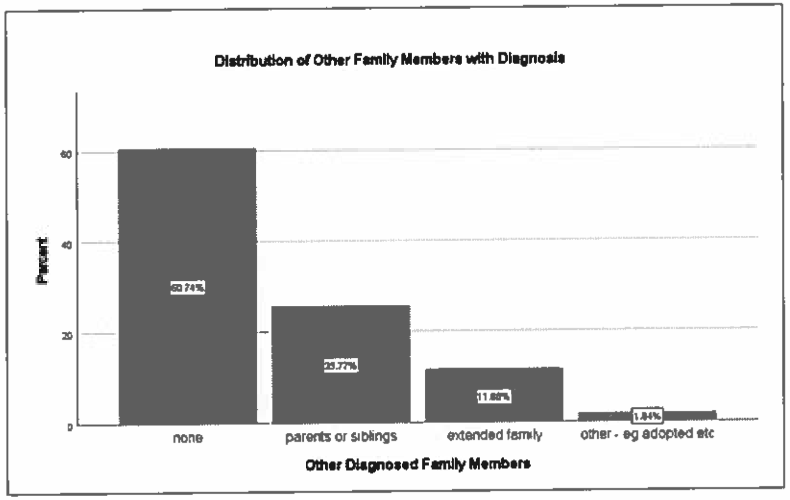
Research indicates that both autism and ADHD have genetic origins and that persons with either autism or ADHD or combined diagnoses may have inherited the condition from one or both of their parents (Grimm et al., 2020; Ronald et al., 2014; Yasuda et al., 2022). This study examined links between the person diagnosed and other family members. 61% of the sample did not have any other family members with diagnosis, while the reaming 39% had either members within the immediate or extended family, or other family members who also has a neurodivergent diagnosis. Table 4.1.32 and Figure 4.1.31 refer.

Table 4.1.32 – Distribution of Familial Diagnoses of Diagnosed Person

Other Diagnosed Family Members

Family Member	**No.**	**%**
No other family members	99	60.7%
Parents or siblings w diagnosis	42	25.8%
Extended family members w diagnosis	19	11.7%
Other – e.g. adopted etc	3	1.8%
Total	**163**	**100.0%**

Figure 4.1.31 – Distribution of Familial Diagnoses of Diagnosed Person



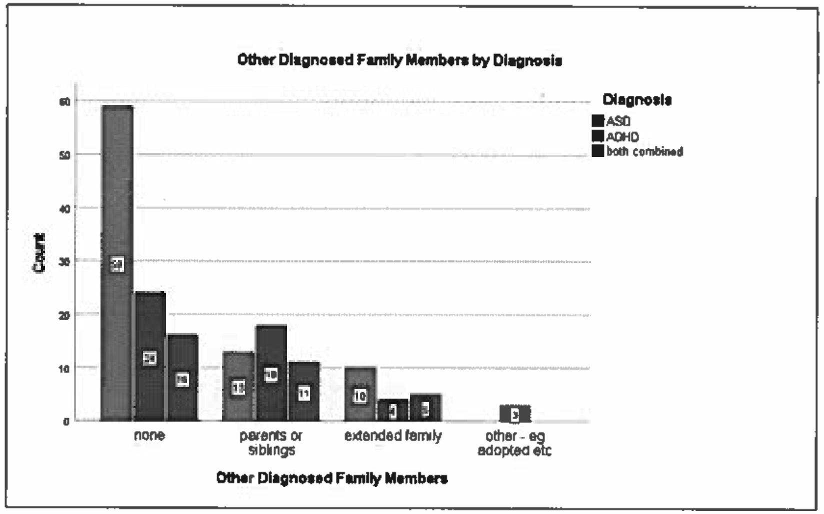
Examining the distribution of other diagnosed family members by diagnosis of cared for person, it emerged that the diagnosis with the greatest percentage of immediate family members, i.e. parents or siblings, who also had a diagnosis was ADHD, with 11% (n=18) of respondents having a parent of sibling that also had a neurodivergent diagnosis, while the percentage for persons with an autism diagnosis was 8% (n=15) and 6.7% (n=11) for persons with a combined diagnosis. However, 6.1% (n=10) of persons with autism and 3.1% (n=5) of persons with autism and ADH combined have extended family members with a diagnosis, as opposed to 2.5% (n=4) of persons with ADHD; whereas only 1.9%, (n=3) persons with ADHD have other family members with a diagnosis, of which two were adopted and one was the partner of a parent. The total number of persons with an autism diagnosis who had any family members who also had a diagnosis was 14.1%, while the figure for persons with for ADHD who had diagnosed family member was almost equal at 13.5%. 9.8% of persons with autism and ADHD combined also had family members with a neurodivergent diagnosis. This means that almost 40% of the sample also had family members with a diagnosis, which, especially allowing for the fact that there could be a number of adult relatives of the persons cared for who remain undiagnosed, reflects findings in the literature that these conditions really do run in families (Ronald et al., 2014; Yasuda et al., 2022). However, no significant association was found between diagnosis and other family members with diagnosis, as the p-value was above the 0.05 level of significance. Table 4.1.33 and Figure 4.1.32 refer.

Almost 40% of the sample had family members with a diagnosis.

Table 4.1.33 – Distribution of Other Diagnosed Family Members by Diagnosis

Distribution of Other Diagnosed Family Members by Diagnosis								
Other Diagnosed Family Members	**Diagnosis**							
	ASD		**ADHD**		**Both combined**		**Total**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
None	59	36.2%	24	14.7%	16	9.8%	99	60.7%
Parents or siblings	13	8.0%	18	11.0%	11	6.7%	42	25.8%
Extended family	10	6.1%	4	2.5%	5	3.1%	19	11.7%
Other – e.g. adopted etc	0	0.0%	3	1.9%	0	0.0%	3	1.8%
Total	**82**	**50.3%**	**49**	**30.1%**	**32**	**19.6%**	**163**	**100.0 %**

Figure 4.1.32 – Distribution of Other Diagnosed Family Members by Diagnosis



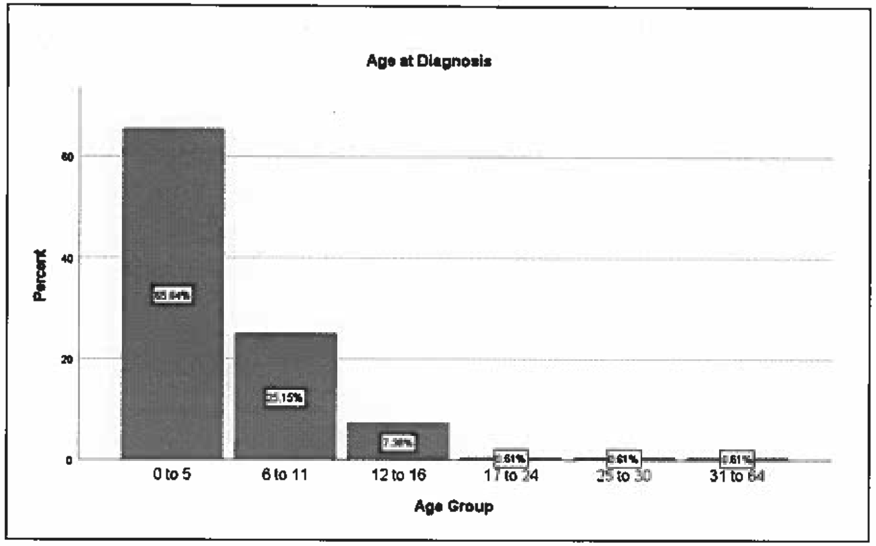
The vast majority of persons cared for, 98.1%, were diagnosed before the end of secondary school, that is, before 16 years of age, with only 1.8% being diagnosed at a later age. Table 4.1.34 and Figure 4.1.33 refer.

Table 4.1.34 – Distribution of Age at Diagnosis of Person Cared For

Distribution by Age at Diagnosis

Age Group	No.	%
0 to 5	107	65.6%
6 to 11	41	25.2%
12 to 16	12	7.4%
17 to 24	1	0.6%
25 to 30	1	0.6%
31 to 64	1	0.6%
Total	**163**	**100.0 %**

Figure 4.1.33 – Distribution of Age at Diagnosis of Person Cared For

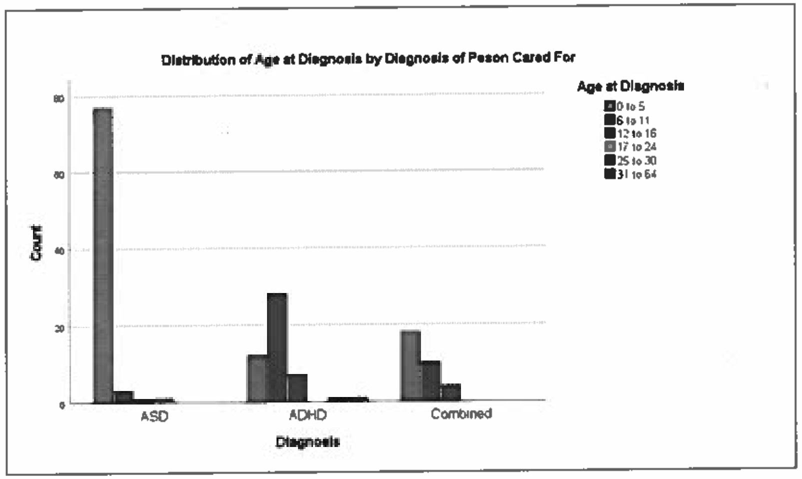


However, when age at diagnosis was examined against type of diagnosis, it emerged that 49% of persons were living with autism before the age of 11 years. As shown above, 50% of this sample were living with autism, showing that the great majority were given a diagnosis by the time they reached 12 years of age, that is, before the age at which typically a person starts secondary school. Given the importance that an early diagnosis has on success in education, as shown in the literature, this is an important result for this section of the cohort. Similarly, the majority - 17.2% out of a 19.6% sample share, of persons with a combined diagnosis were also given a diagnosis before the age of 12 years, although within this study, it is not possible to tell if they were diagnosed with both conditions or only one of them. Regarding persons with ADHD, 24.6% were diagnosed before reaching 12 years of age, leaving 5.4% who were diagnosed after attaining 12 years of age, that is, after Secondary school-age. When compared to sample share of 24.6%, this reveals that diagnosis by end of primary schooling is lagging behind for persons with ADHD compared to person with a diagnosis of autism or both combined. Type of diagnosis was compared to age at diagnosis, using crosstabulation, and was found to be statistically significant, as the Chi square test returned a p-value below the 0.05 level of significance ($p < 0.001$). Table 4.1.35 and Figure 4.1.34 refer.

Table 4.1.35 – Distribution of Age at Diagnosis by Diagnosis of Person Cared For

Age at Diagnosis by Diagnosis								
Age at Diagnosis	**Diagnosis**						**Total**	
	ASD		**ADHD**		**Combined**			
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
0 to 5	77	47.2%	12	7.4%	18	11.0%	107	65.6%
6 to 11	3	1.8%	28	17.2%	10	6.1%	41	25.2%
12 to 16	1	0.6%	7	4.3%	4	2.5%	12	7.4%
17 to 24	1	0.6%	0	0.0%	0	0.0%	1	0.6%
25 to 30	0	0.0%	1	0.6%	0	0.0%	1	0.6%
31 to 64	0	0.0%	1	0.6%	0	0.0%	1	0.6%
Total	**82**	**50.3%**	**49**	**30.1%**	**32**	**19.6%**	**163**	**100.0 %**

Figure 4.1.34 – Distribution of Age at Diagnosis by Diagnosis of Person Cared For

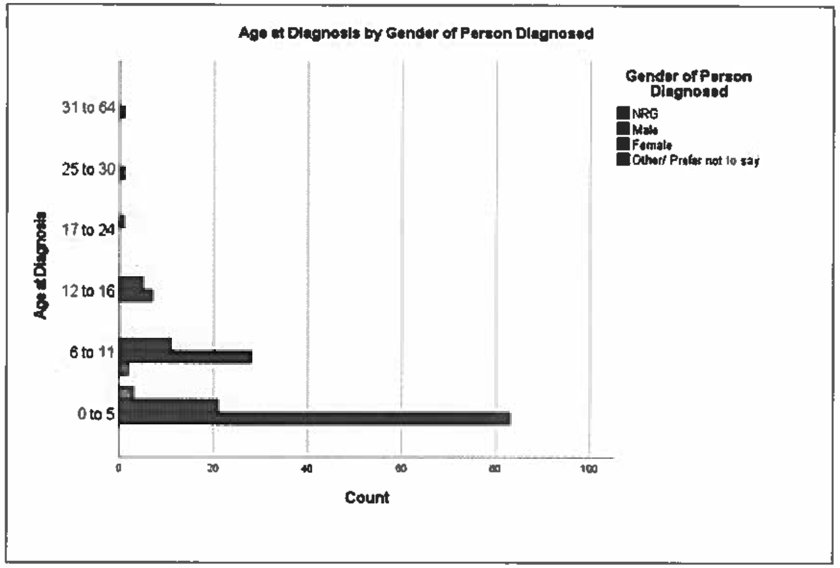


Age at diagnosis was also tested against gender. An aggregate of 3% either did not reply to this question (1.2%) or had replied other/ prefer not to say when asked about their gender. Of the remainder, the majority - almost 90% of the sample, (68.1%, *n=111* of males out of a sample share of 73.6%; and 19.6%, *n*=32 of females out of a sample share of 23.3%) were diagnosed before 12 years of age. A Chi square test retuned a p-value above the 0.05 level of significance, meaning that gender is not significantly associated to age at diagnosis for this sample. Table 1.36 and Figure 4.1.35 refer.

Table 4.1.36 – Distribution of Age at Diagnosis by Gender of Person Cared For

Age at Diagnosis by Gender										
Age	**Gender**								**Total**	
	NRG		**Male**		**Female**		**Other/ Prefer not to say**			
	No.	%	No.	%	No.	%	No.	%	No.	%
0 to 5	0	0.0%	83	50.9 %	21	12.9%	3	1.8%	107	65.6 %
6 to 11	2	1.2%	28	17.2 %	11	6.7%	0	0.0%	41	25.2 %
12 to 16	0	0.0%	7	4.3%	5	3.1%	0	0.0%	12	7.4%
17 to 24	0	0.0%	0	0.0%	1	0.6%	0	0.0%	1	0.6%
25 to 30	0	0.0%	1	0.6%	0	0.0%	0	0.0%	1	0.6%
31 to 64	0	0.0%	1	0.6%	0	0.0%	0	0.0%	1	0.6%
Total	**2**	**1.2%**	**120**	**73.6 %**	**38**	**23.3%**	**3**	**1.8%**	**163**	**100.0 %**

Figure 4.1.35 – Distribution of Age at Diagnosis by Gender of Person Cared For



Age at diagnosis was also tested against district, but nothing of note emerged, and no significant association was found for age at diagnosis and district. Likewise, when age at diagnosis was tested against household composition, no significant association was found.

Caregivers were also asked about their experience with services received. The highest level of satisfaction was registered for the diagnosis process, with 41.7% declaring that they were either 'Satisfied' (14.7%) or 'Very satisfied' (27%) with the process and 34.9% stating that they were either 'Very dissatisfied' (19.6%) or 'Dissatisfied' (15.3%). However, a greater level of dissatisfaction was expressed for access to services after the diagnosis received, with only 18.4% (12.3% 'Satisfied' and 6.1 'Very Satisfied') stating that they were happy with services accessed after diagnosis as opposed to a total of 55.2% (28.2% 'Very dissatisfied' and 27% 'Dissatisfied') who stated that they were unhappy with the availability of services following diagnosis. The greatest level of displeasure was expressed regarding how services were linked together, with an aggregate of 12.8% (6.1% 'Satisfied' and 6.7% 'Very satisfied') asserting that they were content as against 68.1% (38.7 'Very dissatisfied' and 29.4 'Dissatisfied') who were not. Table 4.1.37 and Figures 4.1.36, 4.1.37 and 4.1.38 refer. These

figures show clearly that caregivers accessing services for their children or for individuals that they care for, feel that the services offered are not adequate particularly once a diagnosis is received; and that there is no connection between the various services offered. This reflects other findings discussed above.

Similar sentiments were voiced when asked what services were offered once the diagnosis had been received. 81.6% (*n*=133) of respondents stated that they received no services at all, while only 8% (*n*=13) reported that they received caregiver training and just 7.4% (*n*=12) reported that they received Family Support or Counselling. Table 4.1.38 and Figure 4.1.39 refer.

Table 4.1.37 – Distribution of Level of Satisfaction with Diagnosis Process and Aftercare

Satisfaction with Diagnosis and After Care

Level of Satisfaction	Satisfaction with Diagnosis Process		Satisfaction with Accessing Services After Diagnosis		Satisfaction with How Services Were Linked	
	N	%	N	%	N	%
Very dissatisfied	32	19.6%	46	28.2%	63	38.7%
Dissatisfied	25	15.3%	44	27.0%	48	29.4%
Neither Dissatisfied nor Satisfied	38	23.3%	43	26.4%	31	19.0%
Satisfied	44	27.0%	20	12.3%	10	6.1%
Very Satisfied	24	14.7%	10	6.1%	11	6.7%
Total	**163**	**99.9%***	**163**	**100.0%**	**163**	**99.9%***

*Figure is not 100% due to rounding up.

Table 4.1.38 – Distribution of Support Services Received Following Diagnosis

Support Services Received After Diagnosis

Services Received	No.	%
None	133	81.6%
Family support/ Counselling	12	7.4%
Caregiver training	13	8.0%
Other	5	3.1%
Total	**163**	**100.0 %**

Figure 4.1.36 – Distribution of Level of Satisfaction with Diagnosis Process

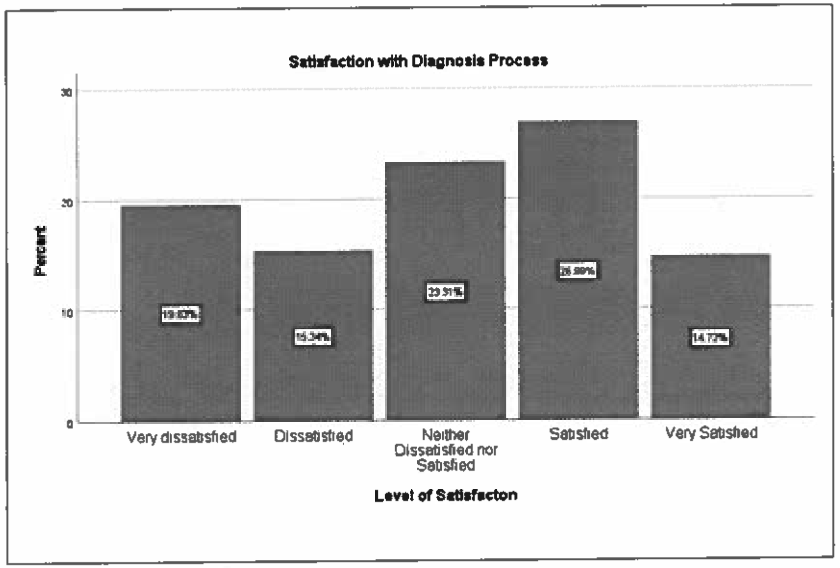


Figure 4.1.37 – Distribution of Level of Satisfaction with Services After Diagnosis

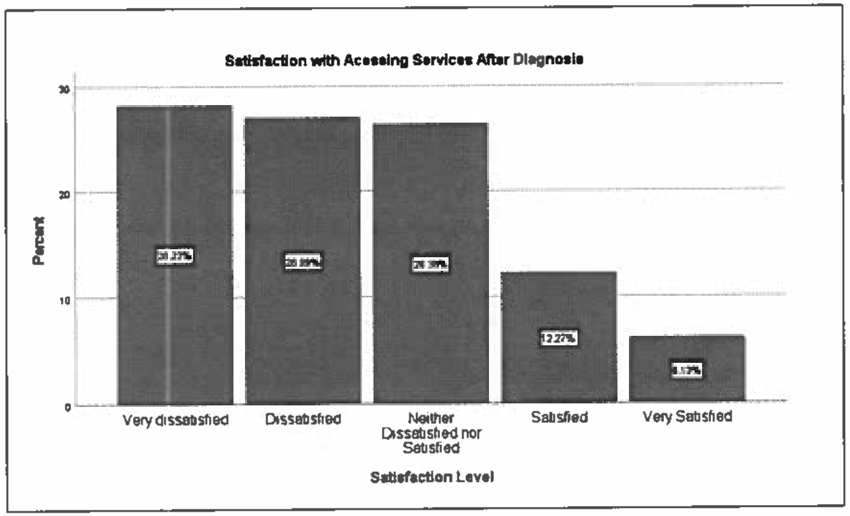


Figure 4.1.38 – Distribution of Level of Satisfaction with How Services Are Linked

Figure 4.1.39 – Distribution of Support Services Received Following Diagnosis

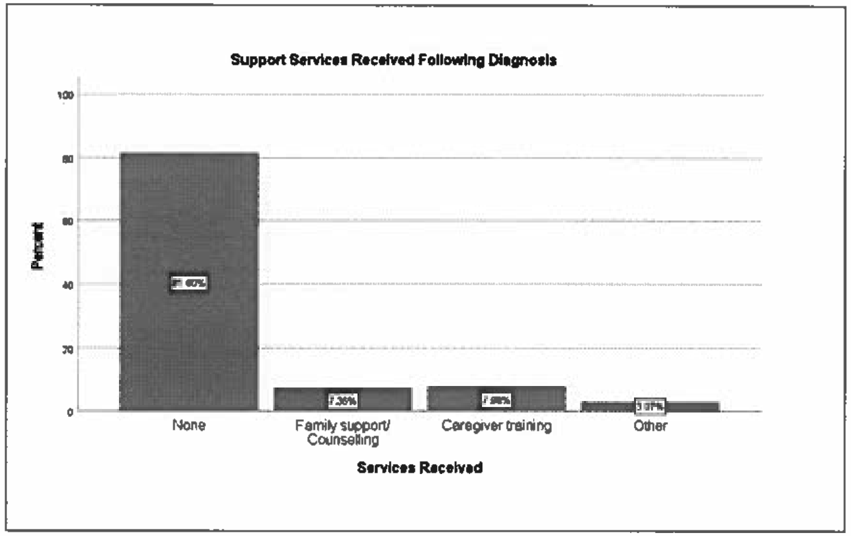


Table 4.1.39 – Support Services Received in the Last Six Months (continued on next page)

Services Received in the Last 6 Months	No. of Mentions
Social/Disability benefit	3
Learning Support Educator (LSE)	19
Medication	7
Therapy/Counselling/Psychologist	8
Speech Therapy	44
Applied Behaviour Analysis (ABA)	4
Occupational Therapy (OT)	25
Child and Young People's Services (CYPS)	15
Inspire	8
Child Development Assessment Unit (CDAU)	3
Online Support Groups	6
Physiotherapy	3
Exam Arrangements	2
Respite	3
Commission for the Rights of Persons w Disability (CRPD)	1
Early Intervention	5
Sensory Integration Unit	4
Anger Management	1
Malta Autism Centre (MAC)	6
Agenzija Sapport	5
Embrace	1
Music Therapy	3
Job Mentoring - Lino Spiteri Foundation	1
Horse Therapy	2
Social Worker	1
Pay Privately	41
None	29

When the caregiver respondents were asked what educational, health, social or support services had been received in the previous six months by the persons they cared for, the service that was mentioned most frequently was speech therapy, with 44 mentions, followed by occupational therapy, with 25 mentions, Learning Support Educator (LSE) with 19 mentions, and the Children and Young People's Services (CYPS) with 15 mentions. Several respondents also mentioned that they pay privately for services (41 mentions) while 29 replied that no services at all were received. Table 4.1.39 lists all services mentioned, with the number of times that each one was mentioned. Figure 4.1.40 also refers.

When asked whether they were satisfied with the services recently received, the majority of respondents expressed overall satisfaction, with 49.7% saying that they were very satisfied (22.7%) or satisfied (27%) with services recently received and only 30.7% replied that they were not content (18.4% 'Very Dissatisfied' and 12.3 'Dissatisfied'). Table 4.1.40, below, refers.

Figure 4.1.40 – Support Services Received in the Last Six Months

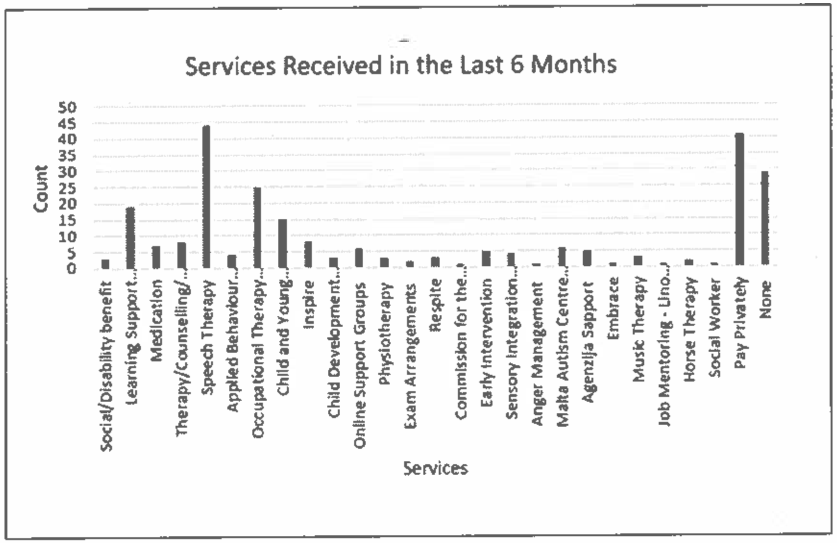


Table 4.1.40 – Level of Satisfaction with Services Received in the Last Six Months

Satisfaction w Services Received in Last 6 Months

Level of Satisfaction	No.	%
Very dissatisfied	30	18.4%
Dissatisfied	20	12.3%
Neither Dissatisfied nor Satisfied	32	19.6%
Satisfied	44	27.0%
Very Satisfied	37	22.7%
Total	**163**	**100.0%**

Caregiver respondents were also asked what they considered to be the most important services for persons with autism and ADHD. By far the service that was considered to be the most important was occupational therapy, with 61 mentions. This was followed by speech therapy with 51 mentions, mental health services (counselling/psychologist) with 40 mentions, and educational support/LSE, with 39 mentions. Behaviour therapy/ABA and social skills/groups were also considered to be highly important with 36 and 35 mentions respectively. Instruction in independent living/life skills (21 mentions) and financial support (20 mentions) were followed by sensory-friendly places and rooms which received 16 mentions. Support for parents/family, and respite/caregiver hours/day care each received 15 mentions, followed by information and coaching for parents with 14 mentions. Table and Figure 4.1.41 list the top 12-ranked services mentioned, while Table 4.1.42 lists all services considered by caregivers to be important for autism and ADHD.

Table 4.1.41 – The 12 Services Considered to be the Most Important for ASD and ADHD

12 most frequent mentions - Top Services	Count
Occupational Therapy	61
Speech Therapy	51
Counselling/ Psychologist	40
Educational Support/ LSE	39
Behaviour Therapy/ ABA	36
Social skills/ Social groups	35
Independent living/Life skills training	21
Financial Support	20
Sensory-friendly places and rooms	16
Support for parents/ family	15
Respite/ Caregiver hours/ Day care	15
Information and Coaching for Parents	14

Figure 4.1.41 – Ranking of the 12 Services Considered to be the Most Important for ASD and ADHD

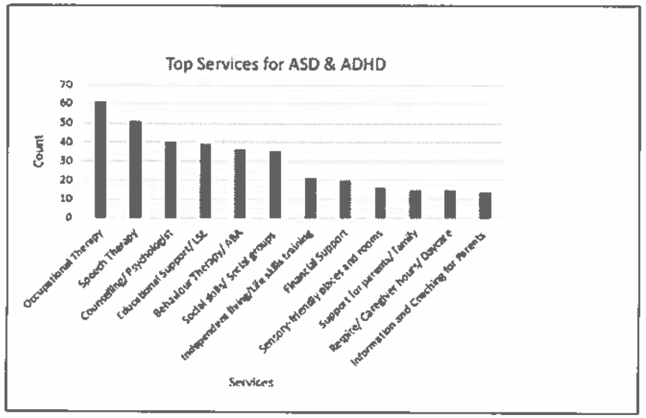


Table 4.1.42 – All Mentions of Services Considered to be Important for ASD and ADHD

Reply to Top 3 Services for ASD and ADHD	Count
Occupational therapy	61
Speech therapy	51
Counselling/ Psychologist	40
Educational support/ LSE	39
Behaviour therapy/ ABA	36
Social skills/ social groups	35
Independent living/life skills training	21
Financial support	20
Sensory-friendly places and rooms	16
Respite/caregiver hours/day care	15
Support for parents/ family	15
Information and Coaching for parents	14
Educating teachers and schools	13
Early assessment/ more frequent assessments	9
Employment support	8
Medication	7
Sports/ extra-curricular activities	7
Extra educational support/tutoring	6
Play therapy	6
Early intervention	5
Facilities in schools	4
Educate the rest of society	4

Key worker/ social worker	4
Professionals	4
Special, dedicated schools	4
Support with handwriting/ literacy/ dyslexia	4
Mindfulness	3
Physiotherapy	3
Safe, dedicated playgrounds	3
Services throughout life	3
Hydrotherapy/ pools	2
Inclusion	2
Inspire	2
Nutritional support/ therapy	2
Animal therapy	1
Boot camps	1
Different assessments in schools	1
Financial literacy	1
Music therapy	1
Special paid leave for parents	1
Support for later life, when parents are not around	1

Examining the ranking of services considered important by parents and caregivers, the services most valued were those that facilitate living within society for the diagnosed individual, that is, services that allow them better movement and communication, and enhance success in education and social environments – hence the importance given to services such as occupational therapy, speech therapy, counselling, education support and behaviour therapy.

Parents are also concerned that in order to achieve a rich and fully independent life, their children will need to fend for themselves and be self-sufficient in future. They also pointed out that they need breaks from the burden of care as they feel burnt out, and expressed a desire for a world that is more understanding and accepting. Caregivers also requested adequate frequency and access to trained professionals, and more regular provision of services. Better and non-generic medication was another point that was brought up, as well as the fact that essential medication is regularly out of stock. Another issue mentioned was the need for longer service hours from service providers since parents need to work, and better support in schooling environments as it was felt that schools do not seem to understand the implications of neuro-divergent diagnoses.

Several of these issues were also brought up when caregivers were asked what barriers they encountered in the provision of services. Long waiting lists which delay access to services was the top-mentioned barrier, followed by cost. The lack of trained professionals was also keenly felt, particularly as it impacts the previous two, since a shortage of personnel leads to longer waiting times and rising costs to access those professionals that are available. Unfortunately, a number of mentions were also made of previous negative experiences with professionals that were off putting for cared-for persons and caregivers, who found this a significant barrier. These experiences have a negative effect in that the person will then not wish to go for treatment or services that could help make their life better, and highlights the importance of disseminating information about these conditions, so that persons accessing services or treatment are treated with dignity. Other barriers highlighted are the fact that public services are infrequent and inconsistent, with the result that the caregiver opts to go to private practitioners, so that results achieved can be maintained. However, a side effect of this is that due to cost, they often have to ended up choosing which services to access, as paying for several services is often overly financially taxing, and this was felt even more strongly for families that have roe than one child or person that need treatment. Another issue that was mentioned was that often there is an age-related cut off for services, so that while they are found to very helpful for the cared-for person, they are cut off at a certain ag, and unless the family can pay for services from the private sector, the person will have to forego treatment. In some case, although the person would have a diagnosis, they are told that they are not eligible for treatment, either because they are not of the right age, or because their case is not deemed severe enough, however as autism and ADHD are lifelong conditions, caregivers feel very keenly that they are being let down. Table 4.1.43 and Figure 4.1.42 refer.

Given that autism and ADHD literature states that these conditions are life long, caregiver respondents were asked whether they felt that services were adequate for the different stages of the life course – hence 0-3 years (first years), 3-4 years (kindergarten age), 5-10 years (primary school age), 11-16 years (secondary school age), 16-24 years (young adults), 25-64 years (more mature adults), 65+ (older persons). Caregivers felt that services are inadequate across the board, with services for the younger years, ages 0 to 10 receiving less disapproval than services for eleven-year-olds and up, where the level of dissatisfaction rises sharply from around 60% to 90%. Table 4.1.44 and Figure 4.1.43 refer.

Perceived adequacy of services for different ages was also tested against diagnosis, to see if any statistically significant associations exist, using the Chi square test. A significant association was found between diagnosis and perceived adequacy of services for ages 0 to 3 years (p-value of 0.002) and 3 to 4 years (p-value of 0.033). For the other ages, as the p-value was above the 0.05 level of significance, no statistically significant association was discovered. Significant associations for ages 0 to 4 reveal that while there are indications that services for older ages are dissatisfactory, for ages 0 to 4 there is statistical evidence that services are widely viewed as inadequate. Table 4.1.45 refers. Perceived adequacy of services was also tested against gender, however no significant association was found between these two factors, as Chi square tests consistently returned results above the 0.05 level of significance for all the age groups.

Figure 4.1.42 – Barriers Accessing Services for ASD & ADHD

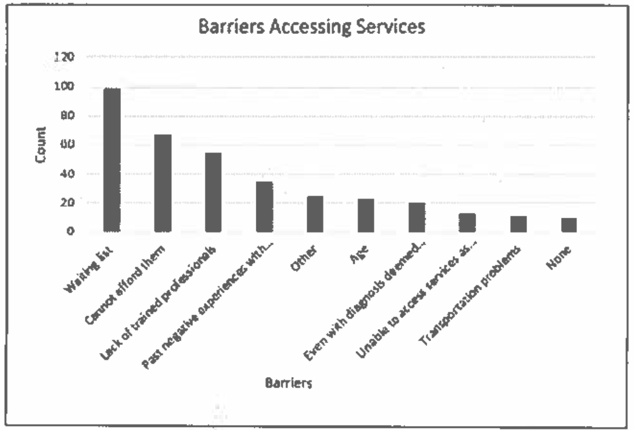


Table 4.1.43 – Barriers Accessing Services for ASD & ADHD

Barriers Accessing Services	Count
Waiting list	99
Cannot afford them	67
Lack of trained professionals	55
Past negative experiences with professionals	35
Other	25
Age	23
Even with diagnosis deemed ineligible	20
Unable to access services as diagnosis does not qualify	13
Transportation problems	11
None	10

Table 4.1.44 – Caregiver views on adequacy of ASD & ADHD services for different age groups

Caregiver Views regarding adequacy of services for various age groups				
Age Group	Yes		No	
	No.	%	No.	%
0 to 3 years	66	40.5%	97	59.5%
3 to 4 years	79	48.5%	84	51.5%
5 to 10 years	58	35.6%	105	64.6%
11 to 16 years	27	16.6%	136	83.4%
16 to 24 years	14	8.6%	149	91.4%
25 to 64 years	9	5.5%	154	94.5%
65+ years	10	6.1%	153	93.9%

Figure 4.1.43 – Caregiver views on adequacy of ASD & ADHD services for different age groups

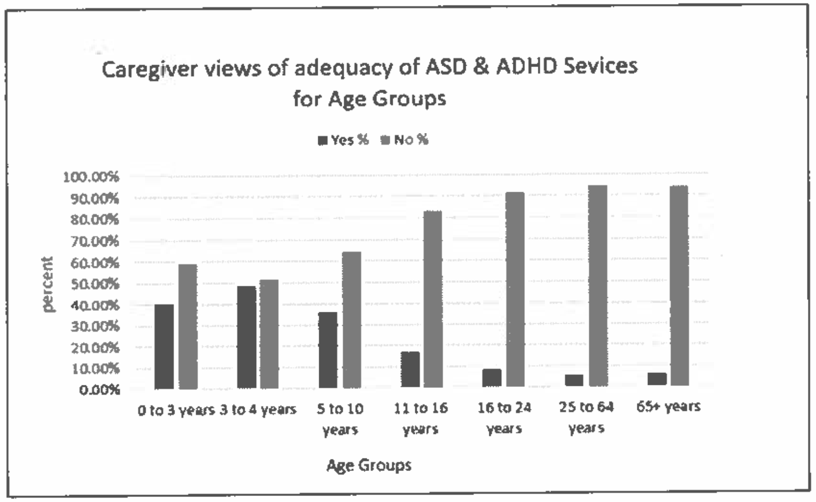


Table 4.1.45 – Distribution of Caregiver views on adequacy of ASD & ADHD services for different age groups by Diagnosis

Distribution of Caregiver Views Regarding Adequacy of Services for Different Ages by Diagnosis																
Age Group	**ASD YES**		**ASD NO**		**ADHD YES**		**ADHD NO**		**Comb. YES**		**Comb. NO**		**Total YES**		**Total NO**	
	No	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
0 to 3	44	27.0	38	23.3	12	7.4	37	22.7	10	6.1	22	13.5	66	40.5	97	59.5
3-4	48	29.4	34	20.9	18	11.0	31	19.0	13	8.0	19	11.7	79	48.5	84	51.5
5-10	32	19.6	50	30.7	18	11.0	31	19.0	8	4.9	24	14.7	58	35.6	105	64.4
11-16	16	9.8	66	40.5	10	6.1	39	23.9	1	0.6	31	19.0	27	16.6	136	83.4
16-24	9	5.5	73	44.8	4	2.5	45	27.6	1	0.6	31	19.0	14	8.6	149	91.4
25-64	4	2.5	78	47.9	3	1.8	46	28.2	2	1.2	30	18.4	9	5.5	154	94.5
65+	5	3.1	77	47.2	3	1.8	46	28.2	2	1.2	30	18.4	10	6.1	153	93.9

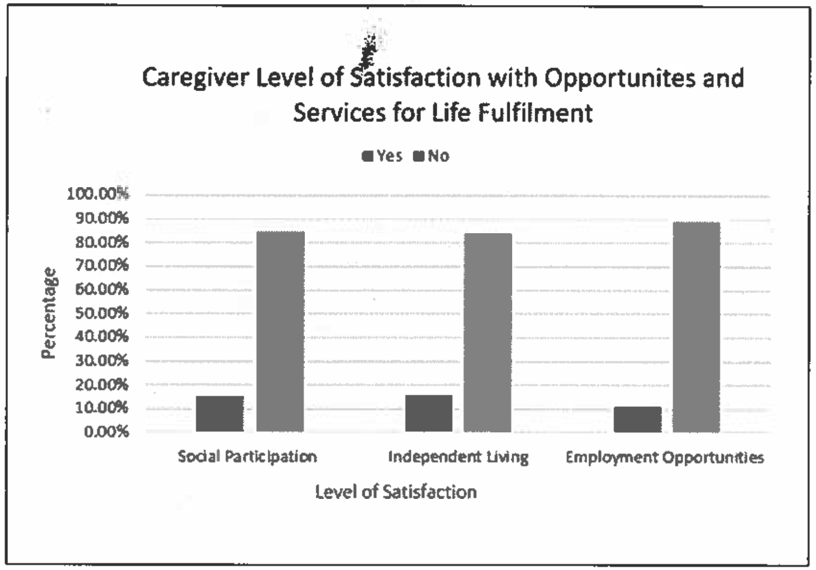
Caregivers were also asked whether they were satisfied with the support and opportunities available for life fulfilment across the categories of Social Participation, Independent Living and Employment Opportunities. Across all three areas, there was a high level of dissatisfaction ranging from 84% for independent living, to 85% for social participation, and 89% for employment opportunities. As all three categories are crucially important in order for persons living with these conditions to lead a fulfilled life, where they feel personal satisfaction and that they are useful members of society, it is important that these areas are given importance in planning and delivering services across all age groups. Table 4.1.46 and Figure 4.1.44 refer.

Caregiver level of satisfaction with services and opportunities for life fulfilment in all three categories was also tested against diagnosis and gender for all three categories, however Chi square tests in all cases returned p-values > 0.05, there no significant associations were found for level of satisfaction and either diagnosis or gender for all three categories of life fulfilment.

Table 4.1.46 – Distribution of Caregiver views on adequacy of ASD & ADHD services for different age groups by Diagnosis

Level of Satisfaction with Support and Opportunities for Life Fulfilment						
Categories	**YES**		**NO**		**Total**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Social Participation	25	15.3%	138	84.7%	163	100.0%
Independent Living	26	16.0%	137	84.0%	163	100.0%
Employment Opportunities	18	11.0%	145	89.0%	163	100.0%

Figure 4.1.44 – Distribution of Caregiver views on adequacy of ASD & ADHD services for different age groups by Diagnosis



The Caregiver questionnaire shed valuable light on the demographics of the cohort, practices surrounding diagnosis, service usage and how services are experienced, barriers to accessing services and which services are considered to be most important by caregivers.

4.1.3 Service Providers' views on the services for persons with Autism and/or ADHD

Professionals involved in providing a service to a particular demographic generally have a very good overview of the demographic, the services provided, and the challenges faced in service provision. In order to gather knowledge and make best use of this wealth of expertise, a questionnaire, specifically prepared for this study, was sent out to gatekeepers to disseminate to their employees, with the aim of gathering an overview from professionals of the services provided for persons with ADHD and/or autism.

Service Providers' views – Services for persons with ADHD

Twenty-five professionals from diverse areas of practice responded, providing services from the areas of education, social and public health services, as well as professionals from the Commission for the Rights of Persons with Disability, across the government, private and Non-Governmental Organisation (NGO) spheres of service provision. The majority of respondents came from organisations offering services provided by the Government – mainly Social (28% of sample), Public Health services (24%), followed by Education Services (16%). Professionals in Private Practice comprised 12% of the sample, while Non-Governmental Organisations (NGOs) comprised 16%. Table 4.1.47 and Figure 4.1.45 refer.

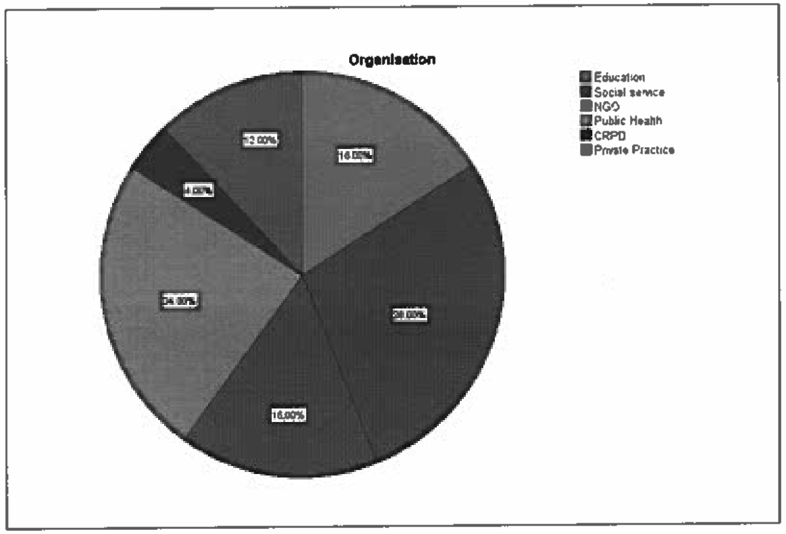
Table 4.1.47 – Type of Respondent by Organisation - ADHD

Organisation	***Frequency***	***Percent***
Education	4	16.0
Social service	7	28.0
NGO	4	16.0
Public Health	6	24.0
CRPD	1	4.0
Private Practice	3	12.0
Total	**25**	**100.0**

Table 4.1.48 – Number of Clients by Organisation - ADHD

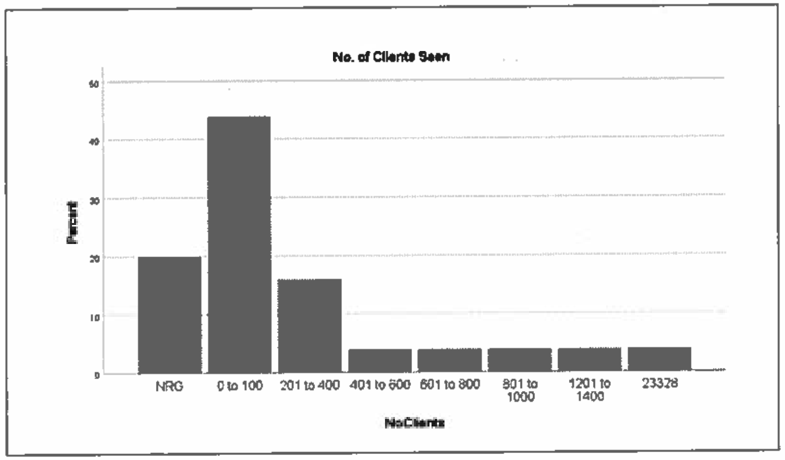
No. Of Clients	Frequency	Percent
NRG	5	20.0
0 to 100	11	44.0
201 to 400	4	16.0
401 to 600	1	4.0
601 to 800	1	4.0
801 to 1000	1	4.0
1201 to 1400	1	4.0
23328	1	4.0
Total	**25**	**100.0**

Figure 4.1.45 – Type of Respondent by Organisation - ADHD



The majority of organisations (44%) cater for less than 100 clients, while 16% cater for between 200 and 400 clients, with CRPD being the largest organisation represented, with over 23,000 clients. Table 4.1.48 and Figure 4.1.46 refer.

Figure 4.1.46 – Number of Clients Seen - ADHD



Studying the services available according to age range, it becomes apparent that the majority of services available to persons with ADHD are for minors. Out of the 25 service providers from different spheres that responded to the questionnaire, only 10 professionals replied that they provide services to adults. Table 4.1.49 and Figure 4.1.47 refer. Of these services available to adults with ADHD, one is provided by the University and caters mainly for access arrangement and support services on Campus; three are public health services and a further three are social services catering for assessment, intervention and inclusion services, two are NGOs and the other one is the Commission for the Rights of Persons with Disability (CRPD), that offers inclusion and support services to persons with disability. No employment services are offered directly to persons with ADHD, which, given the challenges met in this area outlined in the literature review above, seems to be a missed opportunity. In fact, none of these service providers cater specifically for persons with ADHD, as most provide generic services such as social or public health services, and also to minors; meaning that there are no services that cater exclusively to the social service needs of adults (See Table 4.1.50 and Figure 4.1.48, below).

Table 4.1.49 – Service distribution according to age - ADHD

Replies for Age Range of Clients Seen	*Frequency*	*Percent*
0 to 13	8	32.0
13 to 17	1	4.0
Adults: 18+	2	8.0
All ages 0 to 60+	5	20.0
All Minors: 0 to 17	4	16.0
8 to 30	2	8.0
13 to 60	1	4.0
8 to 17	1	4.0
4 to 30	1	4.0
Total	**25**	**100.0**

Within age groups, a further 8 professionals stated that they also provide services for children of a very young age (see Tables 4.1.51 and 4.1.52 and Figure 4.1.49), with most of these being in Private Practice or Assessment Services. For services for children vs services for adults, see Figure 4.1.50.

While the majority of services did not give a reply to the question regarding the gender split of males versus females among their clients; interestingly, and in line with findings from the literature review, most of the service providers who did respond, stated that their clientele is predominantly male, with the divide between genders ranging from 70% male to 30% female, to 60% male vs 40% female. Only two services reported differently – with a community services provider stating that they have a majority of female clients, and a public health service provider reporting a 50/50 gender split.

Figure 4.1.47 – Service distribution according to age- ADHD

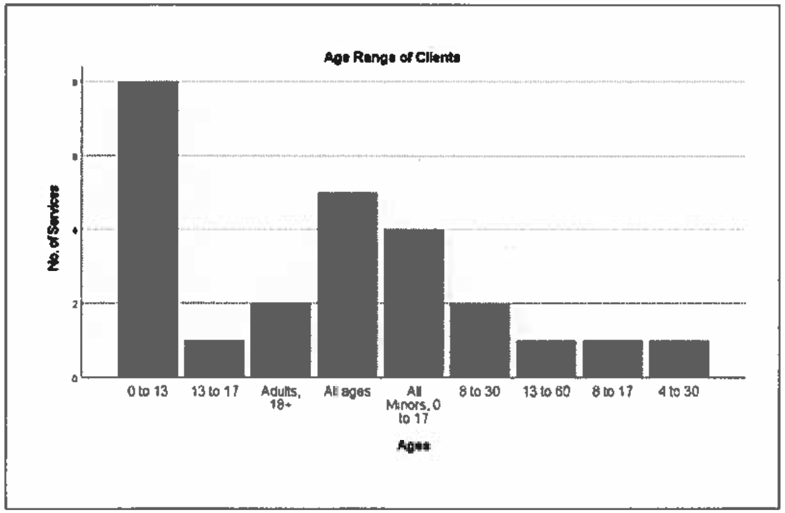


Table 4.1.50 – Services Available to Adults with ADHD

Services Catering for Adults with ADHD by Type	*No. of Services*
University Services	1
Public Health Services	3
Social/ Residential Services	3
NGOs	2
CRPD	1
Total	**10**

Regarding waiting times for service, the majority of respondents, (60%, *n*=15) reported that they do have waiting lists in place for the service they provide, as opposed to 40% (*n*=10) who said that their clients do not need to wait to start receiving their services (Figure 4.1.51). There were no missing answers to this question.

Participants were also asked about the length of time that clients had to wait before they could start receiving services. As seen from Figure 4.1.52 below, the services that tend to have the longest waiting times, that is, of 13 to 18 months or over, are Public Health, Education and Social Service Providers.

A chi-square test was performed for type of organisation and waiting time, however this returned a result larger than the 0.05 level of significance, establishing that there is no significant association between waiting time and type of organisation.

Figure 4.1.48 – Services Available to Adult ADHD Service Users

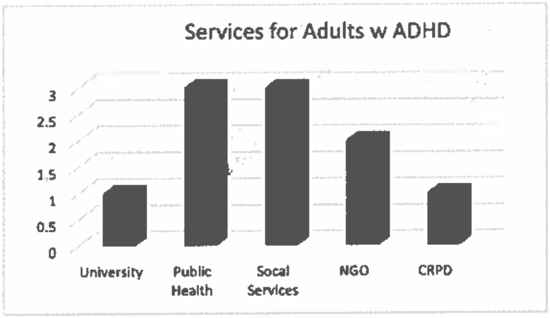


Table 4.1.51 – ADHD Services for the very young, by Age Range

Age Range of Service	***No. of Services for this Age Range***
0 to 3 years	1
0 to 7 years	2
0 to 17	3
0 to 30	1
0 to 12	1
Total No. of Services	8

Table 4.1.52 – ADHD Services for the very young, by Type

Type of Service	***No. of Services within this Type***
Private Practice	2
Assessment	2
Social Service	1
NGO	1
Public Health	1
Education	1
Total	8

Figure 4.1.49 – ADHD Services for the very young

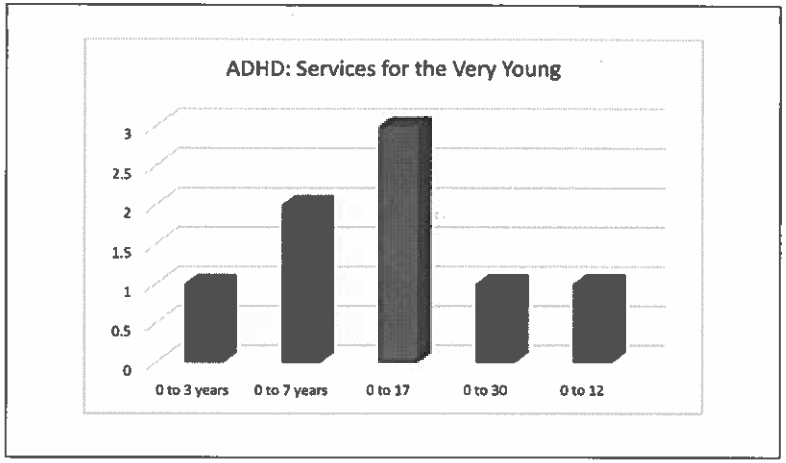


Figure 4.1.50 – Services for Children vs Adults – ADHD

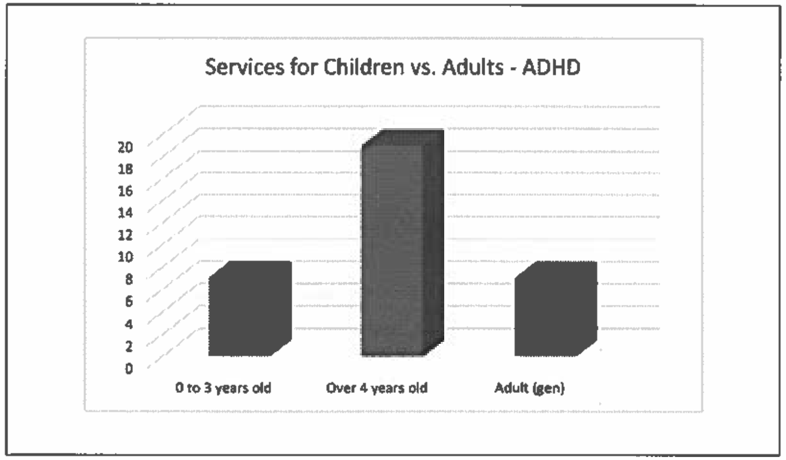


Figure 4.1.51 – Services Having Waiting Lists - ADHD

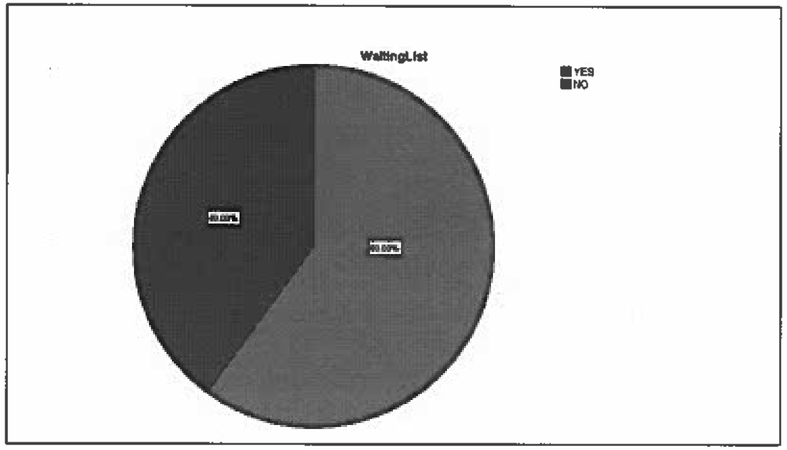
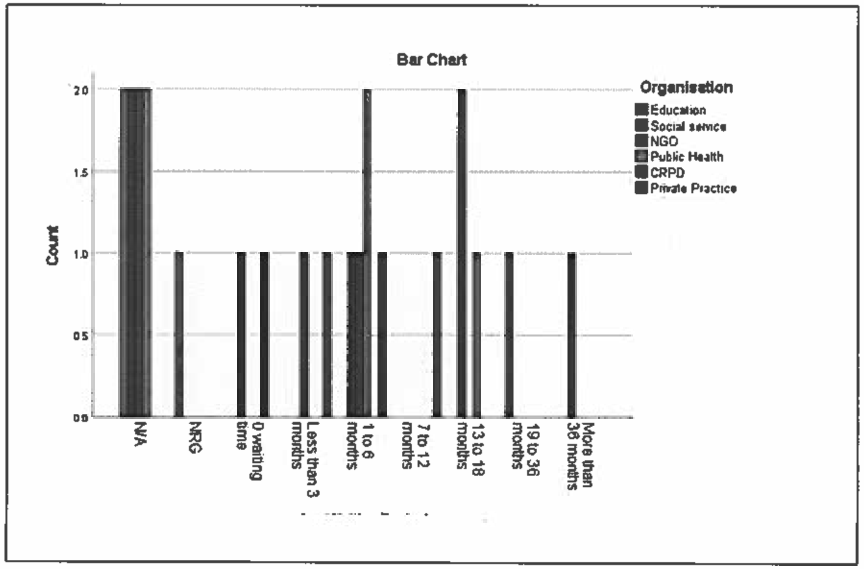
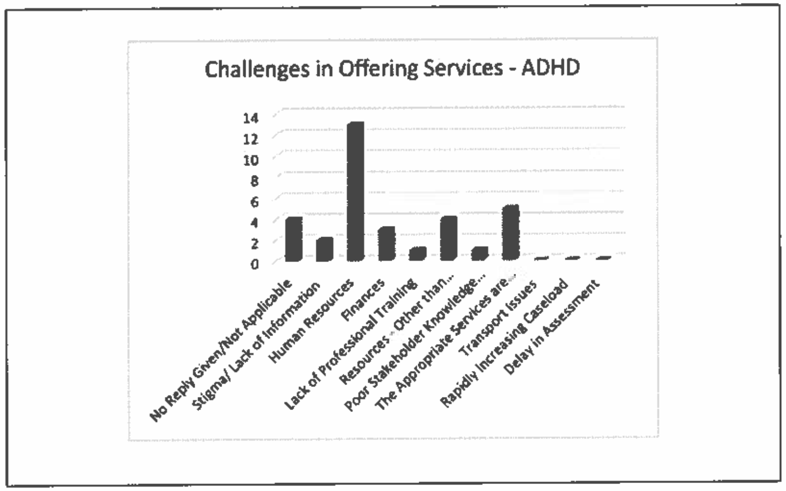


Figure 4.1.52 – Waiting Time per Type of Organisation - ADHD



When participants were asked to comment on what challenges they encountered in offering their services, the greatest challenge reported was lack of human resources, followed by the observation that the appropriate services did not exist and therefore could not be offered to clients. Other challenges mentioned were resources other than human resources, such as lack of space from which to offer the service, and finances. Stigma, lack of proper professional training and poor stakeholder knowledge or cooperation were also mentioned (Figure 4.1.53)

Figure 4.1.53 – Challenges encountered by Professionals in Offering Services - ADHD



Service Providers' views – Services for persons with Autism

Thirty-three valid responses from professionals working in the areas of education, social service, public health, employment (Lino Spiteri Foundation), the Commission for the Rights of Persons with Disability (CRPD), private practice and NGOs, were received to the questionnaire for service providers on the fields of autism and related fields of practice. The largest number of responses was received from professionals working in the areas of Non-governmental Organisations (27.3%), Social Service (21.2%) and Education (18.2%). Table 4.1.52 and Figure 4.1.54 refer.

Regarding how many clients each of the responding entities see, most see less than 200 clients, with 13 entities stating that they see between 0 to 200 persons and only 6 respondents replying that they see more than 600 clients, including CRPD which has over 23,000 persons on its books (Table 4.1.53 and Figure 4.1.55 refer).

Table 4.1.52 – Type of Respondent by Organisation – Autism

Organisation	***Frequency***	***Percent***
Education	6	18.2
Social Service	7	21.2
NGO	9	27.3
Public Health Service	5	15.2
CRPD	1	3.0
Private Practice	4	12.1
Employment (Lino Spiteri Foundation)	1	3.0
Total	**33**	**100.0**

Figure 4.1.54 – Type of Respondent by Organisation - Autism

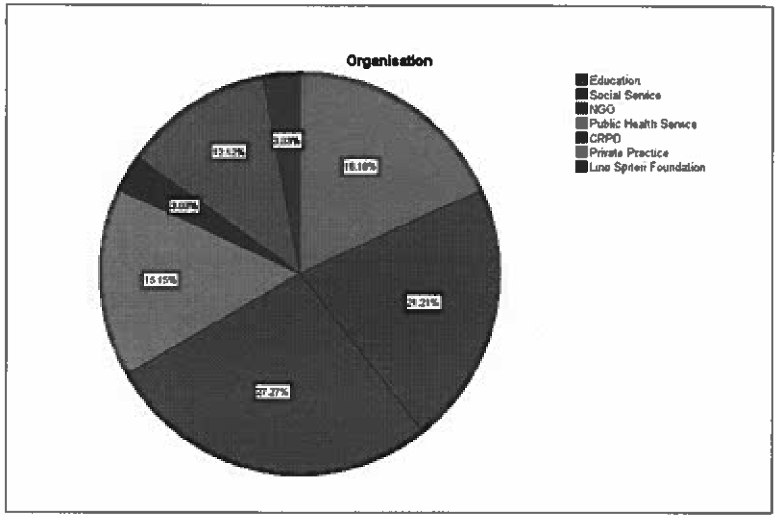


Figure 4.1.55 – Number of Clients Seen - Autism

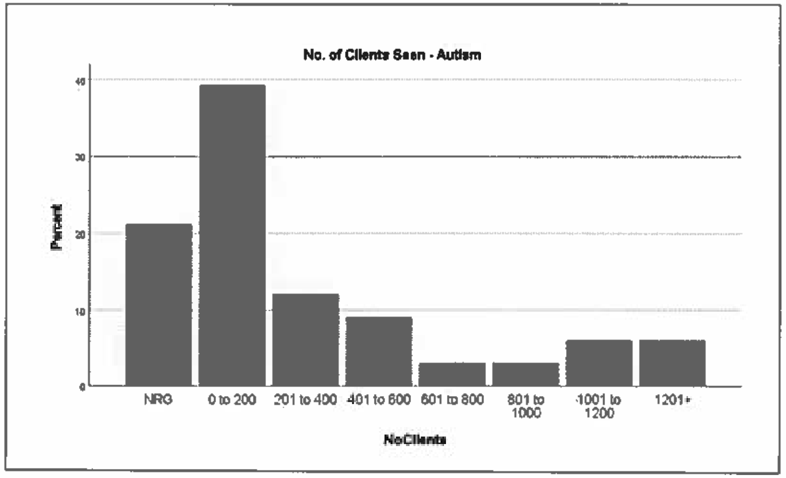


Table 4.1.53 – Number of Clients by Type of Organisation – Autism

Number of Clients by Organisation									
Organisation Type	***No. of Clients***								***Total***
	NRG	0-200	201-400	401-600	601-800	801-1000	1001-1200	1200+	
Education	4	0	1	0	1	0	0	0	6
Social Service	0	3	1	1	0	0	2	0	7
NGO	0	7	0	2	0	01	0	0	9
Public Health Service	2	1	0	0	0	0	0	1	5
CRPD	0		0	0	0	0	0	1	1
Private Practice	1	2	1	0	0	0	0	0	4
Lino Spiteri Foundation	0	0	1	0	0	1	0	0	1
Total	7	13	4	3	1	1	2	2	33

Number of clients seen according to type of organisation was analysed using a Chi-square test of association, and was found to be statistically significant, $p < 0.001$. A similar analysis carried out for number of clients by type of organisation for professionals responding to the Service Provider questionnaire for ADHD did not return a similar significant association ($p > 0.05$).

Examining the ages catered for by the respondent organisations, it immediately becomes clear that there are a number of organisations that cater for clients of a very young age, with 15 different organisations operating in various areas with services starting from babyhood (ages 0 and upwards). While no services cater exclusively for ages 0 to 3, these years are covered by services catering for ages 0 and upwards. A further 11 organisations – making a total of 26 – that offer services starting from the age of 4 years old and upwards. This contrasts with organisations offering services to persons with ADHD, where the number that cater for young or very young children was smaller. Once again, services are observed to reduce with age.

Figure 4.1.56 – Autism Services for the Very Young

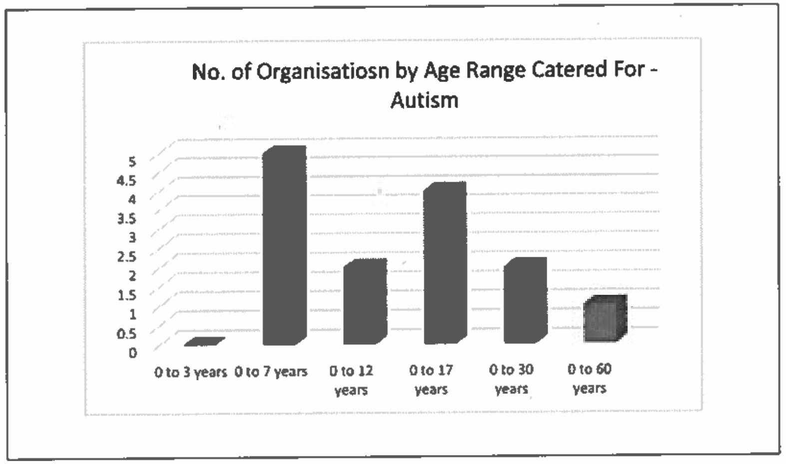
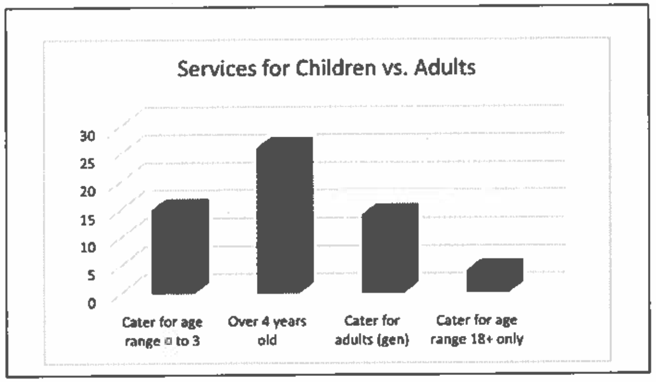


Figure 4.1.57 – Number of Services for Children vs Adults - Autism



Respondents were asked whether the service they worked for had a waiting list for clients, with refence to clients with autism. The majority (54.5%, n=18) replied that they do have waiting lists for clients, while 39.4% (n=13) replied that there is no waiting list, and 6. % (n=2) did not reply to the question. Figure 3.14 refers. The services that tended to have the longest waiting times are Social Services and Public Health Services. A Chi-square test was performed to test for significant association between autism services and waiting time, but no significant relationship was found.

Figure 4.1.58 – Services Having Waiting Lists - Autism

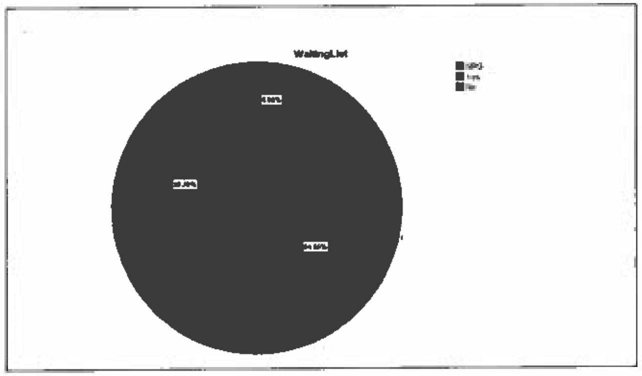
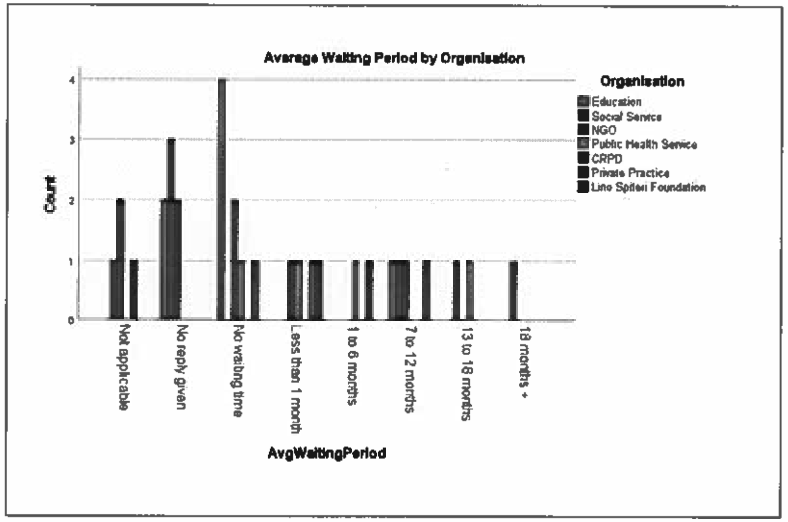
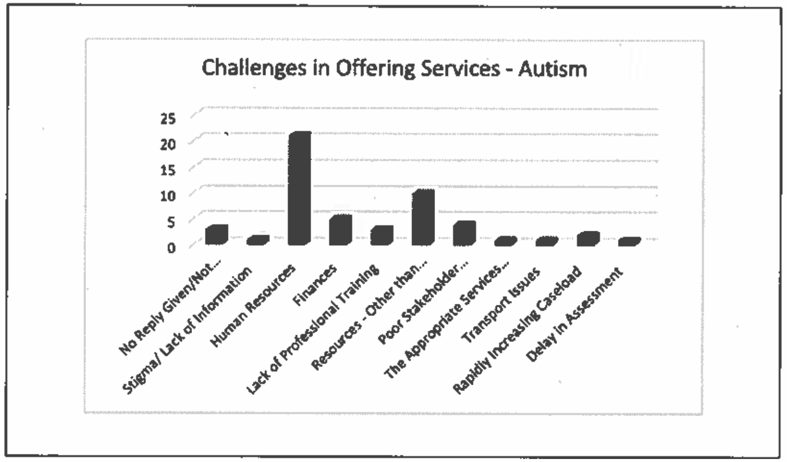


Figure 4.1.59 – Waiting Time per Type of Organisation - Autism



Participants were also asked what challenges they encounter in offering services to persons with autism. As with ADHD, by far the greatest challenge encountered was a lack of human resources. This was also echoed by participants in the qualitative branch of the study with comments such as "*Employees in the public services are stretched to their limits, literally stretched*" (Service Provider Participant 2). Unlike services for persons with ADHD however, the next greatest challenge was resources other than human resources, followed at some distance by challenges in finances. Other challenges mentioned were lack of proper professional training, poor stakeholder knowledge, which was also highlighted throughout interviews with service users, cooperation and rapidly increasing caseload. Interestingly, stigma and appropriate services not available were only mentioned once each. Figure 4.1.60 refers.

Figure 4.1.60 – Challenges encountered by Professionals in Offering Services - Autism



4.2 Finding from the Qualitative Data

4.2.1 Autism Spectrum Disorder (ASD)

From an abundance of data gathered through the qualitative branch of this study, four overarching themes were identified. These are: Services; Education and Employment; Social Interactions; and Personal Impact and Family. These are related to the experiences shared by both the caregivers of persons living with autism as well as autistic adults themselves, however, while some of the subthemes overlap across the two groups, differences were also observed. These will be presented accordingly. Following this, a discussion of the top priority needs identified by interview participants is presented.

Theme 1: Services

This theme captures the experiences of participants with accessing, obtaining, and processing their diagnosis. The distinctions in these experiences for caregivers and autistic adults alike are laid out.

Subtheme 1: Diagnosis

Challenges with the process of diagnosis were mentioned by a larger part of participants, caregivers and even more so autistic adults. In the case of caregivers, most sought a diagnosis at early years, with many being flagged at childcare centres or early school years. The experiences shared talk of a thorough process carried out by a multidisciplinary team who would walk them from one professional to the other in what participants feel was a reliable process until a diagnosis was reached. Although it did take some months to be obtained, participants felt that it was carried out professionally and were overall satisfied with their experience. Notwithstanding this, however, seeking it privately was a better alternative for one of the participants who felt that delays were too long within the public diagnosis system, and also commented on it being carried out by junior professionals. In the case of participants who reached out for a diagnosis as adults however, the experience is entirely inverse to that met by caregivers.

> *"There was no information online, anywhere. None of them [professionals] knew. The information was in no way accessible. I searched but there was nothing about this [diagnosis] for adults"* (Participant 5)

All autistic adult participants expressed the feeling of closed doors and dead ends when seeking a diagnosis as an adult. All participants shared how they found no public channels for diagnosis as an adult and some even encountered difficulties seeking it through private services. Moreover, all participants expressed how while being thorough and, even in this case, being carried out by a multidisciplinary team of professionals, their diagnosis experience was very expensive, costing them well over €500.

When it comes to autistic adult participants, these felt that their diagnosis was delivered to them in a professional manner, although all of them lamented that it was the end of the service they received and were not provided with referrals or recommendations for their next steps.

> *"It is concerning that people do not know the public services"* (participant 4)
>
> *"I had no idea what to do next"* (Participant 6)

Although all of these participants did not feel they need other services at the time of their diagnosis, in retrospect, they now all shared how it would have eased their experience to have been guided towards support or assistance in relation to their diagnosis. In the case of caregivers, the experiences shared also expressed the lack of referral to any follow-up services or channels support.

> *"You were scrambling around in the dark"* (Participant 1)
>
> *"You kind of had to find your own way and navigate your own way"* (Participant 3)

Many lamented not being aware of where to go next, feeling like they were left in the dark. Some shared missing out on important timeframes, such as applying for statementing services that are essential for support in school as a result of this. The general sentiment was that although once they started services at CDAU, these were promptly followed up, no other guidance or support services were offered, including information services for the caregivers or support to the family. Moreover, the experience with the delivery of the diagnosis contrasts that of autistic adult participants. Caregiver participants shared how the diagnosis was first given to them unofficially in a casual manner by medical professionals during their initial meetings at the beginning of the diagnosis process, and eventually, was once again delivered to them officially however in a manner that none of them felt was sensitive to what they were experiencing at the moment.

> *"It's stressful to be told your child has a developmental problem"* (Participant 3)

In addition to it being very matter of fact and medical as an experience, little to no information was given to them as to what it meant, how it would impact their life or where to seek guidance and support. Many expressed how they typically found out about support or therapeutic services by word of mouth or randomly from one professional to another.

Subtheme 2: Autism-related Support and Therapeutic Services

Following their diagnosis, most caregivers shared a story of moving on towards a path of therapies and support services for their offspring in order to assist them with their development. These include occupational therapy, speech therapy, behavioural therapy, and related services. All caregiver participants expressed how overall, services available within the public realm involve extensive waiting lists, sometimes several months, on occasion even beyond a year. This was also echoed in feedback from professionals gathered through the service provider questionnaire. In fact, all of them had sought private services in addition to those being offered to them through the public channels. All of them however expressed that these can be very costly and even in this case, sometimes still include waiting lists, although to a lesser degree than in the public sector. All shared how the disability allowance they received due to their offspring's diagnosis was not sufficient to alleviate the financial burden. Some also expressed how some services, such as behavioural therapy, can even be hard to find locally – with some mentioning the need to seek assistance from therapists living abroad who visit the island from time to time. Some also lamented the lack of preparedness of some professionals on how to work with people with autism.

> *"So the person that is blind can get a dog, but the person with autism has to have money somewhere [for therapy]"* (Participant 1)
>
> *"Like having a house loan a month [referring to private services]"* (Participant 2)
>
> *"You should know as a psychologist working for CDAU that you don't leave a kid waiting for 20 minutes and expect them - a kid with autism – they won't wait, they don't wait. My [offspring] can't wait 20 minutes"* (Participant 3)

In the case of public services, some caregiver participants expressed disappointment with the services being terminated depending on age (such as CDAU terminating services at age 7) because they felt that their offspring could still benefit from the service even beyond that age. They felt that services should proceed depending on the progress and achievements of the child, rather than their chronological age. Other public services, such as Applied Behaviour Analysis (ABA) sessions, were also considered to be not sufficient since only a few, fixed number of sessions were offered, when the benefits of the service can be reached through a more consistent long-term approach. In addition to this, most participants expressed how due to the large demand and the limited availability of professionals in the public sphere, the frequency of services was often limited. They felt that this compromised the results their offspring could reach because of sessions with professionals being too far apart. Difficulties with waiting lists were also expressed by caregivers in relation to respite services, with most participants finding these to be limited in availability as well as somewhat bureaucratic to access. Overall, caregiver participants felt that therapeutic and support services should be more frequent, more readily available and should encompass a wider range of targets, such as sexual education and independent living skills.

> *"The bureaucracy is incredible. You give up [Inkredibbli l-burokrazija. Taqta' qalbek]"* (Participant 2)

When it comes to autistic adults, the experience with services expressed by participants is very different to that experienced by caregivers. All participants in fact shared how they found no support services available to them, with one participant sharing she only found support from other autistic people that they reached out through via social media channels. Two of the participants shared how they reached to social services agencies in order to access services such as having a personal assistant to support them with administration (some shared severe difficulties keeping up with administrative pressures such as bills and appointments) but only found closed doors and an experience that they felt belittled their person and who they were with their diagnosis.

> *"You don't need any help, like, you're fine"* (Participant 5)
>
> *"You'd love to have a social worker, or like an assistant who could help you manoeuvre through the paperwork"* (Participant 6)
>
> *"Oh, you're low support needs. So, you don't need any support"* (Participant 6)

One participant added how they felt even local autism associations often only addressed the needs of autistic children. All participants felt the system was solely designed to cater for people with extreme support needs and/or children but was not adapted for the whole range of struggles that autistic individuals face. One participant felt that when it came to adults, people were either given medication or left unsupported, with no options in between. All participants pointed out how such a severe lack of support for low support needs autistic people can give rise to serious mental health challenges, aside from having an impacting on their immediate quality of life. All pointed out a critical need for services that cater for autistic adults, including those with low support needs, such as for instance, guidance on managing meltdowns as an adult.

Theme 2: Education and Employment

Following the obtaining of a diagnosis and a subsequent process of statementing, autistic children are offered support throughout their educational experience depending on their level of needs. Within mainstream and private schooling, this typically includes one-to-one assistance or a shared Learning Support Educator (LSE). Caregiver participants felt that this was a positive strategy that made it possible for their offspring to be included in schools, however, all of them lamented the fact that *"It's pure luck"* (Participant 1) when it comes to how prepared and trained the support educators working with students are. They shared how the high demand for LSEs often results in people being employed even prior to being trained which sometimes can have serious consequences on the performance of a child in school. In addition to this, some participants expressed concern over the fact that although LSEs assigned to students do change from one scholastic year to another, better transition guidance should be extended in order to aid autistic youngsters handle this change more adequately.

One of the caregiver participants who's offspring had attended a private school shared how their experience was quite traumatic when their offspring reached secondary school age since the school no longer felt they could cater for them due to the child's behavioural difficulties.

> *"They, they are focused on the typical and achieving, academically achieving child. Anybody else that is not, well anybody that hinders them…they're very proud of their schools, you know, the academic schools. If you don't, if you're going to damage those academic schools, you get taken out of the system"* (Participant 1)

Across autistic adult participants, most feel that their performance in school was hindered by their difficulties resulting from autism, for which they had not yet obtained a diagnosis.

> *"I was still struggling and finding it hard. I made the mistake of hiding it [not diagnosed yet but attempting to conceal difficulties], and it's cost me a lot"* (Participant 4)
>
> *"I hated going to school. Actually, it was the lighting itself that was driving me NUTS. I was in a daze for four years of high school because I was not able to comprehend what was going on around"* (Participant 5)
>
> *"I didn't do as well as I could have in the exams that were held in the big halls. […] Issues that arose from the bullying…it made my grades much lower than they could have been"* (Participant 6)

One participant in particular shared experiences of bullying both by peers as well as educators who would expect behaviours such as eye contact.

> *"I ended up with a lot of bullying, from students and teachers […] and specifically the bullying was for my autistic traits"* (Participant 6).

Many shared how sitting for long hours, be it in school or university as a student as well as in training as an adult, resulted challenging to them. Sitting in a room with several other people, unprepared about what was going to happen and subject to noise and other sensory stimuli at times made it hard for them to carry these out successfully. Notwithstanding this, even following their obtaining a diagnosis, participants who were still in education expressed that they still encountered difficulties adjusting their environment with adequate arrangements in order to improve its accessibility.

> *"I'm still struggling to get access arrangements that are actually useful to me"* (Participant 6)

They shared for instance how arrangements were not only necessary for exams, but even throughout the scholastic year, such as the possibility to record lectures so as to be able to listen to them more closely in a quieter setting. One participant even proposed making access arrangements an option even for students who are not diagnosed with a condition since in their case, these would have helped even though they were not diagnosed yet.

On a more positive note, having access to a quiet room in places such as university, can be very helpful.

> *"University calm room is pretty good. It's the best one I've seen locally so far. It has lights that can be switched on and off accordingly. It has bubble lamps. It has different seating of different textures, according to what you prefer. Um, they have projectors. They have a chair that you can connect your Bluetooth too […] It's targeted for adults"* (Participant 6)

At their place of work autistic adult participants also expressing difficulties related to the traits resulting from autism. These include communication difficulties, sensory issues or adjusting to practices that they could not understand.

> *"When I communicate by email, I like communicating very short and sweet and people consider that rude sometimes"* (Participant 4)
>
> *"When they try and explain to you something. They lose their temperature quite quickly, and I think it has nothing to do with ADHD and autism. Like some people still take long to understand"* (Participant 4)
>
> *"People who are autistic suffer from burnouts. It's like, if they see you doing nothing, they decide you're lazy". Maybe you are tired, and when you find five minutes break you decide to take it"* (Participant 4)

> *"The lighting in your face was bothering me a lot, and so I would prefer to the actually put on sunglasses, but I couldn't. So, at the end of the workday I'd come home completely exhausted"* (Participant 5)
>
> *"Certain rules and guidance that didn't make sense to me. […] We're doing it this way because we've always done it this way…and I found that really upsetting, as in, it was constantly a source of obsession and upset"* (Participant 5)

One participant lamented their experience with job promotions and the impact of their condition on this.

> *"I had a job […] they decided not to promote me […] I wasn't bad at my job, or something. It's they, they were saying […] she has anxiety […] We won't sort of give her a promotion, and I was passed up because of that reason, so I would rather hide it"* (Participant 4)

Although their offspring have still not reached employment age, across caregivers, a concern for what will come once they do was nonetheless present. Some for instance were concerned about the interview process itself limiting their offspring's possibilities, whilst in the nearer future, all were concerned that there were very few options available once their offspring reached the age of 22.

> *"People do not put, 'I have autism' on their CV because they think, well, you know, as soon as I put that, it's just going to go in the bin. Um, if they don't put it on their CV and they get to the interview stage, then the interviews are, you know, they're not friendly for neurotypicals, let alone people with condition. So, there's so people who might be able to do the job but fall through in the interview stage because they, they are overwhelmed by the process - they're having to wear a suit they don't normally wear. They have to go to a new place, which they don't normally do. Um, so there are simple things that, you know, can be done to, to help, you know, smooth that process. Um, a lot of people with autism don't get jobs"* (Participant 1)
>
> *"These kids are talented in their own ways, but they can't be trained by just anyone […] it would be nice to have someone to, or a platform where they would receive the proper training. […] Like a sixth form for autism" […] because of the teaching style. […] "It would be nice if you had a choice, maybe a sports school or drama school at, at a creative art school"* (Participant 3)

Theme 3: Social Interactions

When it comes to social skills, people with autism may at times struggle with how to act in different social situations (Sedgewick et al., 2016) and consequently may encounter difficulties forming friendships and relationships (Jamil et al., 2017). Across caregiver participants, a desire for more social groups and opportunities for their offspring to connect with others was expressed. Currently, some shared the availability of social group for youngsters of 16 for which however there is a waiting list.

> *"A child who has got autism, struggling with his own mental situation, figuring out what the hell's going on, seeing his friends grow up, see himself being split from his original friends from his previous school, going through puberty and, and not being able to communicate with his friends"* (Participant 1)
>
> *"Hopefully [they]'ll make more friends as [they] go along"* (Participant 3)

Caregiver participants also presented social challenges that their offspring encounter throughout their day-to-day activities. In particular, most mentioned official instances such as when medical visits need to be carried out or instances dealing with law enforcement. They expressed concerns over a lack of preparedness on behalf of professionals and the impact this may have on their offspring.

> *"Doctors and poly clinics and hospitals and police definitely need to understand autism. They need to know how to handle somebody with autism in a, in a concerning situation. And we've had, we've had situations where there's a, a teen who has to be handcuffed, um, and forced to sit down"* (Participant 1)

The same concern was also expressed by autistic adult participants. They shared how accessing general services can pose challenges to them and many expressed a preference with the use of an application rather than in-person tasks. Difficulties such as driving to a location, having to visit new places and the sensory-stimuli these brings, having to wait in noisy or crowded rooms, and dealing with bureaucracy are amongst the ones discussed. One participant even expressed they would typically opt to pay for a service in order to avoid these obstacles even if the service would otherwise be available for free.

> *"The system is far too complicated to access"* (Participant 5)

> *"I've had to go through about twenty doctors, and almost every single one of those doctors, maybe one. Hasn't said 'No, but you don't look autistic'"* (Participant 6)

Autistic adult participants also discussed the challenges they encounter with social interactions in general. One participant spoke about observing peers in the school ground to understand human behaviour, while others discussed general difficulties they find interacting with people on their day-to-day life. Issues such as social anxiety and social exhaustion were brought up. Overall, it transpired across autistic adult participants that these feel most comfortable in one to one settings and with people who they are familiar and feel safer with.

> *"My mind just shuts down. People see it as rude, but the reality, if it's not interesting to me, I just shut down"* (Participant 4)
>
> *"I've always struggled in a lot of ways socially"* (Participant 5)
>
> *"Studying for eight hours would take like only two spoons [of energy], but me making a phone call will take six"* (Participant 6)

Across caregiver participants none brought up stigma or taboo related to autism or disability and most shared that society is becoming more accepting while still expressing a severe need for more knowledge and awareness. Adult autistic participants felt the presence of stigma somewhat more.

> *"Dismantle the taboo about talking about disability, because through understanding, there's awareness and then acceptance, because right now I don't even feel like we have tolerance to disabled people in general, not only autistic people"* (Participant 6)

Theme 4: Personal Impact and Family

Across autistic adult participants, all shared their experience of feeling different to those around them.

> *"Why is this so difficult for me? Why is everything that other people do with no issues so exhausting for me? Why is it like I don't have the instructions to life, and they do. And I just kept thinking like, what is this? What is wrong with me?"* (Participant 6)

> *"The general lifestyle of Malta is very hectic. It's very busy, and it's very loud. And I just always. I always feel a disconnect to my culture"* (Participant 6)

The notion of coping with "normal" life as being exhausting was also shared by all participants, although all of them also felt that a better understanding of autism could alleviate, if not eradicate most of the problems encountered. One participant shared experiences that she found overwhelming either at an emotional and/or sensory level. The participant explained how these can lead to experiencing a "meltdown" and shared how little or no guidance or support is available to avoid or once they occur, handle these episodes.

> *"You're fine, like, just take some antidepressants or take some this, and that's it, then you're just depressed or you're just struggling, it's normal we all do"* (Participant 5)

All autistic adult participants shared having had issues with anxiety, although all of them reported an improvement in this respect once they obtained their diagnosis. All of them shared they were seeing a counsellor, although some lamented that even in the case of counsellors, more education and awareness was still necessary.

> *"There have been advantages to it [obtaining the diagnosis]. I would say, you know, the fact that you can be independent and think for yourself [...] But yes, it may make things harder for you [being autistic]* (Participant 4)
>
> *"They said outright, 'I'm not specialized in autism. I don't know much, but I will learn from you what you need to do'. That in a way is good, but it would be helpful if someone knew right from the get-go instead of me, you know, having to once again spend energy to explain things that I might not have one hundred percent grasp on myself"* (Participant 6)

In the case of caregiver participants, these expressed a lack of support services when it comes to counselling for their offspring. They shared that specialised personnel are rarely available and if these are made available, for instance, in schools, services are still not frequent enough. Overall, the need for counselling professionals who are trained to work with autistic individuals was highlighted.

> *"No support for people who are nonverbal because you need to be trained to be able to communicate with somebody who's nonverbal"* (Participant 1)

In the case of both autistic adult participants as well as caregiver participants, all expressed a lack of support services offered to the families or support network surrounding the diagnosed individual. Many caregivers shared a concern for lack of information and only a few had been provided access to family services to assist them along their offspring's journey with autism.

Top Priority Needs

Interview participants were asked to identify their top priority service needs. Some distinctions were identified between the needs expressed by direct service users and caregivers of service users. Nevertheless, a number of priority service needs that overlapped both caregivers' and direct service users were also exposed.

Amongst caregivers, all identified similar therapeutic service needs amongst their highest priorities. These included speech therapy and behaviour-related therapies (such as ABA), which were identified by all participants. Other priorities when it comes to services identified by caregivers were specialised counselling services for people with autism, with several participants, adults and caregivers alike, pointing out the lacuna in tailored services that could address the needs to autistic people. Amongst autistic adults, these even branched to identify the need for service such as career guidance, family therapy, couple's therapy as well as support addressing how to deal with meltdowns as an adult. Other priority services mentioned by caregivers were training in independent living skills and general life skills, sexual education and opportunities for social activities such as social groups. Across caregivers as well as adult participants was also the need for more autism-friendly spaces.

> *"There is nothing that is available for young the children. There are, there's a couple of services. [...] But you have children that need more assistance and there's, there's nothing. So, the social aspect is, is really important"*. (Participant 1)

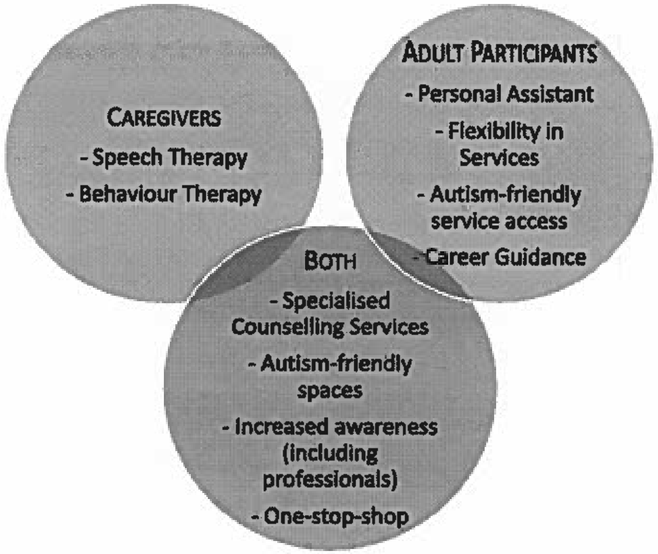


Figure 4.2 – Top priority service needs identified by autistic participants and caregivers of persons with ASD

Amongst adult autistic participants, the need for services such as a personal assistant was identified by most participants. They expressed how such service could be of valuable help, particularly when having to deal with day-to-day administration that, for instance, requires visiting public offices or syphoning through forms and documents. Increased flexibility or exemptions across services was also brought up due to delays or issues that may be incurred along the process. In relation to this, autism-friendly access routes across for services were also mentioned by most autistic adult participants as well as some caregivers, such as the assistance during hospital visits, quieter waiting rooms or shorter waiting periods. The alternative for one-stop-shop service access was also a concept that both caregivers and direct service users felt would be of benefit.

> *"Doctors are not aware of the difference in expressing pain. They think, okay, so autism is the stereotypical five-year-old boy who doesn't speak sort of thing when the spectrum is a lot more complicated than that, and it makes hospital a lot more difficult, because, of course, the sensory overload, being in pain […] And then, me not being like, me, not showing pain how they expect me to. And when I say that I'm autistic, they are not understanding and making the connection. Okay, so pain won't be expressed the same way and obviously, the whole experience is different"* (Participant 6)

Across adult autistic participants and caregivers alike was also a resounding need more awareness and acceptance. Almost all participants in fact, expressed how even amongst professionals such as medical professionals, members of the police force, educators and the general public, including other young children in schools, the need for more information and better understanding was highly present.

4.2.2 Attention Deficit Hyperactivity Disorder (ADHD)

Following data collection, thematic analysis was carried out to analyse the resulting qualitative data, and the themes extracted were grouped according to three overarching categories: Services; Education and Employment; and Family, Social and Personal Life. The next section/chapter will go on to discuss the findings from the qualitative data for ADHD. The three main themes extracted from the interviews were therefore identified through experiences which were shared by persons with ADHD as well as their caregivers. Some issues were pertinent to both groups, but others were substantially different. These findings are presented below and will be followed by a discussion of the most important needs brought up by the interview participants.

Theme 1: Services

This theme portrays the experience of adults with ADHD and caregivers of minors with ADHD in attempting to obtain a diagnosis and gain access to relevant services.

Subtheme 1: Diagnosis

All interview participants mentioned difficulties in getting a diagnosis, whether they were caregivers for minors with ADHD or adults trying to get their own diagnosis. In the case of caregivers, most noticed differences in their children at a very early age, but were unable to get the process started until the children were older.

> *"Peress li kien għad għandhom 4 jew 5 snin ma tkunx tista' tagħtik djanjożi... tatni x'nifhem li ċ-chances huma ta' ADHD"*
>
> *[Since they were still 4 or 5 years of age, she was unable to give us a diagnosis… she advised that it was probably ADHD]* (Participant 8)
>
> *"From day 1 qaltli li 99% hija ADHD imma peress li trid tagħmel xi tests online irid ikollha sitt snin biex tkun kapaċi tuża l-kompjuter... it-test ikkonferma, meta għalqet 6, li hi ADHD"*
>
> *[From day 1 she told me that it was 99% ADHD but since she had to do some online tests, she had to be 6 years of age to be able to use the computer... once she was 6, the test confirmed that she has ADHD].* (Participant 9)

One caregiver explained that children with ADHD are not diagnosed until they are seven or eight years of age, even though their symptoms manifest much earlier. In one case, where a child had already been diagnosed with autism, all his behaviour was blamed on autism, until he was eventually diagnosed with ADHD as well. Caregivers lamented that a late diagnosis is an added hardship on the child and the family as it inevitably delays medication and therapy. Unless the child has an ADHD diagnosis, adequate therapy is not given, and this results in a lack of support which is sorely needed.

> *"It-tifel tiegħi ġie mkeċċi mill-iskola. Iġġib anki frustrazzjoni fil-familji wkoll... kieku l-professjonisti jeħduha bis-serjetà meta l-ġenituri jgħidu 'there is something else'... m'aħniex nesaġeraw. It would benefit lit-tifel, lill-familja, l-iskola... mhux tħalli s-sitwazzjoni teskala. Kieku ingħata l-għajnuna mill-bidu, it-tifel tiegħi mhux qiegħed ġo resource centre..."*
>
> *[my son was dismissed from school. It is frustrating for the families as well… if the professionals believe the parents when they tell me that there is something else… we're not exaggerating. It would benefit the child, the family, the school…*

> *we shouldn't let the situation escalate. Had my son received help at the outset, he would not be in a resource centre…]* (Participant 7)

In the case of adults, the situation was quite different, and the difficulties were even more substantial. A recurring experience was that adults reaching out for help were misdiagnosed and told that they had anxiety and prescribed anti-depressants. Others were told that they did not have ADHD because they didn't fit in with the DSM5 criteria. Certain professionals still believe that non-conformity with these criteria completely rules out ADHD and may potentially lead to misdiagnosis or no diagnosis at all.

With both caregivers and adults with ADHD, diagnosis was difficult and it took long to be completed. In one case, an adult who has been told unofficially by professionals that she has ADHD, is still waiting to be diagnosed and has opted to go privately, as there is a long waiting list. However, even for a private service there is a waiting list, meaning that although the literature shows that earlier diagnosis and receipt of services greatly improves the life and experience of persons with ADHD, getting a speedy diagnosis cannot even by achieved against payment. Being misdiagnosed in particular adds to the distress experienced by the individual, as well as the persons surrounding them, and delays the receipt of appropriate treatment.

> *"I have been followed by my psychologist for two years. During two years of weekly sessions she never mentioned ADHD… She only mentioned depression when I refused to follow her instructions… She told me to go to a psychiatrist because I was going through a depressive crisis… [The psychiatrist] started prescribing me lots of anti-depressants.. Then he came up with the ADHD hypothesis"* (Participant 12)
>
> *"It should not be that if you go to one person you get the right treatment and the right medication and if you go to someone else you don't… a lot of women do end up medicated for anxiety and depression and not for ADHD… when I started the Ritalin it improved drastically"*. (Participant 10)

The adult participants explained how difficult it is to get a diagnosis at that stage of life. Adults with ADHD who were never disruptive in the classroom are not diagnosed because they do not match the standard criteria as listed in the DSM, although some experts believe that the

DSM criteria for ADHD are restrictive and need updating (Barkley, 2022; Wolraich et al., 2019). When they grow older and seek a diagnosis, they still face difficulties, both with expenses involved to get a diagnosis, but also with the lack of services. Female adults with ADHD have an additional hurdle as many professionals do not believe they have ADHD since their behaviour is not in line with what is expected by the established standards, and in fact the diagnostic tools are often criticised as not being structured well enough to catch the nuances of ADHD in women as opposed to men (Smyth & Meier, 2019).

> *"If you're a woman and you're requesting an ADHD diagnosis you have to ask other women 'who diagnosed you'? because that's the only way to find out which ADHD psychiatrists actually know what ADHD looks like in women."* (Participant 11)

Another common complaint was that, following diagnosis, interviewees were not guided towards any services which would have been helpful to them or given information about their condition. A number of these participants said that they had no idea such services even existed and that following the interview they would try to look for any services which might be beneficial to them on their own. The same sentiment was expressed by caregivers who were not given any form of guidance following the diagnosis.

> *"Fendejt għal rasi… ma kellix lil xi ħadd li jikkuntattjani. Anki support group, fittixtu jien… Waħdi ridt nieħu l-inizjattiva li infittex fejn irrid nieħu lit-tfal."*
>
> *[I had to cope on my own… no one contected me. I had to look up a support group myself… I had to take the initiative myself to look for services where I could take my children].* (Participant 8)
>
> *"Qatt ħadd ma ġibidli l-attenzjoni li hemm xi servizzi oħra li nista' naċċessa għall-ADHD"*
>
> *[No one told me of any ADHD-related services that I could access]* (Participant 9)
>
> *"What services? There's no services" (adult with ADHD)* (Participant 10)
>
> *"I assumed that once I told the school something, that someone would sit me down and say 'these are the services you can access". Nothing. Nothing at all."* (Participant 11)

In the case of caregivers, many said that having to wait for the child to get older to get a diagnosis was detrimental both to the child and to the family. A common experience was a sense of unnecessary hardship because of delays in diagnosis, and a sense that they had to experience situations which could have been avoided had they been listened to in the first place. These have repercussions that affect lives, as in the case cited above, where a child was asked to leave the school he was attending due to behavioural difficulties. Had he had an ADHD diagnosis, he could have received the support needed and possibly remained in his school. Other caregivers also said that the support received in the run-up to and following the diagnosis was very lacking. People taking care of children with ADHD have generally spoken out on the lack of information about services provided in connection with ADHD.

Subtheme 2: ADHD-related Support and Therapeutic Services

The caregivers who participated in the interview shared common experiences of getting adequate services for their children. The main trend was that government services are good but that they fall short when it comes to frequency. One mother explained that her son who is both autistic and has ADHD, needs speech and occupational therapy, both of which should be provided regularly to produce lasting results, yet at most he only receives treatment through the government once a month. One appointment a month is not frequent enough and leaves too large a gap between sessions, such that the child to loses all the progress that was gained during the previous session. Many caregivers try to supplement these appointments with private ones, however not all of them can afford to do it, especially on a weekly basis and all mentioned the financial burden.

Unfortunately, some caregivers had never been guided as to the beneficial effects that occupational therapy can have on children with ADHD, however others affirmed that occupational therapy was the most essential service for children with ADHD, however this needed to provided be regularly and frequently enough to be effective. This type of therapy is useful in helping children deal with hyperactivity, aggression, concentration, and literacy among other things (Wennberg et al., 2021). These problems all stem from sensory integration, making occupational therapy a highly important service, which should be prioritised. For those caregivers who had no idea that occupational therapy could help their children, it is vital that they receive appropriate and timely guidance regarding which services could benefit their children. One parent, commenting on services in Gozo, mentioned that occupational therapy services were not up to standard, sessions were too short and the

approach too superficial. However, private services were found to be better organised and delivered: sessions were longer and the therapists delve deeper into the problem, however, the private service is also very costly.

> *"Ix-xogħol ta' OT, daqs kemm hu mportanti għal tfal bl-ADHD, naħseb jiena mhux qed jingħata daqshekk importanza fil-verità."*
>
> *[Occupational therapy is very important for children with ADHD, and I think it's not being given the importance due]* (Participant 7)
>
> *"Għawdex il-faċilitajiet tal-occupational therapy mhumiex up to standard... anki t-tip ta' servizz, is-session kienet tkun wisq qasira, 20-25 minuta. Meta kont immur privat kienet 50 minuta. U anki l-approach... kienet wisq superfiċjali".*
>
> *[In Gozo, occupational therapy facilities are not up to standard... the session was too short, 20-25 minutes. When I went for private sessions, they would last 50 minutes. Even the approach was too superficial]* (Participant 8)
>
> *"Occupational therapy qatt ma ħadtha... occupational, qed insaqsi għalfejn occupational?... Issa nfittex ftit ieħor fuqhom dawn is-servizzi ħalli jekk nista' nibbenefika..."*
>
> *[I never took her [my daughter] for occupational therapy... occupational? Why occupational? I'll look up these services, maybe I can benefit from them]* (Participant 9)

An interesting aspect that was discussed during the interview was that children who have both autism and ADHD get more services than children who only have ADHD.

> *"Ħbieb tiegħi li t-tfal tagħhom għandhom l-ADHD, sfortunatament għandhom inqas servizzi minni. M'għandhomx respite... hemm minnhom lanqas jikkwalifikaw għad-disability allowance".*
>
> *[Unfortunately, my friends whose children have ADHD, are given less services. They don not have respite... some of them do not even qualify for disability allowance]* (Participant 7)
>
> *"Jekk ikollok down syndrome jew diżabilitajiet oħrajn naħseb ifittxuk huma u tingħata l-għajnuna... bl-ADHD, il-fatt li m'hawnx awareness, it is taken for granted u qisu m'għandek xejn gravi. Mhijiex gravi essaċċ imma jekk ma tingħatax is-sapport u l-għajnuna throughout the years, it gets out of hand".*

> *[I believe that if you have down syndrome or other disabilities, you are sought out and given services… with ADHD there is not that much awareness, it is taken for granted, as if you don't have anything serious. It is not that serious, but if you do not get adequate help and support throughout the years, it gets out of hand].* (Participant 8)
>
> *"Għall-autism hawn ħafna, u rightly so għax għandhom l-istruggles tagħhom, imma naħseb li l-ADHD għandha tingħata l-istess importanza".*
>
> *[There is a lot for autism, and rightly so because they have their own struggles. However I think that ADHD should be given the same importance].* (Participant 8)

While services are limited for both autism and ADHD, people with autism tend to have more services available to them, than those with ADHD. Caregivers of the latter are not offered respite servicers at all, and some of them do not qualify for disability allowance, despite the fact that they often end up having to go to private practitioners to get adequate and frequent enough services for themselves or their children, which puts a further strain on family finances. A caregiver of a child who has both autism and ADHD specifically stated that ADHD should be given the same importance that is given to other disabilities.

Most of the caregivers stated that taking their children to private speech, behaviour and occupational therapy is very costly and becomes a very big problem when the family cannot afford it. The caregivers know that their children need these services but are unable to obtain the necessary services due to financial constraints. They make do with government services, despite knowing that the services offered are not frequent enough to make any real difference to their children.

> *"Hemm overload ta' cases. Fil-privat għala m'għandniex din il-problema? Kulħadd qed imur fil-privat għax is-servizz aħjar. Dik qed tagħmel problema mbagħad għal min ma jiflaħx iħallas dawn il-flus u jispiċċa juża s-servizzi tal-Gvern meta s-servizz mhuwiex ta' kwalità tajba. Allura dawn it-tfal qed jintesew, mhux qed jieħdu dak li ħaqqhom fil-verità"*
>
> *[There's an overload of cases. Why is there no such problem in the private sector? Everyone is choosing the private sector because the service is beter. This is causing a problem for those that cannot afford to use private services and end up using Government services when they're of inferior quality. These children are being forgotten, they're not getting what they deserve]* (Participant 7)

In the case of public services, some caregiver participants expressed their disappointment at age-related cut-offs, i.e., when the service being terminated when the child reaches a certain age. One caregiver made reference to the Sensory Integration Service – while highly commending this service and acknowledging the improvement she saw in her child, she lamented the fact that the service was stopped when he reached 5 years of age. The child still needs the service, but he was automatically discharged once he reached the cut-off age. The caregiver had to re-apply for the service and the child has been on the waiting list for more than a year. The caregivers believe that service should be given or stopped depending on the need and progress of the child, rather than based on a cut-off age.

> *"Jekk jibdew minn età żgħira kif beda tiegħi, once li jgħalqu five years, they get discharged. Fil-każ tiegħi nħoss li għad għandu bżonn so kelli nerġa' napplikalu".*
>
> *[if they start at an early age, like my child did, once they are five years old, they get discharged. I felt that he still needed the service so I had to reapply]* (Participant 7)

A very interesting aspect that was given a lot of importance by a number of caregivers, was the fact that following the diagnosis, no information was given about services available. Some caregivers were left in the dark once their child was diagnosed with ADHD and a few said that not even the professionals they took their children to privately had explained to them what services would be beneficial for their child's condition. This seemed to be worse when the caregiver went through private channels, rather than public ones.

When it comes to adults with ADHD, the experience was even more pronounced. Participants explained that while children's services were limited, services for adults were practically non-existent.

> *"What services? There's no services… ADHD Malta offers some services though we're not services providers… but in truth there are no services"* (Participant 10)

Adults need to pay for any therapy that they wish to pursue and these services can be quite costly when used on a regular basis. One participant said that she sees her psychologist and her psychiatrist every 3 to 4 weeks, but that this is a huge expense which is not allowing her to have any savings. The adults who cannot afford this expense have to get by on medication alone. All the participants said that they knew of no public services related to ADHD that they could use.

One of the problems encountered by adults with ADHD is that psychiatrists and psychologists did not listen to them and were not asking the right questions, with the consequence that this could lead to incorrect diagnosis and wrong treatment. A number of adults, especially women, were given medication for anxiety and depression before the professional realised that they had ADHD.

> *"We were going through trial and error... my psychologist told me that I was going through a depressive crisis and since she couldn't prescribe me any medicines... so I decided to go to the psychiatrist and at the beginning he was treating me with anti-depressants. He tried with a lot of different types of anti-depressants, trying to change the dosage but they were not affecting me at all".* (Participant 12)

Subtheme 3: Medication

Interview participants explained that the medication they are offered through the local government system is usually methylphenidate, which is a generic medicine. In certain circumstances, they may get the brand-name Ritalin, which is also a methylphenidate. Although both medicines are meant to be identical, participants explained that they are not effective for the same length of time, and that it is very difficult to gauge the number of top ups needed unless the person knows what he/she will be getting. Professionals too, have difficulties with this system, as they might give a prescription to their clients which would not match the generic medicine they then receive, such as instances where they are prescribed 2 pills that cover 8 hours, but then the pharmacy will provide them with a brand that covers 6 hours, or 10 hours, meaning that the prescription times do not match the medicine they receive.

The adults who use methylphenidate had two differing views about the medication: One participant said that they can get by on whatever medication is provided for free; another said that they would rather buy Ritalin out of their own pocket than have to keep adapting to whatever generic medicine is provided.

> *"While a lot of people taking methylphenidate can describe effects over the time... I do not experience these effects... by changing the medicine I didn't experience any difference at all."* (Participant 12)
>
> *"These are psychiatric medications. They affect your brain chemistry every time."* (Participant 11)

The participant explained that as ADHD medicine is a psychiatric medication and affects brain chemistry, they preferred to pay and know that they were getting a set standard of care, rather than subject themselves to different brands with fluctuating results that were impossible to gauge beforehand.

Aside from the medication itself, experiences shared by caregivers and adults with ADHD reveal that access is also problematic. The main issue is the bureaucratic process involved – one caregiver explained how because the psychiatrist was not available at CYPS, they had to wait for almost 4 hours to get a signature for their offspring's medicine.

> *"It-terturi li tawni biex toħroġ il-karta s-safra... jien kultant narahom burokraziji żejda... darba minnhom il-psikjatra ma kienx is-CYPS u ridt noqgħod nistenna, għamilt kważi 3-4 sigħat just għal firma, meta inti taf li għal tfal b'challenging behaviour ma jistgħux jistennew."*
>
> *[It was so difficult to get the yellow card... this bureaucracy is too much... once, just because the psychiatrist was not available at CYPS I had to wait for 3-4 hours just for a signature, when everyone knows that children with challenging behaviour cannot wait]* (Participant 7)

The long waiting time is an added burden for caregivers since, due to the hyperactive aspect of their ADHD, their children are unable to wait in line. This raises the point that social needs should also be taken into consideration when catering to medical needs, and that people need to be treated holistically.

The adults understand the paperwork involved with regard to POYC, however they explained that for people with ADHD, who typically have challenges with executive function, this can be very daunting due to the different prescriptions, different expiry dates, renewals, some needing a doctor's signature, others needing a psychiatrist, etc.

> *"I have an E-ID, why do I need a piece of cardboard? People with ADHD lose things... lucky for me, the pharmacy I go to keeps my control card for me... you have to renew the control card every year."*
>
> *"You have to remember to go and get your medication once a month... you have to pay for a GP's prescription every month... why this extra tax for getting my medication? Bizzejjed [it's enough] I'm having to pay for it because POYC is a disaster unto itself for ADHD meds."* (Participant 11)

In spite of the e-health system, they have to present a physical card to get their medicine and this needs to be done on a monthly basis, which can be difficult for them as they have a tendency to lose and forget things. All this can lead some people with ADHD to simply forego their medication rather than deal with the bureaucracy.

A final point that emerged from the interviews, is the gap in services when children become teenagers, and again when teenagers become adults. When they're young, children can get services from the Child Development Assessment Unit (CDAU); when they get older or become more challenging, they fall under the Children and Young Persons Services (CYPS). There is however – and unfortunately – no continuation of service between CDAU and CYPS, so professionals need to start assessing their clients all over again from scratch.

> *"There's a gap in services when they become teenagers… the transition between teenagers and adults, there's a big gap in services there as well. Up to a certain age they are covered by CDAU… then they fall under CYPS. The problem is that between CDAU and CYPS there isn't really a carry-over so CYPS will start by re-assessing"* (Participant 10)

There have even been cases where, upon second assessment, caregivers were told that their child was not a clear case of ADHD, so that after years of receiving a certain type of service, the children would start getting different medication and different services.

These gaps show a clear need for homogeneity and communication between services, besides a clear guidance to service users and caregivers about what services they might need following their or their children's ADHD diagnosis; as well as easily-understandable information about the condition itself.

Theme 2: Education and Employment

Subtheme 1: Education

Children with ADHD may seem to be fine when they're not in a structured environment, leading people to often assume that there's nothing wrong, however, when they're at school or in any other setting where they are expected to follow rules or adhere to a rigid structure, problems may start to emerge (Xi & Wu, 2021). These problems may feel extremely overwhelming for

both the children and the caregivers, who constantly need to repeat what their children are supposed to do and remind them how to behave.

The experience of caregivers with schools was quite varied: one 6-year-old was asked to leave mainstream schooling and had to be schooled in a resource centre, i.e. a dedicated school where they cater for pupils with individual educational needs and offer a range of specialised services for their students. However, these are often seen as prioritising social skills over educational achievement (Malmqvist & Nilholm, 2016), which is the opposite of inclusive schooling. The caregiver believes that had her child received help when she asked for it, he might still be in a mainstream school and would emerge from schooling with better educational outcomes.

> *"Kieku ingħata l-għajnuna mill-bidu, t-tifel tiegħi mhux qiegħed ġo resource centre… għad għandu sitt snin u diġa' ġo resource centre. Tant it-tifel ma kellux opportunità li jibqa' ġol-iskola, minħabba li ġie mkeċċi, li ma jafx l-istruttura ta' mainstream"*
>
> *[had he received help at the outset, my son would not be in a resource centre… he's still six and he's already in a resource centre. He hasn't had the opportunity to experience a school, due to his dismissal, so he does not know the structure of a mainstream school.]* (Participant 7)

Another parent described how the school was unhelpful with her child's condition. They did not direct her in any way towards services that would be beneficial, and when questioned about the inclusion aspect of the government curriculum, they replied that the school, which was not a government school, was not bound by it. The parent feels that inclusion in her child's school is just 'sweet talk'. Despite knowing of her child's condition, they are not flexible enough – they treat her too rigidly and seem like they do not accept her.

> *"L-iskola jafu bil-condition, għandi rapport fuq ieħor. Qisha she's not accepted… Hi ribelluża, she answers back, she doesn't take no if you don't explain. Allura l-ikbar piż li ngorr jien hu li dawn iċempluli kull gimgħa… They try to be helpful, imma taparsi"*.
>
> *[The school know about her condition, I have provided many reports. It seems as if she's not acccepted… She's rebellious, she answers back and she doesn't accept no if you don't explain. My biggest burden is that they call me every week. They try to be helpful, but they're just pretending]* (Participant 9)

When it comes to secondary school, caregivers mentioned the need for more support – not just in the form of an LSE. Students in secondary school are already going through challenges and ADHD can make things more difficult. Unless these students find adequate support, they may emerge from secondary school without proper education and eventually face employment problems.

In higher education levels, such as at post-secondary and tertiary levels, there is a need for more knowledge of what ADHD is about and what students with ADHD might need. Some students might simply need someone to look out for them, others might need more support.

> *"They might need someone to look out for them or some extra support… at University… some support is offered but unfortunately students don't know about it… it could be part of the prospectus"* (Participant 10)

At the University of Malta there is a level of support, but many students do not even know about it. It would be very helpful if this type of support were listed in the prospectus, so that anyone needing it would know that it is available and how to access it.

An adult with ADHD speculated that many early school leavers in Malta may have had ADHD that remained undiagnosed or unsupported. Students with ADHD can be very bright, but may leave school with a lack formal qualifications, due to their schools being unable to deal with their traits or not having the necessary know-how and personnel (Garcia et al., 2019).

> *"Probably a lot of early school-leavers in Malta have ADHD that's undiagnosed… School just doesn't match up with ADHD traits so why stay in school? They leave. Often, they're bright but have no qualifications."* (Participant 11)

Subtheme 2: Employment

In the workplace, people with ADHD do very well in certain jobs if they are given adequate support. They can also do well if they opt for a job that makes use of their strong points. In Flippin, 2021, psychologist Kathleen Nadeau explains that having ADHD can be a positive trait and that there are politicians, entrepreneurs and business owners who have ADHD. She adds that the CEO of JetBlue, David Neeleman, created the e-ticket system because he was always losing his travel tickets, and cites this as an example where the effects of ADHD were turned into an advantage.

One interviewee works in management and does well because she cares about her staff. Her problem is that she falls behind if no one follows up on her deadlines. She is aware that her employer is very understanding, however she also knows of people who were not so lucky and who faced disciplinary measures because of undiagnosed ADHD or lack of support.

> *"When you have big projects and you don't have someone managing your deadlines, I'm always falling behind. Then I'm ashamed to tell my boss... he forgives me for not meeting deadlines, but if my boss was different, I would be in serious trouble."* (Participant 11)

Many difficulties faced by people with ADHD at their place of employment are due to their challenges with executive function (Kofler et al., 2019). Neurotypical adults, who generally do not understand what ADHD is and how it manifests itself, expect other adults to act in a certain manner, and if they do not follow what is deemed 'acceptable behaviour', they will label the person with ADHD as being childish and hold judgement against them. Executive dysfunction also makes administrative work feel very overwhelming for a person with ADHD, so much so that some persons with ADHD who would rather take vacation leave than use their sick leave, simply because the paperwork involved can feel overwhelming, for example they might forget to get a doctor's certificate it or lose it.

> *"I'm always late with my admin, because to me, cause of ADHD, admin feels worse than death. We have people at work who use their Vacation Leave instead of taking sick leave because they forget to get a doctor's certificate or they lost [it]."* (Participant 11)

For people with ADHD, employment is a matter of finding the job that brings out the person's strong points while providing support for their weak points. A person may be brilliant at most aspects of their job but struggle with the administrative tasks that for other people might be simple routine. Adequate support and understanding would ensure a better workplace for all involved.

Theme 3: Impact on the Family, Social and Personal Life

Subtheme 1: Impact on the Family

While life for persons with ADHD can be challenging, the impact of ADHD has far-reaching effects that extend beyond the individual. Caregivers of children with ADHD tend to suffer from burnout and unless they have a good support structure that enables them to rest for even a few hours, it can get very difficult. Yet, families living with ADHD do not have the possibility of availing themselves of respite, as is fortunately available for families living with autism. Families with members having ADHD have to be constantly on the go, to single-handedly support their relatives who have ADHD.

> *"Mhux easy jkollok tfal b'ADHD. Iċ-challenging behaviour tagħhom huwa differenti minn challenging behaviour ta' tfal bl-awtiżmu. Ħafna nies forsi ma jirrealizzawx... Il-ġenituri burned out – jekk m'hemmx sapport biex jistrieħu dawk il-ftit sigħat... jien nemmen li anki dawn il-problemi ta' saħħa mentali li għandhom il-ġenituri, kulħadd bid-depression... mhux ovvja jekk dawn il-ġenituri m'għandhomx lok li jistrieħu?"*
>
> *[Having children with ADHD is not easy. Their challenging behaviour is different to that of autistic children. Many people don't understand... The parents are burned out – if there's no support for them to get a few hours' rest... I believe that even the mental health problems and depression that these parents have... isn't it obvious if they don't have the time to rest?]* (Participant 7)

Parents of children with ADHD often use methods that are not in line with their children's needs (Hutchinson et al., 2016). One of the interviewees, a parent with ADHD who also has children with ADHD said that she can only help her children because she understands what they are going through and what they need. She explained how her experience with having ADHD herself enlightened her regarding the best way to help her ADHD son, and highlighted the difficulties that parents who have not gone through ADHD themselves have in teaching their children how to survive in a non-ADHD world, as there is no one to show them.

> *"A lot of the parents don't know how to manage ADHD kids and the way they deal with them is not in line with the way ADHD kids need to be managed." "I teach things to my son in the way I wish someone had taught me"* (Participant 11)

Another issue that was mentioned across all interviews is the cost for private services. Caregivers of minors with ADHD explained how they have to either complement government services with private ones, or forego government services and pay for private sessions. This choice is not capricious – it is simply because the sessions offered for free are not enough to keep up the momentum of improvement in their children.

> *"Il-ġenituri jfittxu servizzi privati, meta aħna għandna servizzi tal-Gvern. Kull m'għandhom bżonn... iktar funding... halli jkun hemm iktar impjegati li jridu jaħdmu f'dan is-servizz. Għandna ħafna nuqqas ta' human resources... hemm overload ta' cases. Fil-privat għala m'għandniex din il-problema? Kulħadd qed imur fil-privat għax is-servizz aħjar.*
>
> *[Parents look for private services even though they have Government services. All that is needed... more funding... to get more employees wanting to work in these services. We have a lack of human resources... an overload of cases... Why does the private sector not have this problem? Everyone is going to the private sector because the service is better.]* (Participant 7)

Costs can be prohibitive for adults with ADHD when it comes to obtaining treatment. They tend to either rely solely on medication or pay for private services, mainly because there are no free services for them. However, these services are expensive, especially when they are availed of on a regular basis. The cost is draining on the family, especially if the family already has financial difficulties to start off with. There are families whose children need more therapy but they have to get by with the free services because they cannot afford to pay for more. The consequence of this is that these children are not getting the support they need and the impact can possibly be felt for years and affect their future relationships and employment (Garcia et al., 2019).

> *"Problema għal min ma jiflaħx iħallas dawn il-flus u jispiċċa juża s-servizz tal-Gvern u s-servizz mhuwiex ta' kwalità tajba. Dawn it-tfal qed jintesew, mhux qed jieħdu dak li ħaqqhom"*
>
> *[This is a problem for those who cannot afford to pay and end up using Government services even though the quality of the service is not good. These children are being forgotten; they are not getting what they deserve].* (Participant 7)

It is also a constant source of worry for the family, who know that they are unable to provide what their children need. The same scenario can happen in the case of adults with ADHD. They might not be in a position to pay for private services. If, as well as having ADHD themselves, they also have children with ADHD, they might choose to invest any money they have in their children and not make use of any services themselves.

Caregivers who have ADHD (and who might also have children with the same condition) face many difficulties, and some of the worse moments are at home. Problems with executive function mean that they feel under constant pressure to perform better. These parents tend to feel guilty because they may forget to send items that are needed for school, or that their children have certain events. Unless someone is there to support and remind them, they forget. They also find it very hard to deal with everyone's executive function when their own is dysfunctional. The start of the school year is a bad period for them because they have to manage everything at once. Mornings are particularly difficult to deal with, because they have to get ready for work, get the children ready for school and try not to forget anything or be late for everything.

> *"I wake up in the morning, I have two hours of extreme stress… getting everyone ready for school and work. I have to wake up my kids, I have to follow everything. I have to check who has brushed their teeth, who has been to the bathroom, have they gotten dressed, is everything on correctly… I am doing their executive function. At the same time, with my dysfunction I'm making lunches, have I included all the things that need to go in the lunch? Have I forgotten a fork? Do they have consent forms?... He had crafts today and I forgot to send his stuff. The chores in the morning, when I wake up are really stressful".* (Participant 11)

This forgetfulness and lack of organisation, which is one of the traits of ADHD, is also the cause of what one of the participants called an 'ADHD tax'. When people with ADHD forget, it costs them money: they forget to file their tax returns and they get fined; they buy fruit, forget it and have to throw it away; they have to buy clean underwear because they forgot to do their laundry and these tasks feel unsurmountable.

> *"When you have ADHD it often costs you money. You buy fruit, you put it in the fridge, out of sight out of mind, you literally forget it's there, it rots, you throw it away. It's money that you wasted. It's ADHD tax… ADHD tax is also because you're impulsive. You go online at 2am, you're feeling good, you buy 300 euro worth of stuff. That's also ADHD tax – If you didn't have ADHD you wouldn't spend the money. Can you return it? Yes. Do you return it? No, because you have ADHD."* (Participant 11)

This is all money that people who do not have ADHD do not spend and it is another thing that adds pressure on the family.

One common concern among caregivers was the future of their children. Many of them expressed fear that not enough support was being offered once children reached a certain age, and the possibility of getting lost in the cracks was very real. They explained how real this danger is especially in the teenage years, when these adolescents not only have to cope with the normal changes of that particular stage of life, but also with their ADHD traits, including their impulsivity.

> *"Tkun challenging ħafna għax apparti li bħal sħabhom ikunu għaddejjin minn changes, huma jkollhom iktar changes. L-impulsività ma tgħinx u anki l-emozzjonijiet tagħhom... ħafna drabi jiġu perceived ħażin... jekk jilħqu jidħlu f'ċerti vizzji jew ċirku vizzjuż, jew challenging behaviour, jekk ma jiġix addressed, dan se joħroġ mill-iskola jew jiġi irrifjutat mill-iskola... jispiċċa b'ħafna problemi, bla edukazzjoni u ovvjament diffikultà fix-xogħol."*
>
> *[It's very challenging as besides the changes that their peers are going through, they have extra challenges. Their impulsivity and their emotions are of no help… they are often perceived badly… if they end up with certain addictions, a vicious cycle, or challenging behaviour and this is not addressed, they will leave school, or be refused by the school… they will end up with a lot of problems, without education and with employment difficulties].* (Participant 8)

A number of interviewees made reference to the case of a youth with ADHD who ended up homeless. Nobody wanted to take care of him because of his behaviour. Someone who believed in him offered him shelter in a private home, the ADHD community raised funds for him, rented an apartment and helped him get back on his feet.

> *"… it breaks my heart li din il-mara daħħlitu fid-dar tagħha, pruvat tgħinu kemm tista'... dan ġbarnilu l-flus, krejnilu flat, sakemm beda jqum fuq saqajh. Illum il-*

> *ġurnata he's flourishing, imma għax xi ħadd emmen fih. Imma bħala servizz le, m'hawnx unfortunately".*
>
> *[... it breaks my heart that this woman welcomed him in her home and tried to help him as much as she should... we collected money and rented a flat for him, until he could cope on his own. Today he's flourishing, but only because someone believed in him. Unfortunately, there are no services...]* (Participant 7)

Such stories highlight that the key between a good outcome or a negative one lies in the services and support received, and that it often does not take much to turn the life of someone with ADHD around, however, as Garcia et al., (2019) point out, if the services are lacking, there will be people falling through the cracks.

Even though AHD is not a life-threatening condition, unless people with ADHD are offered support, it can get out of hand, and the person can end up in a vicious circle that can lead to challenging behaviour and even criminality. Lack of support may come about because there is a gap in services, or it might also be because of a lack of understanding of ADHD. If a service provider does not understand ADHD, it is very difficult to provide an adequate service to the person seeking help.

In spite of their qualms, throughout the interviews, caregivers of children with ADHD were firm in their belief that given a good structure, adequate services, and a willingness by society to invest in them, their children would be able to have a good life.

> *"Jekk ikollhom is-servizzi iva, imma naħseb li bla servizzi ħafna minnhom jispiċċaw ħażin.*
>
> *[If they have services yes, but I think that without services many of them would end up badly]* (Participant 8)
>
> *"Nemmen li jista'... nemmen li jekk ikun hawn programmi li jgħinuh u jissapportjawh, iva, jista' jsib xogħol, jista' jgħix waħdu... pero' kemm is-soċjetà hi lesta li tinvesti, kemm hi lesta li tgħin."*
>
> *[I believe he can... I believe that if there are programmes to help and support him, he can find a job, he can live on his own... it depends on how much society is willing to invest, how much it is willing to help.]* (Participant 7)

Interaction with people who do not have ADHD can be difficult for a person with ADHD. The challenges start at an early age, when children with ADHD start feeling that they are different and misunderstood. A caregiver whose child had to be moved to a resource centre explained how making friends had been very difficult in a mainstream school but the problem seemed to have dissolved in the resource centre, perhaps due to a feeling of belonging.

> *"Meta kien fil-mainstream, it-tfal tipiċi ma nafx għala ma kienx iħobb joqgħod magħhom. Issa li qiegħed ir-resource centre, qiegħed jgħannaqhom, hand-in-hand, għax naħseb he feels that they understand him".*
>
> *[When he was in mainstream, he didn't like staying what the typical children. Now that he's in a resource centre, he hugs them, holds hands with them, maybe because he feels that they understand him].* (Participant 7)

Children with ADHD may behave differently, and this may lead them not to be accepted within a group, also some adolescents may fall in with gangs because it might be the first time that they feel accepted, especially if they didn't find enough support elsewhere (Wehmeier et al., 2010). Interview participants pointed out the lack of services available for adolescents and the problems that they face when having to deal with their ADHD on top of the normal challenges faced by adolescents. Issues like lack of self-esteem and impulsivity can create problems for any adolescent, however this is increased when the adolescent also has to deal with the symptoms of ADHD, particularly when there is no adequate support. The result is an escalation in their behaviour which can eventually lead them to a life of crime, with the criminal system continuing to punish them for something that was not their fault to begin with (Garcia et al., 2019;Wehmeier et al, 2010).

> *"Imbagħad noqogħdu ngħidu għax tifel b'ADHD għamel xi att ta' kriminalità meta jikber. Mhux ovvja? Tagħmel ħafna sens. Jekk is-sistema ma nvestietx fih minn età żgħira! Dawn huma l-ġenerazzjonijiet li ġejjin u m'hawnx investiment fihom".*
>
> *[And then we are surprised when a child with ADHD commits an act of criminality. Is it not obvious? It makes a lot of sense, if the system did not invest in them in their early years. These are the future generations and there is no investment in them].* (Participant 7)

These issues were also bought up with adult interviewees who explained how people with ADHD tend to be loud, talk a lot and overshare. This can be uncomfortable for some people, and they will shy away from the friendship. Another challenge is the forgetfulness, where people with ADHD tend to forget to phone or text their friends. Unless the other person understands and accepts to continue making the effort to keep the friendship, it can simply fizzle out.

> *"We're friends and I like you and get on really well with you, but I never phone you, I never send you a text, I never start a conversation with you because you are not in front of me. You have to start the conversation with me. Why? Because out of sight, out of mind – I literally forget you exist, even if you're my best friend. So, a lot of friends of people with ADHD feel like 'Oh they don't care about me so I'm not going to contact them' and you lose the friends. The best people to have as friends when you have ADHD are ADHD friends who understand".* (Participant 11)

Another trait in people with ADHD is that they go for whatever is new, different and exotic (Wehmeier et al, 2010). An adult interviewee shared her experience in relationships, explaining that her marriage started and ended because of ADHD. Once the novelty wore off, the relationship started going downhill – this can lead persons with ADHD to end up in serial relationships. Unless they know why their relationship has suffered in this way, they can also end up with feelings of guilt and anger.

> *"When the shine wears off in a relationship, as it always does, a lot of adults with ADHD end up in serial relationships... Most ADHD adults don't know this and no one teaches us about it. No one teaches you about relationships to begin with as an adult, let alone if you have ADHD."* (Participant 11)

ADHD can have a serious effect on a person's everyday life. An adult with ADHD explained how her health can suffer because of her tendency to drink coffee, smoke and eat junk food. People with ADHD have a propensity for addiction and they can also end up feeling depressed due to people's constant judgement of their behaviour. Life can become a constant struggle for them and they may feel like every day is an uphill battle. Other people may not understand what they are going through and might think that people with ADHD are over-reacting or being dramatic.

> *"Many of us, if we didn't have kids, we would have ended it, because it is a constant uphill battle... most of us don't find support in our family when we are late diagnosed"* (Participant 11)

5. Discussion

Different but not less (Grandin, 2012)

Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) accompany a person throughout life, across numerous milestones and crossroads (Barkley, 2015). Consequently, for an autistic person for instance, this brings a range of health, community, and social support needs that can vary across their lifespan, bringing age-specific challenges in navigating support and service sectors (Lai & Weiss, 2017). The same is no less true for ADHD. In a 2017 survey across Europe looking into challenges faced by autistic people, Autism-Europe found that in all countries, at varying degrees, autistic people and their families were found to face similar difficulties in accessing a diagnosis, inclusive education adapted to their needs, employment, person-centred and life-long support, and lack services to assist them in moments of transition throughout their lifespan. The findings of this study also resonate with these and add to the literature related to the experience of persons with autism and ADHD in Malta, shedding light on the challenges faced along their progression from childhood, across adolescence and into adulthood. Overall, the data suggests that several barriers in accessing the different services required across the lives and respective milestones of these persons in Malta are present. Notwithstanding the improvements highlighted by several participants along the years, these barriers may lead to many autistic people feeling deprived of the right to enjoy life in the community (Autism Europe, 2017) while hindering the successful development and of persons with ADHD.

Demographics

Responses received to the Service User questionnaire were analysed to examine the experiences of persons living with autism, ADHD or both combined. Out of the 64 responses received, the vast majority (64%) were from persons with a diagnosis of ADHD. However, as this sample is not representative of the general population, we cannot draw any conclusions from this. There are several possible reasons for the predominance of responses from persons with ADHD, especially when considering that the majority of replies received to the Caregiver Questionnaire were received from caregivers to autistic persons. However, although the sample was not representative of the general population, meaning that replies are not generalisable, we can still obtain an idea of trends for this population.

The fact that majority of respondents were female is noteworthy, as even allowing for the fact that females tend to respond better to online surveys (Smith, 2008) cannot on its own account for this and would indeed contradict the widespread impression that autism and ADHD affect males more than females. These results show clearly that females are also affected, and accordingly diagnostic procedures and treatment protocols ought to take this into consideration, as prevalent male-centric practices are not only outdated but also incorrect.

Regarding the distribution of respondents by district, the district split was fairly representative of the population figures per district, leading to the possibility that the geographic distribution of the sample was pretty representative, however while there are indications that this is the distribution trend, no hard conclusions can be drawn as the sample is not representative of the general population. With 25% prevalence, as opposed to a population share of 17% of the total general population, the Northern district registered a relatively high number of persons within this cohort that have a diagnosis of autism or ADHD. The exact reasons for this are not known however it is possible that the Northern region does hold a larger proportion of persons with a neurodivergent diagnosis.

In the case of the caregiver cohort, this was largely composed of caregivers for persons with autism (50%). Caregivers for persons with ADHD comprised 30% of the cohort, while for persons with a combined diagnosis the sample share was 20%. The majority of looked-after persons (74%) were male, with 23% being female. The remaining 3% did not specify their gender. Cross examining gender and diagnosis revealed that there is a sizeable gap between the number of males living with autism and the number of females. This seems would seem to validate the research, which states that autism affects males more than females, possibly with a disparity ration of 4:1 (Halladay et al., 2015; Nag et al., 2018). However, the fact that the discrepancy between diagnosed males and females is much smaller for ADHD, implies that although the idea that ADHD affects males more than females persists, the opposite is likely to be true with real rates being closer to 1:1 (Mowlem et al., 2019). Ages of looked after persons within the sample ranged from 0 to 30 years. The spread of diagnosed individuals largely reflected the regional residence spread of the general population, with two notable exceptions. Interestingly, the percentage of diagnosed individuals residing in the Northern Harbour District was 43% of sample, as opposed to a 33% share within the general population. This would tend to indicate that there is an above-average of diagnosed individuals in the Northern Harbour region. Conversely, there were only 3% of the sample who resided in the Northern Region, as opposed to 17% of the general population. However as this is not a

representative sample, no definite conclusions can be drawn. The majority of cared-for individuals come from 2-parent households. Within this sample, 38% of diagnosed individuals have family members that also have a diagnosis, and although this was not found to be statistically significant it does reflect findings in the literature stating that genetics are a factor in autism, ADHD and combined diagnoses.

When it comes to service providers, in the case of ADHD, amongst the 25 professional participants, the majority (44%) were found to cater for less than 100 clients, while 16% catered for between 200 and 400 clients. As is evidenced throughout most of the data findings gathered from service users and/or their caregivers, it once again became evident that services to adults are less available than those for children. Amongst service providers from different spheres that responded to the questionnaire in fact, only 10 professionals replied that they provide services for adults. Worryingly, no employment services were found to be offered directly to persons with ADHD, which, given the challenges met in this area, can be a cause of considerable unsatisfactory consequences. Moreover, none of the participating service providers catered specifically for persons with ADHD, with most providing generic services such as social or public health services, and also to minors; meaning that there are no services that cater exclusively to the social service needs of adults with ADHD.

Although a larger part of service provider participants did not share information surround client gender trends, in line with findings from the literature review, most of the service providers who did respond, stated that their clientele was predominantly male, with the divide between genders ranging from 70% male to 30% female, to 60% male vs 40% female. Only two services reported differently – with a community services provider stating that they have a majority of female clients, and a public health service provider reporting a 50/50 gender split.

The larger part of participants (60%) reported having waiting lists for service provision. Amongst these, the services with the longest waiting times, that is, of 13 to 18 months or over, were found to be Public Health, Education and Social Service Providers. Most participating service providers expressed their greatest challenge when it came to delivering service was lack of human resources, followed by the observation that the appropriate services did not exist and therefore could not be offered to clients. Other challenges mentioned were resources other than human resources, such as lack of space from which to offer the service, and finances. Stigma, lack of proper professional training and poor stakeholder knowledge or cooperation were also pointed out.

In the case of service providers catering for clients with autism, the views of 33 professionals were gathered. In this case, most saw less than 200 clients, with 13 participants stating that they saw between 0 to 200 persons and only 6 replying that they saw more than 600 clients, including CRPD which has over 23,000 persons on its books. Examining the ages catered for by the respondent organisations, 15 participants were found to cater for clients from ages 0 and upwards. A further 11 organisations – making a total of 26 – that offer services starting from the age of 4 years old and upwards. When compared to services offered for ADHD therefore, it can be observed that in case of autism, the number of organisations offering services to for young or very young children is larger. This however is understandable since autism generally appears in the first 1–2 years of life, while in the case of ADHD a diagnosis can typically only be obtained later than the toddler years. Once again however, services were seen to reduce considerably with age.

In the case of autism too, a large part of service providers (54.5%) did have waiting lists. The services with the longest waiting times were found to be Social Services and Public Health Services, with waiting lists of more than 13 months. As with ADHD, by far the greatest challenge encountered by service provider participants in providing their services was a lack of human resources. This was also echoed by participants in the qualitative branch of the study with comments such as "*Employees in the public services are stretched to their limits, literally stretched*" (Service Provider Participant 2). Unlike services for persons with ADHD however, the next greatest challenge was resources other than human resources, followed at some distance by challenges in finances. Other challenges mentioned were lack of proper professional training, poor stakeholder knowledge, which was also highlighted throughout interviews with service users, cooperation and rapidly increasing caseload. Interestingly, stigma and appropriate services not available were only mentioned once each.

Diagnosis and accompanying support

The pivotal importance of early diagnosis and the appropriate consequential evidenced-based interventions and treatment has long been considered in research to play a crucial role in the outcomes and the quality of life of autistic people and their families (Hyman et al., 2020; Copeland, 2018; European Agency for Special Needs and Inclusive Education, 2017). Receiving a diagnosis is extremely important for individuals who are neurodivergent, as it helps them make sense of how they react to the world and also sets in motion a movement toward a more empowered life, as they can begin to receive services and support (Leigh. 2022; Young et al., 2008). The findings of this study suggest that overall, the experiences of caregivers when it comes to the diagnosis of their offspring are viewed as being carried out professionally, often flagged at early stages and addressed by multidisciplinary teams of professionals. In the case of findings from service users however, within the cohort under study, the vast majority (80%) received their diagnosis during adulthood. The experiences of those who are not identified at a young age and seek a diagnosis as adults, in fact, expose a critical deficiency in the services related to diagnosis for adults. From qualitative findings in fact, it seems that many struggled to even find diagnosis services for adults, and when they did, had to pay dearly for it.

Critical deficiency in the services
related to diagnosis for adults.

Moreover, the process for obtaining diagnosis is not always straightforward. Although within this sample of caregivers the majority of persons received their diagnosis before the age of 12, that is, prior to secondary school years, with only 1.8% versus a 9.2% sample share diagnosed later, cross tabulating age at diagnosis against diagnosis showed that type of diagnosis is a statistically significant factor. While 49% out of the 50% living with autism were diagnosed while in their primary school years, as were 17.2% out of a sample share of 19.6% of persons with a combined diagnosis; for those living with ADHD, the gap was larger, with 24.6% out of a sample share of 30.6% being diagnosed by the age of 11 years, and a further 5.5% being diagnosed after this age. This shows that in some cases, diagnoses for ADHD are not being made as early enough, as the majority of foundation schooling will have happened by this age. As Vibert (2018) states, undiagnosed ADHD can go on to have social and economic impacts on the individual, therefore perfecting diagnostic procedures and pushing for more accurate and early diagnosis is a must – for ADHD as well as autism and autism -ADHD combined.

Diagnoses for ADHD are
not being made early enough.

These findings suggest that the current scenario in Malta is one where individuals who require more support, are flagged and diagnosis is sought at an early stage – this seems to be the case especially with autism or more severe ADHD. On the other hand, people whose challenges are less evident or whose coping skills make their specific needs impact their performance to a lesser degree, tend to slip through the cracks, potentially receiving a diagnosis later in life, or none at all. The latter was also brought to the forefront by a number of participants pointing out they would seek assessment for themselves, having become more aware of these neurological challenges following their offspring's diagnosis. In the case of young people with ADHD for instance, while these may come across as fine when they're not in a structured environment, often leading people to often assume that there's nothing wrong and making the need for a diagnosis or support 'less evident', the truth of the matter is that, when they then find themselves in a setting where they are expected to follow rules or adhere to a rigid structure, problems may start to emerge (Xi & Wu, 2021). This skew in early diagnosis towards individuals with higher demands appears to promptly cater for those with more severe neurodevelopmental challenges – a very important service which paves the way for early support and assistance; however, it also leaves a pool of individuals who, although with less severe or less apparent needs, face challenge after challenge across their development. The latter was strongly evidenced across service user interviewees, where all participants shared experiences of difficulties across social, educational and employment realms. These include sensory issues, academic issues and issues with self-confidence, amongst others. Issues which, because they were not explained by a diagnosis, sometimes led to being mislabelled by society and figures such as parents and educators, with participants sharing experiences of, for instance, being called 'lazy', because the demands of a classroom or workplace where overwhelming to them and they needed frequent breaks. Unfortunately, the large number of diagnoses happening after childhood, means that despite the fact that the literature strongly advises in favour of early diagnosis and treatment or intervention, the reality in Malta is that there is a high number of diagnoses that are happening too late for early intervention.

> 91% of service user respondents had not received any services or information after receiving their diagnosis.

Additionally, while almost half of respondents were happy with the diagnostic process, more needs to be done in this area and particularly in the follow up period. In the case of both those who were given a diagnosis at a young age as well as those who sought one as adults, findings suggest that a lack of information and support for both caregivers and service users alike is greatly present. Raising a child with neurodevelopmental challenges often presents considerable demands on their caregivers (Karst & Van Hecke 2012) and may have a significant impact on their psychological wellbeing (Karst & Van Hecke 2012; Resch et al., 2012; Smith et al. 2012), however findings suggest a feeling of being left in the dark and having to seek information and a way forward by themselves in the local scenario. Support upon receiving a diagnosis was in fact found to be extremely lacking with 91% of respondents stating that they received no information or support. Given the marked effect that these conditions have on families, relationships and seminal areas such as education and employment it is vital that support be offered to assist newly diagnosed persons to come to terms with a diagnosis for what is essentially a life-long condition and also to guide them as to where they can find help and support going forward. Respondents commented on how they received no information about the condition upon obtaining a diagnosis and were left adrift with many questions and uncertainties. Since neurodevelopmental conditions last throughout life, it would greatly alleviate the fear and confusion that several respondents reported feeling after diagnosis, if greater sensitivity was used in communicating the diagnosis, and especially if more information was imparted. It would help recipients of the diagnosis to look at the future not only with fear but also with positivity if information were given, not only about the challenges but also about the positive aspects of neurodiversity. These small adjustments could improve the outlook for both caregivers and persons receiving the diagnosis and allow them to find positive aspects in their neurodiversity rather than see it a life sentence.

Education and employment

Researchers such as Crump et al. (2013) and Dardani et al. (2021) mention that autism and ADHD are often associated with lower educational achievement. Within the sample of service user participants who participated in the questionnaire, almost 60% had attained a university degree, with 20% even holding post graduate degrees. These findings testify to the fact that high education achievement is possible even with a diagnosis of autism or ADHD, although it is important to point that these findings might be truer for ADHD, since the larger part of this group were participants who were living with ADHD (64%). The academic achievements of this group are encouraging, however should not go to underestimating the value of adequate support provision for persons with neurodevelopmental. Barriers and challenges related to their educational experiences were in fact discussed by most participants during interviews. In the case of some, this led to leaving school, or, in other instances, made it too challenging for them to perform up to their full potential.

When it comes to questionnaire participants who were represented by their caregivers on the other hand, the picture appears to be somewhat different. All cared-for individuals represented in this research by caregivers were under the age of 30, with most of them therefore, still in school. Nevertheless, it was noted that more of these were at a lower level of education than their age would suggest. This raises the question of whether these individuals are fulfilling their educational potential or whether traits linked to their diagnosis was schooling. With the larger number (50%) of the caregiver questionnaire participants representing persons with autism or a combination of autism and ADHD (30%), these findings might be suggesting that persons with autism might be encountering larger educational challenges. While in the case of findings from service users, composed more of persons with ADHD, most had attained a university degree, in the case of caregivers, composed in the larger part of persons with autism, educational challenges become more apparent.

When it comes to employment, encouraging figures of 61% of respondents in the service user questionnaire (64% ADHD) being in full time employment or who are self-employed, with only 7% who were unemployed, demonstrate that successful life course outcomes are possible. In the case of caregivers, most caregiver participants were representing persons who were below 30 years of age, with only 9% of the cohort being over 18 years old. Thus, the 5.5% of persons who stated that they had some form of employment (that is, self-employed, part-time full-time, or casually employed) seems reasonable for this cohort. Nonetheless, it is noteworthy that amongst those who were over 18 and were represented in this study by caregivers, only 3 were in full-time employment, with 2 of these having a diagnosis of ADHD, and 1 having a diagnosis of both ADHD and autism.

Given that education and employment are important signifiers of life achievement and satisfaction, these figures indicate that significant achievements are being made, however, the effort, support and determination needed to achieve these goals are not examined in this study, and indeed this research has revealed that the vast majority (61%) of persons with autism and /or ADHD are not satisfied with the services and support offered, most notably in the area of employment where services were found to be pretty much inexistent.

Services – Levels of satisfaction, Quality of provision and Barriers

As for access to services and how well these services are linked together, the majority of service user respondents, across all age groups, expressed dissatisfaction, although the school years seem to be better served, with higher overall respondent satisfaction. Despite this, young adults, adults and older persons report hardly receiving any services at all, which could mean that as a country we are heading for a crash where we will witness increasing numbers of older adults and older persons who are left stranded and unable to cope with the combined challenges of ageing and of their condition. This is a situation that needs to be tacked urgently. Already the vast majority of respondents – over 70% in all categories – reported being dissatisfied with the prospects for lifelong fulfilment.

Young adults, adults and older persons report hardly receiving any services at all.

In addition to this, a finding of this research study is that caregivers are dissatisfied with services for autism and/or ADHD, with both the type and quality of services available, as well as services they actually received. While diagnosis was the service that met with least dissatisfaction, it still garnered a disapproval rating of 35%, followed by access to services after receiving a diagnosis, which had a disapproval rating of 55%, and was also found to be very lacking. The aspect of services that garnered the highest disapproval rating was how they were linked. Caregiver respondents reported that a common experience was that often one professional would have no idea of what other treatments or services the individual was receiving. The proposal to introduce a key worker concept to public health and community services has already been discussed in public fora. In these cases, too, having a key worker would be beneficial and economical, as services would not be duplicated, nor would time be lost chasing information from one professional service to another. It could also help solve the issue whereby no services are given to the diagnosed individual when they are given a diagnosis - 82% of caregivers reported receiving no service whatsoever, and that it is up to the carer or individual to chase after services and advocate for themselves, all of which can be extremely challenging for persons with neurodivergent diagnoses who may have challenges with communication or executive function.

Infrequency, inconsistency and long waiting periods.

The services that were most frequently availed of amongst the caregiver cohort were speech therapy, followed by occupational therapy, educational assistance including LSEs, and the services offered from CYPS. However due to infrequency and inconsistency of sessions as well as long waiting times to access these services, many respondents reported that they went to private practitioners for these services. Yet, when tallying which services are considered most important for persons with autism and/or ADHD, all of these services were among the top-ranked services for persons with these conditions. In fact, the seven services that were considered most important were occupational therapy followed by speech therapy, mental health services, educational services and behavioural/ ABA therapy or services, followed by any training in independent living or social skills. The fact that users and caregivers found public provision to be patchy and unreliable and that several opted to go private, implies that those who cannot pay will not be able to provide good quality essential services to their children and that especially those that have more than one child with neurodivergent conditions may have to choose not only which services to take up, but also how much to provide to each child. This is another area where the deployment of a key worker system would facilitate matters. In the case of medication, several, particularly in the case of ADHD, also lamented that considering persons with ADHD typically have challenges with executive function, a process involving different prescriptions, different expiry dates, renewals, some needing a doctor's signature, others needing a psychiatrist etc., can be quite daunting. Experiences with inconsistencies across medications provided were also reported.

Those who cannot pay will not be able to provide good quality essential services.

Key workers could also help to alleviate barriers that caregivers experienced when accessing services. Main barriers experienced were long waiting lists, high costs and a lack of trained professionals, all of which are interconnected. These findings were also echoed in data gathered from service providers, who in the larger part, shared that there were waiting lists associated with the provision of their services – in some cases, of even more than 13 months, while a review of the services provided amongst participating service providers also reflected the critical reduction in services available for adults when compared to younger ages. As also pointed out by service users and caregiver participants, amongst service provider participants, the largest challenge in offering services both for autism and ADHD was lack of trained professionals.

Suggestions for overcoming lack of professionals, would be to offer incentives for students to opt for these choices at university level. Such incentives are being offered in some foreign universities, for example, financial incentives are offered by Northern Ireland (NI) Universities, to facilitate and encourage enrolment in Social Work Courses, and have been found to be helpful in boosting numbers (Department of Health, 2021). However, once students graduate and have enough experience, they often gravitate out of public service and towards the better-paying private practice roles, so examining ways of incentivizing professionals to stay in government service provision would also be vital. Reviewing the value of jobs in this field that is projected in society, might also uncover that more needs to be done towards valuing careers and the networks of professionals that work within the caring and disability sector. Coming from roots of charity-based services, further work might be necessary to achieve true acknowledgement and value of the workers within these areas. Financial incentives such as improved salary packages and career progression scales, after all, also reflect the value associated with the work carried out. Recognising the worth of this work, in turn, also reflects on its public image and appeal for youngsters, or even adults, to pursue careers in this realm. Alongside, shifting towards a perspective where workers in the caring and disability fields are valued as professionals, can also act as a motivator for these workers to seek continuous professional development and aspire for continuous training and education.

Long waiting lists, high costs and lack of trained professionals

Other barriers towards accessing services mentioned by service users were negative past experiences with professionals and age-related cut offs. Continuing Professional Development (CPD) courses offered to all professionals who have contact with persons with autism and ADHD could go a long way towards remedying these situations, however it is also important to offer training to other personnel, such as employees who answer the telephone, or gatekeep entrance to clinics, hospitals etc. The latter was also highlighted during interviews with services users who felt they sometimes missed opportunities due to having to go past untrained front-row personnel to access a service they needed.

In addition to this, it was also reported by caregivers and service users alike that services tend to diminish strongly once persons with autism and/or ADHD reach youth and even more so adulthood (such as the transfer from the Child Development Assessment Unit [CDAU] to Children and Young People's Services [CYPS]), and even services for children over the age of 10 were experienced to be insufficient, as often age-rated cut-offs for accessing services, probably in place due to shortage of professionals and over subscription of services, would result in the child or person having a service that was proving extremely useful terminated. Additionally, there were not enough services geared towards life fulfilment such as social participation, independent living and employment. One of the fears expressed by caregivers/parents was what would happen to the cared-for individual one the parents were no longer present to look after them. If more focus were given to life fulfilment options, these fears would be alleviated, and the cared-for individual would have better options for their future. These sentiments were shared strongly across the different branches of data collection, both in the quantitative as well as the qualitative exercises.

Services diminish at adulthood

In conclusion, given all that is discussed above, it transpires that although the services that are offered are advantageous and beneficial, they are not offered frequently enough or for as long as the caregivers would wish. A lack of professionals, as well as long waiting lists push caregivers to seek treatment via private practice professionals, at a high expense. These are not issues that can be solved overnight, however, it would certainly be in the best interests of everyone involved, as well as effective and economical, if a government task force were set up to look into the issue of services for persons with autism and ADHD.

Not enough services geared towards life fulfilment such as social participation, independent living and employment.

6. Conclusion and Recommendations

> *"Provide the help and support that each and everybody needs from cradle to grave. Autism doesn't go away. ADHD doesn't go away"* (Participant 3)

Research has often highlighted that autistic children report significantly low in overall wellbeing when compared to their neurotypical counterparts (van Heijst & Geurts, 2015; Meier et al., 2011). With active participation in society considered to be a key factor surrounding wellbeing (Askari et al., 2015), it comes as no surprise therefore that the reduced levels of involvement reported in areas such as social engagement, education, and leisure may be major contributors to this (Desemo et al, 2016). The findings of this study indicate that locally, persons with autism, as well as those living with ADHD or a combination of both, encounter challenges along the way which considerably impact their performance and consequently their wellbeing. While the advances that have been made and the achievements reached are commendable, autistic people and those living with Attention Deficit Hyperactivity Disorder (ADHD) remain at an increased risk of reduced participation for reasons such as physical, cultural social environmental barriers, such as stereotypes and prejudice (Harding et al., 2009; Heah et al., 2007). Inclusive approaches towards addressing the varied needs of today's society and all its components, therefore remain. This section seeks to bring together the findings of this study while bringing forward a number of recommendations that can pave the way for improved access, development and fulfilment of those living with autism and ADHD in the local scenario.

Areas that are critical for fruitful development into adulthood for persons on the spectrum include self-awareness and self-advocacy, individuality, comprehensive support systems, and awareness and education amongst the wider community (Lowinger Pearlman-Avnion, 2019). These have a broad impact and can serve as the foundations for development of self-acceptance, understanding one's abilities and limitations, acceptance as a person within the community who has needs, preferences and rights, access to appropriate person-centred support, and with these, as the wider community learns about autism, the quality of life of autistic people can improve, at least at par with that of their peers. Policies and services should therefore focus on strengths to maximise participation in society for autistic people, through building on individualised support approaches, alongside interventions that target environmental barriers (Thompson et al., 2018). Ultimately, support structures need to be tailored around an individual and focus on improving the social and physical environment they are faced with, rather than the person or their behaviour (Anderson et al., 2018). Moreover, in the case of ADHD, several feel that it should be given the importance it deserves. At the moment, many people with ADHD still feel that there is discrimination between ADHD and other disabilities. More effort is needed to ensure that people with ADHD are given all the services that are required in order to support them and help them live a life of dignity and independence.

Early diagnosis and consequent prompt interventions and assistance are a key component toward improving the outcomes and wellbeing of diagnosed individuals (Hyman et al., 2020; Copeland, 2018; European Agency for Special Needs and Inclusive Education, 2017). Nevertheless, several opportunities for improvement were brought to light directly by those living with one or both of these conditions, or their representative caregivers across this study. Individuals with higher needs appear to be typically flagged at earlier years. In these instances, diagnosis is reported to be carried out professionally by multidisciplinary teams, however disappointment with the lack of information provided, at times sensitivity in the delivering the diagnosis, as well as recommendations for support services – for the diagnosed individual as well as the family surrounding them – was highlighted by most participants. The success of therapeutic pathways is largely rooted upon the establishment of a parent/guardian-professional relationship. In particular, professionals play a key role in enhancing the wellbeing of diagnosed individuals and their families by addressing the needs of the entire nucleus surrounding an autistic person, guiding treatment and support choices, and supporting families to navigate through unfamiliar service systems (Esbati & Roberts, 2009). Meanwhile, for those who, on the other hand, present with lower needs, diagnosis was typically found to be occurring later in life, at times following the primary years of schooling, or even in adulthood. The implications of this are that these individuals are 'left to their own devices', facing a plethora of challenges, across the board juggling the challenges of everyday life through a filter of their condition and often, also misunderstood by society. Additionally, those seeking diagnosis in adulthood, face difficulties accessing this due to the scarcity of services that cater for autism and ADHD in adulthood.

> *"People have the perception that autism is only a childhood condition, which, of course, it isn't"* (Participant 6)

A review of the services addressing the needs of persons living with autism and/or ADHD exposes a catalogue of opportunities for support. Nonetheless, a closer look at the views of the users of these services, uncovers a reality where many seem to go through a process of first being lost, unfamiliar with where to start, eventually latching on to a random professional or NGO who points them towards possible suitable support, to then be faced with bureaucratic ladders to climb in order to access this, eventually accessing it but find that in most cases it is not sufficient or involves waiting lists to long or services too sparse, and cashes out opting for private services, where waiting lists at times may still exist but provision of service is more frequent. These feelings appear to be present across service users and caregivers alike in most services, be it medical, therapeutic, related to education, employment, respite and so on. In the case of young children, educational services, such as the provision of Learning Support Educators (LSEs), appear to be most catered for, although related services such as Speech Therapy, Occupational Therapy, Behavioural Therapy or even the services of a counsellor, appear to be limited in their frequency as reported by most participants. Moreover, several lamented the fact that age cut-off points for provision of services means that their child is often left without the needed support even when this could still be useful. This is also the case for instance, with incentives such as financial aid to help families provide therapeutic services, which many expressed only caters for a small number of sessions when in order to achieve some results, the therapy sessions should be carried out for a much longer period.

In the case of adults, as well as teens, a severe lack in services was highlighted by participants across the study. Through fears of their offspring's future prospects or actual experiences lived, participants uncovered a critical lacuna when it comes to services that cater for autistic people or those diagnosed with ADHD in later years. Needless to say, ageing presents with an even more critical void. So unprepared do local services appear to be for older autistic individuals or those with ADHD that participants who reached out for support reported having their needs belittled or not acknowledged by the service providers, even after they had been given a diagnosis. This leading to closed doors and being left with no support. Not only therefore are services in adulthood scarce, but they are also difficult to access as a result of bureaucracy and paperwork that diagnosed people can struggle with (from filling out too many forms, to needing to making several phone calls or have meetings in unfamiliar places). And when that barrier is overcome, an individual may still be faced with a lack of understanding and even more so, support, only reinforcing their deep-seeded fear of being inadequate and unsuitable in our society and leaving them unaided in their request for help.

The ongoing training of educators was also flagged by a number of participants who have at times shared unhappy experiences with unprepared educators who were unfamiliar with the behaviours or communication styles of their diagnosed offspring due to their condition; while the ongoing training of all professionals from the police force to medical professionals, to service agents and society at large was also resounding across all participants be they service users or caregivers. The proposal of a one-stop shop or a key person to assist with the information, access and provision of services was also brought forward by most. This would allow for a smoother and less fragmented multidisciplinary approach, alongside the administration of things such as medical appointments, sessions with therapists and applications for fundings, badges, respite services, parking permits, etc. The alternative of having online apps to apply and register for services was also suggested, in particular by autistic participants, since it would alleviate the challenges of those who have difficulties manoeuvring through bureaucracy, phone calls or in person tasks – the Pharmacy of Your Choice (POYC) for instance, was often mentioned in these instances, where bureaucracy posed challenges to access the service and suitable supply of medication was at times questioned.

An autistic person or one living with ADHD may find daily scenarios, even apparently futile ones such as visiting a supermarket or waiting in a waiting room, overwhelming. More than one participant in fact shared experiences of waiting for a medical service for several hours, which then resulted in a meltdown. In the case of an adult, they shared how they felt this was unfair on them and how they were unable to find help to address dealing with these meltdowns; while in the case of a child, the caregiver expressed how when the medical appointment eventually took place, the child was in no position to be assessed fairly since they had just had a meltdown. The proposal of having a key person to accompany persons with specific needs in places such as hospitals, guiding them through the building and providing quieter spaces to wait and/or reduced waiting periods was proposed. This person, it was suggested, could also act as a mediator to aid in communication with staff, since particularly in the case of autism, individuals may express pain differently or may encounter communication challenges. Another suggestion was also the introduction of universal design, that is, spaces where levels of noise, lighting and sensory elements are controlled and stimuli are limited, that can be of benefit for everyone; the alternative of a quiet room was also brought up. Afterall, struggles found in a diagnosis of autism or ADHD, are not necessarily exclusive to the condition and others may also find universal approaches more suitable.

The need for ongoing training and improved awareness across professionals, of course, also spills over into the employment realm. Throughout the study, encouraging levels of employment were observed, although these still leave space for improvement. Participants shared experiences of being misunderstood, of being considered to be distracted or lazy, of being passed up for a promotion or of struggling to keep up with instructions or demands at their place of work due to lack of clarity or understanding. The need for more awareness and understanding was in fact highlighted by several adult services users who experience this directly, as well as caregivers, who see the prospects of this on their child's future. Adulthood, and the challenges this brings along, from living independently, to carrying out daily tasks, commuting, being in a relationship and so on, is an area that most participants expressed more work needs to be done to cater for in Malta. Topics such as sexuality and self-advocacy skills were flagged as important needs, as well as opportunities for development such as social groups, specialised counselling services or career guidance assistance, amongst others. Although services catering for independent living in the community are present in Malta (Aġenzija Sapport, 2018), typically, these are address the needs of the family when this is unable to do so (Garland, 2015). Many autistic individuals, therefore, tend to rely on family for their daily support needs (Garland, 2015).

People with autism and/or ADHD bring valuable traits and can contribute fruitfully in society. However, a wide-ranging lack of awareness surrounding these conditions and the experiences and challenges that diagnosed people encounter on a daily basis, can seriously impact this and the fulfilment of their abilities. While progress made is encouraging, a lot of work still needs to be done when it comes to understanding and truly embracing people with conditions such as ADHD and autism within our society. On one hand, society needs to be made aware of what these conditions entail and how they can relate better with diagnosed individuals, rather than expecting people them to adapt to what is considered 'normal'. On the other hand, more work needs to be done within the field, starting from early diagnosis when parents ask for help. Persons who are diagnosed need to be guided as some of them have no idea what these conditions are or how to deal with them. Services need to improve in order to provide those in need with adequate and timely support. Additionally, access to services should not be limited to children and adolescents – support should continue being offered throughout the life course, and indeed there is increasing awareness that these conditions do not disappear with age (Franke et al., 2018).

Over the years, valuable developments have been achieved when it comes to Malta catering for the needs of all of its citizens, including those living with ADHD or autism. Malta's National Autism Strategy 2021-2030 for instance, set the stage for fruitful aspirations in this realm. Several other developments still need to come. The views and experiences discussed in this study have brought several commendations for milestones reached, and have also highlighted several others that still need to be worked as a society towards. Ultimately, awareness and understanding across the different strata and branches of society is at the base of making these developments possible. After all, so varied are the needs and quirks of different people, that catering for diversity and striving for inclusion, should not be viewed as an additional effort made outside the norm. As an Islamic proverb says, "A lot of different flowers make a bouquet". And our aim as a society should be one that at its core seeks to create a norm that is made up of these different expressions, one that understands that different people, no matter how different, still bring beauty and are of value; One where therefore, naturally, effortlessly, everyone is included. Below is list of recommendations that thanks to the valuable feedback provided by the many participants of this study who shared their views, struggles and experiences with us, could pave the way towards improved wellbeing for these individuals and with them, society at large.

> Part of society that, equal to any other of its members, is a valuable part of life that can contribute, be actively involved and should be included and catered for.

Recommendations for Policy

General

1) The wellbeing of autistic people is largely influenced by the manner in which society understands and classifies the autism diagnosis (Micallef, 2019). Across the board, disability, including autism, and no less so, ADHD, should be approached as an accepted part of normality. This implies that the discourses of key stakeholders surrounding the lives of disabled people, including policy makers, medical and educational professionals, family members as well as society in general, should portray and address disability not as an impairment, deficit, or a less worthy person that requires adjustments, but as a part of society that, equal to any other of its members, is a valuable part of life that can contribute, be actively involved and should be included and catered for. A culture shift to respect the equality and human rights of autistic people and those with ADHD should be urged. Consequently, when society becomes truly inclusive of all its members, terminologies like 'inclusive education' will no longer be relevant because the inclusive practices would be genuinely embedded in its rituals and practices.
2) Listen to the voices of children, adolescents and adults living with autism and/or ADHD. Listening to the views of those who ultimately will be mostly impacted by policies, standards and initiatives can give a more realistic and tangible dimension to these efforts while empowering self-advocacy amongst these individuals and dispelling myths about their inability to contribute to their progression. As the primary stakeholders, their effective input in the formulation and implementation of policies and, subsequently instances such as IEPs, manuals of procedures, etc., is crucial for the success of these initiatives. People who are diagnosed with autism and/or ADHD should be directly involved in the design and execution of procedures and approaches that cater for them.
3) Promote the introduction of 'quiet spaces' and/or 'quiet days' where low-arousal approaches, in both a sensory and interactional aspect, are introduced in public buildings and areas to make them more approachable and accessible for persons with sensitivity issues.
4) Review communication practices across departments to improve autism and ADHD friendly approaches, such as for instance, including visuals with important signage, offering online alternative solutions when possible, providing easy-to-understand

formats of documents[1], including with content available in text, pictures and pictograms, and having social story booklets available to prepare children for events such as a visit to the hospital, dentist, etc.

5) Enhance the use of assistive technology and online platforms. Face to face communication can be particularly challenging for some autistic people and/or those with ADHD. The internet can provide a medium for people to be able to exert more control over the timing pace and flow of giving and receiving information. Online communication can provide beneficial experiences for many diagnosed people and service providers should therefore look to this as a method of communication (SCIE, 2011). This can also be developed further through the use of applications (apps) designed to improve communication channels and overall skills for autistic persons[2].
6) Invest in awareness-raising campaigns that can improve the public's understanding of the nature of disabilities such as autism and ADHD. This with the involvement of persons with disability taking an active role, in order to reduce barriers arising from stigma, misinformation or lack of information and improve understanding of the different needs, abilities and aptitudes of different individuals. Initiatives can be the creation of new campaigns through different channels such as online media, print media, brochures and fliers, as well as the development of already established ones, such as the Light It Up Blue campaign. The latter, or other initiatives can be extended to increase their outreach through add-ons such as toolkits for different entities that include recommendations on how they can part of it or get involved in the inclusion of autism in society[3].
7) Across sectors, such as education, sports, employment and recreation, create opportunities and contexts where disabled people, including those living with autism and/or ADHD, can be active agents in their own lives with the necessary support, and where their voices are heard and valued.
8) Deliver opportunities for social involvement, particularly during adolescent years, where much learning is obtained around relationship development. The same almost applies towards initiatives catering for adults, with a long-term view towards services for the ageing population of persons with autism and/or ADHD.
9) Support opportunities for non-formal learning, such as those enhancing the cultural and creative participation of diagnosed people through activities surround the arts, music, cultural events, as well as activities related to sports.
10) Develop channels of communication with local representatives of people with disabilities, in particular those living with autism and/or ADHD, such as NGOs and associations in order to strengthen the continuous sharing of information and collaboration with these representatives.
11) Seek partnerships and collaborations with international working groups, entities and projects (e.g. Non-formal learning Activities for Autistic Teenagers in Europe "NAATE Project"[4]) and promote use of EU Structural Funds initiatives to improve knowledge, develop services and share best practices in unison.
12) Deliver, promote and incentivise (possibly through financial incentives, certification, etc.) training and capacity building activities within the public and private sector aimed at increasing staff awareness and delivering sound understanding of the nature and needs of disabilities such as autism and ADHD, such as for instance, the use of one-to-one communication with certain employees, or the need for flexible work conditions, in order for employers and society to become aware of the different needs, abilities and aptitudes of different individuals. These can be offered through existing channels, such as the University of Malta's Department of Disability Studies, the Lino Spiteri Foundation, or CRPD in collaboration with NGOs that dedicated to this cause. Generic awareness raising can be done as part of general disability training for staff or as a stand-alone training. Management should also be included in these training initiatives in order to be able to anticipate the impact of the organisational structures, processes, environment and resources upon autistic clients, those with ADHD and disability in general, and make executive decisions about appropriate adaptations across the workplace.
13) Align services and practices in public services with the aim of improving awareness and friendly approaches. These can include for instance:
    - Multi-agency planning based on autism and/or ADHD planning groups. This approach can facilitate coordinated planning amongst professionals, agencies and service providers across the social and health sectors, through a joint key commissioner;

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[1] See for instance:
- Autism Europe:https://www.autismeurope.org/wp-content/uploads/2020/03/Autism-Europes-campaign-2020-2021_Guide_Easy_to_Read.pdf

[2] See for instance:
- Autism App Avail: https://availsupport.com/

[3] See for instance:
- Autism Europe: World Autism Awareness Day 2017 Campaign Toolkit: https://www.autismeurope.org/wp-content/uploads/2017/08/WAAD_2017-toolkit-EN.pdf
- 'I can learn, I can work'. Autism Europe's 2020- 2021 Campaign Toolkit https://www.autismeurope.org/wp-content/uploads/2020/03/Autism-Europes-campaign-2020-21_Toolkit_EN.pdf

[4] https://www.autismeurope.org/eu-project-naate-non-formal-learning-activities-for-autistic-teenagers-in-europe-2019-2020/

- Provide a menu of services available through a coordinating entity;
- Establishing the role of a key-worker to act as a point of reference and implement a one-stop-shop approach (Autism Hub, Tait et al., 2013) for autistic individuals and their families in order to coordinate and access required services through a personal, tailored approach, while further promoting coordination amongst services. As well as acting as an information hub for autism, these workers can collaborate with other entities to understand and respond to the needs of the autism community;
- Given the impulsivity element of ADHD and the difficulties faced by autistic people in unfamiliar and sensory-loaded environments which can make experiences such as waiting in line very challenging and may provoke unnecessary and unwarranted issues, consider introducing priority lanes when waiting for certain services, or a card that would allow them to be served more promptly. This applies to children and adult alike. Alternatively, consider introducing the concept of a trained key person who can accompany these individuals in public buildings where services need to be accessed (such as hospital) in order to support their navigating through unfamiliar corridors and spaces, aiding with their waiting periods and acting as a mediator with the service providers involved.
- Assigning mentoring and life-coaching buddy systems[5] that can support autistic persons and/or those with ADHD to navigate daily life, such as paying bills, and improve independence.
- Implementing initiatives to reduce waiting periods across services.

14) In line with the latter point, given that across service providers, the largest challenge encountered was the availability of trained personnel – a point that was also highlighted across service users and caregivers – address the current lack of professionals through, for instance, the creation of incentives for students to opt for related study choices at tertiary level. Incentives however cannot end upon termination of studies and value, including that reflecting in salary packages and career progression scales, needs to be given to these careers throughout.

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[5] See for instance:
- Asperger Autism Network's Life Management Assistance Program in the US: https://www.aane.org/resources/adults/lifemap-coaching/
- Scottish Autism One-Stop-Shop: https://www.scottishautism.org/files/lanarkshire-one-stop-shop-scottish-autism
- The Autism Resource Centre in Glasgow: https://www.glasgow.gov.uk/index.aspx?articleid=17216

15) While the Government currently offers a number of services and therapeutic support that can be of valuable benefit for persons living with autism and/or ADHD, these do not include all therapeutic modalities that are available on the market and are typically not offered frequently enough, often leading to individuals' access to an adequate service to be dependent on their personal finances and whether they are able to pay for these privately. Additional services, in line with positive service available on the market should be sought to be made available and if it is not possible for the Government to offer a particular service, it could offer access to these services through initiatives such as for instance vouchers towards a private service. Additionally, currently vouchers are only offered up till the age of 5 years – this practice should be extended to all age groups since these services can be crucial to the wellbeing of those involved.

16) Instances when adolescents/youth with ADHD find themselves homeless due to their challenging behaviour have been observed. The introduction of a specialised shelter, manned by professionals trained to handle issues such as behavioural challenges can provide these youth with the support required to improve their quality of life without falling into a vicious circle.

17) Ensure adequate training is provided to service providers regarding sexual education.

18) Ensure clear policies addressing sexual education and supported parenthood are in place in establishments providing services to disabled persons.

Health

19) Primary care providers should be familiar with the early indicators and diagnostic criteria for autism and ADHD and concurrent medical and behavioural issues that may present themselves and may affect one's function and quality of life and be able to engage sensitively in a diagnostic discussion with the person concerned and, particularly in the case of children and young people, their family. The provision of adequate training and skills development for practitioners in health and education can facilitate the diagnosis discussion and shed light on helpful ways forward.

20) In line with the above, awareness related to signs that can aid towards early detection can be crucial in the wellbeing of the people involved. Even in cases when 'symptoms' might not be evident, and at first glance, a child or adult may appear not to be encountering difficulties or come across as 'fine', feedback from the individual or those surrounding the person (e.g. parents/caregivers in the case of children, or the person directly involved) who seek help when specific changes or issues are reported should

be heeded. An early diagnosis could help reduce less favourable consequences for those involved and too many too many cases of late detection still appear to be present.

21) Consequently, when a diagnosis is provided, related information and adequate recommendations for support and treatment related to condition, its implications, strengths and weaknesses should be provided. Providing a diagnosed person or their family with information about available services and which ones are available through the public healthcare system/government, including information about coping techniques that would help him/her to deal with the condition can largely alleviate the transition towards dealing with the diagnosis received.
22) Consider the setting up of a dedicated ADHD and Autism clinic, where adults and children can be assisted in a specialised way towards diagnoses, information and support services. Persons with autism and/or ADHD can find accessing different services challenging. Providing tailored services under one roof can be very beneficial.
23) Provide information sessions or courses, aimed at different ages, held at different times of day, for diagnosed persons and their families, preferably to take place promptly within a few months of a person being diagnosed, in order to disseminate knowledge related to the condition and the experience of living with it.
24) Fostering reasonable accommodation of health care premises (including general health, dental care, emergency and preventive services) and diagnostic instruments needed to ensure autistic persons have access to health care of the same quality as other people.
25) Promote training on the needs of diagnosed individuals and accessible communication in the curricula of health professionals and other relevant staff.
26) Improve transitions between services such as the transferring of data for clients who move from Child Development Assessment Unit (CDAU) to Children and Young People's Services (CYPS). Overall, improve the streamlining and links between services for relevant data to be readily available and accessible across different professionals across different branches of service.

Education

27) Educators, carers and other professionals such as nursery staff should be familiar with early indicators of developmental difficulties as well as referral pathways that can provide support and guidance.

28) Prioritising training and in-service opportunities (such as behaviour management) amongst professionals such as educators, sports coaches and leisure activities organisers, counsellors and therapists about the different needs, abilities and aptitudes of different learners, including those on the spectrum or who are living with ADHD, can enhance awareness, address the needs of these pupils more appropriately and can facilitate the role of schools as a catalyst for the formation of healthy attitudes and skills to be inclusive and accepting of diversity.
29) Strengthen transition programme practices services for children living with autism and/or ADHD and others who might be more sensitive to change, while empowering students and their families to own the transition process. This can be done for instance through peer preparation programmes within the first month/s of the scholastic year and can include familiarisation exercises prior to the commencement of a scholastic year.
30) Make ad-hoc career guidance support available to young, diagnosed people in order to increase their possiblilities of attaining fulfilling career experiences and achieving their career potential whilst attending to their specific needs and overcoming barriers.
31) Reviewing existing educational programmes, vocational training opportunities and the contexts or campuses within which these are offered to ensure they are friendly to those with autism and/or ADHD and cater for diversity.
32) Ensure character-developing opportunities are embedded in curricula, for those living with autism and/or ADHD, as well as the entire student population alike. Topics such as self-advocacy skills, sexuality and participating in a team, amongst others, should be at the root of the approach taken in teaching methodologies, placing the learner and their personal development at the forefront alongside academic learning.
33) Ensure appropriate provision of support (through e.g. Learning Support Educators [LSEs]) in education opportunities beyond mandatory schooling, such as Summer schools and tertiary education.
34) Ensure appropriate provision of support measure across tertiary education to enhance participation at the level of education. This can include, for instance, providing students with a plan/agenda for upcoming lectures, allowing recording of lectures where applicable, or potentially offering the alternative of online lecturing. Provisions also need to cater for examination arrangements, such as for instance, familiarity with rooms, the use of smaller rooms, the option of frequent breaks, etc.
35) Encourage the setting up of student bodies representing students with autism and/or those with ADHD representing the voices of these students themselves and involving these in decision-making processes related to their education.
36) Encourage recruitment of suitable number of LSEs and support staff in schools.

37) Create a transition centre that can aid diagnosed students who have been expelled from school due to behavioural difficulties in order to improve their return to school.

38) Provide clear information and/or prospectus for new students and/or parents/guardians in relation to the educational establishment's practices related to services and procedures surrounding persons with specific needs such as autistic people and/or those living with ADHD. This accompanied by efforts such as introductory sessions for new pupils for instance, which can aid in their transition towards the establishment. Information about any services that are available to these persons as well as details on how these services may be accessed should presented clearly and provided promptly to all students, in particular, new ones.

39) Ensure adequate accommodations / adaptations are in place throughout the year and even more so, during examinations, such as the use of a familiar device, ensuring familiarity with a classroom or examination room, the use of smaller spaces where necessary, allowing access to fidget toys, etc.

40) Create a quiet space in schools (see above in General)

Social Services

41) Develop and deliver training, curricula and guidance initiatives for diagnosed individuals as well as their parents/caregiver to meet the needs expressed by families and autistic people, offering practical solutions and strategies to cope with the evolving challenges they face across their lifespan.

42) Increasing measures and incentives aimed at providing regular or daily support and assistance to disabled persons, such as, transportation to/from the place of work or education/training centres.

43) Ensure members of staff involved in the provision of services are trained and understanding towards the needs and expressions of persons living with autism and/or ADHD (see above in General).

44) Align provision of services to improve accessibility (see above in General)

Employment

45) The heterogenous nature of autism and ADHD can bring considerable challenges when it comes to the world of work. Customised, person-centred employment support structures, such as on-the-job support relating to social interactions and job-coaching

can enhance career prospects and effective participation in the labour market. Autism and ADHD-specific strategies should be included through a strength-based approach that can guide individuals translate their unique features into employment benefits.

46) Incentivising and supporting companies to employ diagnosed individuals through financial assistance and schemes promoting the training and the improvements of work environments to be able to accommodate for all employees (as well as clients), including the purchasing of assistive equipment and technology in the workplace.

47) Providing assistance to employers to gain more awareness and understanding about autism and AHD, while enabling channels of communication with sources of support regarding the employment of autistic individuals[6].

48) In turn, the above can support employers to introduce practices that can better cater for the needs of neurodivergent employees and prospective employees. These include, for instance, the use of on-the-job testing instead of interviews during recruitment processes. As pointed out by several researchers, diversity in employee pools can yield advantageous benefits to companies and this is no less the case with neurodivergent employees.

49) Delivering, promoting and incentivising training and capacity building opportunities for disabled persons in the workplace, through direct training initiatives as well as through on-the-job training such as through buddy-systems.

50) Further promotion for increased participation in employment training schemes amongst both employers and individuals with disabilities.

51) With the 2% quota still being perceived by employers as a grey area, review the factors that surround the issue of disability in employment and those that influence employer's awareness and involvement of disabled individuals in the workforce.

Recommendations for Research

1) Review practices and services being provided in local educational settings that in themselves also cater for autistic learners and those living with ADHD, rather than distinguishing them from their peers. This can bring insight into the approaches, decisions and actions that are being taken and the services that are being provided in schools and guide through these good practices in order to raise the standards of the support and genuinely inclusive services they provide.

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[6] See for instance:
Autism @ Work Playbook:
https://www.autismeurope.org/wp-content/uploads/2019/04/Autism_At_Work_Playbook.pdf

2) Understanding gender differences related to autism and ADHD can improve earlier diagnosis of autism in females. Research including larger numbers of females and looking into autistic females can further guide down this path. Looking into comparisons between autistic males and females and neurotypical children can also contribute to the understanding of autism in females and to improved services and resources. The same also applies to ADHD.
3) Develop guidelines for autistic individuals, those living with ADHD as well as key people involved in their life, in the context of the local scenario, to support their self-advocacy throughout transitions and key milestones, such as those to secondary or tertiary education, independent living, etc.
4) Investigate the factors that impact the development of crucial skills. These include self-advocacy, the interplay between anxiety, social engagements and success with romantic relationships, as well as comparisons of romantic relationship anxiety in autistic individuals and neurotypical people, amongst others. These can bring insight for intervention and support.
5) As has been done by this study, continue to listen to the voices of children, adolescents and adults living with autism and ADHD. Participatory research can bring key insight to varying aspects of disability research and can support the empowerment of self-advocacy skills while combatting social stigmas. Research involving the views of those directly involved can guide real-world solutions that can be embedded in practice and policy, community/employer engagement, and person and person-centred services. Moreover, the inclusion of the direct stakeholders' voices can also better determine research advancement priorities and the distribution of funding and resources.
6) Invest in peer-led adolescent exchange groups, with professionals' involvement where necessary, in order to facilitate an environment where individuals with autism and/or ADHD can share their views and experiences. This can bridge research gaps, bringing insight about the lived experiences of autistic people with social connections and can be a platform for voices to be heard, for social connections to flourish, for improving awareness amongst upcoming generations and society, and an opportunity to combat stereotypes and misinformation. Events like these can also translate to a wider audience through media channels.
7) Whilst ample studies have addressed activities enjoyed by autistic children, data into the activities enjoyed by autistic young adults and adults is very limited. Enriching the understanding of autism in late adolescence and adulthood, including ageing, and their significant factors can inform support services, understanding and inclusion while further normalising the concept of differences in society. For instance, longitudinal studies could shed light on life trajectories through research observing enrolment

figures in lifelong learning or further education initiatives, number of jobs held and labour market activity for autistic adults. Additionally, there is little literature that focuses on other aspects of adulthood, such as housing, social networks, relationships) and the impact of these difficulties on individuals. Researching the impact of these individuals (e.g. wellbeing) and communities (e.g. cost of services) can shed led on fruitful ways forward.
8) Develop accessible, culturally-sensitive metrics and methods for intervention assessment for adults living with autism and/or ADHD in the local context.
9) In the context of a nation where overprotectiveness is a defining factor, investigate the difficulties that children with disabilities face in attaining independence within home or in out-of-home contexts.
10) Explore counselling approaches and techniques that autistic children and adolescents find most beneficial.
11) Evaluate the social, emotional, psychological and cognitive experiences of parents and siblings of diagnosed individuals and the way in which these construct their children's autism/ADHD diagnosis within the local context. Giving a voice to these individuals can guide service and support design for those who may be in need of them.
12) Long-term studies looking into the effectiveness of interventions across different ages. This can guide knowledge-based development of support mechanisms, e.g. for aging in people with an autism.
13) Develop and pilot test new models of support tailored for the Maltese context, for instance, in light of the overprotective tendencies observed among parents/caregivers and service providers, and the presence of charity-based approaches towards disability, propose strategies and actions addressing self-advocacy skills.
14) Investigate the impact and use of digital channels on the development of social connections amongst diagnosed individuals. Research can also address areas that can be developed, even through the use of digital applications, in order to understand and design ways to support independence and socialising amongst diagnosed people, particularly youths and adults since the latter age brackets are less addressed in research. These should ideally include first-hand feedback from the people involved (for instance, several studies tend to seek the views of parent observations instead of the direct participants).
15) Increase knowledge sharing and best-practice findings both at national and international level, for widespread policy and practice improvements, together with the social impact these bring with them.
16) Investigating the factors surrounding autism and ADHD among older adults may yield important clues about the aging process in this realm. Moreover, research addressing

this age bracket along the autism/ADHD lifetime can help identify risk factors associated with this group, while guiding appropriate services and support for this elderly population.

17) With most of the literature representing parents' views and focusing on children, investigate youth's perspectives on their interaction with their pets and other animals and how this can impact their overall wellbeing as well as other aspects of their life.
18) Examine the experiences autistic people and people with ADHD who are in employment. Looking into the individuals' experiences as well as those of employers can bring insight towards improved recruitment and management structures for diagnosed individuals.
19) While this study brings valuable insight into the experiences of autistic persons and/or those with ADHD in Malta, a number of findings shed light on possible distinctions between the experiences and challenges faced by those living with one or both of these conditions. Further research looking into the two conditions on a separate level could further develop the findings of this study, such as, for instance, the educational achievements as well as employment figures of persons with autism versus those with ADHD or a combination of both.
20) Examine the effects of the relationship between service providers and persons who are exploring their gender identity or transitioning to another gender identity.
21) Explore the intersection of gender identity, sexuality, and disability.

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Glossary

ABA	Applied Behaviour Analysis
ACTU	Access to Communication and Technology Unit
APA	American Psychiatric Association
APA-M	Autism Parents Association (Malta)
ASAN	Autistic Self Advocacy Network
ASD	Autism Spectrum Disorder
ADHD	Attention Deficit Hyperactivity Disorder
CAT	Computer-Assisted Technologies
CDAU	Child Development Assessment Unit
CPD	Continuous Professional Development
CRPD	Commission for the Right of Persons with Disability (Malta)
CYPS	Children and Young People's Services
DOI	Department of Information (Malta)
DSM-5	Diagnostic Statistical Manual of Mental Disorders (5th Ed.)
EU	European Union
FITA	Foundation for Information Technology Accessibility (Malta)
ICD-11	International Classification of Diseases (11th Ed.)
IEP	Individual Education Plan
ITS	Institute of Tourism Studies (Malta)
KNPD	National Commission for Persons with Disability (now known as CRPD)
LSE	Learning Support Educator
MCAST	Malta Council for Science and Technology
MEDE	Ministry for Education and Employment (Malta)
MIA	Malta International Airport
NCF	National Curriculum Framework
NGO	Non-Governmental/Voluntary Organisation
NICE	National Institute for Health and Care Excellence, UK
POYC	Pharmacy of Your Choice
SCIE	Social Care Institute for Excellence, UK
SCSA	Social Care Standards Authority (Malta)
SEN	Special Education Needs
SJAF	St Jeanne Antide Foundation
SMP	Statementing Moderating Panel
SPS	School Psychological Services
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNCRPD	United Nations Convention of the Rights of Persons with Disabilities
WHO	World Health Organisation

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List of Info Boxes

1 Parts of the Definitions from the Diagnostic Criteria for ASD according to DSM-5 (APA, 2013; Attwood, 2015)
2 Environmental causes for which unemployed disabled persons were not considering looking for employment (Source: CRPD, 2020)

Appendices

Appendix A

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Autism in Malta
Service Provider Questionnaire

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8th July 2022

The Faculty for Social Wellbeing at the University of Malta will be conducting research, in collaboration with the Parliament of Malta. We wish to gain insight into the lived experiences of persons with Autism in order to identify not only their needs but also their aspirations and ambitions.

We would like to invite you to participate in this questionnaire regarding your views and experience as a service provider that offers services to autistic people in Malta. You can complete the questionnaire by filling in a printed form (available from the researchers) or by visiting https://forms.gle/i1PdnY4jq2z57dHZ9. Questionnaires are to be submitted by Wednesday 3rd August 2022. Your participation would help contribute to a better understanding of the current services being provided to autistic persons in Malta. Any data collected from this research will be used solely for the purpose(s) of this study.

Completing the questionnaire should take between 20-30 minutes. Questionnaires will include the name of the entity or department you are representing and will only be accessed by the team of researchers involved in the project. Any data gathered will be destroyed within 2 years of completion of the study: any digital data will be deleted, and any printed material will be deleted and shredded within 2 years of completion of the study, in approximately June 2024. Until then, any printed material will be stored in a locked, safe location.

Participation in this questionnaire is entirely voluntary; in other words, you are free to accept or refuse to participate, without needing to give a reason. If you choose to participate, in accordance with the General Data Protection Regulations (GDPR) and national legislation, you have the right to information, access, rectification, objection, erasure, data portability, and to withdraw your consent, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw your participation, any data collected from you will be deleted, if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives – withdrawal can be carried out by not later than one month from the date of submission of the questionnaire. This is in line with the exemptions provided for in GDPR Article 17(3)(d). Submission of this questionnaire indicates your acceptance to the terms of participation as outlined in this document.

Following submission of the questionnaire, the researchers will code the data gathered. This will be pseudonymised and end-to-end encrypted, so that your confidentiality and that of your organisation and/or department will be respected. The data will be used for the sole purpose of this study, will be stored in an anonymised form and raw data will only be accessed by the team of researchers directly involved in the project. Any data gathered will be destroyed within 2 years of completion of the study: any recordings will be deleted, and any transcribed material will be deleted and shredded. Until then, any printed material will be stored in a locked, safe location separately from any identifying information.

Notwithstanding all the precautions being taken, the local small-island-community context creates a scenario where as professionals, participants may still be identifiable. The research team will therefore further address this matter through the use of gender-neutral names throughout the research (such as Participant 1, etc.), thereby not revealing participants' genders.

Please note that there are no direct benefits that will be extended to you should you choose to complete this questionnaire, other than helping to better the experiences of autistic individuals with local services offered to them. Additionally, completing this questionnaire does not entail any known or anticipated risks.

Thank you for your time and consideration. Should you require any further information, please do not hesitate to contact us by phone or email. Your contribution is of great value to this study. Whilst thanking you in advance, we look forward to your participation.

Yours Sincerely,

Prof Andrew Azzopardi, Ms Olga Formosa and Dr Elaine Burmingham

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Autism in Malta

Service Provider Questionnaire

1. Name of organisation/department ______________________

2. Please give a brief description of your organisation (in the case of a department please provide a description of the services offered by your specific department)

3. How many clients does your agency/department cater for?
(Please specify total figure) ______________

4. How many of these are autistic?
(Please specify total figure) ______________

5. What are the age brackets of autistic clients?
(Please select as many as applicable)

0 to 3 ☐
4 to 7 ☐
8 to 12 ☐
13 to 17 ☐
18 to 30 ☐
31 to 60 ☐
61 or over ☐

6. What is the gender distribution of your autistic clients?
(Please specify total figure for each category)

Male ________
Female ________
Other ________

7. What services do you offer to autistic clients? *(Please give details)*

8. Is there a waiting list for clients, in particular, autistic clients? If so, what is the average waiting period?

Yes ☐
No ☐

Average Waiting period *(please specify)*

9. Do you encounter any challenges in offering services to autistic clients? If so, what are these?
(Please give details below e.g. financial, human resources, etc.)

Yes ☐
No ☐

10. From your experience with autistic clients, do you see a need for any additional services or modifications/improvements in services? *(Please give details)*

Thank you for your participation.

Appendix B

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AD(H)D in Malta
Service Provider Questionnaire

Principal Researcher
Name: Prof Andrew Azzopardi
Email: andrew.azzopardi@um.edu.mt
Contact no: 23402918

Research Support Officers

Name:	Dr Elaine Burmingham	Ms Olga Formosa
Email:	elaine.burmingham@parlament.mt	olga.formosa@um.edu.mt
Contact no:	99884830	99440920

9th July 2022

The Faculty for Social Wellbeing at the University of Malta will be conducting research, in collaboration with the Parliament of Malta. We wish to gain insight into the lived experiences of persons with Attention Heficit Hyperactivity Disorder (ADHD) in order to identify not only their needs but also their aspirations and ambitions.

We would like to invite you to participate in this questionnaire regarding your views and experience as a service provider that offers services to people with AD(H)D in Malta. You can complete the questionnaire by filling in a printed form (available from the researchers) or by visiting https://forms.gle/LU15adFXRq3PeBjWA. Questionnaires are to be submitted by Wednesday 3rd August 2022. Your participation would help contribute to a better understanding of the current services being provided to persons with AD(H)D in Malta. Any data collected from this research will be used solely for the purpose(s) of this study.

Completing the questionnaire should take between 10-15 minutes. Questionnaires will include the name of the entity or department you are representing and will only be accessed by the team of researchers involved in the project. Any data gathered will be destroyed within 2 years of completion of the study: any digital data will be deleted, and any printed material will be deleted and shredded within 2 years of completion of the study, in approximately June 2024. Until then, any printed material will be stored in a locked, safe location.

Participation in this questionnaire is entirely voluntary; in other words, you are free to accept or refuse to participate, without needing to give a reason. If you choose to participate, in accordance with the General Data Protection Regulations (GDPR) and national legislation, you have the right to information, access, rectification, objection, erasure, data portability, and to withdraw your consent, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw your participation, any data collected from you will be deleted, if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives – withdrawal can be carried out by not later than one month from the date of submission of the questionnaire. This is in line with the exemptions provided for in GDPR Article 17(3)(d). Submission of this questionnaire indicates your acceptance to the terms of participation as outlined in this document.

Following submission of the questionnaire, the researchers will code the data gathered. This will be pseudonymised and end-to-end encrypted, so that your confidentiality and that of your organisation and department will be respected. The data will be used for the sole purpose of this study, will be stored in an anonymised form and raw data will only be accessed by the team of researchers directly involved in the project. Any data gathered will be destroyed within 2 years of completion of the study: any recordings will be deleted, and any transcribed material will be deleted and shredded. Until then, any printed material will be stored in a locked, safe location separately from any identifying information.

Notwithstanding all the precautions being taken, the local small-island-community context creates a scenario where as professionals, participants may still be identifiable. The research team will therefore further address this matter through the use of gender-neutral

names throughout the research (such as Participant 1, etc.), thereby not revealing participants' genders.

Please note that there are no direct benefits that will be extended to you should you choose to complete this questionnaire, other than helping to better the experiences of individuals with AD(H)D with local services offered to them. Additionally, completing this questionnaire does not entail any known or anticipated risks.

Thank you for your time and consideration. Should you require any further information, please do not hesitate to contact us by phone or email. Your contribution is of great value to this study. Whilst thanking you in advance, we look forward to your participation.

Yours Sincerely,

Prof Andrew Azzopardi, Dr Elaine Burmingham and Ms Olga Formosa

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AD(H)D in Malta

Service Provider Questionnaire

1. Name of organisation/department ____________________

2. Please give a brief description of your organisation (in the case of a department please provide a description of the services offered by your specific department)

3. How many clients does your agency/department cater for?
(Please specify total figure) ____________________

4. How many of these are diagnosed with AD(H)D?
(Please specify total figure) ____________________

5. What are the age brackets of the clients with AD(H)D?
(Please select as many as applicable)

0 to 3 ☐
4 to 7 ☐
8 to 12 ☐
13 to 17 ☐
18 to 30 ☐
31 to 60 ☐
61 or over ☐

6. What is the gender distribution of your clients with AD(H)D?
(Please specify total figure for each category)

Male ____________
Female ____________
Other ____________

7. What services do you offer to clients with AD(H)D? *(Please give details)*

8. Is there a waiting list for clients, in particular, those with AD(H)D? If so, what is the average waiting period?

Yes ☐
No ☐

Average Waiting period *(please specify)* ____________

9. Do you encounter any challenges in offering services to clients with AD(H)D? If so, what are these?
(Please give details below e.g. financial, human resources, etc.)

Yes ☐
No ☐

10. From your experience with clients with AD(H)D, do you see a need for any additional services or modifications/improvements in services? *(Please give details)*

Thank you for your participation.

Appendix C

Autism and ADHD in Malta - Caregiver Questionnaire

The Faculty for Social Wellbeing at the University of Malta is conducting a study, in collaboration with the Parliament of Malta. We aim to gain insight into the lived experiences of persons with Autism and Attention Deficit Hyperactivity Disorder (ADHD) in order to identify their needs but also their aspiration and ambitions. This questionnaire should take around 5-10 minutes to complete.

The survey can only be completed by consenting adults who are caregivers for a person who has been diagnosed with Autism and/or ADHD. If you are a caregiver for more than 1 diagnosed person, please complete the questionnaire in relation to 1 individual – you may complete the survey once again for a second diagnosed person you are also as caregiver for if you wish.

Please do not answer the survey if you are younger than 18 years. Your participation in this survey is voluntary and anonymous. Should you decide not to participate in the survey, you may stop at any time and your responses will not be recorded if you do not complete the whole survey. You will be asked to provide your consent if you proceed to answer the survey. The information gathered (raw data) will be used for research purposes only and will be deleted once the study unit is completed.

Thank you for your time and consideration. Should you require any further information or should you wish to discuss any requirements, please do not hesitate to contact us.

By proceeding with the questionnaire, you are providing informed consent and understand that you:

Are 18 years old or older;

Are participating in an online questionnaire of approximately 5-10 minutes to share your views as caregiver of a person diagnosed with Autism and/or ADHD;

Wherever possible, have sought the assent of the diagnosed person under your care;

Understand that your participation is completely voluntary and that you may choose to withdraw at any time while completing the questionnaire. However, once the questionnaire is completed you will no longer be able to withdraw your participation.

All responses will remain anonymous. No identifying details (namely, your name, email or IP address) will be noted, and thus, neither you nor your responses can be identified.

Additionally, no one will know whether or not you participated in this study.

You can save and keep a copy of this information by right clicking on the current web page, selecting 'Print' and then selecting PDF.

If you have any questions about this research study, please contact Ms. Olga Formosa on olga.formosa@um.edu.mt or Ms Elaine Birmingham on elaine.burmingham@parlament.mt.

By completing the questionnaire, you agree that you (a) have read the above information, (b) voluntarily participate in this study, (c) are at least 18 years of age.

By clicking 'I Agree', you agree to participate in this study.

1. I am the caregiver of…
(Please select one)

☐ A person diagnosed with Autism
☐ A person diagnosed with ADHD
☐ A person diagnosed with both Autism and ADHD

Unless otherwise specified, please indicate your replies as applicable to the service user you act as a caregiver for.

2. Gender of person diagnosed with autism and/or ADHD
(Please select one)

Female ☐
Male ☐
Other ☐
Do not wish to say ☐

3. Age of person diagnosed with autism and/or ADHD
(Please specify)

____

4. Where does the diagnosed individual reside?
(Please select one)

Gozo and Comino Region ☐
Northern Harbour Region *(Birkirkara; Gżira; Ħal Qormi; Ħamrun; Msida; Pembroke; San Ġwann; Santa Venera; St Julian's; Swieqi; Ta' Xbiex; Tal-Pietà; Tas-Sliema)* ☐
Southern Harbour Region *(Cospicua; Fgura; Floriana; Ħal Luqa; Ħaż-Żabbar; Kalkara; Marsa; Paola; Santa Luċija; Senglea; Ħal Tarxien; Valletta; Vittoriosa; Xgħajra)* ☐
South Eastern Region ☐

(Birżebbuġa; Gudja; Ħal Għaxaq; Ħal Kirkop; Ħal Safi; Marsaskala; Marsaxlokk; Mqabba; Qrendi; Żejtun; Żurrieq)

Western Region ☐
(Ħad-Dingli; Ħal Balzan; Ħal Lija; Ħ'Attard; Ħaż-Żebbuġ; Iklin; Mdina; Mtarfa; Rabat; Siġġiewi)

Northern Region ☐
(Ħal Għargħur; Mellieħa; Mġarr; Mosta; Naxxar; St Paul's Bay)

5. Level of Education of diagnosed individual
(Please select one)

- Primary level of education *(primary school, middle school)* ☐
- Secondary level of education *(junior lyceum, area secondary school, etc.)* ☐
- Post-Secondary / Vocational level of education *(MCAST, ITS, Junior College, etc.)* ☐
- Tertiary level of education *(diploma, degree, etc.)* ☐
- Postgraduate level of education *(post-graduate certification, masters, etc.)* ☐

6. Employment Status of diagnosed Individual
(Please select one)

- Self-Employed ☐
- Full-time employment ☐
- Part-time employment ☐
- Casual employment ☐
- Unemployed ☐
- Retired ☐
- Other ☐

7. Composition of diagnosed individual's household
(Please describe the composition of the diagnosed individual's household e.g. individual occupant, 2 parent household, etc.)

____

____

8. Does anyone else in the diagnosed person's immediate family have a diagnosis of Autism and/or ADHD?
(Please select one and specify if 'Other')

- Sibling / s ☐
- Parent / s ☐
- None ☐
- Other (Please specify) ________

9. How old was the person when they received their diagnosis of Autism and/or ADHD?
(Please select one)

- 0 - 5 ☐
- 6 - 11 ☐
- 12 - 16 ☐
- 17 - 24 ☐
- 25 - 30 ☐
- 31 - 64 ☐
- 65 or over ☐

In the following section, please select one number to indicate your answer – 1 indicates least satisfied whilst 5 indicates most satisfied.

10. How satisfied are you with…

a. The diagnosis process?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

b. Accessing services once you were given a diagnosis?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

c. How services were linked together so that when you access one service they know what other services you were accessing and had the necessary information?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

11. Following the diagnosis, did the diagnosed individual's family / caregivers receive any support services?

(Please select at least 1 or more as applicable and specify if 'Other')

- ☐ None
- ☐ Family support/counselling
- ☐ Respite care
- ☐ Caregiver training
- ☐ Other *(please specify below)*

____

____

12. What education, health, social or support services (including therapeutic modalities) has the person with a diagnosis of Autism and/or ADHD received, if any, in the last 6 months?
(Please list as applicable or 'none')

____________________________ ____________________________

____________________________ ____________________________

____________________________ ____________________________

13. How satisfied are you with these services?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

14. Regardless of what services the diagnosed individual is receiving or whether these are available or not, what do you consider to be the top 3 service and/or support needs for persons with Autism and/or ADHD?
(Please list 3)

15. Did the diagnosed individual experience any barriers in accessing services needed?
(Please select at least 1 or more as applicable and specify if 'Other')

- ☐ Cannot afford them
- ☐ Negative experiences with professionals in the past
- ☐ Waiting list
- ☐ Lack of trained professionals
- ☐ Not able to access services because diagnosis does not qualify for services
- ☐ Even with a diagnosis, was deemed ineligible for services
- ☐ Age
- ☐ Transportation problems
- ☐ None
- ☐ Other *(please specify below)*

16. Do you feel that there are adequate services for persons with Autism and/or ADHD for the following age groups...
(Please select Yes or No for each age group)

	Yes	No
First years (0 - 3 years)		
Kindergarten (3 - 4 years)	☐	☐
Primary School Age (5 - 10 years)	☐	☐
Secondary School Age (11 - 16 years)	☐	☐
Young Adults (16 - 24 years)	☐	☐
25 to 64 year olds	☐	☐
Older persons (65 years old and over)	☐	☐

17. Are you satisfied with the support and opportunities for persons diagnosed with Autism and/or ADHD to enjoy fulfilling lifestyle in Malta?
(Please select Yes or No for each category)

	Yes	No
Social participation	☐	☐
Independent living	☐	☐
Employment opportunities	☐	☐

17. Would you like to add any other comments?

Thank you for your participation.

Appendix D

Autism and ADHD in Malta - Service User Questionnaire

The Faculty for Social Wellbeing at the University of Malta is conducting a study, in collaboration with the Parliament of Malta. We aim to gain insight into the lived experiences of persons with Autism and Attention Deficit Hyperactivity Disorder (ADHD) in order to identify their needs but also their aspiration and ambitions. This survey should take around 5 - 10 minutes to complete.

The survey can only be completed by consenting adults who have been diagnosed with Autism and/or ADHD. Please do not answer the survey if you are younger than 18 years. Your participation in this survey is voluntary and anonymous. Should you decide not to participate in the survey, you may stop at any time and your responses will not be recorded if you do not complete the whole survey. You will be asked to provide your consent if you proceed to answer the survey. The information gathered (raw data) will be used for research purposes only and will be deleted once the study unit is completed.

Thank you for your time and consideration. Should you require any further information or should you wish to discuss any requirements, please do not hesitate to contact us.

Acceptance to participate in this study implies that you:
Are 18 years old or older;
Are participating in an online questionnaire of approximately 5-10 minutes to share your views as a person diagnosed with Autism and/or ADHD;
Understand that your participation is completely voluntary and that you may choose to withdraw at any time while completing the questionnaire. However, once the questionnaire is completed you will no longer be able to withdraw your participation.
All responses will remain anonymous. No identifying details (namely, your name, email or IP address) will be noted, and thus, neither you nor your responses can be identified.
Additionally, no one will know whether or not you participated in this study.
You can save and keep a copy of this information by right clicking on the current web page, selecting 'Print' and then selecting PDF.
If you have any questions about this research study, please contact Ms. Olga Formosa on olga.formosa@um.edum.mt or Ms Elaine Birmingham on elaine.burmingham@parlament.mt.

By completing the questionnaire, you agree that you (a) have read the above information, (b) voluntarily participate in this study, (c) are at least 18 years of age.
By clicking 'I Agree', you agree to participate in this study.

1. About you
(Please select one)

I am…
☐ A person diagnosed with Autism
☐ A person diagnosed with ADHD
☐ A person diagnosed with both Autism and ADHD

2. Your Gender
(Please select one)

Female ☐
Male ☐
Other ☐
Do not wish to say ☐

3. Your Age
(Please specify)

____

4. Where do you reside?
(Please select one)

Gozo and Comino Region ☐
Northern Harbour Region *(Birkirkara; Gżira; Ħal Qormi; Ħamrun; Msida; Pembroke; San Ġwann; Santa Venera; St Julian's; Swieqi; Ta' Xbiex; Tal-Pietà; Tas-Sliema)* ☐
Southern Harbour Region *(Cospicua; Fgura; Floriana; Ħal Luqa; Ħaż-Żabbar; Kalkara; Marsa; Paola; Santa Luċija; Senglea; Ħal Tarxien; Valletta; Vittoriosa; Xgħajra)* ☐
South Eastern Region *(Birżebbuġa; Gudja; Ħal Għaxaq; Ħal Kirkop; Ħal Safi; Marsaskala; Marsaxlokk; Mqabba; Qrendi; Żejtun; Żurrieq)* ☐
Western Region *(Ħad-Dingli; Ħal Balzan; Ħal Lija; H'Attard; Ħaż-Żebbuġ; Iklin; Mdina; Mtarfa; Rabat; Siġġiewi)* ☐
Northern Region *(Ħal Għargħur; Mellieħa; Mġarr; Mosta; Naxxar; St Paul's Bay)* ☐

5. Your Level of Education
(Please select one)

Primary level of education *(primary school, middle school)* ☐
Secondary level of education *(junior lyceum, area secondary school, etc.)* ☐
Post-Secondary / Vocational level of education *(MCAST, ITS, Junior College, etc.)* ☐
Tertiary level of education ☐

(diploma, degree, etc.)
Postgraduate level of education ☐
(post-graduate certification, masters, etc.)

6. Your Employment Status
(Please select one)

- Self-Employed ☐
- Full-time employment ☐
- Part-time employment ☐
- Casual employment ☐
- Unemployed ☐
- Retired ☐
- Other ☐

7. Composition of your Household
(Please describe the composition of your household e.g. individual occupant, 2 parent household, etc.)

8. Aside from yourself, does anyone else in your immediate family have a diagnosis of Autism and/or ADHD?
(Please select one and specify if 'Other')

- Sibling / s ☐
- Parent / s ☐
- None ☐
- Other *(Please specify)*

9. How old were you when you received your diagnosis of Autism and/or ADHD?
(Please select one)

- 0 - 5 ☐
- 6 - 11 ☐
- 12 - 16 ☐
- 17 - 24 ☐
- 25 - 30 ☐
- 31 - 64 ☐
- 65 or over ☐

In the following section, please select one number to indicate your answer – 1 indicates least satisfied whilst 5 indicates most satisfied.

10. How satisfied are you with…

a. The diagnosis process?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

b. Accessing services once you were given a diagnosis?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

c. How services were linked together so that when you access one service they know what other services you were accessing and had the necessary information?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

11. Following the diagnosis, did your family receive any support services
(Please select at least 1 or more as applicable and specify if 'Other')

- ☐ None
- ☐ Family support/counselling
- ☐ Respite care
- ☐ Caregiver training
- ☐ Other *(please specify below)*

12. What education, health, social or support services (including therapeutic modalities) have you received, if any, in the last 6 months?
(Please list as applicable)

13. How satisfied are you with these services?

1	2	3	4	5
Very dissatisfied	Somewhat dissatisfied	Neutral	Somewhat satisfied	Very satisfied

14. Regardless of what services you are receiving or whether these are available or not, what do you consider to be the top 3 service and/or support needs for persons with Autism and/or ADHD?
(Please list 3)

15. Did you experience any barriers in accessing services needed?
(Please select at least 1 or more as applicable and specify if 'Other')

- ☐ Cannot afford them
- ☐ Negative experiences with professionals in the past
- ☐ Waiting list
- ☐ Lack of trained professionals
- ☐ Not able to access services because diagnosis does not qualify for services
- ☐ Even with a diagnosis, was deemed ineligible for services
- ☐ Age
- ☐ Transportation problems
- ☐ Other *(please specify below)*

____

16. Do you feel that there are adequate services for persons with Autism and/or ADHD for the following age groups...
(Please select Yes or No for each age group)

	Yes	No
First years (0 - 3 years)	☐	☐
Kindergarten (3 - 4 years)	☐	☐
Primary School Age (5 -10 years)	☐	☐
Secondary School Age (11 - 16 years)	☐	☐
Young Adults (16 - 24 years)	☐	☐
25 to 64 year olds	☐	☐
Older persons (65 years old and over)	☐	☐

17. Are you satisfied with the support and opportunities for persons diagnosed with Autism and/or ADHD to enjoy fulfilling lifestyle in Malta? *(Please select Yes or No for each category)*

	Yes	No
Social participation	☐	☐
Independent living	☐	☐
Employment opportunities	☐	☐

18. Would you like to add any other comments?

____

____

____

____

Thank you for your participation.

Appendix E

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INFORMATION SHEET – Caregiver Interviews

Principal Researcher
Name: Prof Andrew Azzopardi
Email: andrew.azzopardi@um.edu.mt
Contact no: 23402918

Research Support Officers

Name:	Ms Olga Formosa	Dr Elaine Burmingham
Email:	olga.formosa@um.edu.mt	elaine.burmingham@parlament.mt
Contact no:	23403720	99884830

8th July 2022

Dear Sir/Madam,

The Faculty for Social Wellbeing at the University of Malta will be conducting research, in collaboration with the Parliament of Malta. We wish to gain insight into the lived experiences of persons with Autism in order to identify not only their needs but also their aspirations and ambitions.

We would like to invite you to participate in this research, which would involve voluntarily participating in an interview regarding your offrsping's experience as a person on the spectrum in Malta. Participation is entirely voluntary; you may accept or refuse to participate without needing to give a reason for your choice. Your participation does not entail any known risks. Below you will find information about what your involvement would entail, should you decide to take part. Your participation would help contribute to a better understanding of the experiences of persons with autism within the local context. Any data collected from this research will be used solely for the purpose(s) of this study.

Should you choose to participate, the one-time interview will be held online via Zoom at a time convenient for you and will take approximately an hour. During the interview, you will be asked to discuss your views regarding your offspring's experience and aspirations. Interviews will be audio recorded for later written analysis. This recording will make use of Zoom security features such as end-to-end encryption. Your name and surname and any other personally-identifiable details will not be used in the study or disseminated in any way.

Following the interview, the researchers will transcribe and code the data gathered. This will be pseudonymised upon transcription and end-to-end encrypted, so that you and your family's personal data and identification will remain confidential. The data will be used for the sole purpose of this study, will be stored in an anonymised form and raw data will only be accessed by the team of researchers directly involved in the project. Any data gathered will be destroyed within 2 years of completion of the study: any recordings will be deleted and any transcribed material will be deleted and shredded. Until then, any printed material will be stored in a locked, safe location separately from any identifying information.

If you choose to participate, in accordance with the General Data Protection Regulations (GDPR) and national legislation, you have the right to information, access, rectification, objection, erasure, data portability, and to withdraw your consent, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw your participation, any data collected from you will be deleted, if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives – withdrawal can be carried out by not later than one month from the date of the interview. This is acknowledged in point 2 of the consent form and is in line with the exemptions provided for in GDPR Article 17(3)(d).

If you choose to participate, please note that there are no direct benefits to you other than helping to better understand the experiences of persons with autism in Malta, and that your participation does not entail any known or anticipated risks. In order to participate you will need to sign a consent form.

A copy of this information sheet is being provided for you to keep and for future reference. Should you require any further information, please do not hesitate to contact us by phone or email. Thank you for your time and consideration. Your contribution is of great value to this study. Whilst thanking you in advance, we look forward to your participation.

Yours Sincerely, Prof Andrew Azzopardi, Ms Olga Formosa and Dr Elaine Burmingham

Appendix F

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INFORMATION SHEET – Service User Interviews

Principal Researcher
Name: Prof Andrew Azzopardi
Email: andrew.azzopardi@um.edu.mt
Contact no: 23402918

Research Support Officers

Name:	Ms Olga Formosa	Dr Elaine Burmingham
Email:	olga.formosa@um.edu.mt	elaine.burmingham@parlament.mt
Contact no:	23403720	99884830

8th July 2022

Dear Sir/Madam,

The Faculty for Social Wellbeing at the University of Malta will be conducting research, in collaboration with the Parliament of Malta. We wish to gain insight into the lived experiences of persons with autism in order to identify not only their needs but also their aspirations and ambitions.

We would like to invite you to participate in this research, which would involve voluntarily participating in an interview regarding your experience as a person on the spectrum in Malta. Participation is entirely voluntary; you may accept or refuse to participate without needing to give a reason for your choice. Your participation does not entail any known risks. Below you will find information about what your involvement would entail, should you decide to take part. Your participation would help contribute to a better understanding of the experiences of persons with autism within the local context. Any data collected from this research will be used solely for the purpose(s) of this study.

Should you choose to participate, the one-time interview will be held online via Zoom at a time convenient for you and will take approximately an hour. During the interview, you will be asked to discuss your views regarding your experience and aspirations. Interviews will be audio recorded for later written analysis. This recording will make use of Zoom security features such as end-to-end encryption. Your name and surname and any other personally-identifiable details will not be used in the study or disseminated in any way.

Following the interview, the researchers will transcribe and code the data gathered. This will be pseudonymised upon transcription and end-to-end encrypted, so that your and your family's personal data and identification will remain confidential. The data will be used for the sole purpose of this study, will be stored in an anonymised form and raw data will only be accessed by the team of researchers directly involved in the project. Any data gathered will be destroyed within 2 years of completion of the study: any recordings will be deleted, and any transcribed material will be deleted and shredded. Until then, any printed material will be stored in a locked, safe location separately from any identifying information.

If you choose to participate, in accordance with the General Data Protection Regulations (GDPR) and national legislation, you have the right to information, access, rectification, objection, erasure, data portability, and to withdraw your consent, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw your participation, any data collected from you will be deleted, if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives - withdrawal can be carried out by not later than one month from the date of the interview. This is acknowledged in point 2 of the consent form and is in line with the exemptions provided for in GDPR Article 17(3)(d).

If you choose to participate, please note that there are no direct benefits to you other than helping to better understand the experiences of persons with autism in Malta, and that your participation does not entail any known or anticipated risks. In order to participate you will need to sign a consent form.

A copy of this information sheet is being provided for you to keep and for future reference.

Should you require any further information or should you wish to discuss any requirements, if necessary, please do not hesitate to contact us by phone or email.

Thank you for your time and consideration. Your contribution is of great value to this study. Whilst thanking you in advance, we look forward to your participation.

Yours Sincerely,

Prof Andrew Azzopardi, Ms Olga Formosa and Dr Elaine Burmingham

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Appendix G

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CONSENT FORM – Caregiver Interviews

The Faculty for Social Wellbeing at the University of Malta will be conducting research, in collaboration with the Parliament of Malta. We wish to gain insight into the lived experiences of persons with autism in the local context.

Thank you for considering taking part in this research. Please fill in this form after reading the Information Sheet and the information listed here. If you have any questions, please ask the researchers before you decide to sign this consent form and participate in this research.

I, the undersigned, give my consent to take part in the study conducted by Prof Andrew Azzopardi, Ms Olga Formosa and Dr Elaine Burmingham. This consent form specifies the terms of my participation in this research study.

1. I have been given written information about the purpose of the study; I have had the opportunity to ask questions and any questions that I had were answered fully and to my satisfaction.
2. I also understand that I am free to accept to participate, or to refuse or stop participation without giving any reason and without any penalty. In the event that I choose to withdraw from the study, any data collected from me will be erased if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives and that withdrawal can be carried out by not later than one month from the date of the interview. Should I choose to participate, I may choose to decline to answer any questions asked.
3. I understand that I have been invited to participate in a one-time interview in order to discuss my offspring's experiences and aspirations as an autistic person in Malta. I am aware that the interview will take approximately one hour and that it will take place online, via Zoom, at a convenient, previously-agreed time.
4. I am aware that, if I give my consent, the Zoom interview will be audio recorded and converted to text as it has been recorded (transcribed). This recording will make use

of Zoom security features such as end-to-end encryption. The recording will be deleted two years from completion of the study, in approximately June 2024.

5. I am aware that upon transcription, my data will be pseudonymised, that is, my identity and that of my family will not be noted on transcripts or notes from my interview, but instead, a code will be assigned. The codes that link my data to my identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer, and only the researchers will have access to this information. Any hard-copy materials will be stored in a secure place. Any material that identifies me as a participant in this study will be stored securely for the duration of the study and destroyed within two years of completion of the study.
6. I am aware that, if I give my consent, extracts of the interview may be reproduced in the study outputs in a pseudonymised form (made-up name/code e.g. respondent A).
7. I am aware that my identity and that of my family and personal information will not be revealed in any publications, reports or presentations arising from this research.
8. I understand that my participation does not entail any known or anticipated risks. Notwithstanding, the researcher will have available a list of support services that I can make use of should this possibility arise.
9. I understand that there are no direct benefits to me from participating in this study but that my participation can contribute towards better understanding of the experience of being autistic in Malta.
10. I understand that, under the General Data Protection Regulation (GDPR) and national legislation, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased.
11. I understand that all data collected will be stored in an anonymised form and only the research team will have access to the raw data. Data will be erased within two years of completion of the study.
12. I have been provided with a copy of the information and recruitment letter and understand that I will also be given a copy of this consent form, which includes the contact details of the researcher.

I have read and understood the above statements and agree to participate in this study.

Participant's name ______________________________

Participant's signature ______________________________

Date ______________________________

Name of Academic researcher: Prof Andrew Azzopardi

Contact: andrew.azzopardi@um.edu.mt Tel no: 23402918

Researchers:	Ms Olga Formosa	Dr Elaine Burmingham
Email:	olga.formosa@um.edu.mt	elaine.burmingham@parlament.mt
Tel. No.:	23403720	99884830

Appendix H

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CONSENT FORM – Service User Interviews

The Faculty for Social Wellbeing at the University of Malta will be conducting research, in collaboration with the Parliament of Malta. We wish to gain insight into the lived experiences of persons with autism in the local context.

Thank you for considering taking part in this research. Please fill in this form after reading the Information Sheet and the information listed here. If you have any questions, please ask the researchers before you decide to sign this consent form and participate in this research.

I, the undersigned, give my consent to take part in the study conducted by Prof Andrew Azzopardi, Ms Olga Formosa and Dr Elaine Burmingham. This consent form specifies the terms of my participation in this research study.

1. I have been given written information about the purpose of the study; I have had the opportunity to ask questions and any questions that I had were answered fully and to my satisfaction.
2. I also understand that I am free to accept to participate, or to refuse or stop participation without giving any reason and without any penalty. In the event that I choose to withdraw from the study, any data collected from me will be erased if this is technically possible, unless erasure of data would render impossible or seriously impair achievement of the research objectives and that withdrawal can be carried out by not later than one month from the date of the interview. Should I choose to participate, I may choose to decline to answer any questions asked.
3. I understand that I have been invited to participate in a one-time interview in order to discuss my experiences and aspirations as an autistic person in Malta. I am aware that the interview will take approximately one hour and that it will take place online, via Zoom, at a convenient, previously-agreed time.
4. I am aware that, if I give my consent, the Zoom interview will be audio recorded and converted to text as it has been recorded (transcribed). This recording will make use of Zoom security features such as end-to-end encryption. The recording will be deleted two years from completion of the study, in approximately June 2024.
5. I am aware that upon transcription, my data will be pseudonymised, that is, my identity and that of my family will not be noted on transcripts or notes from my interview, but instead, a code will be assigned. The codes that link my data to my identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer, and only the researchers will have access to this information. Any hard-copy materials will be stored in a secure place. Any material that identifies me as a participant in this study will be stored securely for the duration of the study and destroyed within two years of completion of the study.
6. I am aware that, if I give my consent, extracts of the interview may be reproduced in the study outputs in a pseudonymised form (made-up name/code e.g. respondent A).
7. I am aware that my identity and that of my family and personal information will not be revealed in any publications, reports or presentations arising from this research.
8. I understand that my participation does not entail any known or anticipated risks. Notwithstanding, the researcher will have available a list of support services that I can make use of should this possibility arise.
9. I understand that there are no direct benefits to me from participating in this study but that my participation can contribute towards better understanding of the experience of being autistic in Malta.
10. I understand that, under the General Data Protection Regulation (GDPR) and national legislation, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased.
11. I understand that all data collected will be stored in an anonymised form and only the research team will have access to the raw data. Data will be erased within two years of completion of the study.
12. I have been provided with a copy of the information and recruitment letter and understand that I will also be given a copy of this consent form, which includes the contact details of the researcher.

I have read and understood the above statements and agree to participate in this study.

Participant's name
Participant's signature
Date

Name of Academic researcher: Prof Andrew Azzopardi

Contact: andrew.azzopardi@um.edu.mt Tel no: 23402918

Name of researchers:	Ms Olga Formosa	Dr Elaine Burmingham
Contact:	olga.formosa@um.edu.mt	elaine.burmingham@parlament.mt
Tel. No.:	23403720	99884830

Appendix I

Persons with Autism Caregiver Participant Interview Guide

1) How old is your son/daughter who has been diagnosed with ASD?
2) Aside from autism, has your son/daughter been diagnosed with any co-occurring physical or mental health diagnoses?
3) How was the process to get a diagnosis of autism for your son/daughter?
4) Once you obtained a diagnosis, how easy was it accessing services? Did you know where to go? Were services coordinated?
5) Once you obtained a diagnosis, did your family receive any support services (caregiver training, family support/counselling, respite care)?
6) What health or disability services has your son/daughter received in the last 6 months? Any other services that are relevant to ASD?
7) Did you experience any barriers in accessing these services *(cannot afford them, negative experiences with professionals in the past, waiting list, lack of trained professionals, not able to access services because his/her diagnosis does not qualify them for services, even with a diagnosis, was deemed ineligible for services, is too young to receive the services that s/he needs, is too old to receive the services that s/he needs, transportation problems, other [Douma et al., 2006])*?
8) How satisfied are you with these services (frequency, quality, etc.)?
9) What are your son/daughter's current top 5 service needs, regardless of what services they are receiving?
10) Do you think local provision of services caters for your son/daughter's needs along the different stages of their life (adolescence/adulthood/elderly)?
11) Do you feel that your son/daughter is able (or will be able to as they grow older) to enjoy a fulfilling lifestyle in Malta?

    [Or broken down into 2:

    - *i. live independently (e.g. transportation, employment, housing)?*
    - *ii. participate in society (friendships and relationships, social participation, etc.)?]*
12) What are your main concerns for your son/daughter's wellbeing and that of other autistic individuals?
13) How would you address these?
14) Any additional comments?

Appendix J

Persons with Autism Service User Participant Interview Guide

1) How old are you and how old were you when you were first diagnosed with autism?
2) In addition to autism, were you diagnosed with any co-occurring physical or mental health diagnoses?
3) If you were an adult when you were diagnosed, or if you are aware of it (maybe you remember or were told about it), how was the process to get a diagnosis?
4) Once you obtained a diagnosis, do you know if it was easy accessing services? Did you or your family know where to go? Do you know ifere services coordinated?
5) Once a diagnosis was given, do you know if your family received any support services (e.g. caregiver training, family support/counselling, respite care)?
6) Have you received any health or disability services in the last 6 months? Or any other services that are relevant to autism? What are these?
7) Did you experience any barriers in accessing these services *(cannot afford them, negative experiences with professionals in the past, waiting list, lack of trained professionals, not able to access services because his/her diagnosis does not qualify them for services, even with a diagnosis, was deemed ineligible for services, is too young to receive the services that s/he needs, is too old to receive the services that s/he needs, transportation problems, other [Douma et al., 2006])*?
8) How satisfied are you with these services (frequency, quality, etc.)?
9) What are your current top 5 service needs, regardless of what services you may be receiving?
10) Do you think local provision of services caters for your needs along the different stages of your life (adolescence/adulthood/elderly)?
11) Do you feel you are able to enjoy a fulfilling lifestyle in Malta?

    [Or broken down into 2:

    i. live independently (e.g. transportation, employment, housing)?

    ii. participate in society (friendships and relationships, social participation, etc.)?]
12) What are your main concerns for your and other autistic people's wellbeing?
13) How would you address these?
14) Any additional comments?

Appendix K

Persons with ADHD Caregiver Participant Interview Guide

1) How old is your son/daughter who has been diagnosed with AD(H)D?
2) Aside from AD(H)D, has your son/daughter been diagnosed with any co-occurring physical or mental health diagnoses?
3) How was the process to get a diagnosis of AD(H)D for your son/daughter?
4) Once you obtained a diagnosis, how easy was it accessing services? Did you know where to go? Were services coordinated?
5) Once you obtained a diagnosis, did your family receive any support services (caregiver training, family support/counselling, respite care)?
6) What health or disability services has your son/daughter received in the last 6 months? Any other services that are relevant to AD(H)D?
7) Did you experience any barriers in accessing these services *(cannot afford them, negative experiences with professionals in the past, waiting list, lack of trained professionals, not able to access services because his/her diagnosis does not qualify them for services, even with a diagnosis, was deemed ineligible for services, is too young to receive the services that s/he needs, is too old to receive the services that s/he needs, transportation problems, other [Douma et al., 2006])*?
8) How satisfied are you with these services (frequency, quality, etc.)?
9) What are your son/daughter's current top 5 service needs, regardless of what services they are receiving?
10) Do you think local provision of services caters for your son/daughter's needs along the different stages of their life (adolescence/adulthood/elderly)?
11) Do you feel that your son/daughter is able (or will be able to as they grow older) to enjoy a fulfilling lifestyle in Malta?

    [Or broken down into 2:

    i. live independently (e.g. transportation, employment, housing)?

    ii. participate in society (friendships and relationships, social participation, etc.)?]
12) What are your main concerns for your son/daughter's wellbeing and that of other individuals with AD(H)D?
13) How would you address these?
14) Any additional comments?

Appendix L

Persons with ADHD Service User Participant Interview Guide

1) How old are you and how old were you when you were first diagnosed with AD(H)D?
2) In addition to AD(H)D, were you diagnosed with any co-occurring physical or mental health diagnoses?
3) If you were an adult when you were diagnosed, or if you are aware of it (maybe you remember or were told about it), how was the process to get a diagnosis?
4) Once you obtained a diagnosis, do you know if it was easy accessing services? Did you or your family know where to go? Do you know if services were coordinated?
5) Once a diagnosis was given, do you know if your family received any support services (e.g. caregiver training, family support/counselling, respite care)?
6) Have you received any health or disability services in the last 6 months? Or any other services that are relevant to AD(H)D? What are these?
7) Did you experience any barriers in accessing these services *(cannot afford them, negative experiences with professionals in the past, waiting list, lack of trained professionals, not able to access services because his/her diagnosis does not qualify them for services, even with a diagnosis, was deemed ineligible for services, is too young to receive the services that s/he needs, is too old to receive the services that s/he needs, transportation problems, other [Douma et al., 2006])*?
8) How satisfied are you with these services (frequency, quality, etc.)?
9) What are your current top 5 service needs, regardless of what services you may be receiving?
10) Do you think local provision of services caters for your needs along the different stages of your life (adolescence/adulthood/elderly)?
11) Do you feel you are able to enjoy a fulfilling lifestyle in Malta?
    [Or broken down into 2:
    - *i. live independently (e.g. transportation, employment, housing)?*
    - *ii. participate in society (friendships and relationships, social participation, etc.)?]*
12) What are your main concerns for your and other persons with AD(H)D's wellbeing?
13) How would you address these?
14) Any additional comments?