JDC Israel Unlimited

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The Partnership for Planning and Development of Services to Promote and Integrate the Disabled in the Community. Established by: JDC-Israel, Ruderman Family Foundation, Ministry of Social Affairs and Social Services, Ministry of Health, Ministry of Finance, National Insurance institute

Mapping the Needs of People With Asperger Syndrome

A Study be Yonatan Drori

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Preface

There are many stages to the transition from adolescence to adulthood: graduating, integrating into the workforce, making the transition to living independently, establishing an adult identity, finding a partner, starting a family, and building a circle of belonging.

Today in Israel, there are some 105,000 young people aged 21 to 35 with disabilities[1] (this figure is an underestimate, based as it is on the number of young people with disabilities who graduate from Israel's education system every year, and not including those who acquire disabilities subsequently). The difficulties these young adults face, while being similar to those of their peers without disabilities, are compounded by the particular obstacles they encounter in various spheres, including social and familial barriers, lack of faith in themselves and their abilities, lack of available and accessible information on their options for integration, lack of coordination between service providers, social ostracism, lack of access to services, and lack of support systems.

These obstacles deny these young adults equal opportunity to attain goals associated with adulthood (such as housing, education, employment, management of finances, family, romance, and recreation). They also make it difficult for them to separate from their parents, who are often overprotective, and, at times, financially dependent on the disability allowances they receive. To make choices, young adults with disabilities need access to information on the options available to them, consultation services, an attentive ear, help with decision-making, and support services. **They must also be allowed to play an active role in this process so that they gain confidence in their abilities and try their hand at various options.**

Israel Unlimited is a strategic partnership between JDC Israel, the Government of Israel, and the Ruderman Family Foundation, devoted to the development of services to help integrate adults with any type of disability into the community. To better understand how young adults with disabilities, their families, and professionals perceive their needs, Israel Unlimited launched this study, which focuses on the needs of those with high-functioning autism and Asperger syndrome.

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[1] Naon, D., *Adults with Disabilities in Israel,* Jerusalem: Myers-JDC-Brookdale Institute, 2009, Catalog Number DM-09-537.

We aim to conduct further studies of young adults with other kinds of disability in order to develop tailored and human-oriented services that emphasize abilities over disabilities, and allow them to integrate into the community and live independently, while receiving the support they require.

We are deeply grateful to the Asperger–Israel Association (“Effie”) for their cooperation; to Yonatan Drori, for leading and writing up this study; to Ronit Goldiner, who initiated the study while working at Israel Unlimited; to Lili Abiri, the director of the Service for Autism, who supported this study and provided professional assistance; and to Efrat Stern, the director of the Personal Services Department and Head of the Supportive Housing Program at Israel Unlimited, for her professional support throughout.

Avital Sandler-Loeff

Director of Israel Unlimited

Mapping the Needs of People with Asperger Syndrome

Yonatan Drori

Asperger Syndrome and the Autism Spectrum

The terms "Asperger syndrome" and "autism spectrum" have both undergone a lengthy process of evolution. In 1943, Austrian psychiatrist Leo Kanner coined the term "infantile autism" to describe children who had a hard time interacting and communicating with society, exhibited stereotypical behaviors, had unique and narrow interests, and found it difficult to handle changes. Around the same time, Hans Asperger described a syndrome with a similar set of traits. In 1993, the World Health Organization recognized Asperger syndrome and included it in its ICD-10 (International Catalog of Diseases) manual. In 1994, the American Psychiatric Association also recognized the syndrome and included it in DSM-IV, the association's diagnostic manual, under the title of "PDD—Pervasive Developmental Disorder." In March 2013, Asperger syndrome was removed from the American diagnostic manual (DSM-V). This manual cancelled the umbrella diagnosis of Pervasive Developmental Disorder (PDD) and all of the conditions it referred to, including Asperger syndrome, and in its stead, defined a new diagnostic spectrum for autism, based on level of functioning.

Prevalence and Trends in Israel and Around the World

Over the past few decades, studies of autism spectrum prevalence have found a steep rise by a factor of anywhere between 25 and 50, going from a rate of 1 case per 2,500 people in the 1960s and 1970s, to a rate of 1–2% in more recent studies. The diagnostic trend observed in Israel is consistent with this global trend. This rise has led to increased research and the development of services for this group. In Israel, too, there is a growing need to develop services for autistic adults interested in living an independent life. This has produced a number of programs, including, inter alia, the Supported Housing program, a partnership between Israel Unlimited and government institutions to provide housing and support enabling people with disabilities to live independently in the community. The present study was conducted as part of this program, funded by JDC Israel and Israel Unlimited, and with the cooperation of the Asperger–Israel Association ("Effie"), in order to map the needs of adults on the autism spectrum.

Study Goals—Needs Mapping

For the purposes of adapting the Supported Housing program model to adults on the autism spectrum, we sought to collect information about people over 18 with Asperger syndrome who live in their parents' homes or independently, and receive no assistance from community housing services. The study set out to examine the functional, social, and personal attributes of this group—a pioneering endeavor to describe this population. Our findings are presented in this report.

Interviewees

The primary characteristics of the study population were as follows:

Age and diagnosis: There were 80 interviewees, 67 men (84%) and 13 women (16%). Their average age was 26.7, with a standard deviation of 6.3. Fifty interviewees (62.5%) reported that they had received at least one other psychiatric diagnosis.

Housing: 71% of the interviewees live with their parents, 20% live alone, and 9% live with a partner or roommate(s).

Education: 67% of the interviewees graduated from high school with a full matriculation certificate. About half of them are students or possess academic degrees. The remaining 33% of the interviewees gained either a partial matriculation certificate or none at all. 21% possess professional certification.

Method

The study used a specially-designed semi-structured questionnaire, which covered various aspects of interviewees' functioning and life skills, including the following: IADL (Instrumental Activities of Daily Living), housing, employment, social life, health status, and more. Data collected by means of this questionnaire was subjected to qualitative and quantitative analysis.

Uniqueness of this Study

People with Asperger syndrome can properly describe how they perceive the world, explain their needs, and express their opinions on existing services. However, until today, only a few qualitative studies have been conducted that focus on these questions, and these studies have used small groups of interviewees. What makes this study unique is its relatively large sample size of interviewees, and the wide range of topics covered. Thus, it provides a statistical basis from which we can derive a general picture, and allows us to better understand the implications of the data by means of the commentary provided by the interviewees themselves.

Main Findings

1. Diagnosis and Official Certification

Asperger syndrome is a developmental disorder that first appears in early childhood, but nearly half of the interviewees were only diagnosed during adolescence. This can be explained by general and objective factors related to increased awareness and the development of diagnostic tools used to identify autism spectrum disorders, both over the last two decades. Among other explanations is a reluctance to be diagnosed due to fear of the stigmatization it may bring, and this led many of the interviewees (who, in some cases, acted under the advice of their families) to do their utmost to avoid or delay diagnosis.

The structured nature of the settings inhabited by the interviewees during the transition period between childhood and adulthood (educational frameworks, and sometimes, military and national service frameworks) allowed them to obfuscate their difficulties, integrate into society, and advance, and even to moderate their feelings of failure and crisis. Once they were no longer in those settings, however, they had to actively create their own frameworks—most importantly, employment and higher education, social life, and family life. Many interviewees described this period as a time of personal crisis. Indeed, this was the stage at which many of the interviewees in this study were diagnosed, and their diagnoses recognized by state authorities. The diagnostic process is gradual. On the one hand, it allows individuals to come to terms with themselves and understand that their difficulties stem from an “objective” difficulty; but on the other hand, it entails fears of being labeled as “disabled” and stigmatized, and creates a gap between the person diagnosed and their family members.

Though 78 (or 97.5%) of the interviewees were indeed diagnosed as being on the autism spectrum, only 52 of those 78 interviewees (67%) were recognized as such by the National Insurance Institute, and only 34 (44%) were recognized by the Ministry of Social Welfare. This echoes the data trends published by Ministry of Social Welfare and the National Insurance Institute. A significant number of those diagnosed had never applied to the state authorities for recognition. This can be explained by a lack of knowledge about existing services, the fact that services are not properly adapted to the needs of the group of interviewees, and a lack of faith in the authorities. Moreover, based on earlier and inaccurate or incorrect diagnoses, some interviewees had been referred to treatment programs that were inappropriate for them, leading them to mistrust health and social welfare professionals.

The challenge presented to us by the interviewees, some of whom are academics, is to establish an array of services that will help them fully integrate into society, and allow them to realize their potential. Employees of the various state authorities (such as the education, health, and social welfare systems) must also be familiar with the existing services, so that they can direct and guide those who contact them.

2. Skills

People with Asperger syndrome have varying levels of function in terms of instrumental activities of daily living (IADL). Moreover, each individual often displays variance in his or her levels of functioning in different areas. The difficulties described in this report include gaps between having normative abilities in areas considered challenging (such as acquiring higher education) and having only limited abilities in areas considered simple and basic (such as cooking). It is important for these gaps to be explained, as they may cause individuals to misinterpret their difficulties and label themselves as lazy (either honestly, or because they prefer that designation to “disabled”), instead of addressing the core reasons for not having developed certain skills.

Consequently, a detailed map of needs must be created, with no assumption that adequate function in one complex area implies a similar level of function in a simpler area. Training based on breaking down a task into its components are writing a detailed set of procedures, as well as engaging in constant guided practice, are good ways to address the general effects of this syndrome, and are thus relevant in helping trainees acquire various skills.

Most of the interviewees in this study need help when trying to exercise their rights in the public sector (working with entities such as government offices, municipalities, and government-owned companies), and when they require services from private companies, such as banks, cellular phone companies, and so on. They need this assistance because of their communication difficulties; these types of interactions tend to be one-time or ad-hoc occurrences, and as a result, many of the interviewees try to avoid initiating them rather than face the inevitable struggle. Data from the interviews suggests two possible solutions: The first is to train accessibility officers in the public sector who can intervene and facilitate when “clients” don’t know how to demand the things they are entitled to; these officers could also be contacted in cases of suspected exploitation. The second solution involves making it easier for them to communicate with various entities using computer-based means. This alternative helps the interviewees better exercise their rights, and provides communication channels that many of them feel more comfortable using.

3. Housing

Of those interviewed for this study, 71% live with their parents, 20% live alone, and 9% live with roommates or a partner.

Approximately three-quarters of the 57 interviewees living with their parents would like to live on their own, that is to say, outside of their parental home, but would not like to join a group home. They gave various reasons for this, including the fear of being supervised or having to live with group rules; the fear of stigmatization and the concern that such an arrangement would be perceived negatively by others; the desire to live a normal life and develop their identity as independent individuals; a preference for a less intense social life; and more. While the interviewees weren't interested in the existing group living frameworks, they would have a hard time transitioning to independent living on their own.

There is much to learn from the experiences of those who have lived independently for years. Their stories demonstrate that adults with Asperger's can be independent economically, socially, and functionally, but that they also have weaknesses with which they need help, or that require intervention. The study reveals that there is a genuine need for support services that will help these individuals learn how to become more independent, and how to respond during extreme situations, whatever their chosen housing arrangements. Over the past decade, group homes have been established, and this is a welcome process. However, the data from the interviews indicate that a wider range of options is required, as is the provision of a continuum of housing services throughout the country, from hostels, via cooperative housing, to independent housing.

Regarding assistance in assessing housing options, the interviews demonstrated the need for service providers to reach out to individuals and help them understand whether their abilities are sufficient to enable them to fulfill their aspirations, both in terms of chosen housing arrangement and of the right time to leave their parents' homes. It appears that visits from professionals to the parental home when individuals are in their early to mid-twenties, with the aim of assessing needs and desires and reviewing together the available housing options, can help address many important questions. These questions include: By living on their own, would they be fulfilling their social aspirations? Would it be easier or harder for them to leave their parents' homes later? A relatively short consultation, similar in length to the interviews conducted for this study, can be sufficient to produce a comprehensive picture that will help young adults with Asperger syndrome set realistic goals in light of their aspirations.

4. Employment

Being able to earn a salary and integrate into the workforce has far-reaching ramifications for adults with Asperger's. It affects their ability to live independently and fulfill their aspirations, it provides a routine, and it has a positive impact on the individual's physical and emotional state. Earning a salary makes them less dependent on their family and their social environment, and allows them to make a positive contribution to the national economy.

Of those interviewed for this study, 47% are employed in the open labor market, 20% do not work, 15% are university students or studying to complete their matriculation exams, 11% are soldiers (or National Service volunteers), 4% work at sheltered workshops, and 3% are volunteers. Of the 43 working or volunteering interviewees, 40% were hired through placement services or the government's Employment Office service, 30% found their jobs independently (either on their own or after seeking help from an employment agency), and 30% received help from family members. The group of subjects in this study represents a challenging sample, because many of them are educated, possess theoretical skills, and exhibit high potential, though their ability to achieve results in practice does not reflect their theoretical abilities. With support during the placement stages, proper integration into the workplace, and on-the-job vocational coaching, these employees stand a better chance of choosing a work environment that matches their skills, integrating successfully into their workplace, and succeeding in their work, and will change jobs less frequently. A substantial number of interviewees were university students; placement assistance for these individuals should be provided in collaboration with the academic institutions at which they study. This will help ensure that they are offered jobs in line with their skills, and are able to receive assistance whenever necessary.

For many interviewees, any kind of change in the workplace is experienced as a crisis they need to adjust to. Today's work environments entail frequent changes in personnel and demands made of employees, and often require flexible responses. Consequently, adults with Asperger syndrome, despite having professional skills, often struggle to find a job they can hold on to over time, which would allow them to make full use of the knowledge they acquired in their field of study. For employers wishing to help people with Asperger syndrome integrate into the job market, the main challenge lies in their being prepared to focus more narrowly on worker output, and in particular, to exempt these employees from performing side duties, which typically presents a challenge for those with Asperger syndrome. As well as guiding and supporting employees, employers should also themselves receive adequate guidance and have their questions answered.

These challenges do not require intensive intervention by placement officers in the workplace. Rather, they demand that significant assistance be provided during the placement stage, and that flexible solutions are available following placement in the workplace, to enable employees to adapt to a changing environment. These steps can help people with Asperger's to make full use of their skills and live satisfying everyday lives, allowing them to feel that they have a good reason to get up in the morning. Society will also benefit from these individuals being productive workers, instead of paying them allowances.

5. Social Life

One key trait of Asperger syndrome and the autism spectrum is a difficulty with social interaction and social communication. The interviewees' attitudes to the social realm are complex.

A gap exists between their desire for social interaction, particularly romantic relationships, and their ability to achieve it. Interviewees expressed their ambivalence, helplessness, passivity, and fear of being harmed or exploited. Together, these create a cycle of fear and avoidance that prevents them from forming social relationships. Over time, this aversion led to gaps between the interviewees and their peers.

Nearly 50% of the interviewees stated that what they felt was most lacking in their lives was a relationship with a partner. The associated difficulties and the coping strategies surveyed indicate a need for guidance and facilitation during the various stages of a romantic relationship: a personal assessment regarding the type of relationship the individual is interested in; assessing and practicing various ways of meeting partners; forming and maintaining the relationship; and the ability to learn lessons for the future, if the relationship fails. As in many other areas, there is great variance among individuals when it comes to social interactions—including intimate relations—in terms of their needs, the intensity of their relationships, and the most suitable communication methods within those relationships. Therefore, a curious and respectful approach toward interpersonal variance and the unique nature of individual relationships, and more specifically, intimate relationships, is in order when dealing with people with Asperger syndrome.

Many of the interviewees could benefit from joining a group setting, in which they could meet other people, practice social skills, and enjoy their leisure time. However, most of them do not participate in any kind of group framework. According to the interviewees, the reasons for this were linked to interpersonal variance, in terms of both individual levels of functioning and what they wanted to get out of those connections. As such, it would be preferable for them to participate in an assessment before joining a group, to help them specify their social needs and identify their goals—for example, are they interested in having fun in their free time, enriching a particular professional subject area, meeting others with the aim of forming an intimate relationship, practicing life skills, or in some other goal? This type of assessment makes it possible to form groups in which the group members share common interests and goals, and using this type of approach could offer new opportunities for those who do not participate in any social group to improve their social lives.

Conclusion

The diversity and uniqueness of each of the interviewees in this study are consistently reflected throughout this report, which reveals an interesting characteristic pattern: the interpersonal variance in each area is great, and while each area presented difficulties for different segments of the sample population, no single area can be identified as being the most challenging for most of the interviewees. For each individual, their level of functioning differs markedly across various domains of life, and cannot be predicted for any given area based on their level of functioning in another.

These findings emphasize the importance of creating a detailed map of the individual's needs, aspirations, and abilities. In terms of functioning, this map must be created without assuming that an ability to execute complex tasks guarantees an ability to execute simpler tasks. Regarding social interactions, the mapping should bear in mind the variance in needs and the uniqueness of the relationships that different people desire. And as for setting goals, the mapping process should clearly recognize the right of every individual to choose priorities that reflect their own values and abilities.

In many subject areas, the study revealed a need for flexible services that can meet individuals' differing needs at different stages of their life. Regarding employment, this flexibility needs to encompass intensive intervention during periods of crisis, interspersed with long periods of time during which no intervention is required. For housing, intensive intervention must be available prior to and following a move away from the parental home, and in order to help the individual acquire life skills; but minimal intervention is necessary during other stages of life. In terms of social interaction and intimate relationships, individuals need help in learning and practicing skills, making decisions, and learning from their experiences.

The type of interventions described above can go a long way toward helping adults with Asperger syndrome realize their potential, with important and far-reaching consequences—affording them a sense of personal fulfillment, improving their physical and mental health, helping them become significantly more productive, and reducing the burden shouldered by their relatives and society at large.

Possible Directions for Future Study

This needs-mapping study is a pioneering endeavor, providing as it does a broad description of the trends occurring within a group that is not well researched. The study paints a comprehensive picture and describes general trends, but it does not discuss patterns characteristic of sub-groups or individuals. Future studies might define subgroups, for instance, according to co-diagnoses, or by age group, gender, or other characteristics. These important questions exceed the scope of this study.

Contents

Acknowledgments

First and foremost, I am grateful to the interviewees who came from near and far and contributed their time and life experiences. Thank you for your openness, your candidness, and your cooperation during the interviews. I hope that this report accurately conveys your intentions and will help you receive the assistance that is right for you.

I am deeply grateful to Efrat Stern, the program director at JDC Israel's Israel Unlimited program, who read this report countless times, commented and responded with wisdom and sensitivity, and was such a pleasant partner in the thought and writing processes.

Thank you to Shula Shiran, the CEO of the **Asperger–Israel Association** ("Effie"),[2] who supported this study and report from their inception through to publication, and contributed constructive input derived from her rich life experience.

Conducting a study to map the needs of people with Asperger syndrome was an initiative led by Ronit Goldiner, from JDC Israel's Israel Unlimited program (which funded the study), as well as Avital Sandler-Loeff, who heads Israel Unlimited. It was Ronit and Avital's brainchild to construct the study as a collaboration between Israel Unlimited and Effie, for which I am truly grateful to them.

Thank you to Lili Abiri, the Director of the Service for Autism at the Ministry of Social Welfare, who supported the project from the beginning, and played a significant role in the work of the project's steering committee. The committee provided support during the research stage, and served as both a source of professional knowledge and a personable forum for discussion. The members of the steering committee were: Dr. Tamir Epstein, director of the Keshet Clinic for Adults with ASD at Sheba Medical Center—Tel Hashomer; Ronit Goldiner, of Israel Unlimited; Michal Mizrahi from Effie; Arie Syvan, coordinator of the employment project at Effie; and Shula Shiran, director of Effie.

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[2] The Asperger–Israel Association ("Effie") is a parental non-profit organization established in March 2001 to advance and promote the wellbeing of children and adults with Asperger syndrome and their families. It operates an information, public relations, support, and advocacy center for families struggling with the condition, and maintains regular contact with the education and social service systems in the interest of promoting the successful integration of adults and youth with Asperger Syndrome into the education system, the IDF, the workplace, and the community.

Thank you to those who read drafts of this paper at various stages: Dr. Nitzan Almog from JDC Israel, a program director at Israel Unlimited who is also responsible for knowledge development; Prof. Ofer Golan, chair of the Clinical Psychology Department at Bar Ilan University; Yafit Zelinger at the Jerusalem Center for Mental Health (the Mental Health Community Clinic in Kiryat Yovel); Prof. Amia Lieblich, president of the Academic College of Society and the Arts in Netanya; Tamir Atsmon, director of the community housing program at Beit Ekstein; Dr. Sola Shelly, one of the founders and long-time activists at ACI Israel[3]; and Yechiel Shereshevsky, former director of rehabilitation at the Ministry of Health's Mental Health Service. I'd like to thank the editor, Yoram Blum, for his dedicated, patient, and thorough work. Last but not least, thank you to Einat, my dear, beloved wife.

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3. ACI Israel, the Autism Spectrum Community of Israel, is an association of Israelis working on behalf of Israelis on the autism spectrum. Its members operate a self-directed community offering mutual and independent support and assistance, facilitating connections between people with autism, and promoting acceptance of neurodiversity in Israel and of people with autism.

Preface

My first encounter with Asperger syndrome occurred while I was working as a counselor in a community housing program. Working intensive shifts, I became exposed to how people with Asperger syndrome truly lived—getting up in the morning and completing their morning routine, going to work, developing life skills such as cleaning and cooking, and coping with the challenges of living in society and maintaining relationships. I was also exposed to their various familial relationships, as well as the process of "leaving the nest" and what it meant for both the parents, who now needed to gradually transfer responsibilities to their sons and daughters, and for the "residents" themselves (that is what we called them). This work was a major part of my professional life, but it also permeated my personal life. This was because of the continuous interest taken by the residents in my family, in various tidbits concerning my past, and in various developments in my life. This natural interest taken in my personal life persists, in different ways, even today, years after I left.

One of the things I learned was that often, asking a simple, direct question will result in an honest answer, while being overly cautious and asking roundabout questions will lead to awkwardness, since your questions aren't properly understood. Thus, when preparing to conduct the interviews used in this study, I adopted a curious, simplistic, and open posture. I expressed my interest in various arenas of life, and asked the questions as someone who sincerely doesn't know the answers. In this context, I'll quote from the works of Jim Sinclair, an autistic person and a well-known personality within the autism community:

> *I had a friend—not a parent driven by love and obligation to want to reach me, not a professional who made a career of studying my condition, but just someone who thought I was interesting enough to want to get to know better—I had a friend who, with no formal background in psychology or special education, figured out for herself some guidelines for relating to me. She told me what they were: never to assume without asking that I thought, felt, or understood anything merely because she would have such thoughts, feelings, or understanding in connection with my circumstances or behavior… In other words, she learned to ask instead of trying to guess. (Sinclair, 1992).*

The first interviews were based on a questionnaire created for this very purpose, and they served as a pilot for the study. The interviewees answered the questions openly and candidly, but their replies also tended to be brief, circumscribed, and lacking in detail. This was why we needed to add follow-up leading questions. During these initial interviews, I found myself stopping the interviewees and asking their permission to jot down the exact wording they used in their answers. I felt their wording was more precise than anything I could have written on my own.

In retrospect, after reading all the interviews, I'm glad I had the opportunity of helping people with Asperger syndrome have their voices heard, and I'm pleased that we can listen to them instead of just talking about them. Their phrasing and their insights are critical, since these constitute the most accurate depiction of the challenges they face, and teach us how we can further amplify the strengths of these individuals, who have great potential but experience difficulty in realizing it.

I'd like to clarify that the identifiers and names used in this study report are fictitious. I would be happy to receive comments or reactions to this report from anyone interested in responding. These can be sent to the following email address: yonatandrori@gmail.com.

1. Introduction and Methodology

1.1 Introduction

1.1.1 Asperger syndrome and the autism spectrum

> *I'm sure you know that the Asperger's label is falling out of use. In a short while, we will just have "high-functioning autism."*
> *(Gilad, age 30)*

The terms "Asperger syndrome" and "autism spectrum" have both undergone a lengthy process of evolution. In 1943, Austrian psychiatrist Leo Kanner coined the term "infantile autism" to describe children who had a hard time interacting and communicating with society, exhibited stereotypical behaviors, had unique and narrow interests, and found it difficult to handle change. Around the same time, Hans Asperger described a syndrome with a similar set of traits (on the differences between diagnoses, see Frith, 1991). Asperger's research only reached English-speaking communities in the early 1980s (Wing, 1981), since when there has been extensive academic discussion of the diagnostic differences between Asperger syndrome and autism (for example, Schopler, 1996; Wing, 1981, 1991). In 1993, the World Health Organization recognized Asperger syndrome and included it in its ICD-10 (International Catalog of Diseases) manual (World Health Organization, 1993). In 1994, the American Psychiatric Association recognized the syndrome and included it in DSM-IV, the fourth edition of the association's diagnostic manual, under the title "PDD—Pervasive Developmental Disorder."

In March 2013, Asperger syndrome was removed from the American diagnostic manual (DSM-V). This edition cancelled the umbrella term of Pervasive Developmental Disorder (PDD) and all of the conditions it referred to, including Asperger syndrome, and replaced it with a new diagnostic range for the autism spectrum, based on level of functioning, called "ASD—Autism Spectrum Disorder." The list of traits described in DSM-V for diagnosing ASD are as follows (American Psychiatric Association, 2013):

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

    1. Deficits in social-emotional reciprocity;

    2. Deficits in non-verbal communicative behaviors used for social interactions;
    3. Deficits in developing, maintaining and understanding relationships;

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
    1. Stereotyped or repetitive motor movements, use of objects, or speech;
    2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior;
    3. Highly restricted, fixated interests that are abnormal in intensity or focus;
    4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment;

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

When developing their new definition for ASD, the editors of the manual aligned themselves with those researchers who believe that the difference between autism and Asperger syndrome lies not in the traits inherent to each, but rather in their relative severity and the degree to which they have an impact on function (see, for example, Wing, 1991). Relative to the diagnostic criteria for Asperger syndrome that appeared in the previous manual (DSM-IV), in DSM-V emphasis was placed on stereotyped and strictly repetitive behavioral traits (paragraph B above), the option of the emergence of some of the traits solely during childhood was added (paragraph C above), and the criteria concerning language impairment were removed.

There was concern that a considerable number of those who had, until that point, fulfilled one of the diagnostic criteria of the PDD subgroup would not meet the new ASD criteria. The findings on conformity with the new criteria are not conclusive. Some researchers found a 76%

correspondence (Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012), while others reached the conclusion that the correspondence rate is 91% (Huerta, Bishop, Duncan, Hus, & Lord, 2012). Those who could not be characterized as exhibiting stereotyped and highly-restricted behavior (such as restricted interests and repetitive behavior) but do exhibit considerable difficulties in social understanding and social communication would now be assigned the new diagnosis of SCD—Social Communication Disorder. A review of this subject can be found in Lai, Lombardo, Chakrabarti, & Baron-Cohen (2012).[4]

The prevalent diagnostic language, which includes the words "disability" and "deficit", is far from a peripheral issue. Many people with autism feel that they are a minority with a unique neurological structure. They say that this uniqueness can be an advantage, or a disadvantage, depending on the situation, but that this does not meet the definition of a "deficit." Many leading researchers in this field also believe that the term "variance" is to be preferred, and that this term more accurately describes this group. (see Jaarsma & Welin, 2012 for a review of the subject).[5] However, as long as receiving services and support from state agencies is conditioned on being defined as "disabled" or "impaired," those terms must be used (Baron-Cohen, 2002).

1.1.2 Prevalence and global trends

Over the past few decades, autism spectrum prevalence studies have demonstrated a steep rise by a factor of 25 to 50, from the rate of one case per 2,500 people in the 1960s and 1970s (Gillberg & Wing, 1999) to 1–2% in more recent studies (Lai, Lombardo, & Baron-Cohen; Schieve et al.; Blumberg et al., as quoted in Centers for Disease Control and Prevention, 2014). However, changes in diagnostic definitions make it more difficult to compare the various prevalence studies (Fombonne,

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[4] The terms "Asperger's" and "high-functioning autism" are used interchangeably in this report. This choice reflects the lack of clarity on the differences between these diagnoses, as described above. Another reason for this choice lies in the way people with autism or Asperger syndrome define themselves. Some prefer the use of one of the terms over the other, for various reasons, including their preference for (or dislike of) a self-definition that associates them with a wider group within the autism spectrum.

[5] Another related claim is that using the terms "a person with autism" or "a person with Asperger syndrome" implies a distinction between the person and the condition with which they have been diagnosed. This is a different approach from the one described above, which sees people with autism as having a different, but no less valid, neurological structure. The choice of terms used in this report does not necessarily reflect the author's views on this topic.

2004). The US Centers for Disease Control and Prevention publishes data produced by its Autism and Developmental Disabilities Monitoring network (ADDM), which provides an updated view of the scope of autism spectrum diagnoses, and associated trends, in 11 American states. Data has been collected by ADDM since 2000, and shows a steep and steady rise in autism spectrum diagnoses. Data collected during 2010 indicate a prevalence of one case per 68 people (1.47%) among eight-year-olds—a rise of 30% over the previous survey conducted two years earlier, which reported a rate of one case per 88, or 1.13%, for the same age group.

Another finding was that the largest increase in the number of diagnoses between 2002 and 2008 occurred among minorities (Hispanics and African Americans) and children without any cognitive impairment. The most recent survey found that 46% of those diagnosed had a normal IQ level (IQ>85) (Centers for Disease Control and Prevention, 2014).

Thus, a considerable portion of the increase during the past decade can be attributed to the high-functioning segment of the autism spectrum. Those diagnosed with Asperger syndrome (up to the introduction of DSM-V) are highly representative of this group.

1.1.3 Prevalence and trends in Israel

There is no comprehensive database on people with autism in Israel (The State Comptroller, 2012, p. 904), and thus there are no specific data on people with Asperger syndrome. Existing data is based on reports from government bodies, which reflect requests from individuals or their relatives for official recognition of their condition from one of the state authorities (a necessary step for securing access to services or rights). Many interviewees who had been diagnosed did not request certification from the authorities, because they were at the high-functioning end of the autism spectrum and aspired to function without any special help. It is therefore entirely reasonable to assume that there is significant under-reporting of people with high-functioning autism in Israel, and this is consistent with the data gathered in the United States (Centers for Disease Control and Prevention, 2014).

The diagnostic trend observed in Israel is consistent with the global trend of a steady increase in the number of autism diagnoses. This rise is apparent in the data concerning those who receive National Insurance allowances due to a PDD/autism diagnosis, which shows a five-fold increase between 1990 and 2004, from 0.1% in 1990 to 0.55% in 2004 (Inter-Ministerial Team for Regulating the Treatment of the Autistic Population, 2013). It is also reflected in data from the Ministry of Social Welfare, which reveals a sharp and continuous increase in the number of people registered as being on the autism spectrum between 2004 and 2012. During that time, the number of these individuals grew by a factor of 5.5, from 1,507 in 2004 to 8,283 in 2012 (Abiri, 2012). The final figures vary significantly among the different state authorities.

As noted above, in 2004, 1,507 people were certified by the Ministry of Social Welfare as being on the autistic spectrum, representing 0.022% of the population, while the number of those receiving National Insurance payments that year was much greater, at 0.55% of the population. Clearly, then, many of those who receive allowances from the National Insurance Institute do not request certification from the Ministry of Social Welfare in order to access services.[6] In addition, despite the general increasing trend of autism diagnoses, the autism spectrum diagnosis rate in Israel is significantly lower than the rate observed in developing countries (State Comptroller, 2012, p. 903; Inter-Ministerial Team for Regulating the Treatment of the Autistic Population, 2013).

1.1.4 Significance of the global and Israeli trends

The trends described above regarding the general increase in autism diagnoses and, more specifically, the increase in high-functioning autism led the authorities in various countries to begin conducting research and developing services for this group. As noted, in 2000, the Center for Disease Control and Prevention (CDC) began collecting data on autism in the United States. In 2010, the British government launched a strategy for dealing with autism, which included improving awareness, diagnosis, accessibility to services, employment, and more. The declared goal of this strategy was to foster a change in public services provided to people with autism, so that autistic adults could live independently and find employment (Department of Health, 2010). In Israel, too, there is a growing need to develop services for autistic adults interested in living an independent life. This has resulted in a number of programs,

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[6] This topic is discussed below, in sections 2.3 and 2.6.3.

including, inter alia, the “Supported Housing” program—the context in which this needs-mapping study was launched.[7]

1.1.5 Research question and study goals

The launch of the “Supported Housing” program necessitated the collection of information on people over 18 with Asperger syndrome who live in their parents’ homes or independently, and who do not receive any assistance from community housing services. This study was thus launched to provide a picture of the functional, social, and personal attributes of these individuals and their needs—a pioneering endeavor to describe this little-studied group. This current report presents the study’s findings.

1.2 Methodology

1.2.1 Study population and interview method

As stated above, no comprehensive database on people with autism exists in Israel, meaning that there are no specific data on people with Asperger syndrome. It is clear that there is a population, of unknown size, of individuals with Asperger’s who are not recognized by state authorities (the National Insurance Institute or the Ministry of Social Welfare) and do not receive services from the state. This was the group that this study sought to explore. To overcome the difficulty of finding interviewees, we were helped by the Asperger–Israel Association (“Effie”), a parental non-profit with an extensive member database that includes people who have not sought certification from state authorities. It was decided that only those who cumulatively meet a number of criteria would be approached:

- Those aged 18 and up
- Those living independently or in their parents’ homes
- Those who do not receive community housing services

Approximately 150 matching candidates were found through Effie, and were contacted over the phone. Over half of them agreed to be interviewed, and 75 attended the interview. Five additional phone interviews were conducted. Most of the interviews were conducted at the Effie offices

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[7] A description of the “Supported Housing” program appears in Appendix 2 below.

in Tel Aviv. Several interviews were conducted at community centers in Haifa and Beer Sheva, and two were held in the interviewees' homes. Other organizations were also contacted: diagnosis centers, the Keshet Clinic for Adults with ASD at Sheba Medical Center—Tel Hashomer, and Bait 1, which was founded by the Association for Children at Risk. However, these attempts yielded a very limited response.

1.2.2 The interviewees: general data

Diagnosis: 78 of the 80 interviewees were diagnosed with some form of pervasive developmental disorder (PDD)—Asperger syndrome, high-functioning autism (HFA), or not otherwise specified (PDD-NOS). Two interviewees had not received a diagnosis, and they are over 40 years old. Fifty interviewees (62.5%) reported that they had received at least one additional psychiatric diagnosis.[8]

Age and gender: The interviewees' average age was 26.7 (standard deviation: 6.3). 67 men (84%) and 13 women (16%) were interviewed.[9]

Housing: 71% of the interviewees live with their parents, 20% live alone, and 9% live with a partner or roommates.[10]

Education: 67% of the interviewees graduated from high school with full matriculation. About half of these are students in higher education or possess academic degrees. 33% of the total sample hold either partial matriculation certificates or none at all. 21% of all interviewees reported having undergone professional training independently of their academic or high-school education (e.g., various courses run by the Ministry of Labor, culinary training, etc.), and possess professional certification.[11]

1.2.3 Method

1.2.3.1 **Semi-structured questionnaire**

For this study, a semi-structured questionnaire was drawn up, covering various aspects of functioning and life skills: IADL (instrumental activities of daily living), housing, employment, social life, health status, and

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[8] See Appendix 4, below.

[9] Similarly, 78% of those registered at the Ministry of Social Welfare are men (Abiri, 2012).

[10] See Figure 4 and Appendix 3 below.

[11] See Appendix 5 below.

more.[12] First, a pilot study was conducted, in which 10 interviews were carried out. The findings from those interviews were brought to the steering committee, and led to improvements to the questionnaire.

1.2.3.2 **Unique issues concerning interviewing people with Asperger syndrome**

Asperger syndrome is characterized by significant difficulties in social interaction and nonverbal communication. A number of interviewees preferred to correspond by email or over the phone, as they felt more comfortable with these alternate means of communication. However, we chose to use a semi-structured questionnaire in a face-to-face interview, for several reasons:

- Questions can be clarified and explained during a meeting, especially when it is suspected that they may not have been properly understood. The interviewer interacts closely with the interviewees and is fully aware of their reactions.
- Using a questionnaire based on concrete content makes it possible to identify topics for focused discussion.
- When specific responses are given, the interviewer is able to ask follow-up questions on the topic at hand, which the interviewee can answer effectively. This is an important factor for two reasons: First, if the interviewee feels that s/he has succeeded in providing a response (given feedback from the interviewer), s/he feels more at ease and will be more likely to respond to vaguer questions. Second, since some interviewees tend to respond with very short and concrete answers, the information gained without the use of follow-up questions would be very limited.
- It is easier to cope with attention deficit issues in a face-to-face meeting (35% of the interviewees reported having an attention deficit disorder; see Appendix 4 below).

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[12] See Appendix 1 below.

1.2.4 Procedure

As stated, Effie is a parental non-profit. As such, parents were contacted in advance by phone. If they consented, a telephone conversation was then conducted with their child, and a request was made to schedule an appointment. The study was presented as an interview in which individuals could talk about various aspects of their lives, and their strengths and weaknesses. It was also explained that no tangible benefit was being offered in return for participating in the interview; the only benefit would be the opportunity to tell us about their lives, as well as the theoretical future possible benefit of participating in the "Supported Housing" program. This was relevant if the interviewee lived in an area where the project was active, if they expressed interest in participating, and if they were found to be suitable for the program. At this stage, we received different types of response:

- The parent considered the option and decided whether to proceed, without consulting the child
- The child was contacted and given full autonomy to decide
- A combination of both options: the parent considered the option, and spoke with the child to reach a joint decision.

Some interviewees travelled great distances, mostly by public transport. Some stated that they came knowing that they didn't need any help, but that they wanted to provide information that could help others. The duration of the interviews was between 30 and 90 minutes. The data collected includes answers to closed-ended questions, as well as answers to open-ended follow-up questions, which were transcribed during the course of the interview. I contacted the interviewees and asked for their permission to use the interviews I conducted with them for the purpose of writing this report. The quotes that appear in the report are of interviewees who consented to their use.

1.2.5 Data analysis

Data was collected using a semi-structured questionnaire. A quantitative analysis of answers to closed-ended questions was performed. The answers to the open-ended questions required content analysis to render them dichotomous.[13] Whenever an answer to an open-ended

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[13] These responses address areas of functioning, as presented in Figure 3 below.

question could not be clearly converted into a dichotomous result, the answer was not included in the results.

A qualitative analysis was also conducted. First, the data was grouped by the subjects appearing in the questionnaire form. For each subject area, a new document was formed containing the relevant responses of dozens of interviewees. Central themes were identified in these new documents, using grounded theory, which Charmaz defines as an inductive process wherein categories emerge from the text, without the use of any prior assumptions or suppositions (Charmaz, 1995). In this study, the data was grouped from the beginning into general categories in which central themes were identified. These categories form the subject of each of the subsequent chapters in this report, and they provide the context for the statistical data collected and its interpretation. No numerical encoding of qualitative content was performed (that is, the number of times a theme manifested itself was not investigated), but an effort was made to choose themes representing content that emerged during many interviews, and examine their implications and significance. This approach is also called the "hermeneutics of faith" (Josselson, 2004), in which conclusions are not drawn from interpretations of things that were not stated explicitly. However, the choice of questions asked contains implicit hypotheses. We attempt to discuss this in the report wherever relevant.[14]

1.2.6 Reliability of the study

The collected information is based on self-reports and reports from family members. Corroboration of self-reports on diagnosis came from a variety of sources. If an individual receives services from the Service for Autism at the Ministry of Social Welfare, this would demonstrate that a diagnosis exists.[15] Moreover, most of the interviewees were able to state the name of the person who had diagnosed them (the psychiatrist, the psychologist, or both), and usually, they stated the names of professionals and diagnostic centers that specialize in

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[14] For instance, the descriptions of IADL (instrumental activities of daily living) appearing in Chapter 3 support an implicit hypothesis that non-development of certain skills indicates an impairment that must be corrected. Conversely, openness to the option of the study of skills according to preference is emphasized.

[15] However, the receipt of an allowance from the National Insurance Institute does not corroborate the existence of an autism spectrum diagnosis, since these allowances can be granted for other conditions as well.

diagnosing autism spectrum disorder. Further evidence of reliability was manifested by the fact that contact was initiated through a non-profit organization for parents of people with Asperger syndrome. Some interviewees specified another diagnosis, besides the autism spectrum disorder diagnosis. Some specified diagnoses of conditions such as anxiety or depression. These interviewees were asked follow-up questions designed to validate their statements. For instance, interviewees were asked to specify the names of medications they were taking or had taken previously. A considerable number of interviewees underwent several diagnostic shifts within the autism spectrum, although no internal subdivision between these diagnoses was made for the purposes of this study. Overall, the diagnosis held by most of the interviewees was Asperger syndrome. Thus, the study and its findings are mainly relevant to those with Asperger syndrome, but can also be applied to a wider group of people who are currently given the diagnosis of "high-functioning autism spectrum disorders."

1.2.7 Uniqueness of the study

People with Asperger syndrome can properly describe how they perceive the world, explain their needs, and express their opinions on existing services. However, until today, only a few qualitative studies focusing on these questions have been performed, and these studies have focused on small groups of interviewees (Griffith, Totsika, Nash, & Hastings 2011). What makes this study unique is its relatively large sample size of interviewees, and the wide range of topics covered. Thus, it provides us a statistical basis from which we can derive a general picture of the situation, and allows us to focus on the meaning of the data by being attentive to the descriptions provided by the interviewees. The process of writing the report included requesting and responding to feedback from various people.[16] These included a number of interviewees who read quotes from interviews in which they had participated. I also met with Dr. Sola Shelly, who defines herself as "somewhere on the [autism] spectrum" and who was diagnosed with Asperger syndrome, in order to receive feedback on the entire report. With these steps, this document aims to at least partially satisfy the demand that there be "nothing about us without us".

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[16] See the "Acknowledgements" chapter at the beginning of this report.

2. Diagnosis and Certification by the Authorities

> *It took me a long time to accept my diagnosis. [...] It took me time to accept that I had special needs, and that I didn't need to take things too harshly. It might be important, because I've met others on the autism spectrum, and from what I can see, many of them have a hard time acknowledging that they have special needs. And that's OK. It's tough to get over the social embarrassment, and it's clearly one of the reasons people on the autism spectrum fall between the cracks—they simply don't feel that they need to ask for help. This is how it was for me for quite some time (Gilad, 30).*

2.1 Diagnosis and certification

Diagnosis occurs when a diagnostic label is assigned by certified professional, based on the criteria specified in an up-to-date psychology manual (the ICD or the DSM). Certification can only be granted after a diagnosis has been made, and occurs once the individual registers with the authorities, usually in order to receive various services. The main authorities from which certification can be requested are:

- The National Insurance Institute, which provides allowances to those eligible. The Rehabilitation Division of the Ministry of Health, which provides auxiliary services such as professional courses
- The Service for the Treatment of People with Autism and PDD at the Ministry of Social Welfare and Social Services, which mainly provides housing and professional placement services, as well as other community services.

2.2 Age at diagnosis

Seventy-eight of the eighty interviewees stated that they had undergone a psychiatric evaluation that resulted in the appropriate diagnosis: Asperger syndrome, PDD-NOS, or HFA (high-functioning autism). The two interviewees who were not diagnosed were born in the 1960s, and were high-functioning. One of the reasons they hadn't sought diagnosis was that they didn't know about the existing services they could benefit from.

Figure 1. Distribution of age at diagnosis by age group (N=73)

Age Group	Number of Interviewees	Average Age at Diagnosis (Standard Deviation)
18–21	16	11.1 (4.5)
22–25	21	9.4 (4.7)
26–30	21	18.4 (5.4)
31 and above	15	27.9 (7.8)

Figure 1 demonstrates that of the interviewees aged under 25, the average age at diagnosis was approximately 10, while the average age at diagnosis for the next age group (26-30) jumped to 18. The average age at diagnosis for the next age group was 28.[17] This is due to the process of increased awareness and the development of diagnostic methods for autism spectrum disorders over the past two decades in Israel (as described in the introduction above).

Although Asperger syndrome is a developmental disorder that appears during early childhood, nearly half of the interviewees were diagnosed in adolescence. These people had faced difficulties for many years, and it was only at a later stage in life that they received confirmation that their difficulties were characteristic of a specific group of people, not simply particular to them as individuals. In their article “The Not Guilty Verdict: Psychological reactions to a diagnosis of Asperger syndrome in adulthood,” which was based on interviews with ten adults with Asperger syndrome, Punshon, Skirrow, & Murphy (2009) identify several themes connected with diagnosis during adolescence. These themes will be referred to later in this report in different contexts.

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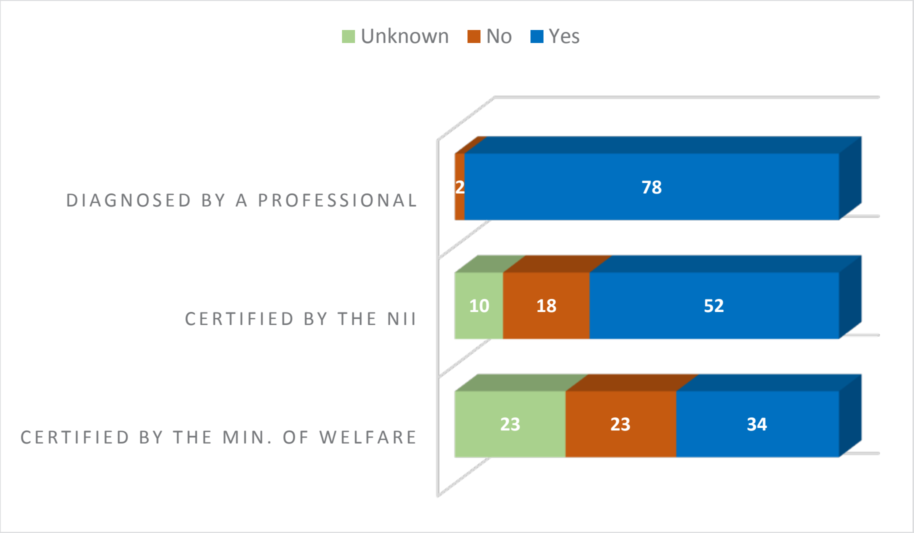
17. The age at diagnosis is the exact age specified in the interview. Three interviewees indicated an age range that appears in the questionnaire, and the age calculated as their age of diagnosis was one year above the range minimum. For example: The age at diagnosis defined for an interviewee who specified an age range of 11–14 is 12. Five interviewees who could not specify an age range, as well as two non-diagnosed interviewees, were not considered in this context.

2.3 Diagnosis versus certification by the National Insurance Institute and the Ministry of Social Welfare

Figure 2. Diagnosis and recognition by authorities



As is evident from Figure 2, although 78 (97.5%) of the interviewees were professionally diagnosed, of these, only 52 (67%) were certified as such by the National Insurance Institute, and only 34 (44%) were certified by the Ministry of Social Welfare. These trends correspond with the data published by Ministry of Social Welfare and the National Insurance Institute.[18]

A number of interviewees could not answer the question on official certification (indicated in the green portions of the chart). It can be assumed that most of them are not certified, since they had reported that they were not receiving the main available services (professional placement, housing and social services from the Department of Social Welfare, and a general disability allowance from the National Insurance Institute).

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[18] See section 1.1.3 (“Prevalence and trends in Israel”) above.

To better understand these figures, the main themes tied to diagnosis and certification will be reviewed below. These themes are divided into positive and negative aspects of diagnosis and certification, and they can explain why the authorities are contacted for diagnosis and certification, and what prevents people from initiating such contact.

2.4 Positive aspects of diagnosis

2.4.1 External reasons leading to diagnosis

1. Desire to obtain certification from the authorities

Many interviewees indicated a causal relationship between diagnosis and certification. In other words, their desire to be certified (and gain access to services) led them to seek a professional diagnosis. “We wanted to approach the Ministry of Social Welfare, and to do so, I needed to get an accurate diagnosis” “The people assessing whether I should receive a disability allowance decided that I didn’t fit into that category there... they decided the diagnosis should be PDD-NOS to make it unambiguous for the National Insurance Institute.”

In most cases, National Insurance Institute certification was sought in order to receive general disability allowances. Certification by the Ministry of Social Welfare was mentioned during the interviews, mostly in the context of difficulties integrating into social settings during adult life, for both social and vocational reasons.

2. Difficulties in social integration—the lack of a framework

> *It was much harder as an adult. When I was a little girl, I’d go to school, and I was within a certain framework. Even if you aren’t as good at interacting with people as others are, the framework imposed this environment on you and forced you to progress. But when you’re an adult, you don’t have those permanent frameworks (Rachel, 40, diagnosed around ten years ago).*

Rachel discussed her social difficulties, which she had also experienced as a child, but she added that being within an educational setting forced her to “make progress.” When these structured settings were removed, a typical event during the transition to adulthood, she was prompted to seek a diagnosis.

3. Difficulties in integrating into job settings

> *I was diagnosed with Asperger syndrome when I was 28, and I'll tell you why... I was discharged from the army, and I went on to study computers. I couldn't find a job after I graduated, and that, more or less, was the trigger. For about two years, my situation was very desperate, and I was even having suicidal thoughts... I'm skipping forward here a bit. After two years of struggling to find a job, I became open to ideas that I had disregarded earlier (Yair, 40, diagnosed at 28).*

Again, external difficulties often lead people to seek diagnoses and apply for certification. The interviewees, who had always struggled, had also participated quite often in normative frameworks, such as school and the army, and they managed to pull through without seeking diagnosis and applying for certification, as long as they remained within those settings. The trigger that led to the diagnosis was the job search, in the absence of a structured setting: for the first time in their lives, they needed to create a setting for themselves.[19]

2.4.2 The impact of diagnosis on internal processes

Many interviewees reported that the diagnostic process they underwent had an impact on internal issues.

1. Self-acceptance and self-understanding

A theme that has been identified in research in this context (Punshon et al., 2009) is that of "Effects of diagnosis on beliefs" Many interviewees stated that the diagnosis led to a change in how they perceived their past struggles. They mentioned new insights into their social and romantic struggles and their anxiety, and a new understanding of the "punishments" they received from people around them:

> *Originally, I had struggled to accept this fact—that this was the result, that I had Asperger syndrome. On the other hand, today, I understand where all of those social difficulties were coming from (Ayelet, 27, diagnosed about a year ago).*

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[19] This topic is discussed later in this report in chapter 5, which covers employment.

> *I have been living with anxiety for years. Today, thanks to my Asperger's diagnosis, I'm suddenly realizing why I was living like that. Still, why did every girl I date tell me I was strange? Why do I think people mean the opposite of what they actually mean? Suddenly, I realized why I was getting all of these punishments my whole life. It was because of Asperger's issues, and I constantly go back to them. A punishment is a punishment. I did something wrong, so I was punished. Fine. But now, I'm starting to understand that this is an Asperger's issue (Nir, 35, diagnosed a year ago).*

This description of gaining new understanding, the rejection from girlfriends and boyfriends, and the use of the term "punishments" demonstrate how neither Nir nor Ayelet had been able to understand the reasons for their difficulties until now. We can imagine how this affected their self-perception, and how this frustrating situation may have led to feelings of guilt and failure. Nir describes the relief he felt after understanding what was causing his anxiety, his difficulty with building a romantic relationship, and behaviors that led to constant "punishment." He describes a shift in his worldview, which has given him a different understanding of his life.

2. "A full diagnosis of myself"

Interviewees described the different diagnoses they had received in the past. Most saw the autism spectrum diagnosis as a full diagnosis, and felt that previous diagnoses were completely wrong, or had described them only to a limited extent. "Identity formation" is another theme described by Punshon et al. (2009), and it comes into play very dramatically in an Asperger's diagnosis. This theme is a continuation of the previous one, but it expresses a more general aspect of self-acceptance:

> *The (Asperger's) diagnosis occurred when I made a full diagnosis of myself, so I'm not so concerned with previous diagnoses. They don't interest me. A few years ago, I suspected that I had Asperger's, and not actual autism. However, I'm not a professional. I have a paramedical degree... but since I'm not a professional, I didn't pursue the issue. When they [the clinic specializing in diagnosing adults on the autism spectrum] showed me the*

> *report, I told them that I had suspected for years that this was what I had, and now that they were saying it, too, I had their seal of approval (Ilan, 35, diagnosed a year ago).*

Ilan continues by describing the change the diagnosis made in his life:

> *Today, I accept myself for who I am. In the past, I was confused and constantly feeling hurt and insulted. What I say today is that this is who I am, and if anyone doesn't like it, tough. I'm also stronger and more mature in every respect.*

These descriptions concern the positive impact of a diagnosis, how it allows people to change their beliefs and thoughts about themselves, and how it enables a change in identity leading toward self-acceptance. The last quote demonstrates how a person leading a diagnostic process forward, driven by an internal certainty, can integrate the process into the identity they had constructed for themselves.

2.4.3 The aim of seeking diagnosis: "To know, or to get help"

Responding to the question of "What advice would you give to someone in the midst of a diagnostic process?", Dina provides a nice, accurate description of both sides of the impact described above:

> *It depends on the person's level of functioning, how much they need it: whether it's just about knowing, or about getting help (Dina, 35, diagnosed at 25).*

Dina succinctly describes the essence of what the individual must clarify for themselves, along with the distinction that professionals need in order to help: What are the person's functional gaps, and consequently, what are their needs? Should the focus be on knowing oneself and "what one has," or on more concrete needs for assistance? Naturally, a solution to a concrete need can also lead to increased self-acceptance, and vice versa; the two processes are intertwined.

2.5 Negative Aspects of Diagnosis

2.5.1 Avoiding diagnosis and implications for family relationships

Interviewees described how they had resisted getting diagnosed, while their family members encouraged them to do so. Avigail felt that the diagnosis made the gaps between her and her siblings palpable:

> *My brother said this years ago—at least two years ago. He thought that I had Asperger syndrome, and he told me I should speak to people in the field... I was embarrassed, and it even saddened me to even think about it. I felt that he didn't see me as a normal sister. He saw me as different. He wasn't trying to insult me, but I was really insulted, because I wanted to identify with him and have a close relationship with him, and share with him things that were happening to me, but he didn't share with me (Avigail, 40, recently diagnosed).*

2.5.2 Diagnosis and stigma

Many interviewees described how they had tried to avoid being diagnosed for years, and how the diagnostic "seal" led to stigmatization and created a certain distance between "diagnosed people" and "normal people":

> *I was against it because I said that I wasn't disabled, and that I didn't need these things (Itzik, 40, diagnosed at 25).*

> *I found it [the diagnosis] difficult to accept, maybe because of the fear of stigmatization, and maybe because all of this was so new and sudden (Ilan, 29, diagnosed at 20).*

2.5.3 Lack of faith in the medical establishment due to past misdiagnoses

As mentioned earlier, most interviewees saw the autism spectrum diagnosis as a full and accurate diagnosis, and felt that previous diagnoses were completely wrong, or had described them only to a limited extent.

> *When I was a child, no one knew what Asperger's was. I remember that I had a lot of anxiety and intrusive thoughts in primary school. It was very hard for me, since I had attention deficit disorders caused by anxiety and intrusive thoughts. I also had outbursts. I felt frustrated, because I felt I was different, but I didn't know what was wrong with me (Yigal, 25, diagnosed at 15).*

> *I had many other diagnoses, which were more general. In other words, I had always had difficulties. We always classified them as either psychological or neurological. It's some combination of both. I was diagnosed with Asperger's when I was 25 (Itzik, 40, diagnosed at 25).*

Yitzhak, who has a doctorate in the natural sciences, relates something similar. As a child, he was suspected of suffering from a developmental cognitive disability:[20]

> *My first diagnosis was an intelligence test, to see if I wasn't retarded, you know... That's what they had back then (Yitzhak, 47, never sought a formal diagnosis).*

It's clear how the interviewees could have ended up suspicious of the medical establishment and its diagnoses, and lost all faith in them:

> *As a child, I had learning disabilities, social problems, and any other disabilities you could imagine, including motor disabilities... We thought that "learning disabilities" was the term for all of these, and the professionals never encouraged us to think that we needed to look beyond that. I think that they could have said the word "Asperger's" even when I was very young, but there wasn't any awareness. I haven't paid any attention to this for a long time now, because this is something you can call "a passing fad," in quotation marks, and it really isn't important any more what they call me the next time I get diagnosed (Anat, 35, diagnosed at 30).*

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[20] The term "retarded," which the interviewee used, was the accepted term at that time.

2.6 Barriers to applying for certification from the authorities

2.6.1 Parental decision not to seek help

Unlike the situations described above, wherein family members encouraged interviewees to seek a diagnosis, some interviewees felt that their family members were the reason they never asked for help, while they themselves seemed to be indifferent about the decision:

> *My mother can explain everything. I know the short version, according to which I didn't get official certification because they didn't want me to be labeled, and so on. [In response to my follow-up question – would it have bothered you?]: Probably not (Dan, 20, diagnosed at 16).*

2.6.2 Lack of faith in the authorities

> *I think that there are people who are hesitant to turn to any of these state authorities, such as the National Insurance Institute, and I can understand them in a way, because on the one hand, this hesitation comes from the fact that it's hard to admit that I have some kind of problem or difficulty, and besides, I think that people hesitate to approach any institution that is state-run. Sometimes, people think that anything that belongs to the state is full of liars and thieves (Itzik, 40, diagnosed at 25).*

2.6.3 Ignorance of rights

When asked why they hadn't applied for certification from the Ministry of Social Welfare, some interviewees stated that they didn't know that option had existed:

> *I was well-integrated into my workplace, and I worked three-quarter time, so by that point, I didn't need any allowance from the National Health Insurance. I was let go after six years, and then, I needed to go through the entire process from scratch. That's also when I registered with the Ministry of Social Welfare. I didn't know about the option of getting help from social services before then (Itzik, 40, diagnosed at 25).*

This fact is understandable, because, among other factors, treatment of people with autism was under the responsibility of the Ministry of Health until 1999 (Abiri, 2012). Again, at that time, awareness of high-functioning autism was low.

2.6.4 Not receiving an allowance due to salary level

A number of interviewees earn salaries that exceed minimum wage, and described how their application for certification from the National Insurance Institute was rejected:

> *I got the claim form from the National Insurance Institute for receiving an allowance for rehabilitation, I imagine you're familiar with this. I spent an entire month putting together the paperwork, including salary slips. I sat with my mother, who's knowledgeable of this area. We put together the paperwork, she filled in forms, and so did I. A month went by, and we submitted the document to the National Insurance Institute. Ten days later, we received a letter: your claim was rejected. They concluded that even my meager salary was beyond what they were prepared to accept, so they rejected my claim (Tamir, 35, diagnosed this year).*

These interviewees may have been certified by the National Insurance Institute as having ASD (for the sake of determining the medical disability rate), but were not certified for a loss of earning capacity or a degree of incapacity that would entitle them to a general disability allowance.

2.7 Discussion: Diagnosis and certification

Low awareness of Asperger syndrome in the scientific community, and a desire to avoid diagnosis for fear of external and internal stigmatization, led many of the interviewees (who, in some cases, were influenced by family members) to do their utmost to avoid or postpone diagnosis. The structured settings during the transition period between childhood and adolescence (educational settings and, sometimes, military and national service settings) allowed them to obfuscate their difficulties, integrate into society, and advance, and they were even effective at dulling feelings of failure and crisis. Once they were no longer in those settings, a long period ensued in which they need to actively create settings (most importantly, employment and higher education, social life and family life). Many interviewees saw this period as a time of crisis in their lives. Indeed, many of the interviewees in this study underwent a diagnosis during this time, and their diagnoses were also certified by state authorities.

The diagnostic process is gradual. On the one hand, it allows individuals to come to terms with themselves and understand that their problems stem from an "objective" difficulty; but on the other hand, it entails fears of being stigmatized and labeled as "disabled," and distances the diagnosed from their family members.

A significant number of interviewees were diagnosed on the autism spectrum but did not apply for certification from the authorities. This disparity can be explained by a lack of knowledge about existing services, the fact that services are not properly adapted to the needs of the group of interviewees, and a lack of faith in the authorities. Moreover, based on earlier and inaccurate or incorrect diagnoses, interviewees were occasionally referred to treatment settings that were inappropriate for them, leading them to mistrust health and social welfare professionals.[21] The challenge that the interviewees in this study, some of whom are academics, present to us is to establish a network of services that will help them integrate fully into society and enable them to realize their potential. Furthermore, employees of the various state authorities (such as in the education, health, and social welfare systems) must ensure that they are familiar with existing services, so that they can advise and direct those who need them.

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[21] See Appendix 5 below.

3. Skills

Skills are utilitarian—not a goal in themselves, but tools for achieving values.

(Sola Shelly)

Aside from describing the interviewees' functional state, this chapter is also dedicated to a discussion of the significance of functional level for the individuals themselves, their ability to cope with their challenges in a way that aligns with their values. The first part of the chapter presents a functional profile in each of three areas: cooking, cleaning, and mobility. Each of these fields is complex, entailing a range of different needs arising across the group of interviewees. The second section looks at facilitating access to services. The picture it reveals demonstrates a very clear need for assistance.

3.1 Functioning Level

The functioning profile assessment is based on the "instrumental activities of daily living" (IADL), a tool used to assess individuals' dependence on their environment. Most of the activities described are instrumental—mobility within the community, and independent functioning in activities such as medical care, cooking, maintaining cleanliness, and shopping (Bookman, Harrington, Pass, & Reisner, 2007). Instrumental ADL is directly related to individual independence. Any activity that a person is unable to do alone creates a dependency on another person (such as a relative), or requires the use of a paid service.

Figure 3. Independence Level[22]

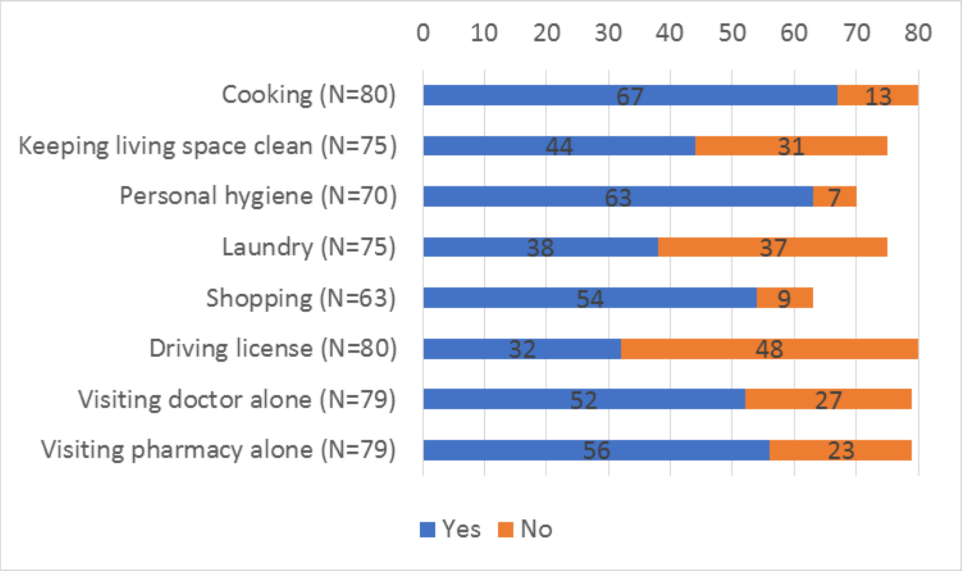

Figure 3 shows that most interviewees know how to cook, clean, and shop. Most don't have a driver's license, and the majority use public transportation independently, and even visit the doctor on their own when necessary. However, many interviewees mentioned at least one area of activity in which they do not function independently. Sometimes, these activities are tied to basic functions, such as brushing their teeth. Others described struggling to reach a destination they hadn't visited before on public transportation, or not knowing how to operate a gas range or a washing machine. Two main trends arise from these findings:

1. There is a great deal of interpersonal variance with regard to areas of activity. There is no one area of activity that most of the interviewees found difficult.
2. For each individual, their level of functioning is different across the various fields; their level of functioning in any given field cannot be predicted based on their level of functioning in another field.

It should be noted that 71% of interviewees live in their parents' homes. Consequently, there is a question as to whether function disparities

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[22] Some of the interviewees did not respond to all of the questions, so some of the columns display numbers that do not add up to 80 (the number of interviewees in the study).

in areas such as cooking and cleaning should be linked to a stage of normative life or to Asperger syndrome. A preliminary answer to this question can be found in the stories told by the older interviewees in the study, who live independently. They exhibit functional gaps, in a similar manner to the other interviewees, indicating that the main contributing factor is Asperger's; were these gaps attributable to a normative stage of life, these interviewees should have been able to describe a state of normal function. A more profound answer, which seeks to understand the gaps in functioning and explore possible solutions, is provided in the rest of this chapter.

3.2 Cooking skills as a representative field of activity

Every individual needs access to cooked food to live and stay healthy. Being able to cook increases one's independence in this important area of daily life. The alternative is to eat store-bought food and/or have food prepared by family members, but the first option is expensive, and the second implies dependency on family. Acquiring cooking skills is not a goal in and of itself; rather, it is a means of attaining and expressing values—in this case, the values of independence and preservation of health. Cooking is explored here in greater detail, as being representative of other areas of functioning. It is a rather complex field, which allows us to learn about the interviewees' daily struggles and their coping strategies.

Cooking requires a combination of motor skills (such as igniting the flame in a gas range, cutting vegetables, and using measured-out quantities of oil and spices), maintaining focus (following a procedure), and speed (performing activities within a strict time frame). All of these activities require prior planning, and an ability to foresee difficulties and find quick solutions. In light of these requirements, people diagnosed on the autism spectrum, particularly those with Asperger syndrome, tend to have sensory regulation problems (Leekem, Nieto, Libby, Wing, & Gould 2007), a certain degree of clumsiness and poor motor skills (Manjiviona & Prior, 1995), and attention deficits and an impairment of executive functions (Nyden, Gillberg, Hjelmquist, & Heiman, 1999). For some people with Asperger syndrome, what may, at first, seem to be a trivial task turns out to involve a combination of weaknesses and difficulties.

Another aspect tied to this area is eating preferences. Individuals on the autism spectrum are often pickier and more limited in their choice of food. Sensory inputs such as smell, texture, color, temperature, and more, play a role in this (see a study on this subject by Cermak, Curtin, & Bandini, 2010). At times, this tendency leads to poor nutrition and a need for food supplements (Bowers 2002; Williams, Dalrymple & Neal, 2000).

Thus, poor cooking skills could be tied to various factors, and there is no single way of dealing with them all. Most interviewees (83%) know how to cook, at least to a limited extent. However, many of them stated that they do not cook, in practice, in their day-to-day lives, and that they don't know too much about cooking.

3.3 Interpersonal variation in cooking function and in other areas

It shouldn't surprise us that, given the difficulties described above, no connection has been found between the functional level for IADL in people with Asperger syndrome and their intellectual abilities (Gaus, 2011). Likewise, this study, too, demonstrates that there is no link between intellectual capacity and general functioning. Quotes from three interviewees living in rented or owned accommodation illustrate this point:

1. An interviewee with advanced cooking skills who has a regular job, and holds a partial high-school matriculation certificate:

> *I have a Class 1 Cook's Certificate—this is a ten-month course. I have undergone training that taught me how to cook, and I really like trying new things. I don't always have time to cook, but when I do, it makes me very happy (Idan, 30).*

2. An interviewee with moderate cooking skills, unemployed, with an academic education (holds a doctorate):

> *[In answer to my question of "What can you prepare?"] Bread with jam, and I can warm things up in the microwave. In general, I tend to eat like little children do: lots of sweets, and lots of dairy products. That's still how it is... I don't know how to turn on the gas (Yitzhak, 47).*

Yitzhak states that he has always been a picky eater. His food choices meant that he never needed to learn how to cook, and make him less motivated to do so.

3. An interviewee with poor cooking skills who has a regular job and holds a full matriculation certificate:

> *Cooking—I don't cook, and I never have... I'm always scared that the gas will cause an explosion (Eran, 28).*

As stated previously, the three selected interviewees live independently. They illustrate the great interpersonal variance in the ability to cook, and the individual variance across different functional areas for each of them.

3.4 Understanding the difficulty and overcoming it

To know how to address this difficulty, we need to understand more about what it is and what the individuals need in order to overcome it. Many interviewees told us that to learn to cook, they needed to practice alongside a skilled individual, and they needed the cooking stages to be spelled out in great detail.

3.4.1 Ongoing practice alongside a guide and a lack of awareness of the rules of cooking

> *This is something I'm rather fond of. I'm always trying to learn new tricks and other stuff. I manage pretty well as long as there's someone who can help me with the first recipe. I learned that even after I've done it once, I still have a few problems. It's a learning process, and you need to learn from your mistakes. My problem is that I don't pay too much attention and [I'm not] aware of the rules of cooking (Evyatar, 20).*

> *My dad taught me how to cook rice a few months ago, or rather, he reminded me how to cook rice. He also taught me how to boil water for spaghetti, though I haven't tried this alone yet (Hanan, 30).*

3.4.2 Detailing the stages of cooking

> *I cook sometimes, but I need to get a very detailed list of instructions from somewhere. I do OK if there's a detailed recipe or if someone tells me what to do (Yarden, 25).*

These descriptions highlight the need to regularly practice the core skills required in cooking, such as using a gas range, boiling water or following a procedure listed in a recipe. One way to cope with this type of difficulty is to undergo training centered on learning how to break down a task into its components, and writing a procedure. The procedure would include steps that, to us, seem obvious. A guide would also need to be present, until full mastery of the studied skills is achieved. As demonstrated in the examples above, these are people with normal skills in various fields (like academia and work), but they need one-on-one guidance on things that are ostensibly simple. These quotes also illustrate the gap between the ability to describe a difficulty and the inability to overcome it. This gap is characteristic of the interviewees, in other fields as well.

3.4.3 Motivation to achieve change, and "laziness"

Aside from difficulties in the practicalities of learning how to cook, there are also challenges tied to motivation:

> *I don't know how to make too many types of food [...] There's usually someone who can make my food for me. This is something I'm quite lazy about. In the morning, I eat plain bread, because it's the easiest thing to prepare, but if I really wanted to, I could cut the bread and put something in it. You could say that this is the extent of my cooking skills (Beni, 23).*

This self-judgment of being "lazy" is thought-provoking and should be assessed in terms of the complexity of the required skills (see also a discussion of this topic at the end of this chapter).

3.5 Coping with difficulty indirectly

Aside from investigating why they were having trouble functioning, some interviewees described how they coped with this, and how they could achieve their goal without actually learning how to cook.

3.5.1 Difficulties with skills, help from the environment, limiting the menu

Nirit, who has a bachelor's degree and holds a regular job in a hi-tech company, lives with her parents, but would like to live independently. Here, she describes her struggles with cooking:

> *I don't know how to do it. [When I asked her "You don't like to cook at all?", her response was the following]: I don't like to deal with fire; you need to light the gas, and I find it difficult to turn the knob. You need to be good with your hands, and that's something I don't have. [In response to the following question: 'Then how do you manage?]: I eat food that other people prepare, raw food, or things I warm up in the microwave (Nirit, 30).*

Nirit finds indirect ways to deal with her difficulty: she eats what other people cook for her, uses the microwave instead of the gas range, or eats raw food.

3.5.2 Limiting the menu, and making up the difference with food additives

Yigal also limits his menu, while maintaining his health:

> *[Smiling] This might not sound too good, but I make sure that I have whatever I need to avoid getting sick. I know that I need protein, so I eat cheese several times a week. I also have a multivitamin, which I can take without a prescription. I generally don't cook—all I eat is cheese, bread and cookies, and I drink coffee, and that's it (Yigal, 43).*

Like the interviewees quoted above, Yigal limits the types of food he eats, and doesn't mention feeling frustrated or unsatisfied as a result.

3.5.3 Cost-Benefit Considerations

Yigal, who has a bachelor's degree, discuss how he weighs cost versus benefit:

> *It takes time and you need to clean, and I don't have time because I work two jobs (Yigal, 43).*

All of us carry out cost-benefit calculations every day. The reason for including them in this study is to emphasize how important it is to refer to this group as being normative in many ways. When mapping levels of functioning, it's also important to remain open to the choice of not acquiring certain skills for a variety of reasons, a choice often made by members of the general population as well.

3.6 The need for facilitation in order to access services from various bodies (both private and public)

The question that was asked regarding facilitation was: Did you ever need mediation or assistance with receiving various services (from the Ministry of Social Welfare, the National Insurance Institute, a health fund, income tax, a bank, a cellular phone company, the broadcasting authority, etc.)? 71% of the interviewees reported that they receive or need assistance. Only 29% of them said that they don't need any help. Ordinary citizens struggle when trying to interact with the authorities, so it follows that those with communication impairments would struggle even more. Most interviewees reported that they get help from their family members, who mediate with service providers. A number of focused topics emerged which allow us to understand these difficulties in more detail:

- Difficulty performing non-routine activities
- Aversion to initiating contact with strangers
- Discomfort with direct human contact, and a preference for indirect contact or mediation
- Difficulty negotiating with businesses

In addition to these difficulties, the interviewees mentioned solutions that had already helped them cope, or recommended ways to make the existing services more efficient.

3.6.1 Difficulty performing non-routine activities

One of the core traits associated with the autism spectrum is that of restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). This is exhibited in various ways, including a possible tendency among people with high-functioning autism to avoid new experiences and try to preserve existing routines. Contacting institutions and businesses for service is usually a one-time activity, so regardless of dealing with other aspects of this activity, even picking up the phone to make a call can be an obstacle.

> *I have a basic aversion to all these things. I didn't even get a parking permit for my car because I don't like... I don't know... I don't like these things [...] Getting a discount on municipal taxes too, things that you don't do every day, things that you aren't used to doing (Gil, 30).*

3.6.2 Aversion to initiating contact with strangers

When contacting government agencies, direct contact must be made with unfamiliar people. Interviewees who described having difficulty communicating with others in general found it difficult and intimidating to communicate with someone they don't know.

> *I've been fighting this for at least 15 years, and I'm managing—I'm fighting my Asperger's. There was a time I couldn't call my internet company's technical support. Now, I can talk to clerks and even sales reps without any effort. I'm totally fine. I distinguish between those people and regular people—those people are service providers, and service providers aren't scary (Yaniv, 25).*

The coping strategy that Yaniv describes here—distinguishing between service providers and "regular people"—helps us understand how intimidating communication with strangers can be.

3.6.3 Discomfort with direct human contact, and a preference for indirect contact or mediation

Often, people with Asperger syndrome prefer indirect communication, through either electronic media or mediation via someone they know:

> *I always used mediators [when communicating with] organizations. Especially my Dad [...] I prefer to get things done with as little human contact as possible, I prefer working through the internet, and if that doesn't work, then over the phone. I prefer to keep human contact to a minimum (Idan, 30).*
>
> *It would be great if I could get some coaching, because let's say I call Alut [the Israeli Society for Autistic Children), they could say some things to me. But I would like, not someone who deals with autism in general, but someone specific I can talk to, whom I can tell that I've been to the Ministry of Social Welfare and that I'm waiting for this and that, and that person would be able to direct me (Rachel, 40).*

We thus see that when communicating with these organizations or their representatives, the problem is two-fold: this is not a routine activity, and it requires speaking to a stranger. The interviewees indicate that if someone they know helps them, or alternatively, if they can go online to get things done instead of speaking to a representative, then this difficulty could be mitigated. This finding is consistent with findings on how people with Asperger syndrome feel more comfortable with communication over the internet (Jones & Meldal, 2001; Benford & Standen, 2009).

3.6.4 Difficulty negotiating with businesses

Another difficulty the interviewees typically face involves trying to access services from companies without mediation. Yifat describes an extreme situation in which she tries to reduce the price of her data plan for her mobile phone, and she always ends up with a more expensive plan. After all her attempts fail, she resorts to getting help from her mother:

> *There are financial issues, so sometimes, I have trouble understanding. I bought a cell phone from a cell phone company, so I wanted to take down the price. I got the price to 1,500 shekels a month. Each time, he said to me "take another line," and they gave me a whole bunch of SIM cards. Every month for two years, I paid 1,500 hundred shekels. That's not normal. Each time, I'd get upset about it, until my Mom intervened. I'd be paying for six phone lines, and I didn't need them (Yifat, 25).*

3.7 Discussion: Skills

As demonstrated with cooking, people with Asperger syndrome have varying levels of functionality for various types of IADL. Moreover, there are often interpersonal functionality gaps across various areas. Consequently, a detailed need map must be created, without assuming that adequate functionality in one complex area implies a similar level of functionality in a simpler area. At the same time, while seeking to help people address and overcome their difficulties, respect should be shown for the individual's choice to avoid confronting areas they find particularly difficult, in order to save their strength for other challenges.

The principles described as coping strategies for cooking—including training based on breaking down a task into its components, writing a detailed set of procedures, and engaging in constant guided practice—address the general difficulties common to people with Asperger syndrome, and are thus relevant in helping them acquire other skills. Adopting an open and inquisitive stance toward understanding the source of the individual's difficulty can help caregivers and rehabilitation facilities develop effective intervention methods, and create motivation for change and development.

The word "lazy" is repeated in the various interviews, in different contexts. This is indicative of the interviewees' honesty and the fact that they are not trying to whitewash reality, even if it is unflattering to them. However, other possible explanations exist for their choice to consider themselves as being "lazy."

The difficulties described in this report include gaps between adequate abilities in areas considered challenging (such as acquiring higher education) and limited abilities in areas considered simple and basic (such as cooking). These gaps demand explanation, and they may cause an individual to misinterpret their difficulties by labeling themselves as lazy, instead of addressing the real reasons for not having developed specific skills. In addition, many of the interviewees share a desire not to be labeled as being disabled,[23] and thus may prefer being called "lazy," which is at least still a "normative" trait.

Most of the interviewees in this study need help when trying to fully exercise their rights in the public sector (dealing with such institutions

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[23] See above in chapter 2, particularly sections 2.5.1 and 2.5.2.

as government offices, municipalities, and government-owned companies), and when they require services from private companies, such as banks, cellular phone companies, and the like. They need this help because of their communication difficulties, and because these types of requests are usually one-time or ad-hoc occurrences, which many of the interviewees in the study try to avoid.

Data from the interviews suggests two possible solutions.

- Training accessibility officers in the public sector who can intervene and facilitate when inquirers don’t know how to demand things they are entitled to. These officers could be contacted in cases of suspected exploitation (see: Equal Rights for Persons with Disabilities Law, 1998; Equal Rights for Persons with Disabilities [Adjustments for Access to Service] Regulations, 2013).
- Making communication over the internet with various entities more accessible would help individuals fully exercise their rights, and offer them communication channels that many of the interviewees would feel more comfortable using. This provision should be carried out in consideration of paragraphs32–29 of the Equal Rights for Persons with Disabilities (Adjustments for Access to Service) Regulations, 2013.

4. Housing

> *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.*
>
> *(UN Convention on the Rights of People with Disabilities, 2006)*

The right of people with disabilities to choose their own housing arrangements is enshrined in the UN Convention on the Rights of People with Disabilities. The State of Israel signed this convention on March 31, 2007, and ratified it on September 28, 2012. However, the development of services to support those with Asperger syndrome living in the community, or those interested in doing so, is still underway. In 1999, responsibility for institutional care of people with autism was transferred to the Service for the Treatment of People with Autism at the Ministry of Social Welfare. According to data from 2012, 123 people with Asperger syndrome or autism were living in a "community housing system" or in a "satellite apartment" (Abiri, 2012). The option of living independently in the community and receiving support without being affiliated with a housing system was created in 2012, and was put into practice through a pilot program known as Supported Housing.[24]

> *For many years, all the options were either to go to a hostel or to manage on your own, and I manage, more or less... If there was an option of finding a way to help people who aren't suited to the hostel system, this could really help everyone, a lot of people who function on a slightly higher level (Gil, 25, studying for an undergraduate degree in social science).*

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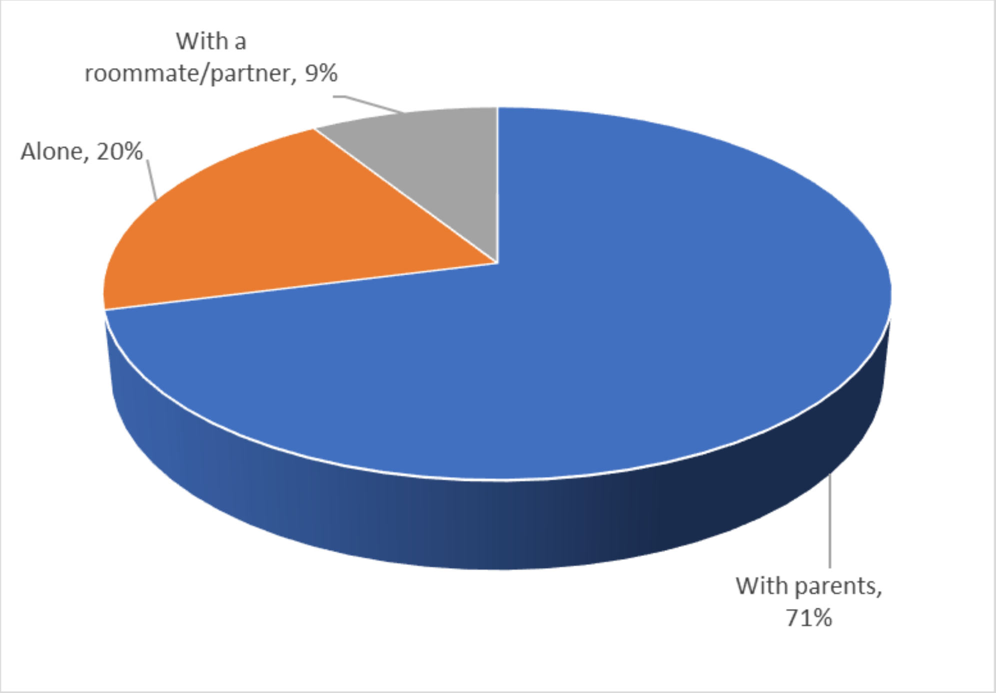
[24] See section 1.1.5 in the introduction, "Research question and study goals"

Figure 4. Current Housing (N=80)



Of the interviewees in this study, 57 live with their parents, 16 live on their own, and seven live with partners or a spouse. Of those living with their parents, approximately 75% are interested in moving to live independently, but are not interested in living in a community housing setting (see also Appendix 6).[25] Of the 23 remaining interviewees who either live on their own, with a spouse, or with roommates, many expressed interest in receiving support without participating in alternative housing systems.

Of those who live with their parents, half are interested in living on their own in the future, and half would like to live with roommates. Of those who already live independently, two-thirds live alone, and one-third live with a roommate or a spouse (see also Figure 4, above). These figures, concerning the number of those who live independently and of those who wish to do so in the future, demonstrate that an interpersonal variance also exists in housing preferences.

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[25] Most of the 24% of the interviewees who responded that they were not currently interested in beginning to live independently are in their early 20s, so in this case, their lack of interest can be considered normative. The above finding corroborates the conclusion that most of the interviewees in the study express interest in living independently.

4.1 The community housing system or satellite apartment

The following reasons were cited by the interviewees for their decision to forego receiving community housing services:

- Outward appearances and labeling resulting from being affiliated with a housing system
- A desire for normative integration into society
- An uneasiness with how much collectivity exists in these systems
- Limits and rules in force in this system
- A fear of conflict in housing arrangements with roommates

4.1.1 Outward appearances and labeling resulting from being affiliated with a housing system

Invisible disabilities are defined as disabilities that aren't exhibited through unusual phenomena or functional limitations that can be seen (Braithwaite & Thompson, 2000). Developmental disabilities, including Asperger syndrome, are often invisible, as they tend not to have prominent outward manifestations. Some of the interviewees expressed a fear of being associated with a setting that would make their difficulties visible:

> Sometimes, I'm scared by the thought of living somewhere that shows that something is wrong with you. Some people like this idea, because there, there's help and all of that, but what frightens me is that this is a place meant for people with problems. I consider this, how should I put it, debasing (Daniel, 22).

Similarly, Amos and Osnat describe their discomfort with the labeling that comes with joining a community housing system:

> I'm not interested. I didn't want to be labeled as an Aspie and live in an Aspie house, and be Asperger Number 7 in Apartment 7, like livestock (Amos, 28).

> We decided that this would be selling myself short, to attach a label that doesn't suit me. Where do you live? In a hostel. That's no good at all (Osnat, 35).

Amos and Daniel mention the issue of outward appearances and social labeling as significant considerations. "Somewhere that shows that something is wrong with you" or an "Aspie house" are statements indicating a desire to continue maintaining a normative outward appearance. The use of the word "hostel" has negative connotations associated with a place meant for people with serious disabilities. The stigma associated with living in a hostel operates on two levels—how society observes and judges those people, and how the people living there feel about themselves. Chapter 2 (Diagnosis and Certification by the Authorities) describes how, for some interviewees, their Asperger syndrome diagnosis was an important part of the formation of their identity and the self-acceptance process.[26] Conversely, Daniel, Amos and Osnat emphasized their sense of identity that is not based on their diagnosis. They stressed components of their identity as independent and functional individuals, as well as their desire not to identify as disadvantaged. Another dimension raised during the interviews was the desire to integrate into society and avoid isolation.

4.1.2 A desire for normative integration into society

> I have always been strongly opposed to living in a hostel... because I'm not prepared to live in a bubble, detached from society… Because for me, emotionally, a hostel would become a hospice... I'd feel detached from society, and then, I'd feel emotionally dead. You know what a hospice is, right? (Yaniv, 20).

Yaniv's statement is intriguing. He "isn't prepared to live in a bubble," and would not like to be detached from society. He sees living in a hostel as paramount to being in hospice care, which is meant for the chronically ill and people who are dying. Yaniv fears that he'll feel "emotionally dead." He would like to be part of society, and face this challenge, even if it entails difficulties.

4.1.3 Uneasiness with the extent of collectivity involved

Living in a community housing system or satellite apartment requires a certain degree of collective living. Usually, these are apartments with between three and five residents. Several interviewees discussed the

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[26] See above in section 2.4.2.

need for personal space.

> *It’s a bit too collective for someone like me. I’m used to having my own corner... I find it a bit odd that they do things like that, I guess that some of the people there wouldn’t like this collective aspect (Eitan, 45).*

4.1.4 Limits and rules

Another factor mentioned by the interviewees in this study for rejecting community housing systems is the restrictive rules associated with living in a housing system:

> *I heard negative comments from people living in a hostel... that it feels like “Big Brother,” with counselors who tell you to be home by a certain time (Shahar, 26).*

4.1.5 A fear of conflict in housing arrangements with roommates

Anat has been living independently for over a decade. She discusses her attempt to live with a roommate and her transition to living on her own.

> *Afterwards, [I lived] in a rental unit. It was a catastrophe. I had a very hard time with the roommate. It was hard for me to tolerate someone else in my environment. Lots of conflicts, lots of tension and lots of misunderstandings, and lots of running back home. For me, it was a time of suffering. A year later, it was living alone that restored my emotional equilibrium, a pleasant and peaceful place (Anat, 35).*

Anat is happy to be living alone. She has a social life, and has made various attempts at having a relationship, though she still needs her personal space, which she can have now that she lives independently.

4.2 Reaching out with help for assessing housing options

Echoing the findings on the need for facilitation in accessing services from various organizations (see also section 3.6 in chapter 3), interviewees also expressed a need for help with assessing the various options for housing:

> *I tried to look for information on the internet. I felt that the information there wasn't enough... If there were someone who could sit down with me and try to work out together what was right for me and what wasn't, that would have helped (Eitan, 40).*

Housing is a complex issue for people with high-functioning autism. The interpersonal variation and varying levels of individual functional across different areas described above explain why Eitan wanted to "try to work out together what was right for me."[27] "For me", personally.

4.3 Leaving the parental home: Timing

Several interviewees talked about their inability to decide on the right time to leave their parents' home:

> *I had always lived at [my parents'] home... Apparently, it wasn't such an urgent need. I don't know when the right stage is, at what age. I'm a bit confused (Gal, 25).*

4.4 The need for support outside of a housing system

While justifying their objections to joining a community housing system, the interviewees also stressed their need for support:

> *On the one hand, I feel that I would very much like the support that I can get in a setting like that, but on the other hand, I feel that this would involve a major concession. Right now, I'm living in a three-bedroom apartment, and I have a lot of privacy and space (Yisrael, 38).*
>
> *On the one hand, it isn't so pleasant to have a counselor constantly telling you what to do, because I also need my privacy and my flexibility... but on the other hand, it's true that they want to prepare us for living independently (Yaakov, 28).*

Yisrael and Yaakov describe the tension between their desire for support and help with preparing for living independently, and the need for privacy. They illustrate the need for a service that provides a solution

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[27] For more on interpersonal and intrapersonal variation, see sections 3.1 and 3.3 above.

for those who choose to live independently, without using community housing services. This kind of service is important because it provides support to those with the greatest potential for living independently. This support would include help in emergency situations.

4.5 Coping with emergency scenarios

Daniel, who has been living on his own for over a decade, describes some of his worries:

> *[In response to my question of "Are you happy to be living alone?"]: That's the million-dollar question—yes or no. I'm happy because I have a lot of space and it's quite comfortable... I have a lot of privacy, which is both an advantage and a disadvantage. It's an advantage because I'm in charge of myself. It's a disadvantage because if something happens to me, the main scenario that I think about is getting sick. But lots of things can happen. I don't know, if I need to have surgery, or if I am hurt and need someone to help me (Daniel, 40).*

Daniel talks about the practical aspects of living alone, and the possibility of something happening to him that would result in his needing assistance. As the interview progresses, it turns out that these fears are based on a real event that had occurred a couple of years earlier:

> *If I need to have surgery, from my experience at hospitals, they aren't so prepared for it. You need to have someone to watch over your wallet, and you need someone to accompany you. From my experience, I am thinking of an operation I had two years ago. About two weeks after the operation, when they removed the stiches, I had serious bleeding for a day, and I was alone at home. I didn't have anything. I didn't know what to do. I can tell you what I did. I changed clothes a few times – twice, three times, I can't remember. After that, I went to the nurses' station at the health fund, on foot. The nurse who attended to me was very alarmed. Naturally, she bandaged the area, applied ice, all of that. They wanted me to see a surgeon. There wasn't a surgeon there, so they called in an ambulance for me, and sent me to the emergency room. To make a long story short, this is*

> *a situation that I'd have an easier time dealing with had I had someone else with me at home... This is why I say that living alone is very difficult.*

This case illustrates the need for a response during times of crisis. Seemingly, along with a desire to live independently, where they have their personal space, interviewees also need protection, support, and advice during times of crisis.

4.6 Discussion: Housing

A large number of interviewees in this study are interested in living independently, outside of their parents' homes, but would not like to join a group living framework for various reasons, including: fear of being supervised or having to live with group rules; fear of stigmatization, and fear that such an arrangement would be perceived negatively by outsiders; desire to live a normal life and create a non-needy identity; preference for a less intense social life; and more. While the interviewees are not interested in the existing group living frameworks, they would have a hard time transitioning to independent living on their own.[28]

We can learn from the experience of those who have been living independently for some years. Their life stories reveal that they can be independent economically, socially, and functionally, but that they also have weak points with which they need help, or that require intervention. The study reveals that there is a genuine need for a support service to help them become more independent, and to provide responses during extreme situations, regardless of the individual's choice of housing. Over the past decade, new housing arrangements have been established, and this progress is admirable. However, the data from the interviews demonstrates that a wider range of options is needed, as is the establishment of a continuum of supportive housing services throughout the country.

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28. The need for a cooperative setting is clear—and not just for technical reasons, such as renting a common apartment, the comfort of having staff members accessible, or saving various costs. There are also more fundamental reasons: a common housing setting provides exposure to more people, and it enables people to make new acquaintances and develop contacts, when ordinarily those people would struggle with such tasks. However, there are other options that enable having a social life without having to live together.

Regarding reaching out with help for assessing housing options, the interviews reveal a need for individuals to receive consultation on aligning their aspirations with their needs and abilities, both in terms of the choice of housing arrangement and in terms of the right time to leave the parental home. It appears that providing home visits, for individuals in their early to mid-twenties living with their parents, from professionals who can help them review and assess the available housing options, would be very significant in addressing a number of questions, including: Are they able to live independently in the way they desire? By living on their own, would they be fulfilling their social aspirations? Would it be easier or harder for them to leave their parent's home at a later time? From conducting the short interviews for this study, we saw that it is possible to paint a fairly broad picture for individuals within a relatively short period of time that can help them set realistic goals to match their aspirations.

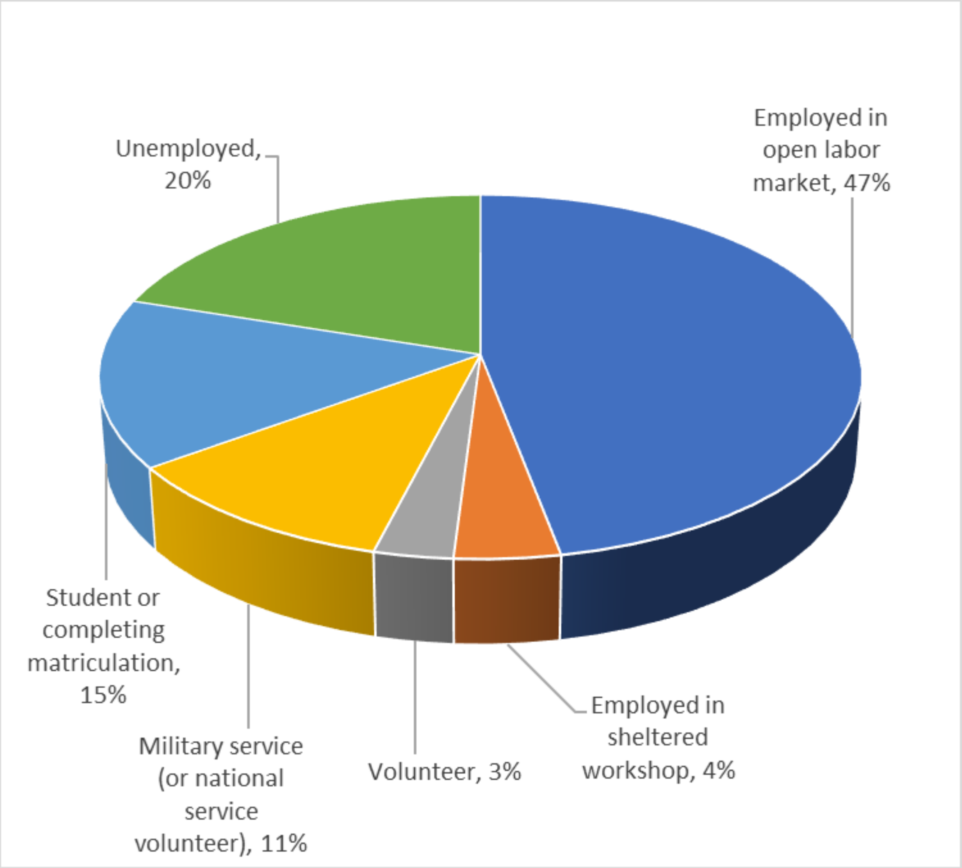
5. Employment

> *Sitting at home is so depressing and so exasperating. If there's a reason to get up in the morning, to shower... to be active for a few hours, it improves your quality of life significantly... What's important here is the routine. If it's twice a week on different days each week, it doesn't help that much (Binyamin, 34).*

Researchers have found that the probability that people with autism but with no cognitive impairment will not be employed on a daily basis is three times higher than for those with autism who do also have a cognitive impairment. This is apparently due to a lack of adapted placement settings (Taylor & Seltzer, 2011). Indeed, various researchers have found that around 50% of those with Asperger syndrome or high-functioning autism are employed (Vogeley, Kirchner, Gawronski, van Elst, & Dziobek, 2013). However, when this group received support while in the stage of preparing for employment and integrating into the workplace, through programs designed to help them with training and placement, the rate of employment rose to 87% (Vogeley et al., 2013; Wehman et al., 2014). Moreover, it has been found that support while working at regular jobs ("supported employment") improved the quality of life of employees, while sheltered workshops did not lead to a similar improvement (Garcia-Villamisar, Wehman, & Navarro, 2002).

Echoing the data provided above with regard to the 50% employment figure, about half of the interviewees in this study work. Of those, three work in sheltered workshops (see also Figure 5).

Figure 5. Current employment status among interviewees



With regard to salaries (see Figure 6 below), 29 of the interviewees work in the open labor market and earn at least minimum wage (working at least half-time); six earn “adjusted minimum wage”; and three are employed at sheltered workshops, earning wages that are essentially a reimbursement of expenses.[29] As described above, the existence of this group employed in the open labor market demonstrates that people with Asperger syndrome have the potential to be productive members of society.

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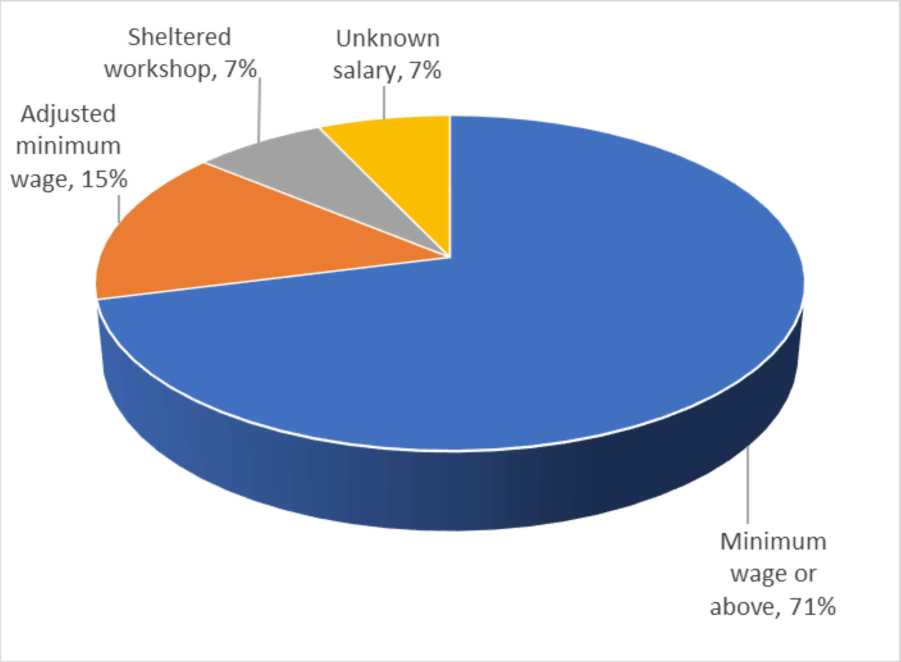
[29] Adjusted minimum wage is lower than the legally-defined minimum wage: “The law and the regulations permit setting lower wages than the legally-stipulated minimum wage for those with lower work capacity. The adjusted salary is determined by conducting an assessment to determine a worker’s work capacity in comparison with a non-impaired employee working in the same position.” (Ministry of the Economy, 2015)

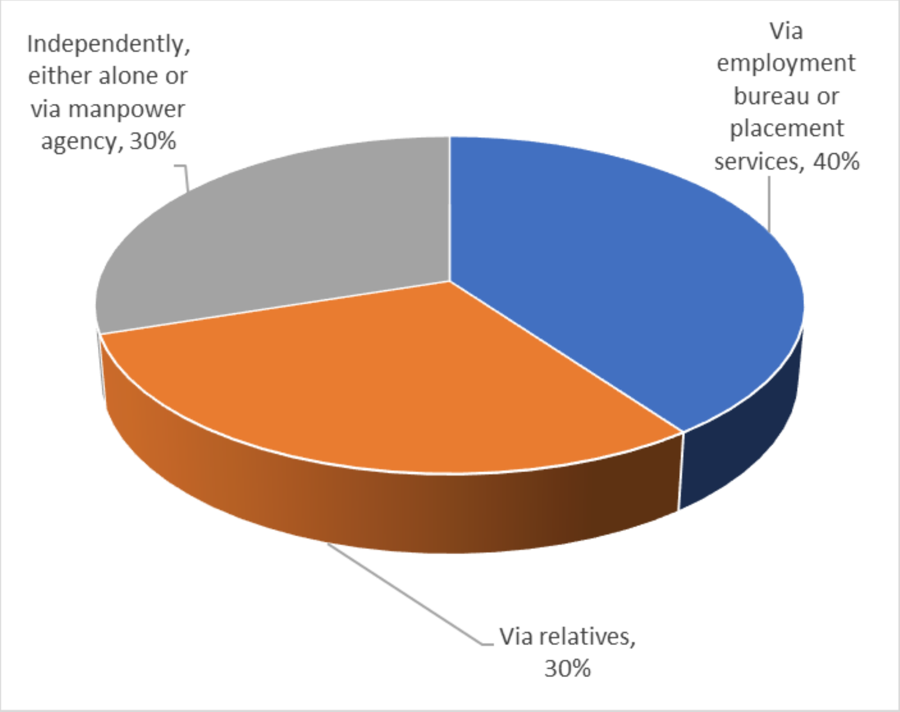
Figure 6. Salary level (N=41)



5.1 Methods of finding appropriate employment

As in other functional areas, employment is a field that exhibits interpersonal variation in terms of needs and skills. Finding employment is an initial and critical stage of being able to integrate into the job market for a considerable length of time.

Figure 7. Method of finding employment or volunteering position (N=43)



Echoing the known figures from the Ministry of Social Welfare,[30] only a minority (40%) of the working or volunteering interviewees found their job through dedicated placement services or through general employment bureaus. Thirty percent of the interviewees in this study found their jobs with help from family members.

> *After being at home for 11 months, my mother found [me] a job. If I hadn't had that connection, God only knows how much longer I would have been sitting at home—maybe until today (Avishai, 35).*

Thirty percent of the interviewees in this study found their jobs independently (either by themselves or through a placement agency).

> *Through a newspaper ad, and a lot of initiative on my part. I work in sales, so I know how to initiate. I call some company and send them my C.V. (Nehama, 40).*

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[30] See section 2.3 above.

Many interviewees revealed they had moved jobs many times, and that it was hard for them to persist at a particular job over time. These descriptions present a complex mosaic of skills coupled with limitations that make it difficult for many of the interviewees in this study to fulfill their vocational potential.

5.2 Strengths, or finding one's relative advantage

The variance expressed in different ways in many areas of this study was also present with regard to the interviewees' occupations, which included teacher, kindergarten teacher, medical secretary, programmer, salesperson in a clothes store, warehouse manager, waitress, computerized warehouse manager, cellular phone quality controller, video editor, photographer, fitness trainer, zookeeper, and more. In some cases, interviewees managed to couple their areas of interest and their strengths with a need that currently exists in their place of work. A few interviewees described how they succeeded in bringing an area of interest or a particular character trait to bear in the workplace, in a way that proved helpful:

> *In the beginning, it went well. [In response to my question of: "You need to interact with people to be a sales representative, right?"]: It didn't require a lot of interaction. It's not about the persuasion skills, it's about finding people who need the insurance. On the contrary, someone who seems like he doesn't have persuasion skills, someone who isn't a performer, is good. Because you see someone who isn't acting, who isn't good at persuasion games (Shalom, 40).*

Shalom was a successful sales representative, because his inability to be a "regular" sales representative could prove to be an advantage. It was precisely because he did not focus on "persuasion games" that he would seek out people who genuinely need insurance, show them what he has to offer, and move on. This idea, of finding every employee's competitive advantage, is very important as it makes it possible to make the most of each employee's individual talents, and even to compensate for their weaknesses.

Unfortunately, Shalom wasn't able to maintain this job for too long. An environmental change occurred in the field he was working in, and he was unable to adapt to the new situation—not a unique occurrence, as explained in the next section.

5.3 Difficulties in coping with changes in the workplace

One characteristic associated with the autism spectrum is “insistence on sameness, inflexible adherence to routines … (e.g. extreme distress at small changes, difficulties with transitions)” (American Psychiatric Association, 2013). Most jobs require certain adjustments and modifications from time to time. When Shalom was required to undergo changes, he ended up leaving a field he was successful in:

> In 2000, the situation deteriorated, I needed to have better political skills, work with other businessmen, and then, I totally collapsed. It wasn’t right for me (Shalom, 40).

Similarly, Rinat, who is a professionally-certified saleswoman, told us about a previous sales and marketing job she had worked in, and about how she struggled to communicate with her new boss:

> *I had a boss who wasn’t too tough, at the marketing and sales job that I liked the most. We were like friends. As long as we were like friends, and I was good at my job, I got along. But all of a sudden, they replaced my boss and brought in someone who was very strict. She always thought I wasn’t listening to her. They fired me. This was a job I really liked, and it really broke me... maybe she thought I wasn’t listening. And it’s not that I wasn’t good at what I did, I was raking in contracts (Rinat, 40).*

For Rinat, too, a change had occurred at the workplace, mainly with regard to interpersonal communication. Although she reported having good performance capabilities, Rinat was fired, and she is now unemployed.

Yitzhak also described experiencing change in his work circumstances:

> *Ultimately, they gave me a doctorate, but I would have preferred to continue as a doctoral student. [In response to my question of “What do you mean by ‘continue’?”]: The way a doctoral student makes a living is much better suited to me. A post [post-doctorate] is also ok, because a doctoral student only does research on a*

> *particular subject, without everything that goes along with it, such as managing the laboratory, teaching, academic writing, and all those kinds of things (Yitzhak, 47).*

Like Shalom and Rinat, Yitzhak succeeded in his main occupation—research—but he gave up when he found himself having to take on other responsibilities that required social skills in order to secure an academic position. Shalom and Rinat were diagnosed in their thirties, while Yitzhak was never diagnosed. All three of them have struggled to integrate into the job market, and in particular to get jobs that match their skills and education. The three of them demonstrate how changes in the workplace are a serious challenge for people with Asperger syndrome, even if the difficulties are unrelated to the essence of the work itself.

5.4 Facilitation and self-advocacy

The above themes described by the interviewees illustrate a need for workplaces that can take advantage of the professional strengths of people with Asperger syndrome, while also being mindful of their difficulties with integrating into a structured environment, with work relationships with colleagues, and with coping with change:

> *The ideal situation is to have a higher level, for them to appreciate how hard I work. I don't demand a very high salary. I'm prepared to work for a low salary and to invest a lot in my work, so in that way, I'm pretty much an ideal employee. But what's most important is that they can ignore the fact that I don't talk to people, and that sometimes, I do weird things, that I sometimes have anxiety, and that I'm scared they'll sack me. So the idea is that they'll be able to ignore these things. Not to take it too hard. And not to take it personally if I happen to say something offensive. This is the type of service I need, and I don't have that facilitation (Noga, 30).*

We're moved to hear what Noga says about facilitation, but she has never disclosed that she has Asperger's at work.

> *For me to talk about it, it's about trying to be honest and to say that this is my problem, and I'm asking people to be mindful... There was one place where people knew about it, and I think*

> *that this is what screwed me, and this is why I was afraid to say something where I am now.*

Noga’s story is far from unique. Self-representation and self-advocacy aren’t easy, and anyone who has already been “burned” once hesitates the next time.

5.5 Mediation in interpersonal conflicts

It emerged from the interviews that, other than the need for support when changing jobs, there’s also a significant level of mediation needed in social settings at the workplace. Many interviewees describe struggling to react when their colleagues or customers speak to them in a way that seems insulting to them.

> *I have a problem when people speak to me impolitely. I freeze up right away. I can’t speak politely to someone who speaks to me impolitely. I have this kind of problem. I can’t negotiate with angry customers, and if I come across something like this, I become confrontational and do the opposite of what I should (Yaron, age 30).*

> *I would come down on agents who would yell at other people. I wouldn’t hold my tongue for anyone. But I was good at what I did, I knew the material back to front (Lior, 35).*

These quotes illustrate a difficulty to react in moderation when an interlocutor speaks disrespectfully, raises their voice, or is perceived to be aggravated. The social code that determines that service providers do not raise their voices at a customer, an employer, or a colleague, does not serve to inhibit their response. This exacts a personal price. These situations require mediation as a first step, and learning effective communication methods for the future. All of these could reduce the chances of dismissal.

5.6 Vocational support

In the context of developing vocational services, various proposals have been made for methods to ensure a successful placement. For instance, an extensive program developed in Germany involves making incremental progress in each of the following areas:

- Assessment: clinical assessment, neuropsychological assessment, and vocational assessment
- Job coaching: pre-employment coaching (in groups), coaching to impart social skills through role-playing games (simulations), coaching to impart social skills with digital tools, on-the-job coaching, and helping resolve problems in the workplace
- Instruction of non-autistic peers (colleagues and superiors): educational sessions for co-workers; briefings on the symptoms of Asperger syndrome; individual coaching for superiors; and discussing topics relevant for managing people with autism (e.g., communicating goals explicitly, avoiding mental underload, providing a suitable sensory work environment) (Vogeley et al., 2013).

Several examples of successes and failures in vocational support experienced by the interviewees are provided below.

5.6.1 Successful vocational support: a fishing rod instead of fish

A number of interviewees described how vocational support helps and supports them when needed. Idit described struggles similar to those related earlier in this chapter:

> *Last year, I almost lost my job because some team members were demeaning toward me. I was disrespected and looked down upon. Tolerance, listening, and mutual respect are important to me. If I do something slower, don't get upset. Wait patiently. (Idit, 30).*

When Idit got into arguments with some members of the educational staff who work with her, she contacted the placement officer, who helped mediate with her coworkers. This enabled her to attain the independence at work she was seeking:

> *Previously, I needed mediation with staff members. This year, I've tried to calm down, think, and then say to her, "I'd like to talk to you privately about something that bothered me."*

Idit tells us that nowadays, she's learned effective communication methods that help her when conflicts with colleagues erupt. Her ability to cope with interpersonal difficulties when they arise allows her to keep her job over time. This description illustrates not only the facilitation needed for specific incidents, but also Idit's ability to learn and acquire the skills she needs to cope with similar situations in the future, without needing facilitation each time.

5.6.2 Interviewees' criticism of vocational support

Several interviewees criticized existing placement services, citing several issues:

5.6.2.1 **Placement in jobs that they feel aren't suited to their level**

Many interviewees said that they were disappointed with the types of job they were being referred to. Often, these positions were described as monotonous and technical, whereas the interviewees feel capable of far more challenging and complex work:

> *I did the simplest and most annoying tasks… things that I didn't consider very challenging, not things that I had studied in the course. I did these kinds of simple jobs, and not the more complex tasks that I could have done (Rami, 31).*

5.6.2.2 **Difficulty acclimating to placement service workers, who change frequently**

The interviewees in this study stated that it was important for there to be stability with placement service workers, instead of a high turnover:

> *In terms of vocational support, they [the placement companies] simply take advantage of the fact that they're the only ones in this field. They were constantly replacing placement workers… I'd expect them to give their workers better job conditions, and to bring in more competent workers (Lior, 35).*

5.6.2.3 **Unavailability of placement service workers during times of crisis**

Most of the interviewees do not need daily support, but they do need support during times of crisis, when it's important they have someone to talk to and get advice from, and who can mediate between them and their employers.

> *If I say that things are going to explode, don't say "Oh, you're great and you're doing fine," and just let the explosion happen (Lior, 35).*

5.6.2.4 **Inadequate guidance and support regarding sexual harassment**

In two interviews, interviewees described sexual harassment or molestation incidents. Michal experienced sexual harassment once at her workplace, and tells us how placement services could have intervened and helped:

> *The work was a type of life-saving [activity]... We felt this esprit de corps... but there was an atmosphere of exploitation toward people like me... One of the workers sexually harassed me, but I didn't lodge a complaint... This is where I went wrong. Perhaps I could have found more sophisticated ways to get this to stop, and not let it get out of hand (Michal, 32).*

Michal describes two aspects of training and support that, in hindsight, could have helped her deal with sexual harassment where she worked:

a. Preparatory training on sexual harassment at the workplace

> *The people at [the name of the contracting organization] never talked about this. Why not bring these things up before we get started, and only afterwards say "why didn't you say so?" Why not?*
>
> *They are Mom and Dad, they need to prepare you. I tried, on my own, to ignore this, because that was my way of dealing with it. I think that this is something that you need to address when you send, you know what, even when you send men, you never know if there will be someone who will sexually harass men, instead of women, the disabled... especially people like us, a population like us with communication problems… In other words, our behavior could be interpreted as sexual harassment. So why not raise this, in both directions? (Michal, 32).*

We should note that Michal is talking not only about preparation for the possibility that the employee will be subjected to sexual harassment, but also for the possibility that the employee himself (or herself) will harass other employees because of impaired social cognition.

b. Response availability

As in other incidents described above, response availability is an important factor, and it is referred to in this case as well:

> *It took a week until they [the contracting organization] got around to talking to me. They didn't handle it right away, and even then, they had no way to help me, even though it's something that happens in the workplace. As far as I'm concerned, they really screwed up here (Michal, 32).*

5.7 Discussion: Employment

The ability to earn a salary and integrate into the workforce has far-reaching ramifications for people with Asperger syndrome. It affects their ability to live independently and fulfill their aspirations; it creates routine; and it has a positive impact on their physical and mental state. By earning a salary, they become less dependent on their family and social environment, and also contribute to the economy and the country's productivity.

The picture painted by the interviewees in this study is a complex one, because while many of them are educated, possess theoretical skills, and exhibit high potential, their ability to deliver in practice was inconsistent with their abilities. Given support during the placement stages, effective integration into the workplace, and on-the-job training and facilitation, these individuals stand a better chance of finding a work environment consistent with their skills and being successful in their jobs, and thus of being able to remain in the same workplace for longer. A substantial number of interviewees are university students, indicating that placement assistance should be provided in collaboration with academic institutions so that these individuals can find work appropriate to their skills when they graduate, and have access to assistance whenever they need it.

For many interviewees, any kind of change in the workplace requiring them to adjust is experienced as a crisis. Today's work environments frequently entail changes in roles, skills, and personnel, and often, they require employees to be capable of responding flexibly. Thus, individuals with Asperger syndrome, while they may possess professional skills, struggle to find work they can hold on to over time, and which also allows them to make full use of the knowledge they acquired in their field of study. Employers who wish to help people with Asperger syndrome integrate into the job market must be able to focus on worker output (rather than social skills), and most importantly, be prepared to exempt them from performing side duties, which people with Asperger's typically find much more difficult. It is therefore important that, alongside guidance and support for employees with Asperger's, suitable guidance and information should also be provided for employers.

These challenges do not require intensive intervention by placement officers in the workplace. Rather, they demand that significant assistance be provided during the placement stage; subsequently, what is needed are flexible solutions that can help employees adapt to a changing environment. Somewhat paradoxically, people with Asperger syndrome, who tend to adhere to routine, are in need of flexible employment support services that respond to changing needs as changes occur in the workplace. This type of solution can help people with Asperger's to make full use of their skills and live satisfying everyday lives, allowing them to feel that they have a good reason to get up in the morning. Society will also benefit from these individuals being productive workers, instead of paying them allowances.

6. Social Life

One of the core traits associated with Asperger syndrome and the autism spectrum is a difficulty with social communication and social interaction (American Psychiatric Association, 2000, 2013). This chapter will examine three main aspects of socialization: general socialization, social life within a social group or a group therapy, and relationships.

The interpersonal variance described in other chapters of this study is evident to an even greater extent in the realm of social interaction. This is how Uri, who rents an apartment and works in the open labor market, describes it:

> *I feel out of place because I can't find anyone who even reminds me of myself. Each person is different; if there were people who were like me, that I could talk to... In the groups, I felt like a counselor, and not like one of the participants (Uri, 28).*

Most of the interviewees said that they were not in a relationship, and that they were interested in improving their social lives. When, toward the end of the interview, they were asked, "What is the most important thing that you lack today?", 46% mentioned, at their own initiative, the subject of relationships. Along with the responses that focused on social life and improving relationships with family members, 56% of the interviewees said they considered interaction with society the area they feel is most lacking in their lives. Despite feeling that their social lives are lacking, less than half of the interviewees participate in a social group or group therapy. [31] The interpersonal variance Uri described above can partially explain the gap between the desire for social and romantic interaction, and the reluctance to participate in settings designed to help them with these areas.

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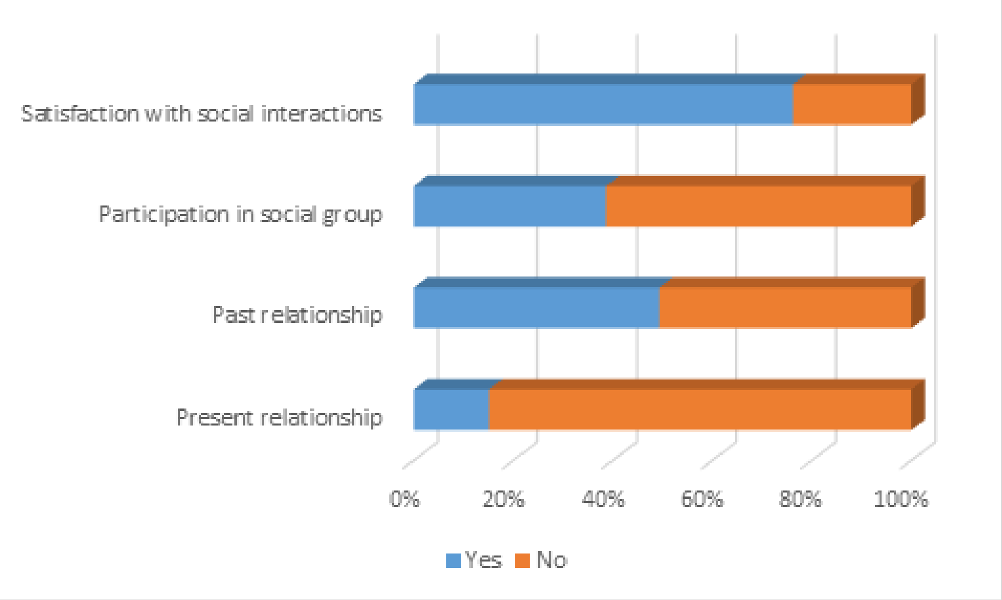
[31] For more on interpersonal and intrapersonal variance, see sections 3.1 and 3.3, as well as chapter 4 (the end of the introduction), and section 5.1. See also sections 6.1.1, 6.1.2, 6.2.1, and 6.4 of this chapter, which appear below.

Figure 8. Social life



6.1 Social needs and satisfaction with social relations

Interviewees were asked about how satisfied they were with their existing social relations. This question did not address the content or intensity of their social life, but rather how personally satisfied they are with the current situation.[32] About three-quarters of the interviewees were at least partially satisfied with their social lives, and only 23% were completely unsatisfied with their social relations.

Exploring this topic further, we examine three main aspects:

- Social interaction: A specific benefit or a wider context?
- Ambivalence about the desire for social relations
- Why social relations are difficult

6.1.1 Social interaction: A specific benefit or a wider context?

The interviewees described a variety of social needs, including both the number of social connections they wanted, and their desired intensity and content. Satisfaction was measured based on the correlation

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[32] This question was worded thus since different people (among those both with and without Asperger syndrome) define their social needs in different ways.

between the current situation and the desired end-result, not the quantity or intensity of existing relations. Some interviewees stated that they needed social relations solely to satisfy a concrete need:

> *I have about five or six friends. I see them once a month, or once every two months. It's a shame, because I'm all alone on weekends, and it's painful in a certain way, and it's a shame (Nadiv, 27).*

Nadiv's satisfaction is measured according to the extent to which a need is satisfied during his free time, whereas Noam and Avi distinguish between friends and people with whom they can have fun during their free time:

> *I don't necessarily consider everyone I hang out with a friend. You know that someone is a friend if he's there when it counts, and not because I hang out [with him] (Noam, 23).*
>
> *I don't really have any friends... I guess there are people that I could go to a movie with, but I haven't seen the point in doing that (Avi, 25).*

These diverse perceptions of social life explain why different people are not equally satisfied with the same social situation, and consequently, why each person sets different goals for themselves. A person who seeks social relations in order to realize concrete goals will be satisfied to the extent that their relations meet their day-to-day, substantive needs. Conversely, a person seeking a friend "who is there when it counts," to help navigate the more complex challenges in life, would not be satisfied just by having people in their life who answer their immediate needs, such as going to a movie with them once in a while.

6.1.2 Ambivalence about the desire for social connection

Satisfaction is also affected by the desire to be part of society and the desire to be alone, and interpersonal variance exists here as well. Interviewees who expressed an unequivocal desire to be part of society also spoke about how frustrated they were with their current social situation, while those who presented complex positions tended to have come to terms with their social situation.

> *I'm not someone who always needs to be surrounded by other people. I'm happy with having a few good friends that I talk to*

> *here and there on the phone, and I don't need anything beyond that (Nitzan, 20).*
>
> *I think that the main feature of Asperger's syndrome in my case is the social difficulty, but I can't alleviate it. It isn't that I'm always miserable, because I also like it when it's quiet, and when I'm alone (Neri, 28).*

6.1.3 Why social relations are difficult

Regardless of the differences in their needs, and in the types and intensity of relations they seek, the majority of the interviewees expressed interest in having social relations, and shared their struggles with developing and maintaining them. The interviewees described a number of difficulties:

6.1.3.1 **Passiveness and helplessness**

> *Generally speaking, I don't know how to initiate social relationships. Usually, it's the others that initiate (Elad, 24).*
>
> *[In response to my question of "Would you like some friends?"]: Yes. [In response to my question of "Are you doing something about it?"]: Not really, there isn't anything I can do about it. How can I make friends? Should I put out an ad saying that I'd like friends? (Michael, 25).*

6.1.3.2 **Fear of being used**

> *[I have] friends, here and there, you know, but not at any price. After what I've been through, really, not at any price. Who says that the people I meet today won't hurt me later? So today, I'm a skeptical and suspicious person, in light of what I've gone through (Naama, 25).*
>
> *Today, I'm more capable of contemplating, and asking myself who the person is and if we share a common language, [and telling myself] that this isn't just someone who is trying to use me (Jon, 29).*

6.1.3.3 **Life habits and gaps created over the years**

> *[The interviewee says that he has two friends he's in contact with over the phone. In response to my question of "Are you OK with this?"]: I think that it's hard to answer that question, because, you know, at a certain age, you get used to something. When you're 20, you're still open to ideas, but at my age, you're already set [in your ways]. You are the person that you are. You can't change it. Let's put it this way: even if I meet new people, at my age, I won't have any way of communicating with them. Almost everyone will be married. They will have had friends for many years. They are people who know how to interact with others. They know how to initiate and create, and in these cases, you sit, and you don't have anything to add or share, and you feel the way I've felt all my life—like some kind of outsider (Netanel, 35).*

Feelings of helplessness and passivity and the fear of being hurt or used reinforce each other and create a cycle of fears and aversion of creating social contacts. Over time, this aversion has led to gaps between the interviewees and others their age.

6.2 Social groups and therapy groups

6.2.1.The reasons for avoiding social interaction in a group

> *[Social interaction is an area] that needs major improvement. Unfortunately, my skills are quite good, relatively speaking. [In response to my question of "Why unfortunately?"]: Because I could have done better, but there's something deep down that holds me back, and there's something that keeps getting lost. I need a framework that would set boundaries, and maintain the connection with the person for me. Although I have a friendly or informative relationship... you need a framework to preserve the more personal relationship... I'm swimming, and not swimming. I'm not drowning, but I'm not swimming well (Yifat, 35).*

Despite the need for a “framework that would set boundaries,” over 60% of the interviewees do not participate in a social group or in group therapy. Most have participated in such groups in the past. Two main reasons emerged for why interviewees do not participate in social groups:

6.2.1.1 **Interpersonal variance**

As described above, significant interpersonal variance can be noted among the interviewees with respect to their social needs, both in terms of the intensity and frequency of the desired social relations, and of the relations’ character—whether a romantic relationship, friendship based on a specific interest, or general social companionship. As such, even in a group where common ground should be apparent, members have the experience of being different and not belonging.

> *For many years, I’ve been trying to figure out where I could create social connections... I went to all sorts of groups, and it doesn’t really... I feel that it’s a little below me (Baruch, 27).*
>
> *I felt that everyone in the group understood each other, I felt that they were more successful than me, I felt that we didn’t have the same problems (Nadav, 31).*

6.2.1.2 **Stress from group settings and a preference for private settings**

For some interviewees, participating in a social framework is like jumping into the deep end of a pool:

> *Over the years, I tried out groups, but I never related to them. I feel that trying to work with a group is really hard for me. I do well working one on one, but a group becomes too stressful for me (Avinoam, age 31).*

Coping with social difficulty can be done in a group setting. However, if a negative experience in a group setting isn’t sufficiently processed or followed up, the participant ends up disappointed and loses the motivation to try again.

6.2.2 The benefits of trying social groups

Those who manage to overcome the hurdles described above also mention a number of ways they benefitted from participating in groups: friendships were created within the group which endured outside of the group setting as well, participants met partners for new relationships, and there was an opportunity for corrective experiences to help overcome previous situations in which they had experienced rejection.

> *I had lots of social problems. I tried to buddy up with people, and I felt that they were always rejecting me. When I joined a social group, I felt that things had changed for the better. Suddenly, I was busy looking for time to meet friends and setting times to meet and have fun (Tamar, 30).*

6.3 Relationships

> *You could say that the difficulty I have with relationships is like my social difficulty, taken to a new level. I'm afraid of approaching people. So how can I try to flirt with someone if I'm afraid of approaching people, for more modest reasons? Do you know what I mean? I'm not very knowledgeable about these things. A few years ago, I thought that flirting is synonymous with sexual harassment (Dan, 23).*

Nearly 50% of the interviewees stated that the area they feel is most lacking in their lives is having a relationship with a partner. About half of the interviewees said that they have been in a relationship in the past. Only 15% of them are currently in a relationship. Apparently, within the realm of social interaction, relationships are the most frustrating and more urgent issue for the interviewees. As we heard from Yitzhak, who is quoted above, relationships are an area akin to general social interaction, but with a greater degree of complexity. All of the difficulties described above concerning general social relations—including ignorance of how to initiate, a tendency to be passive, the fear of being used, and ambivalence toward social contact—are encountered and magnified in relationships. Interviewees described a number of difficulties in this context:

6.3.1 Ambivalence about wanting to be in a relationship

> *[In response to my question of "Would you like to be in a relationship?"]: That's something I ask myself. It's worth mentioning that it's hard, that one of the struggles a person goes through is trying to understand what he or she really wants, and I'm still not sure what I really want (Nitzan, 30).*

6.3.2 Tension between the desires for personal space and for intimacy

> *On the one hand, I have a hard time thinking about the concept of commitment, because I still want to have my own space. On the other hand, what I had, the intimacy, was good (Ilan, 28).*

6.3.3 Difficulty deciding whether there's a match

> *I'm not even sure about how I can decide whether someone is right for me, based on what and how you meet people, so I don't know (Yaniv, 24).*

6.3.4 Difficulty learning from past experience

> *They always dump me after a month, none of them lasted more than a month, they all [ended] within four weeks. It's as though they've been in contact over the internet, as if they're corresponding... (Dani, 36).*
>
> *A few years have gone by since we broke up. I went through a tough time of not knowing why. What was it that broke her and made her dump me? I still don't know today (Raanan, 28).*

6.3.5 Passive approach

Ambivalence about wanting an intimate relationship and the difficulty in finding a compatible partner can explain a passive approach to relationships that was observed.

> I don't "run after" this. I'd like it, but you won't find me going out of my way, for better or for worse (Yarden, 35).

6.3.6 Active yet ineffective approach

> I went on many dates. Mom laughs and says: “I see that you’re not giving up on this.” Like a train without brakes that keeps on going (Maayan, 33).

6.3.7 Suggestions for coping with relationship difficulties

A number of interviewees suggested methods they had developed for dealing with relationship difficulties:

6.3.7.1 **Learning and practice**

> *I still have difficulties [with relationships], I think that the best way to learn how to deal with social circumstances is simply to experience them. There’s the aspect of learning how things technically work, and then, implementing them (Natan, 21).*

Natan suggests a two-pronged approach: studying the technical aspects of how to behave when in a relationship, and then, implementing this behavior.

6.3.7.2 **Talking and listening**

Another aspect that requires learning and practice, which already comes into play during the stage of getting acquainted, is speaking and listening at the appropriate times.

> *Maybe I come and talk about things I shouldn’t. Tactless... it could be that I’m not paying attention. Eventually, I started to accumulate more experience, OK, listening more and talking less. But not to keep completely quiet, because then, the other side won’t get to know you (Maayan, 33).*

The technical study of the rules of communication and striking the right balance between talking and listening, as well as gaining practical experience, and, following an encounter, investigating what went well and what could be improved—all these can help improve interpersonal skills, particularly with relationships. People with Asperger syndrome often need to actively study the kind of social communication that comes intuitively to other people.

6.3.8 Coping when in a relationship

Despite the difficulties interviewees described in finding a partner and maintaining a relationship, a number of interviewees were in a long-term relationship, and a few of them were even married. Orit's experience demonstrates the unique nature of relationships involving people with Asperger syndrome.

> *I've been dating someone, who also has Asperger's, for a few years... [In response to my question of "How is the relationship going?"]: It's going well. Generally, I'm the one who calls him, not the other way around. We usually go on a date once every few months. We go to some shopping mall, walk around in the stores a bit, and talk about all kinds of things. But I'm really happy with him. He might have Asperger's, but he's an amazing guy. We talk on the phone once or twice a week (Orit, 30).*

Orit is the one who takes the initiative in her relationship, and this helps compensate for her partner's passivity. She says that she's very satisfied with the intensity of the relationship, which involves a phone conversation once or twice a week, given how it has developed over time.

> *It's a very significant achievement. Listen, when I met him, we would only talk once a month, just so that you understand what a significant achievement this is, at least for me.*

Once again, this example illustrates why the important question is how satisfied a person is with the relationship, and not how objectively intense it may be. Orit tells us what she likes in her partner:

> *Even though we have completely different core interests, we can each tell the other entire stories about our own areas of interest, without the other cutting off our train of thought with irrelevant questions.*

Orit mentions an important tip for people who want to be in a relationship: you must be able to listen and give your partner the feeling that you aren't "cutting off their train of thought," even though she knows that her partner's interests are very different from her own. For Orit, the ability to find space for her partner and his interests has proved rewarding. The intensity and pace of their relationship illustrate how important it is to be open and respectful to the needs and desires of people with Asperger syndrome in the field of relationships as well.

6.4 Discussion: Social life and relationships

The interviewees' attitudes toward the social realm are complex. A gap exists between their desire for social interaction, particularly romantic interaction, and their ability to obtain it. Interviewees expressed their ambivalence, helplessness, passivity and fear of being harmed or taken advantage of. Together, these create a cycle of fear and avoidance that prevents them from forming social interactions. Over time, this has led to gaps between the interviewees and others their age.

As in the fields covered in previous chapters, here too, it cannot be assumed that people with Asperger syndrome all have the same social needs. We observed interpersonal variation in terms of needs, relationship intensity, and successful communication methods within relationships.

Nearly 50% of the interviewees stated that what they feel is most lacking in their lives is having a relationship with a partner. The associated difficulties and the coping strategies surveyed demonstrate the need for guidance and facilitation during various stages of a romantic relationship: assessing the particular type of relationship the individual is interested in; assessing and practicing various ways of meeting partners; developing and maintaining the relationship itself; and, if the relationship fails, being able to learn lessons for the future.

With regard to social life and relations, too, when dealing with people with Asperger syndrome, an open and respectful approach toward interpersonal variation and to the unique natures of their relationships (particularly, romantic relationships) is very much in order.[33]

Many interviewees could benefit from group settings in which they could become acquainted with other people, practice social skills, and enjoy their leisure time. However, most of them do not participate in any

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[33] The intimate aspects of romantic relationships are worthy of a separate discussion, though they are not discussed in this study.

kind of group framework. Again, the reasons interviewees specified are related to interpersonal variance, in terms of both function and desired content.[34]

Thus, the preliminary stage before arranging for participation in a group setting should include specifying social needs and identifying goals—for example, is the individual in question seeking to have fun in their free time, enrich a particular professional subject area, meet others with the aim of forming an intimate relationship, practice social skills, or some other goal? This type of assessment makes it possible to form groups around specific subject areas that the group members are interested in. Potentially, this type of approach can offer new opportunities for improving the social lives of those—like 60% of our interviewees—who do not participate in any social group.

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[34] See sections 6.1.1, 6.1.2, and 6.2.1 above.

7. Conclusion

> *Their minds are not alike, and their faces are not alike (Babylonian Talmud, Tractate Brachot, 58a).*

This report looks at various aspects of the lives of people with Asperger syndrome: receiving a diagnosis and obtaining certification from relevant authorities; their general life function and instrumental activities of daily living (IADL); and their abilities and desires concerning housing, employment, and their social lives (with an emphasis on relationships). The diversity and uniqueness of each of the interviewees in this study are consistently reflected throughout the report, which reveals an interesting pattern: the interpersonal variance in each area is great, and the study could not identify one particular area which the majority of the interviewees found difficult. Each individual has different levels of functioning across various areas of life, and their functioning in any given field cannot be predicted based on their functioning in any other field.

> *I know that there's a spectrum, and I looked at the entire spectrum, and I didn't see myself anywhere (Daniel, 28).*

A certain tension exists between the study's objective of presenting and characterizing the specific needs and abilities of people with Asperger syndrome, and this interpersonal variance, which defies generalizations, and which itself can be considered as characteristic of people with Asperger syndrome. This gives rise to the need to develop detailed maps of these individuals' needs, aspirations, and abilities. On the functional level, these maps must be created without assuming that an ability to execute complex tasks guarantees an ability to execute simpler tasks. On the social level, mapping should bear in mind the variance in different people's needs and in the type of relationships they seek. In terms of setting goals, mapping should be done without presuming that the individual has the same needs that we are familiar with from our own life experience, and should also emphasize and respect the right of every individual to choose priorities that reflect their own values and abilities.

In many subject areas, the study revealed a need for flexible services that can meet different needs at different periods during the individual's life. In terms of employment, this flexibility needs to extend to intensive intervention at times of crisis as well as zero intervention during long periods when the individual requires no assistance. With regard to housing, intensive intervention may be needed when an individual leaves their parents' home, or to help them acquire life skills, but minimal intervention is necessary during other stages of life. As for social interaction and intimate relationships, skills should be taught, while individuals also need to engage in practice and learning from past experience.

> *For most of my life, I was very confused about what I could do and what I did well, and in hindsight, I believe that early diagnosis and early placement are the two most important things that can be done (Amihai, 31).*

This study sheds light on a group that is not well known; one with great potential, yet which struggles to fulfill that potential. This group has grown significantly over the past few decades. It presents us with a double challenge: listening to those who are different, without any preconceptions or prejudices based on our own personal experience; and establishing flexible services that can adapt to the needs of a population that encompasses considerable interpersonal variance. Ensuring the provision of these kinds of flexible interventions could make a significant contribution to this group fulfilling its considerable potential. This would have a broad impact, helping these individuals feel more personally fulfilled and improving their physical and mental states, while also reducing the burden shouldered by relatives and society at large, and making this group significantly more productive.

Possible Directions for Future Study

This needs mapping is a groundbreaking study, in that it paints an overall picture of the trends within an unfamiliar group. However, it does not discuss patterns characteristic to particular sub-groups or individuals. Future studies might define and examine subgroups, for instance, based on co-diagnoses, or according to age groups, gender, or other characteristics. These important explorations exceed the scope of this study.

8. Appendices

Appendix 1: Questionnaire for Subjects with Asperger Syndrome

Hello,

This questionnaire is worded in the masculine, but is addressed to both men and women.

It is the product of a joint initiative of the **Asperger–Israel Association** ("Effie"), JDC Israel, and the Ministry of Social Welfare.

Our objective is to develop new services for adults with Asperger syndrome to help them with their social lives, employment, and housing. We are therefore asking you for details about yourself concerning these subjects.

You do not need to fill in the entire questionnaire.

The purpose of the questionnaire is to help us learn which of your needs are not being sufficiently met today. All of this information will be kept confidential and will only be used for the purposes specified above. Please circle your answers or write them out, as the case may be.

Thank you,

Yonatan Drori, questionnaire editor

Personal Details:

First and last name: ______________________________________

Gender: Male/Female

Date of Birth: ____

E-mail address you can be contacted at: ______________________

Phone number: ____

Diagnosis and Certification by the Authorities

This chapter discusses the issue of whether you were diagnosed with Asperger syndrome, and the diagnosis and certification procedures.

Have you been diagnosed with Asperger syndrome? (If another diagnosis has been made, please specify.)

Yes/No/Other: ____

____

Where were you diagnosed? By whom? _____________________

____

____

How old were you when you were diagnosed?

Under 5 / Aged10–5 / Aged 11–14 / Aged 15–18 / Aged 19–21 / Aged 21 or over

If you were not diagnosed with Asperger Syndrome, why not?

I went to the psychiatrist, who said that I do not have Asperger Syndrome / I am in the process of being certified with Asperger, and it isn't over yet / I don't want to be certified / other:

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____

Are you certified as having Asperger syndrome by the Ministry of Social Welfare?

Yes / No / I don't know

Are you certified as having Asperger syndrome by the National Insurance Institute?

Yes / No / I don't know

The certification process: please describe the certification process.

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____

Have you been diagnosed with anything else?

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____

Were you originally diagnosed with something else?

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____

If so, what was the diagnosis? You may use this space to specify any details you consider relevant to the certification process.

____

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____

____

Did you need assistance with the certification process? Did you receive assistance? If so, from whom?

Yes, I received help from my relatives / Yes, I received help from my relatives and the Ministry of Social Welfare / Yes, I received help from the Asperger–Israel Association (“Effie”) / Yes, but I did not receive any help / I didn’t need any help / other:

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____

Do you have any suggestions for how to help someone in the process of certification?

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____

Housing

Current housing status:

Living with my parents / at a hostel / through a special housing arrangement (apartment in the community, a satellite apartment, etc.) / living independently with roommates / living on my own / other:

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____

Where have you been living until now? Please specify the places you have lived in and the reason for moving between these places.

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Please elaborate as much as possible about your current daily routine (cooking, cleaning, laundry, etc.).

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Do you do these things on your own? Do your family members help you, or do these things for you?

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Where would you like to live, and why (would you prefer to live in an urban or a rural setting)?

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Have you considered living in a hostel or housing arrangement tailored for people with Asperger syndrome? Please specify the reasons why you do not live in a hostel.

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Education

What is your educational status?

High school with no matriculation / high school with partial matriculation / high school and full matriculation / studying for my bachelor’s degree / have earned a bachelor’s degree / studying for a master’s degree / have earned a master’s degree / studying for a PhD / have earned my PhD / other:

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____

Would you like to study in the future? If so, please specify what you would like to study.

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Workplaces and Volunteering

Current Employment:

Working for pay in the open labor market / working for adjusted minimum wage in the open labor market / working at a sheltered workshop / volunteering / I do not work or volunteer / other:

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How did you find your current job?

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____

Current employment: Please describe your current job.

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Previous job experience: Please describe where you have worked or volunteered in the past. Please specify the circumstances in which you stopped working, and describe your experiences as a worker.

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____

Help with work: Did you need any help with finding a job or with learning what you needed to do? Did you receive assistance? If so, from whom?

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____

Please describe your ideal workplace.

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Social Interactions

Interactions with friends: are you satisfied with your social interactions?

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What would you like to see happen with them?

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Do you participate in any social group activities? ________________

What are they?

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When was the last time you went on a trip with friends? Please provide details.

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Relationships: Please describe your past and present relationships.

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Mobility and Independence

How do you travel from one place to another?

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Do you have a driver's license? Do you ride the bus or take taxis? Do your parents drive you to places you need to go to?

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____

Did you ever need a facilitator or assistance with receiving various services (from the Ministry of Social Welfare, the National Insurance Institute, a health fund, income tax, a bank, a cellular phone company, the broadcasting authority, etc.)? Would you like help in this area?

____

____

____

____

Health

When you are sick and need to see a doctor, what do you do?

I go to the doctor's office alone / A family member or someone else accompanies me to the doctor / Other:

____

____

____

____

When you get a prescription for medication, what do you do?

I go to the pharmacy and buy the medication / Someone else buys the medications for me / Other:

____

____

____

____

Do you take medication on a regular basis? If so, please specify how the medication is administered. (Do your parents give it to you? Do you take medication on your own?)

____

____

____

____

Do you ever forget to take your medication?

I seldom forget (about once a month) / I forget occasionally (up to once per week) / I often forget (at least once a week)

How often do you see a psychiatrist for a checkup?

Once every six months / Once every three months / Once every two months / Once a month / I don't see the psychiatrist on a regular basis.

How often do you see a general practitioner for a checkup?

Once every six months / Once every three months / Once every two months / Once a month / I don't see a general practitioner on a regular basis.

Would you be interested in having someone you could speak to regularly, someone who can listen to you? What kind of support would you like from this person?

____

____

____

____

Aspirations for the Future

What are your aspirations for the future?

____

____

____

____

What is the most important thing that you lack today?

____

____

____

____

In your case, what is the main way that Asperger syndrome is expressed?

____

____

____

____

Are there specific subjects that you weren't asked about, which you would like to elaborate on? If so, please specify them here.

____

____

____

____

How would you describe your experience with filling out this questionnaire?

____
____
____
____
____

Thank you for dedicating time to fill out this questionnaire.

Yonatan Drori, questionnaire editor

Appendix 2: Supported Housing

The Supported Housing program was developed under the auspices of JDC Israel's Israel Unlimited program (a partnership between the Israeli government, JDC Israel and the Ruderman Family Foundation), in partnership with the Ministry of Social Welfare's Department for the Rehabilitation and Provision of Services for Persons with Autism and PDD, and with local authorities. The program's objective is to help young people who are interested in moving out of their parental home or an institutional setting to an independent apartment, but who are struggling to do so on their own. It is also designed to help those who have already moved out and are living on their own, and acclimating to their new environment. The program helps participants to find an apartment and acquire skills associated with running a household and other life skills, and also provides support in the absence of a personal care-giver.

Currently, the program serves people aged 20-50 with severe physical disabilities, mild cognitive disabilities, and high-functioning autism (Asperger syndrome). Program participants are eligible for augmented support sessions for six months (about six hours per week), and receive regular services for the remainder of the time (about three hours per week). The team responsible for providing support is made up of a treatment coordinator and an independent living coach. Treatment coordinators maintain regular personal contact with program participants and work with them to develop and implement a personal plan. The independent living coach supports the participant in various areas. Participation in the program costs participants NIS 50 a month.

Before extending the program nationwide, it was decided to conduct a pilot study in three regions, with services being provided to 25 participants in each region. Services are provided through three contracting organizations:

- The Northern Region (Nahariya, Kiryat Yam, Haifa), managed by Kivunim (a non-profit organization).
- The Central Region (Ra'anana, Ramat Hasharon, Ramat Gan, Herzliyah), managed by Ednam Ltd.
- The Southern Region (Ashdod), managed by Slav Ltd.

This program is expected to expand into ten regions during the first phase, and a further geographical expansion will follow.

The pilot study began in 2012, and as of 2013, 30 people aged 30-40 were participating in the program. Six of the participants were already living independently in an apartment, and joined the program to receive support that will allow them to complete the process of integrating in the community. Seven of the participants have transitioned to independent living through the program, and 17 participants are preparing for this transition. Most of the participants had lived in their parents' homes before moving to their own apartment, and a few had been living elsewhere.

Appendix 3: Interviewees’ Place of Residence

- Beer Sheva and the south—3 (3.75%)
- Haifa and the north—16 (20%)
- Jerusalem and environs—9 (11.25%)
- Tel Aviv and the central region—52 (65%)

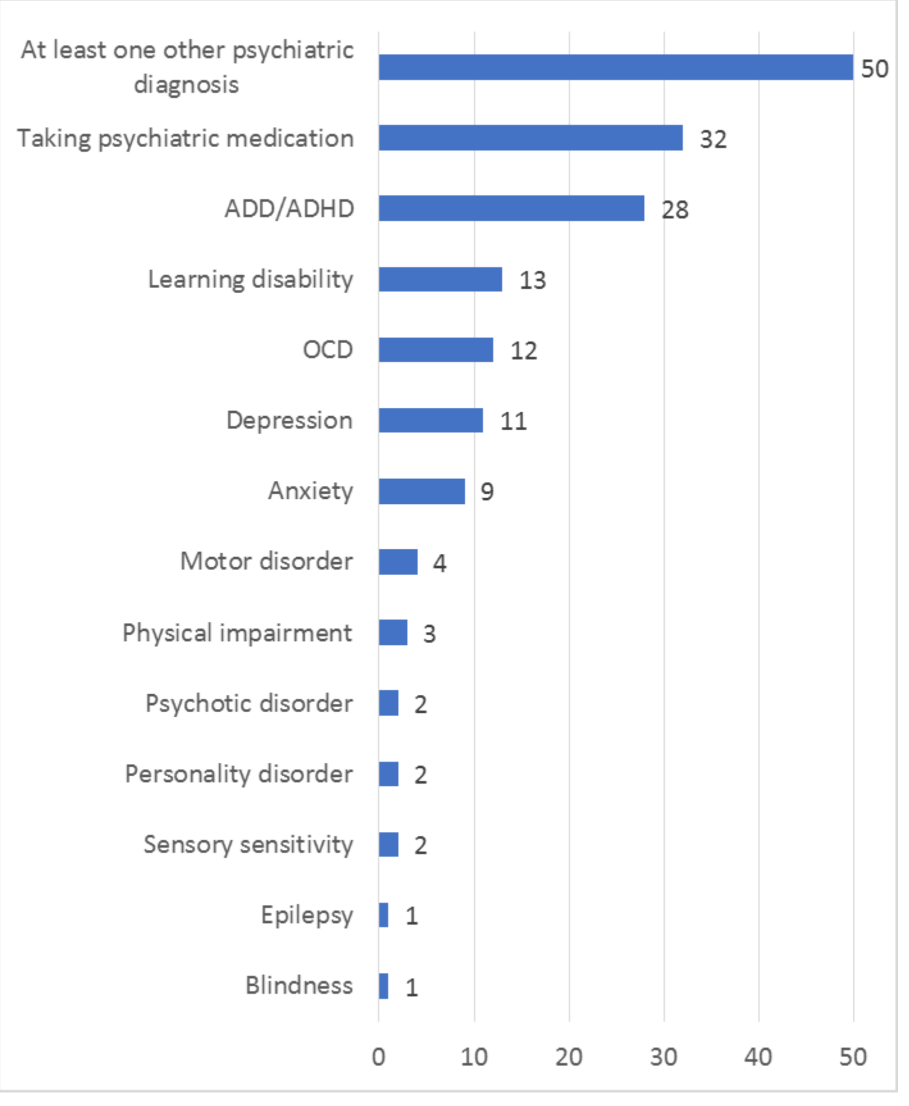
Appendix 4: Other Diagnoses

Of the 80 interviewees in this study, 50 (62.5%) reported that they were diagnosed with at least one other psychiatric condition: 28 (35%) reported having an attention deficit disorder (ADD/ADHD); 13 (16%)—learning disability; 12 (15%)—obsessive compulsive disorder (OCD); 11 (14%)—depression; 9 (11%)—anxiety disorder, 4 (5%)—motor disorder, 2—psychotic disorder; 2—personality disorder, 2—hypersensitivity disorder; 1—epilepsy; 1—blindness; 3—other physical disability.

32 interviewees (40%) reported that they were taking psychiatric drugs.

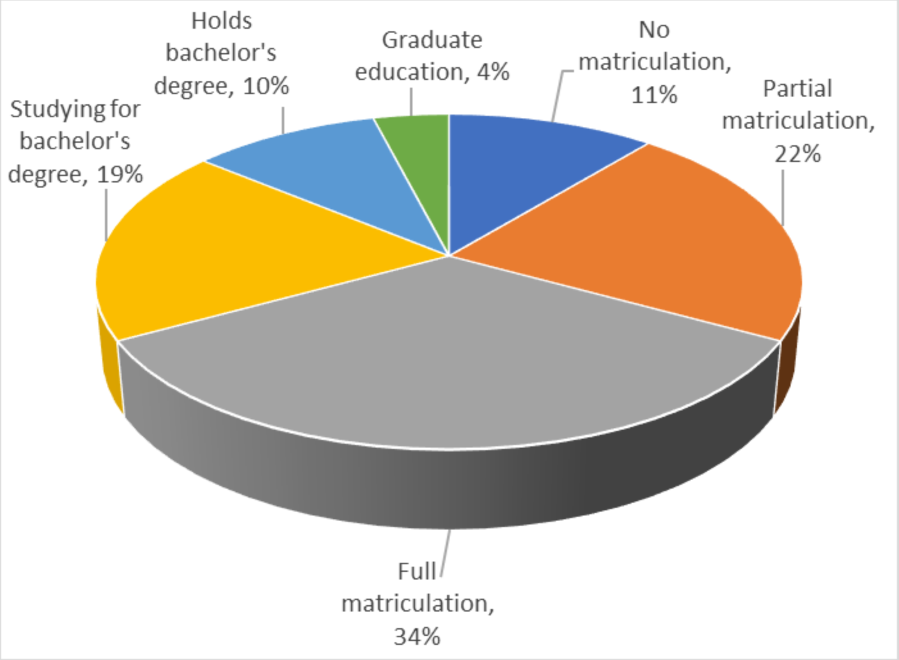
This data is consistent with what we know from the professional literature (see the overview in Ghaziuddin, 2002).

Figure 9. Other diagnoses (N=80)



Appendix 5: Education

Figure 10. Education data (N=80)



21% of the interviewees reported having undergone professional training outside of high school or academic studies (e.g., courses run by the Ministry of Labor, culinary training, etc.), and possess professional certification.

Appendix 6: Housing

Figure 11. Interest in leaving parental home (N=55)[35]

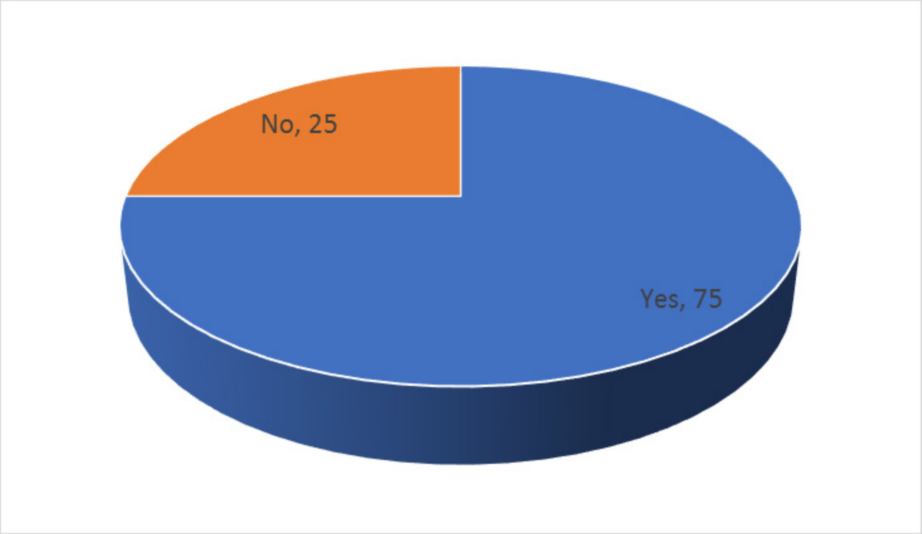
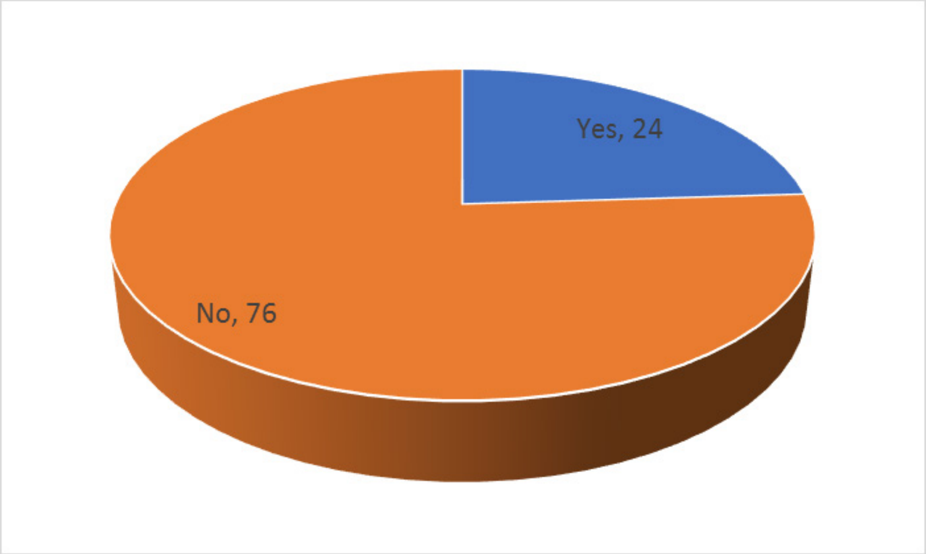


Figure 12. Would consider living in a community living setting (N=54)[36]



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[35] Two interviewees living with their parents did not respond to this question.

[36] Three interviewees living with their parents did not respond to this question.

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