KEPAKY

THE ANDREAS SOFOCLEOUS CENTRE FOR THE PROVISION OF SOCIAL SERVICES

JOINING HANDS CREATING JOY

A Practical Guide for Individuals with Autism in Cyprus: Rights and Provisions from Governmental and Non-Governmental Services.

A Practical Guide for Individuals with Autism in Cyprus: Rights and Provisions from Governmental and Non-Governmental Services.

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FOREWORD

This project is dedicated with much love to all of you, parents, friends, professionals, who have in one way or another stood by individuals who have Autism Spectrum Disorders.

The development of this handbook resulted from a global approach to the issue, with the involvement of specialists from the private and government sector. This project contains a collection of necessary and valuable information, while at the same time it brings together the viewpoints and experiences of the parents, a fact which undoubtedly renders this guidebook more alive and richer. Our intention, after all, is to stay informed and update our guidebook via the internet.

For our foundation, the present guidebook was a vision which has now been realized. From the bottom of our hearts we hope that it will be an effective and useful tool for all. As Paolo Coelho once said: "…no man is an island, isolated in the middle of the ocean. He must discuss his strategy, ask for help". Thus, we assure you that you are not alone. The Andreas Sofocleous Centre for Provision of Social Services (KEPAKY) and its friends have long been sensitized to the issue of autism and are ready to be your respectful co-travelers on this path of life.

The Founder, Andreas Sofocleous

And the President of the Board of Directors, Azucena Sofocleous

"Joining hands, creating joy"

"Vivir no es sólo existir, sino existir y crear, saber gozar y sufrir y no dormir sin soñar…"

Gregorio Marañón (1887-1960) médico y escritor español

Dear Parents, Friends and Teachers,

It is with great pleasure that we welcome this project, which aims to help and guide parents, friends, teachers and case workers. It is a project of which the development was indeed very important, as it explores a specific issue which unfortunately, to date, no one has focused on, dedicating the necessary time to bring it to fruition. For this reason, we extend a heartfelt thank you to Kepaky, which on its own initiative moved forward to create this important work. From the moment it became acquainted with us, Kepaky embraced the Cyprus Association for Individuals with Autism and has been by our side in every practical way to this day. One part of this practical support is the establishment of the Specialised Centre for Sensory Integration which was created to offer treatments to children and adults with autism.

In closing, we would like to thank all those who contributed to the latter. Special thanks go to the Founder of Kepaky, Mr. Andreas Sofocleous, the President of the Board of Directors, Mrs. Azucena Sofocleous and all the board members for their huge contributions towards children with autism and their families.

In the past year, the Cyprus Association for Individuals with Autism has had the opportunity to visit Israel and get informed about the services that are available for children and adults with autism. We hope and pray that the relevant government services, which traveled along with us, will not leave all that we have gained from our trip to go unutilized and instead put it into action, giving our children what they need, that is education, treatment, vocational rehabilitation, occupation and care so as to lead a dignified life within society. This experience has provided us with a model to which to aspire to.

In closing, we would like once again to extend our gratitude to Kepaky, which made the decision to continue to provide its support to our Association throughout the year 2013 in a very significant way, in the area of ‘family psychological support’, which is considered a necessary component of our work but one that unfortunately as an Association we were unable to provide until now. This contribution is huge and we are certain that it will alleviate the pain experienced by many parents and provide them with the strength to continue their daily struggle.

Tasoula Georgiadou

President of the Pancyprian Association for Individuals with Autism

ACKNOWLEDGMENTS (1st edition, 2011)

The Andreas Sofocleous Centre for the Provision of Social Services would like to give special thanks to all those who helped create this guide. The contributions of all involved were instrumental to the preparation of this work. We owe a huge thanks to the President of the Pancyprian Association for Individuals with Autism, Mrs. Tasoula Georgiadou, for the undivided help and support she offered to us. At the same time, the Board of Directors, the staff and members of the Association took part in essential ways throughout our efforts. We extend special thanks to Dr. Christos Christofi, for his cooperation and the valuable information he provided us with, and Maria Kyriakou, Child-Psychologist for the help and support she gave so openly. In addition, thanks go to the various government officers and particularly Mrs. Maro and Mrs. Christiana for their valuable help, as well as to the various professional associations which helped us by providing us with useful information. In addition, we would like to thank Chrystala Neofytou for editing the document. Moreover, we would like to give special thanks to the therapists, who, via personal interviews, informed and guided us regarding all the treatments they provide. Thanks also go to Christos Psindros who helped us in designing the cover of the guide, and the company and staff of Simplex who helped us to upload the guide on the Kepaky webpage. A huge thank you also goes to the parents who took part in our research and completed interviews – their personal experiences helped us complete the guidebook. The parents of children with autism are unsung heroes who battle every day in order for their children to have a dignified life.

Additional acknowledgments for the second edition 2013

Kepaky continues its social activities around the issue of Autism. It is with great pleasure that we are able to extend this guidebook and keep it alive by enriching and revising the information it contains.

In order to make the revision of this guidebook possible, we utilized the support of various individuals and organisations, both private and public, including those mentioned above, which we wholeheartedly thank. In particular we would like to thank the ministries of Education and Culture, Labour and Social Insurance, Health, the child-psychologist Dr. Costa Fransi and the Institute of Genetics and Neurology. The co-operation of all these individuals helped us attain and implement our goal.

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1.0 INTRODUCTION

The Andreas Sofocleous Foundation for the Provision of Social Services ‘Kepaky’ was founded in 2008 on the initiative of the Andreas Sofocleous Group of Companies, registered as number 268 in the Registrar of Associations and Societies, with the aim of continuing in a more modern but also organized way, its social, culture and charitable offerings. Kepaky is a not-for-profit organisation comprised of an eleven-member board of directors which offers its services on a volunteer basis to those who are in need. Kepaky’s activities are focused around four basic poles: **Autism, Social Integration, Prevention against the use of addictive substances, and Study grants.**

As far as Autism is concerned, in its short history so far, Kepaky has already made its presence known, always working closely with the Cyprus Autistic Association.

Kepaky’s activities are both variable and noteworthy. Its largest achievement with regards to Autism is creating and equipping the Model Centre for Occupation, Care and Treatment. As of October 2010, we have handed over the management of the Centre to the Cyprus Autistic Association.

Following this, and having observed the need for parental awareness in terms of legislation, provision, grants and other rights, Kepaky took the initiative to create a guidebook. Specifically, the guidebook contains useful information with a special focus on treatments, services, legislation, European Union documents, the rights of these individuals and the procedures necessary to claim these benefits.

The first guidebook was prepared after performing social research, which was conducted methodically and professionally by the sociologists of our foundation. At the initial stages, qualitative research was conducted to confirm the empirical knowledge of the foundation and to gather further information, which required personal interviews with special therapists, doctors, government workers and parents of children with autism. The information gathered was categorized and split into separate units. The information in each unit which has been rechecked was obtained from reliable, scientific sources.

As the first year since the creation of the guidebook came to an end, and after communicating with the relevant services, we observed that a lot of the information needed to be amended. After all, this was to be expected, since our aim was to review the guidebook in order for it to be up-to-date with new empirical data. And so began the process of revising the guidebook.

Keeping in mind the significance of the literature, the new information was derived from various, very recent, valid and reliable sources from within the last years. At the same time, aiming to improve the guidebook in the best way possible, we combined a professional way of writing with a simpler one, by including tables illustrating the main points of each subsection. The point of this adjustment was to make the guidebook as useful and as accessible to both parents, and professionals who work with these disorders.

A very pleasant fact, which comes from dealing with the topic of Autism over the last years and particularly through creating this guidebook, is the experience and knowledge that Kepaky has gained on ASD. The result of this experience is that the Foundation has become a beacon which receives this information and emits it outwards, in the form of a very reliable document.

The guidebook is available online so as to be accessible to all. The revision of the guidebook and inclusion of new information will be completed when deemed necessary.

2.0 AUTISM SPECTRUM DISORDERS

2.1. The concept of Autism and its development

The term autism was first used by psychiatrist Eugen Bleuler in 1911. Initially he referred to an essential anomaly of the psychic world, that is, a drastic limitation of relationships with people and the social environment, a limitation so extreme it appeared to abandon everything, except for the self. The restriction of these relationships could be described as a withdrawal from the fabric of social life, accompanied by internalizations and withdrawal into oneself. The term was also initially used to describe some of the withdrawal symptoms in schizophrenia.

The term was reintroduced in 1943 by Leo Kanner in order to describe 11 children who had a very particular clinical presentation, which he named Autistic Disturbances of Affective Contact[1]. A year later, independently from Kanner, an Austrian pediatrician, Hans Asperger described children having a similar presentation, which he named Autistic Psychopathy in Childhood. Unfortunately his work, which was published in German, did not garner much attention until the '80s when it was discovered and translated by Uta Frith.

A long period then followed during which the concept of Autism was explored in depth and three main issues arose and were subsequently resolved:

a) The relationship with schizophrenia. Despite Kanner's objections, the two disorders were quick to be linked, with Autism being considered a childhood form of schizophrenia. The issue was finally resolved with Kolvin and Rutter's[2-3] studies, which illustrated that the disorders were discrete and not a continuation of one another.

b) The relationship between an early traumatic psychological event in the relationship of a possibly sensitive child and a 'cold' mother (parent). Despite his initial stand that "these children have come into the world with innate inability to form the usual biologically provided affective contact with people", Kanner himself moved on to this approach, where he considered the parents to be 'cold rationalists' and 'psychotoxic' with regards to the etiological basis of their child's disorder.

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[1] Kanner L. (1943) Autistic disturbances of affective contact. Nervous Child 2, 217-250

[2] Kolvin I. et al. (1971) I-VI articles on childhood psychoses. BJP 118:381-419

[3] Rutter M. (1972). Childhood Schizophrenia reconsidered. Journal of Autism and Childhood Schizophrenia, 2,315-337

A plethora of studies in the last 40 years have definitively rejected this approach and have proven not only that the etiology of the disorder is not psychogenic, but also that the parental style of parents of children with autism does not differ from that of children with other disorders.

c) The relationship with mental retardation. Although mental retardation often accompanies autism, it is not an interchangeable concept and also fails to explain the central difficulties of these individuals which seem to be independent of intelligence.

The resolution of the above issues allowed for rapid development of the concept: The developmental dimension of the disorder was confirmed in 1980 in the third revision of the Diagnostic and Statistical Manual of the American Psychological Association (DSM-III).

In 1979, at Camberwell, Great Britain, Lorna Wing's work brought forth the concept of a triad of difficulties which characterize Autism and form the basis for any type of conceptual understanding[1]. These difficulties concern social interaction, social communication and imagination (limited play, rigidity, repetitive behaviours and difficulties accepting change).

The triad is often accompanied by a restrictive and repetitive repertoire of activities, repetitive gestures and atypical reactions to sensory stimuli. In time, other similar disorders were added to the original Autism diagnosis, gradually introducing the concept of a spectrum of disorders which would capture the diverse nature of Autism, both on the level of clinical symptoms and severity and the limitations on the individual's functioning.

Main points

√ Autism comes from the Greek word "self".

√It was first described by Kanner and Asperger in the early '40s.

√It is now clear that it is not an early clinical presentation of Schizophrenia, cannot be attributed to early trauma (i.e. cold mother), and should not be confused with mental retardation.

√Autism is a developmental disorder which is characterized by difficulties in socialisation, communication and imaginative play (Wing's triad) It is accompanied by repetitive and stereotyped behaviours and gestures, as well as atypical responses to sensory stimuli.

√The diversity in clinical presentation and in the consequences to the individual's level of functioning is now captured by the concept of a spectrum.

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[1] Wing, L. & Gould, J. (1979), "Severe Impairments of Social Interaction and Associated Abnormalities in Children: Epidemiology and Classification", Journal of Autism and Developmental Disorders, 9, pp. 11-29.

2.2 Classification – Criteria

In contemporary psychiatry, disorders are classified on the basis of descriptive criteria in two main diagnostic systems which are regularly revised according to new data: that of the World Health Organisation and that of the American Psychiatric Association. At present, the most recent editions are the following: the International Classification of Diseases, 10th revision (ICD-10) and the Diagnostic and Statistical Manual, 4th edition, text revision (DSM-IV-TR). Regarding Autism, these two systems are extremely similar in the way they classify the disorder and the criteria they use (Table 1). However, as of 2013, the fifth edition of the Diagnostic and Statistical Manual will be complete, which will in fact be put in effect just before the 11th revision of the International Classification of Diseases. In the interest of staying up to date, in this guidebook we will refer both to the current classifications as well as the one that will replace them, namely the DSM-V.

Table 1. ASD in the classification systems

ICD-10	**DSM-IV-TR**	**DSM-V/ICD-11**
F84.0 Childhood Autism	299.0 Autistic Disorder	**Autism Spectrum Disorders**
F84.3 Childhood disintegrative Disorder	299.10 Childhood Disintegrative Disorder	
F84.5 Asperger's syndrome	299.80 Asperger's syndrome	
F84.1 Atypical Autism	299.80 Pervasive Developmental disorder not otherwise specified	
F84.8 Other pervasive Developmental Disorders		
F84.9 Pervasive Developmental disorders, unspecified		
F84.2 Rett syndrome	299.80 Rett Syndrome	
F84.4 Overactive disorder associated with mental retardation and stereotyped movements		

In the current systems, the term pervasive developmental disorders (PDD) is adopted in order to define a group of developmental disorders that are neither generalized, as in the case of mental retardation, nor restricted to certain areas of functioning, as the specific developmental disorders of language/communication, learning and motor skills. These disorders (with the exception of Rett syndrome) are also named Autism Spectrum Disorders (ASD), a term which reflects their relationship to classic autism disorder. The term ASD is in fact a forerunner for use in the revised editions of the two classification systems (DSM-V and ICD-11). To be given a diagnosis of Childhood Autism or Autistic Disorder, there must be at least six symptoms present from all three areas (table 2) and the onset of the disorder must be before the age of three.

Table 2. List of DSM-IV-TR criteria for Autistic Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
A_1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
A_2. Failure to develop peer relationships appropriate to developmental level.
A_3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by lack of showing, bringing, or pointing out objects of interest.
A_4. Lack of social or emotional reciprocity
B. Qualitative impairments in communication as manifested by at least one of the following:
B_1. Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime.
$B_{2.}$ In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
$B_{3.}$ Stereotyped or repetitive use of language or idiosyncratic language.
$B_{4.}$ Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
C. Restricted repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
C_1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in either intensity or focus.
$C_{2.}$ Apparently inflexible adherence to specific, nonfunctional routines or rituals.
$C_{3.}$ Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements).
$C_{4.}$ Persistent preoccupation with parts of objects.

Individuals with **Asperger's syndrome**, have equivalent difficulties in the social domain and with regards to repetitive behaviours and interests, however it is required that there is no language delay (although difficulties communicating will be present) and intelligence is at least borderline. If the criteria are not met either in number or type of symptoms, and/or age of onset, then a diagnosis of Atypical Autism or Pervasive Developmental Disorder, Not otherwise specified is given. There is the misguided perception that Asperger's syndrome and Atypical Autism are milder forms of the disorder. However, studies indicate that when the person's intelligence quotient is taken into account, classification within the spectrum is not considered a long-term positive predictor. Thus, the presence or absence of language development in individuals with ASD that are of similar intelligence (High functioning autism or Asperger's syndrome) does not condemn the outcome[1], while at the same time the number and severity of symptoms is not always accompanied by deficits in functioning[2].

In the extremely rare case that in the first two years of life there is normal development with regards to socialisation, communication, language and play, and the onset of loss of skills is observed after the age of three to four years old (definitely before the age of 10), with a clinical presentation that is similar to classic autism with some degree of mental retardation, then a diagnosis of **Childhood Disintegrative Disorder** (previously Heller's syndrome) is given. In this case, one must distinguish between this disorder and the phenomenon of 'developmental regression' which is seen in approximately 30% of cases with Autistic Disorder.

In the latter case, close to normal development (rarely is it completely typical) is observed with some subtle symptoms and/or delays up to around 18-24 months, at which point a gradual or sudden loss of skills occurs, which for the majority of cases concerns communication and language (in addition to other skills).

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[1] Howlin P. (2003) Outcome in high-functioning adults with autism with and without early language delays: implications for the differentiation between autism and Asperger syndrome. J Autism Dev Disord. 33(1):3-13

[2] Szatmari P, et al (2002) Quantifying dimensions in autism: a factor-analytic study. J Am Acad Child Adolesc Psychiatry. 41(4):467-74.

In the revisions[1] of the classification systems which are now underway (DSM-V & ICD-11), it is recommended that all of the above disorders be included in a single diagnostic category under the title ASD, since on the one hand, the distinction between the separate disorders is not being done in a consistent and valid manner, and on the other hand, these are defined by a common constellation of behaviours. In order for the general category of ASD to be specific to each person's clinical presentation, it is recommended that clinical definitions are used (e.g. severity, language skills and development and so on) as well as accompanying characteristics (e.g. mental retardation, epilepsy, known genetic etiology and so on). The three areas of symptoms are reduced to two, with communication and sociability being united into one, since it is difficult to distinguish between the two. Language delay is not exclusive to ASD, but merely one factor, and the decision to combine the two is supported also from the statistical analysis of large databases. The second domain encompasses the limited interests and repetitive behaviours, and for the first time sensory particularities are also included within it. Both areas are further defined by dimensional severity which is described in the criteria. The available criteria will be fewer and more limiting and examples will be given according to age and language level.

Regarding the clinical spectrum, a broader autism phenotype is also described which is characterized by mild behavioral characteristics concerning relative isolation, where this can also be found in the relatives of the patients (parents, siblings). The specific difficulties range from language and sociability, to personality characteristics such as rigidity, compulsions, routines, etc. The intensity level and the number of these symptoms will not be sufficient to give a diagnosis of ASD, but do suggest an inheritable phenotype or intermediary phenotype as indicated in genetic studies.

Main Points

√ The current classification systems distinguish between the various subcategories on the autism spectrum, such as autism, Asperger's syndrome, atypical autism, etc.

√ Contrary to common belief, this categorization is not indicative of the progression of the individual in terms of functionality (if intelligence is taken into account).

√ Since the distinction between categories is not supported by data from studies, in the new classification (2013) all cases will be included in a single category and named Autism Spectrum Disorders (ASD).

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[1] American Psychiatric Association DSM-V development: http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#

2.3. Clinical Presentation

Included among the core clinical characteristic of ASD is on the one hand, the diversity of presentation of symptoms and on the other hand, the significantly unequal and asynchronous development of skills. Regarding the area of socio-emotional development there are deviations with regards to the process of typical attachment, the ability for joint attention, theory of mind, comprehension and expression of emotions, insight, social reciprocity, imitation and lastly, in understanding two-way interactions. The difficulties in sociability are independent of intelligence and for the most part are qualitative in nature, rather than quantitative. Thus, the individual with ASD may be socially *withdrawn* (acting as if there are no others present), *passive* (with peculiar and inappropriate sociability) or *overly ritualistic and rigid* (faithfully following rules which are not truly understood).

The deficits in communication include a delay or absence of language development, frequently due to a difficulty in understanding the concept of communication and the opportunities that it can offer. While phonology and form of language is not affected in ASD, there are significant deviations in content (semantics) and use (pragmatics) of language. Thus, these individuals present with disordered non-verbal communication (limited gestures, inexpressive face, peculiar tone of voice – prosody), with literal understanding, particularly in usage of certain words and/or neologisms, difficulty in initiating and maintaining a conversation (particularly with regards to topics that are not included in their own special interests) and difficulty narrating and describing, having difficulties regulating that amount of information they need to use in order to be understood by others (at times giving too many details, and at others exhibiting telegraphic speech).

The third area includes limited and exceptionally specialized interests, which are excessively time-consuming, repetitive behaviours and routines, as well as stereotyped hand and body gestures, the absence of imagination and imaginative play (imagination and imitation, while construction games are not impaired), as well as odd reactions to sensory stimuli (hypo- and hyper- sensitivity). Other characteristics include self-harm, fixation on certain objects, resistance to change (both in their schedule and in their environment, odd posture and gait and unusual fears (often for seemingly insignificant issues).

The subjective cognitive characteristics include the high levels of stress experienced by these individuals, the inflexible and literal way of thinking, difficulty discerning between what is imaginary and what is real, a focus on detail, difficulty distinguishing between significant/insignificant and relevant/irrelevant in terms of information, difficulty generalizing what is learnt, a tendency to think more in terms of images and less so in terms of concepts, a difficulty in creating concepts and understanding sequences and their typically, exceptional visuospatial ability.

Attention may be exceptionally limited in focus (narrow ‘spotlight attention’), it may be difficult to switch focus or have extreme deficits, being easily distracted by internal and external stimuli. While visual memory is often extraordinary, other types of memory may be lacking, a frequent expression of the asynchronicity mentioned above. The same is also observed in the intelligence profile with extreme deviations, both between the verbal and performance IQ, and between the subscales of each of the scales.

Main Points

√ There is great variability in the clinical presentation of ASD, which renders each individual’s profile unique.
√ Socially, an individual with ASD may be withdrawn, passive, energetic but also odd or very ritualistic.
√ The development of language may be absent or delayed, and there may be issues in its content or use. Individuals with ASD present with difficulties in initiating or maintaining a conversation, narrating and describing events or situations, while their understanding of language is very often literal.
√ They have difficulties in non-verbal communication: limited hand gestures, limited facial affect, and an odd tone of voice.
√ They have restricted and specialized interests, repetitive behaviours and routines, stereotyped hand and body movements, they have difficulties with imagination and imaginative play and odd reactions to sensory stimuli.
√ Other characteristics include self-harm, attachment to objects, resistance to change, odd posture and gait and unusual fears.
√ Subjective deficits: High levels of stress, inflexible and very literal way of thinking, a focus on details, difficulty generalizing what they learn, difficulty understanding time related sequencing, difficulty in attention and discrepancies between their ability in various types of memory and skills that comprise intelligence.

2.4. When do parents become concerned?

A parent may be concerned due to a delay in the language development of their child and turn to a pediatrician, who may reassure the parent with responses such as: “Boys are late to talk” or “he is lazy or difficult”, “He doesn’t want to talk”, “Let’s wait until he is a little older”, “You are stressing too much”. Thus it is not uncommon for a diagnosis to be delayed resulting in significant consequences for the child’s development. It is not of course out of the question that a parent may be “stressing”, however this should not be a specialist’s first thought, particularly if what is causing the parent to be concerned is not language development per se, but instead lack of communication and/or other characteristics, such as the ones mentioned below (table 3). In fact, studies indicate that parental concerns are one of the most reliable, early indicators for a diagnosis[1] and thus should be granted appropriate attention.

Table 3. Behaviours of a child with ASD divided into subcategories, which may frequently be a concern for parents[2].

Communication Concerns	**Socialisation Concerns**
• Does not respond to name • Cannot tell me what he wants • Language is delayed • Doesn't follow directions • Appears deaf at times • Seems to hear sometimes but not others • Doesn't point or wave bye-bye • Used to say a few words but now he doesn't	• Doesn't smile socially • Seems to prefer to play alone • Gets things for himself • Is very independent • Does things `early' • Has poor eye contact • Is in a world of his own • Ignores us • Is not interested in other children

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[1] Ozonoff S, et al (2009) How early do parent concerns predict later autism diagnosis? J Dev Behav Pediatr. 30(5):367-75

[2] Charman & Baird (2002) Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. J Child Psychol Psychiatry. 43(3):289-305.

Behavioural Concerns	**Absolute indications for immediate further evaluation**
• Tantrums • Is hyperactive/uncooperative or oppositional • Doesn't know how to play with toys • Gets stuck on things over and over • Toe walks • Has unusual attachments to toys (e.g., always is holding a certain object) • Lines things up • Is oversensitive to certain sounds or textures • Has odd movement patterns	• No babbling by 12 months • No gesturing (pointing, waving bye-bye etc.) by 12 months • No single words by 16 months • No 2-word spontaneous (and not just echolalic) phrases by 24 months • ANY loss of ANY language or social skills at ANY age

If a parent or pediatrician observes any of the above, then the development of the child should be assessed with an emphasis not on language and speech but on communication and sociability. There are certain screening tools that a pediatrician may use, but if he/she is not familiar with these or if the child presents with any of the absolute indicators for assessment, he/should refer the child to a specialist (child-psychologist, developmental pediatrician)

Main points

√ Parents are usually concerned about a delay in speech
√ If parents are concerned about difficulties in communication, sociability or behavior, it is important to know that these are among the most reliable indicators. Further evaluation should be conducted so as not to allow precious time to be lost
√ Certain symptoms (table 3) are considered indicators for immediate referral to a specialist child-psychologist or developmental pediatrician.

2.5. Diagnosis – Assessment

An important point with regards to ASD is the absence of a single (pathognomonic) symptom which is either sufficient or necessary to confer the diagnosis. The individual must present with a combination of several symptoms while taking into account his/her developmental level[1].

The diagnosis can be made reliably from the ages of 2-2.5 years old if the specialist uses the appropriate tools. However, in younger ages, again using the appropriate tools (e.g. Toddler ADOS or the Autism Observation Scale for Infants, etc.) and with good clinical experience, it can be considered a provisional diagnosis. In Cyprus, both in the government hospitals and in the private sector, there are specialized physiotherapists and occupational therapists that are able to examine the infant's movement and sensory responses and note any deviations from typical development. The concept of provisional diagnosis can be explained to parents as a possible explanation that due to the child's young age cannot be explored in a more effective and definitive way. That step will of course follow in the future.

However, the child's difficulties should be approached as falling into the ASD, in order for the appropriate intervention to begin, avoiding the loss of valuable time. It should be noted that there are worldwide efforts being made to reduce the time of diagnosis to under 18 months, as research shows that the earlier the intervention, the greater the improvement that may be achieved[2].

The diagnostic process begins by obtaining a detailed developmental history in order to look for any characteristic delays and (for the most part) deviations which are included in ASD. These are available in semi-structured form, such as the Autism Diagnostic Interview-Revised (ADI-R), the Diagnostic Interview for Social and Communication Disorders (DISCO) and the Developmental, Dimensional and Diagnostic Interview (3Di). Subsequently, clinical observation of the individual in question is needed in order to detect the equivalent behaviours (semi-structured observation is recommended with the Autism Diagnostic Observation Schedule – ADOS) and frequently observation in the person's natural environment, for instance in the school. Self-report and teacher/parent report questionnaires are also helpful in reaching a diagnosis, but particularly during the process of assessment.

After diagnosis, a detailed assessment of the individual (speech capabilities, occupational/sensory skills, mental, functioning and learning abilities) is completed in order to detect the specific weaknesses and strengths and to formulate an individualized intervention plan

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[1] Lord C, et al (2006) Autism from 2 to 9 years of age. Arch Gen Psychiatry. 63(6):694-701.

[2] Dawson G. (2008) Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. Dev Psychopathol. 20(3):775-803.

The para clinical and laboratory testing which needs to be conducted to give a child a diagnosis of ASD need not be particularly extensive as is the case in some clinical situations. As with any other disorder, assessment should be guided by the recommended steps for the specific disorder as well as the presence of clinical symptoms. An extensive assessment will only burden the child and the family, without contributing in an essential way to the diagnosis or the way in which the difficulties are dealt with.

Listed below are some recommendations[1-2]

- A good neurological assessment since often these children present with milder symptoms (soft signs).
- A hearing assessment, even if clinically there do not seem to be any impairments
- A skin examination (using a Wood's lamp) for possible signs of tubular sclerosis –TS (40% of children with TS have ASD, however, 1-4% of children with ASD have TS, with that percentage rising to 8-14% when there are seizures) or Neurofibromatosis-NF (approximately 1% of children with ASD). The relevant testing is conducted by a child-neurologist.
- Many recommend standard genetic testing for Fragile X syndrome (FXS0, since on the one hand, 2-6% of children with ASD have FXS and on the other hand the presence of the syndrome will affect both the prognosis (mental retardation becomes more common) and genetic counseling, if the family wants to have additional children. The testing in Cyprus can be performed by the Institute of Neurology and Genetics in Nicosia.
- Further genetic testing can be ordered only if the geneticist detects signs or symptoms which indicate a known syndrome (e.g. Angelman/Prader-Willi, etc.) which is associated with the disorder. It is estimated that in up to 25% of cases it is possible to detect some genetic variation (extra or absent genetic material, CNVs, etc.) particularly in specialized centres located abroad. However, such testing should not be part of a standard assessment, except in cases where the doctor assesses that it will be useful with regards to genetic counseling (locating de novo mutations).
- Standard imaging screening (CT scan or MRI) is not necessary since the possible findings will not be specific to ASD (findings are no different than

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[1] Filipek PA, et al. (2000) Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. Neurology 55: 468–479.

[2] CLINICAL PRACTICE GUIDELINE: Quick Reference Guide for Parents and Professionals AUTISM / PERVASIVE DEVELOPMENTAL DISORDERS ASSESSMENT AND INTERVENTION FOR YOUNG CHILDREN (AGE 0-3 YEARS) http://www.health.ny.gov/publications/4216.pdf

those of normally developing children) and will not contribute anything significant, unless of course there are clinical indications. MRI scans may not be harmful to children, but it must be remembered that the child will need to be sedated.

- Assessment using an Electro Encephalogram (EEG) is only required when there is evidence of seizures or when the children present with sudden loss of speech which is at a greater age than what is expected in ASD (3-7 years old instead of 1.5-2.5) and the doctor may suspect that Landau-Kleffner syndrome may be present. A report[1] was published recently in which EEGs are used in diagnosing ASD, but this is still under investigation and requires a complex way of recording and analysis which is well beyond what is required in a regular EEG.
- The possibility of a metabolic disease (including mitochondrial disorder) in ASD is <0.5% and thus standard testing[2] is not needed unless the clinical presentation of the child suggests it needs to be explored.
- The latter holds true also regarding immunological and allergy testing.
- Lead testing should be performed if the child presents with Mental Retardation and Pica (consuming non-edible substances)

Main Points

√ There is no absolute point that needs to be reached which is either necessary or sufficient for giving a diagnosis.
√ The diagnosis is given with confidence at around the age of 2-2.5 years old. Any earlier than that and it is given as a provisional diagnosis.
√Assessment includes taking a detailed developmental history, clinical observation, and naturalistic observation (e.g. at the child's school).
√ Following the diagnosis, a detailed assessment of the child's difficulties is needed in order to develop his/her Individualized Educational Plan for intervention.
√A standard assessment for ASD includes a neurological exam, a hearing test, skin test (using a Wood's lamp) and testing for Fragile X syndrome.
√ Any other examination should be conducted only if the child's clinical presentation indicates it is necessary.

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[1] Duffy & Fhals (2012) A stable pattern of EEG spectral coherence distinguishes children with autism from neuro-typical controls - a large case control study. BMC Med. 26;10(1):64

[2] Schiff M, et al. (2011). Should metabolic diseases be systematically screened in nonsyndromic autism spectrum disorders? PLoS One. 6(7):e21932. Epub 2011

2.6 Epidemiology – Comorbidity

Broadening the way in which we understand this disorder and subsequently expanding the criteria has led to a significant rise in the estimated prevalence, from 5: 1,000 which concerned the narrowly defined disorder (classic or Kanner’s autism) to percentages which are just above 1% for all ASD (although much higher percentages of up to 2.6% have been reported in exceptionally well conducted studies in the general population[1-2]). According to the literature, this rise in prevalence cannot be completely accounted for by the change in diagnostic criteria and more accurate detection of such cases, indicating that a small rise in incidence cannot be ruled out. In table 4 we report the estimated prevalence for Cyprus based on international studies, since there is no epidemiological data for the island, as well as data from the National Census of 2011.

Table 4. Estimated prevalence of Autistic Spectrum Disorders in Cyprus

	Per 10.000	Number of minors (<19)	Number of adults	Total
Autistic disorder	30	620	1490	2110
Other ASD (Asperger, Atypical)	80	1653	3973	5626
Total	110	2273	5463	7736
Individual with mental retardation (IQ<70)		16-40%	1237-3094	

The ratio of ASD for boys and girls is between 2,5: 1 and 5: 1 with the difference becoming smaller as functionality and intelligence level also decrease, and rising as these rise, without these however reaching the high figures reported in the past (e.g. 9:1), which have been attributed to the difficulty of detecting high functioning ASD in girls. Studies in the general population indicate that between 16 and 40% also have mental retardation (IQ<70), while as 7-12% have high intelligence (IQ>120). What is most disturbing is that to a large degree (up to 60%) ASD goes undiagnosed, with children attending mainstream school and receiving no treatments.

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[1] Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators; Centers for Disease Control and Prevention CDC). Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. MMWR Surveill Summ. 2012 Mar 30;61(3):1-19

[2] Kim YS, et al (2011) Prevalence of autism spectrum disorders in a total population sample. Am J Psychiatry. 168(9):904-12.

In addition to MR, **epilepsy** is also a disorder that frequently appears alongside ASD in approximately 15-25% of cases. It is more frequently found in individuals with more restricted mental and language abilities but not in individuals who have presented with autistic regression. The seizures typically appear after the age of 10 and are more frequently tonicoclonic in type.

In recent years there has rightfully been a particular interest in comorbid **gastroenterological difficulties** which develop in individuals with ASD. Although there is no consensus as to whether these appear more frequently than in the general population[1], the attention afforded to these is related to the fact that they can be the cause of many behavioral disorders (e.g. outbursts due to strong pain) but also due to the difficulty of a percentage of sufferers to express their symptoms. The main gastroenterological problems which are present are chronic constipation, stomach pain with or without diarrhea and encopresis as a consequence of constipation. Also, it is not uncommon to find gastro esophageal reflux disease, flatulence, lack of disaccharidase and findings of inflammation in the gastrointestinal system[2]. Additionally, due to the frequently limited diet of individuals with ASD, they may present with nutritional disorders and deficiencies, while the risk of obesity is higher than in the rest of the population between the ages of 12-19 (but not before). As part of their evaluation, children should be tested for allergies (a frequent occurrence in ASD), which may tax gastrointestinal functioning (e.g. colitis). In order for symptoms of the gastrointestinal system to be evaluated, explored and dealt with, the specialist must modify the equivalent protocols which are used for typically developing individuals[3].

Finally, reports of a possible correlation between these symptoms and the severity of autism, the approach that these intestinal dysfunctions may trigger or aggravate autism have yet to be adequately supported.

Around 50-80% of children with ASD have **sleep difficulties** (compared to 9-50% of typically developing children of the equivalent age) and this occurs independently from their mental capabilities[4-5]. These differences are directly related to the special characteristics of brain functioning in individuals with ASD (e.g. continuing high arousal due to reduced GABA activity, etc.). These difficulties are more pronounced in children who have presented with developmental regression, epilepsy and anxiety disorders. Sleep disorders have significant consequences on the cognitive

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[1] Bolton PF et al (2011) Epilepsy in autism: features and correlates Br J Psychiatry. 198(4):289-94.

[2] Buie T. et al (2010) Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. Pediatrics, 125 Suppl 1: S1-18.

[3] Buie T. et al (2010) Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs. Pediatrics, 125 Suppl 1: S19-29.

[4] Kotagal S. & Broomall E. (2012) Sleep in Children With Autism Spectrum Disorder. Pediatric Neurology 47(4): 242-251

[5] Vriend JL. et al (2011) Behavioral interventions for sleep problems in children with autism spectrum disorders: current findings and future directions. J Pediatr Psychol 36(9):1017-29.

development of the child, the memory, learning and behavior, while they also take a toll on the rest of the family.

The most common sleep disorders found in individuals with ASD are the following: a) disorders in the circadian rhythm and the secretion of melatonin, which results in delayed sleep at night or atypical cycles of sleep and wake cycles during the day, b) insomnia from behavioral causes, such as difficulties with emotion regulation, intense anxiety, difficulties distracting his/her attention from previous stimuli, etc. The latter is characterized by relating sleep to a certain routine (e.g. being in the parent's arms) which needs to be performed in order for the child to fall asleep and repeated if the child awakens during the night, c) Insomnia related to Rapid Eye Movement (REM) sleep, of the type found in Parkinson's disease and in dementia. It is characterized by vivid dreams during which individuals move vigorously, where muscular activity is maintained (absence of muscle relaxation) during REM sleep. The child may cry and shout, move vigorously, gesture or kick and hit whoever is nearby. If the child is talking, he/she may describe vivid dreams, d) Sleepiness during the day due to reduced and/or disordered sleep during the night or circadian rhythm disorder with increased melatonin secretion during the day and decreased secretion during the night, e) Insomnia due to other comorbid disorders, such as "restless leg" syndrome, periodic movement of the lower extremities or nocturnal sleep apnea. Some medication given to children with autism (Risperidone, serotonin inhibitors) may also have a negative effect on sleep.

It is necessary to carefully document all the difficulties and habits of the child and to conduct an appropriate evaluation[1-2] in order to detect the real issue and select the equivalent treatment – behavioural, medicinal or a combination. For details on this matter, we refer interested readers to the relevant literature. We report only the use of melatonin which in many cases, depending on the type of insomnia, can be used effectively. If the problem lies only in a delay in sleep onset then it is administered in a small dose (0,5mg) on an empty stomach, 5-6 hours before bedtime. If the difficulties extend to maintaining sleep as well, then 1-6mg is administered, 20-30 minutes before bedtime for a few weeks. It is best to avoid meals 2-3 hours before taking the medication. There have been no significant side-effects reported from its use.

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[1] Kotagal S. & Broomall E. (2012) Sleep in Children With Autism Spectrum Disorder. Pediatric Neurology 47(4): 242-251

[2] Vriend JL. et al (2011) Behavioral interventions for sleep problems in children with autism spectrum disorders: current findings and future directions. J Pediatr Psychol 36(9):1017-29

Despite the fact that the DSM-IV does not allow a dual diagnosis of **Attention Deficit Hyperactivity Disorder (ADHD)** in ASD, clinical experience, as well as research[1], indicates that the two disorders may co-occur and in high percentages (28-50%). However, diagnosis requires caution and experience as the frequently observed deficits in "attention" and/or "hyperactivity" can also be the consequences of ASD (lack of understanding, lack of interest, sensory overload, etc.) and not the outcome of comorbid ADHD. This distinction needs to be made in order to avoid the unnecessary prescription of medication for ADHD, which not only will not deal with the difficulties (since ADHD is not present) but some may even worsen symptoms.

Other disorders which may co-occur with ASD include tics and Tourette's syndrome at around 22%, anxiety disorders in up to half of cases[2-3], depression – especially in high functioning individuals[4] and Obsessive Compulsive Disorder, although caution is warranted (as in the case of ADHD) as to whether symptoms constitute an additional disorder (in which case medication is needed) or not. Contrary to what was previously believed schizophrenia does not appear to occur more frequently in individuals with ASD, even though certain delirium type pseudo-psychotic symptoms may erroneously be interpreted as genuine psychotic symptoms.

Particular attention must be given to **Catatonia** which appears with ASD in up to 14% of cases after the age of 12[5]. A sudden, severe deterioration in functionality and everyday skills is observed in these children, such as slowness in movements and difficulty initiating movement, passivity, odd gait and posture, "freezing", impulsive actions which cannot be stopped, problems sleeping, etc.[6]

Finally, it should be noted that contrary to popular belief, a child with **Down's Syndrome** may present with ASD in percentages that reach 19%. One should suspect ASD when the child does not present with the good sociability that typically characterizes this syndrome, and difficulties in behavior, obsessions and some skills that are not consistent with his/her mental abilities are observed.

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[1] Canitano & Vivanti (2007) Tics and Tourette syndrome in autism spectrum disorders. Autism. 11(1):19-28

[2] Canitano & Vivanti (2007) Tics and Tourette syndrome in autism spectrum disorders. Autism. 11(1):19-28.

[3] Francis K (2012) The projection of Autism Spectrum Disorders (ASD) in adult life. Psichiatriki 23: P66-P73

[4] Kakooza-Mwesige A. et al. (2008) Catatonia in autism: implications across the life span. Eur Child Adolesc Psychiatry. 17(6):327-35

[5] Wing & Shah (2006) A systematic examination of catatonia-like clinical pictures in autism spectrum disorders. Int Rev Neurobiol. 72:21-39.

[6] Hallmayer J, et al (2011) Genetic heritability and shared environmental factors among twin pairs with autism. Arch Gen Psychiatry. 68(11):1095-102.

Main Points

√ The frequency of ASD is estimated at 1-2% of the general population, that is, in Cyprus there are more than 7,500 sufferers of all ages.
√ ASD is 3-5 times more common in boys than it is in girls.
√ Around 16-40% of children with ASD also has Mental Retardation, while 7-12% has high intelligence.
√ 60% of individuals with ASD remains undiagnosed.
√ 15-25% of individuals with ASD has seizures.
√ Gastrointestinal problems and sleep difficulties are often present in children with ASD.
√ ADHD co-occurs in a large percentage of individuals with ASD, however not all deficits in “attention” and/or “hyperactivity” constitute ADHD.
√ An individual with ASD may also present with tic disorders, anxiety disorders, depression, Obsessive Compulsive Disorder and Catatonia. However, there does not appear to be increased risk for the development of Schizophrenia.

2.7 Causation

Genetic and familial studies revealing an astoundingly higher concordance in diagnosis for monozygotic rather than dizygotic twins, but also the association of the disorder with other known genetic disorders, such as Fragile X and Tubular Sclerosis, point to the strong presence of a genetic substrate. The risk of the disorder occurring again[1] in a family with one child who already has ASD is estimated at around 18,7%. This is thought to be equivalent to 26% when the next child is a boy and 9.6% if it is a girl. If there is a child with ASD, the risk is 13.5%, while as if there is more than one child it comes to 32,5%. The severity of ASD in the child does not appear to be related to the degree which will develop in the next child. A significant drop in the risk of reoccurrence from around 19% in siblings to a much lower percentage in second degree relations, as well as the increased risk for boys, indicate a powerful effect which includes interactions between several genes.

The presence of monozygotic twins who do not share the diagnosis indicates that there are interactions with environmental factors, mainly through epigenetic mechanisms[2-3]. These genes may be expressed in characteristics with continuous distribution in the population (as is evident by the wider autistic phenotype), which may add up, surpassing a certain threshold in order for ASD to occur.

A large number of cases, often with a negative family history, can be attributed to mutations on a number of copies of the individual’s genes (Copy Number Variants – CNVs), that is, automatic omissions or multiplication of genetic material during the process of reductions, which may not be present in the parents.

This genetic substrate can be expressed in a multitude of ways in the developing brain, beginning with the early gestational phase (a disorder in migration of neural cells has been found), influencing a plethora of functional (and secondary anatomical) structures, through a continuous interaction with the environment.

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[1] Hallmayer J, et al (2011) Genetic heritability and shared environmental factors among twin pairs with autism. Arch Gen Psychiatry. 68(11):1095-102

[2] Grafodatskaya D, et al (2010) Autism spectrum disorders and epigenetics. J Am Acad Child Adolesc Psychiatry. 49(8):794-809.

[3] Helt M, et al (2008) Can children with autism recover? If so, how? Neuropsychol Rev. 18(4):339-66.

This altered neural substrate leads to cognitive deficits and variations which are described in neuropsychological theories, such as the following: a) Theory of Mind – the difficulty of the individual with ASD to attribute mental states to him/her self and others , and thus to recognize others feelings and intentions, b) dysfunction of executive functions along with deficits in working memory, planning, and inhibition and c) weak central coherence, according to which there is a specific cognitive style of information processing which favors piecemeal processing instead of holistic processing, and thus a focus on detail rather than interpretation based on the more general context. None of the existing neuropsychological theories can independently explain all the particularities which collectively constitute ASD.

Main Points

√ The etiology of ASD has a very strong genetic substrate – predisposition, a result of the interaction of many different genes.
√ The genes are derived from the parents, but in rare cases they can be the result of a new (de novo) mutation, which does not exist in either of the parents.
√ If a family has a child with ASD, the likelihood of having another one is 26% if the next child is a boy and 9% if it is a girl.
√ As in all psychiatric disorders, there is an interaction between genes and environment.
√ The genetic substrate of the disorder influences the development of the child's nervous system and leads to a brain which functions in a much different way than that of a neurotypical individual.

2.8 Progression and Prognosis

The most basic characteristic in the progression and prognosis of ASD is the huge diversity, a fact which was verified by Kanner's first observation study. The data from the literature should be approached with caution for two other reasons: a) The samples from longitudinal studies are often diagnosed with the more restrictive criteria of older classification systems and thus their results may have a much lesser value for the individuals we now consider as suffering from ASD (relative higher functioning and with milder symptoms) and b) in older studies the interventions methods as well as the time they were implemented were clearly very different from those used in contemporary times (many innovative methods – very early intervention).

Researchers agree there appears to be a relative improvement in most of the symptoms (although a significant percentage shows stability), such as improvement in acquiring new skills and a reduction in maladaptive behaviours. More specifically, in the area of communication there is an improvement which is more significant to speech problems (e.g. antonym reversal), and much less when it comes to non-verbal communication. In the area of sociability the improvement is smaller and typically regards the tendency to withdraw. Nevertheless, the difficulties in quality of relationships (e.g. friendships) still remain, although the overall adjustment is relatively good. The improvement in the third area is likely the smallest. With regards to mental capacity there has been a moderate drop in the performance intelligence scale and a mild increase in the verbal scale.

Additionally, several studies support that a percentage of individuals, which may reach a percentage of 10-20%, may be diagnosed as not fulfilling the criteria, or more rarely that the symptoms of the disorder no longer exist[1]. These individuals are typically high functioning with less severe symptoms and higher mental abilities. However, clinical observations limit the percentage of individuals which are "cured" to less than 5%.

As far as long-term prognosis is concerned, previous studies were much bleaker with only a small percentage reported as becoming fully independent, pursuing studies, marriage or a competitive career. For instance, 25% had been reported as having good prognosis, 25% with moderate prognosis and 50% with poor prognosis.

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[1] Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47(7):493-9.

These percentages should be interpreted with caution, not only for the aforementioned reasons but also because in clinical practice, as well as in research, many parents of children with ASD are described who also meet full criteria for the disorder (and thus they have positive prognosis themselves).

In recent years a significant percentage of children with ASD attend regular schools, on the hand due to the fact that the diagnosis is given to milder cases, and on the other hand because new policies promote integration and support of these individuals in regular surroundings. Particularly during adolescence a temporary deterioration has been reported in about half of the cases (particularly if there had already been significant difficulties during childhood), with 20% experiencing permanent deterioration, especially if epilepsy also develops.

Positive prognostic signs include the presence of functional speech before the age of 5 (particularly important for the prognosis of social development), mental capacity (individuals with mental retardation have a more limited development and more maladaptive behaviours), the earliest possible diagnosis and intervention, the severity of symptoms, and finally, the continuing provision of suitable social support (e.g. work place support). Gender does not appear to be an important factor influencing prognosis.

Main Points

√ The progression of ASD and the level of functioning that can be accomplished varies from person to person.
√ The percentage of individuals who are “cured” is less than 5%.
√ Positive indicators in prognosis are the presence of functional speech before the age of 5, good mental abilities, early intervention, the absence of comorbid diagnoses, and suitable support in the social environment.

3.0 LEGISLATION AND RIGHTS (CHAPTER IS GOING TO CHANGE DUE TO THE CHANGE OF LAW. THE FOUNDATION WAIT THE RENEW).

3.1 The rights of individuals with autism

CHARTER OF THE RIGHTS OF PEOPLE WITH AUTISM

At its 4th Congress in Hague, on May 10th, 1992, Autism Europe, voted for the following Charter of the rights of people with autism.

People with autism should share the same rights and privileges enjoyed by all of the European population where such are appropriate and in the best interests of the person with autism.

These rights should be enhanced, protected, and enforced by appropriate legislation in each state.

The United Nations declaration on the Rights of Mentally Retarded Persons (1971)[1] and the Rights of Handicapped Persons (1975)[2] and other relevant declarations on Human rights should be considered and in particular, for people with autism the following should be included:

1. THE RIGHT of people with autism to live independent and full lives to the limit of their potential.

2. THE RIGHT of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment.

3. THE RIGHT of people with autism to accessible and appropriate education

4. THE RIGHT of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected.

5. THE RIGHT of people with autism to accessible and suitable housing.

6. THE RIGHT of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence.

7. THE RIGHT of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life.

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[1] United Nations “Declaration on the Rights of Mentally Retarded Persons”. Proclaimed by the UN General Assembly in its Resolution 2856 (XXVI), of the 20th of December 1971.

[2] United Nations “Declaration on the Rights of Disabled People” Proclaimed by the General Assembly of the UN in its Resolution 3477 (XXX) of the 9th of December, 1975

8. THE RIGHT of people with autism to participate, as far as possible, in the development and management services provided for their wellbeing.

9. THE RIGHT of people with autism to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with all protective measures taken.

10. THE RIGHT of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual.

11. THE RIGHT of people with autism to accessible transport and freedom of movement.

12. THE RIGHT of people with autism to participate in and benefit from culture, recreation and sport.

13. THE RIGHT of people with autism to equal access of and use of all facilities, services and activities in the community.

14. THE RIGHT of people with autism to sexual and other relationships, including marriage, without exploitation or coercion.

15. THE RIGHT of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights

16. THE RIGHT of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution.

17. THE RIGHT of people with autism to freedom from abusive physical treatment or neglect.

18. THE RIGHT of people with autism to freedom from pharmacological abuse or misuse.

19. THE RIGHT of people with autism and their representatives to all information contained in their personal, medical, psychological, psychiatric and educational records.[1]

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[1] Reproduced verbatim from the Autism Europe website "Charter of Rights" http://www.autismeurope.org/publications/rights-and-autism-2/charter-of-rights-4/ (12/2/2013)

3.2 Legislation in the European Union and in Cyprus:

As mentioned, autism is a complex developmental disorder. The autism spectrum is quite large and influences many aspects of the organism of individuals who suffer from the disorder. To begin with, individuals with autism present with a type of handicap, since often transportation and self-care is not feasible. This of course depends directly on the individual in question and how severe his/her difficulties are. At this point there is automatically a distinction between individuals who meet criteria for a handicap and those who don't. The latter is clearly a matter of the diagnosis given by doctors.

It is quite clear however, that autism is recognized as a condition which directly influences the individual's mental abilities. Thus, all individuals with autism are recognized by the state as having special needs.

3.3. European Union:

Approximately 80 million people in the E.U. suffer from some type of mild or severe form of disability. The natural obstacles faced by these individuals, for instance access to school or the work place, render them vulnerable to social exclusion. Due to a lower level of employment and education, the percentage of poverty for individuals with disabilities is 70% higher than the average percentage. Given this, the European Union has put into action the scheme "Europe Without Obstacles to People with Disabilities". This European strategy aims to help these individuals live their everyday life in the same way as other people and enjoy their rights as citizens of the E.U. This strategy gains access to funding from the E.U., raises awareness regarding matters of disability, and encourages the co-operation of member states in eliminating obstacles to social inclusion. It also contributes to the fulfillment of obligations undertaken by the E.U. in 2007, with the joint signing with member-states, of the Convention on the Rights of Persons with Disabilities.[1]

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[1] European Committee "Justice and Citizens Rights" http://ec.europa.eu/news/justice/101115_el.htm (15/06/12)

The E.U. and its member-states are under strict instructions to improve the social and financial situation of individuals with disabilities.

- Article 1 of the Charter of Fundamental Rights of the EU states that "Human dignity is inviolable. It must be respected and protected".
- Article 26 states that "The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community".
- Additionally, Article 21 prohibits any type of discrimination due to disability.
- According to the Treaty on the functioning of the European Union, the EU is obliged by defining and implementing its policies and activities, to combat any type of discrimination due to disability (Article 10) and has the authority to adopt legislative measures in order to deal with such discrimination (Article 19).
- The United Nations Convention on the rights of persons with disabilities, which constitutes the first legally binding instrument for human rights which has been adopted by the EU and its member states, will soon be in effect in the entire EU. The Convention calls on subscribed states to promote and protect the human rights and fundamental freedom of individuals with disabilities.

According to the Convention, included among the individuals with disabilities are **those who have long-term physical, mental, intellectual or sensory impairments** which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others[1].

As of January 1st of 2011 in the Justice, Fundamental Rights and Citizenship portfolio of the European Union includes the following:

- *Finding and keeping jobs:* People with disabilities represent around one-sixth of the EU's overall working-age population, but their employment rate is comparatively low. Disabled people are almost twice as likely to be inactive as non-disabled people. The EU's policy efforts on Social Protection and Social Inclusion support EU countries in developing policy for social inclusion, health care and social services. This will improve the chances for disabled people to find and keep work.

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[1] Disability Now "European Union" http://www.disabled.gr/lib/images/33345.pdf (15/06/12)

- *Education for all:* Equal access to quality education and lifelong learning enable disabled people to participate fully in society and improve their quality of life. The European Commission supports the inclusion of children with disabilities in mainstream education. It has launched several educational initiatives for disabled people. These include the European Agency for Development in Special Needs Education as well as a specific study group on disability and lifelong learning. EU programmes like the Lifelong Learning programme are bringing the education and training of disabled people into the mainstream.
- *Living independently:* The aim is to provide disabled people with the same individual choices and control over their daily lives as non-disabled people. Care and support services are to be tailored more to the specific needs of people with disabilities. The European Commission promotes: affordable, accessible and quality social services; support through consolidated social and inclusion provisions.

Among the legislative modifications in favor of individuals with disabilities on an international level is the **SUNDBERG Declaration**[1] of 1981, which had as its basic principles the participation, inclusion and personalization of individuals with disabilities, decentralization and interprofessional coordination. Bearing in mind the Universal Declaration of Human Rights (UN 1948) and other relevant instruments of the United Nations and particularly the Convention on the Elimination of All Forms of Discrimination against Women (UN 1979)[2], Convention on the Rights of the Child (UN 1989)[3], the Declaration on the Rights of the Disabled Persons (UN 1975)[4] and the Declaration on the Rights of the Mentally Retarded Persons (UN 1971)[5], it underlines the following:

"the importance of rehabilitation and integration as far as possible of disabled persons, steps being taken to ensure that every person receives rehabilitation services and other support and assistance that might be needed to reduce the handicapping effects of disability, in order to bring about the maximum possible integration of disabled persons and enable them to play a constructive role in society."

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[1] UNESCO Sundberg Declaration. Final report of the International Conference of UNESCO and the Spanish Government, Malaga, Spain, 2-4 November, 1981.

[2] United Nations "Convention on the Elimination of All Forms of Discrimination against Women". Proclaimed by the Committee of the Committee of the same name (CEDAW), on the 30th of September 1996. Document CEDAW/C/TZA/2-3-/30-9-1996.

[3] United Nations "Convention on the Rights of the Child". Proclaimed by the UN General Assembly on the 12 of December 1989. Doc. A/RES/44/25/12-12-1989.

[4] United Nations "Declaration on the Rights of Disabled People" Proclaimed by the General Assembly of the UN in its Resolution 3477 (XXX) of the 9th of December, 1975

[5] United Nations "Declaration on the Rights of Mentally Retarded Persons". Proclaimed by the UN General Assembly in its Resolution 2856 (XXVI), of the 20th of December 1971.

According to the principles of the **SUNDBERG declaration:**

1.) Full participation of disabled persons and their associations in all decisions and actions concerning them shall be ensured;
2.) Disabled persons shall have the benefit of all services and participate in all activities of the community; likewise actions and strategies of a general character decided on for the community as a whole shall take due account of disabled persons;
3.) Disabled persons shall receive from the community services adapted to their specific personal needs;
4.) Through decentralization and sectorisation of services, the needs of disabled persons shall be taken into account and satisfied within the framework of the community to which they belong;
5.) The activities of the various professional organisations and special bodies catering for the needs of disabled persons shall be co-ordinated in such a way as to promote the overall development of their personality.

3.4. Cyprus:

The Mentally Retarded Individuals Law of 1989[1] is issued through publication in the official Cyprus Gazette according to Article 52 of the Constitution.

Preamble:

SINCE a dignified way of living and social insurance are among the fundamental rights of human beings, regulated by Article 9 of the Constitution and the value of equality before Law and Governance, also regulated by Article 28, and calls for the provision of the necessary means to vulnerable members of society ensuring human dignity, in addition to the manifestos of the General Assembly of the United Nations of 1971 and 1975 for the rights of individuals with mental retardation, as well as the obligations of the state towards its disadvantaged members, as stated in the European Social Charter which has been with the European Social Charter Law of 1967 **(April of 1967)**.

Concise Title:

The present Law shall be referred to as the Mentally Retarded Individuals Law of 1989.

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[1] L.117/1989

Basic Rights of Individuals with Mental Retardation:

(1) Any individual with mental retardation has a right to a dignified way of living and social insurance adapted to its needs and abilities. The responsibility for legally protecting and fully ensuring these rights lies in the state. It is the state's responsibility to provide the individual with mental retardation with the necessary means of care to ensure human dignity, a healthy lifestyle and development to the degree that his/her abilities allow.

(2) Once the provisions of this passage in the current article and Article 4 are met, it is the state's obligation to protect the dignity of the individual with mental retardation and provide or contribute according to his/her needs, daily and medical care and support which includes the following:

  (a) Special education in suitable schools or education centres and professional training[1].
  (b) Residence, daily and medical care in institutions.
  (c) The creation of opportunities for vocational rehabilitation.
  (d) Care and support in the home of the individual with mental retardation who is living with his/her parents or relatives.
  (e) Securing a place of residence and the care of the individual with mental retardation who is living with his/her parents or relatives following their death or in the event that they are rendered incapable of offering the necessary care to the individual.
  (f) Favorable treatment in Social Insurance schemes.
  (g) Adopting legislative measures to protect the individual with mental retardation in society.
  (h) Providing the necessary support in order to socialize individuals with mental retardation and integrate them in society to the degree to which his/her abilities allow.
  (i) Appointing suitable persons to manage the property and protect the interests of the individuals with mental retardation.
  (j) The provisions of this paragraph do not relieve the parents of their own duties towards their children.

The State's Obligations

The state undertakes the fulfillment of its obligations towards individuals with mental retardation as they are laid out in article 3, directly or indirectly, in part or in whole, as a matter of priority in the context of state abilities, keeping in mind the ascertainments of the Committee.

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[1] L. 113(I)/1999 Special Education and Training of Children with Special Needs Law of 1999

The Individuals with Disabilities Law of 2000[1] is issued through publication in the official Gazette of the Republic of Cyprus, in accordance with Article 52 of the Constitution.

Preamble:

SINCE the General Assembly of the United Nations approved the standard Rules regarding Equalization of Opportunities for Persons with Disabilities, during its 85th Session, with a voting number of 49/96, and

SINCE the Standard Rules represent a strong moral and political commitment of Governments to take action to attain equalization of opportunities for persons with disabilities, indicating important principles for responsibility, action and cooperation, indicating also areas of vital importance for quality of life and attainment of full inclusion and equality and

SINCE the Standard Rules provide an instrument for policy-making and action for individuals with disabilities and their organisations.

Concise Title:

The present law shall be referred to as the Individuals with Disabilities Law of 2000.

Basic Rights of Individuals with Disabilities:

(1) Every individual with disabilities has the right to independent living, for full integration into the community and equality regarding the financial and social aspects of life in this country.
(2) Without being influenced by the generality of this paragraph, individuals with disabilities have the following rights:
(a) Early clarification and diagnosis of their disability, treatment and intervention for any further consequences of their condition, provision of healthcare, restoration of functions, including the provision and training in the use of prosthetic and corrective devices, as well as psychological and other forms of support for the individual and his/her family.
(b) Personal support with the use of assistive devices, other means and services, which help in the daily life and work of the individual, including an interpreter or escort, as well as any other necessary support, when this is deemed necessary.
(c) Accessibility to housing, buildings, streets and overall to the natural environment and public or other means of transport.
(d) Access to integrated education according to their needs.
(e) Access to information and communication using special means, wherever this is necessary, and particularly for certain groups of people with sensory disabilities.

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[1] L.127(I)2000

(f) Access to services of social and financial integration, vocational assessment and orientation, professional training and employment in the open labor market.
(g) A dignified level with regards to quality of life, through financial provision and social services.
(h) The creation of a private and family life.
(i) Participation in cultural, social, athletic, religious, and entertainment activities.

4.0 TREATMENTS

4.1. Basic principles of treatment

The lack, to this date, of a treatment that targets the etiology of ASD or even a treatment intervention of which the effectiveness is based on methodologically sound studies, leads to the recommendation of a plethora of interventions, often without any research support[1]. These interventions target aspects of the disorder, at times of a different range, and not the pathophysiological substrate or the core of the disorder.

Until the discovery of an etiological treatment or a treatment with proven effectiveness, when one evaluates a therapeutic suggestion the expected results should be investigated in addition to the following: (a) whether the rationale of the intervention corresponds to the current knowledge and understanding of ASD, (b) the potential side-effects/negative consequences, (c) the training and experience of those who will provide the treatment, (d) the burden on the family (time, application, relationships, financial) and (e) the evidence which supports its effectiveness, published in recognized scientific journals on the catalog available from PubMed.

All of the above should be taken into account when a new “experimental” intervention method is being suggested. In this event, we will not have evidence of its effectiveness however the attempted intervention needs to have a rational relationship with existing data on the disorder, perhaps some experimental data and information on possible negative side-effects. In the event of family participation, some ethical points need to be taken into account: a) The above needs to include an Informed Consent document which needs to be signed by both the researchers and the parents, b) The financial burden of the intervention should rest on the research foundation and not the family and c) The family should be informed about the results of the intervention once it is concluded.

Based on research data, the most effective components of an intervention for ASD include the use of behavioral techniques and structured education which is assisted by visual aids, the presence of an individualized therapeutic plan with goals and ways in which to promote success, the inclusion and training of parents with regards to the treatment, but also of anyone else who works with the child, such as teachers. The entire intervention must be included in, guided and coordinated by an Individualized Education Plan (see below).

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[1] Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47 (7):493-9.

Main Points
√ To date, there is no etiological treatment for ASD √ All treatments to date target aspects of the disorder, aiming to improve functionality. √ In order to select a treatment, we need to weigh the expected results, consider whether the rational of the intervention corresponds to ASD, the possible side-effects, the training and experience of the professionals providing it, the consequences on the family and the evidence which supports its effectiveness. √ In research based interventions all involved must sign an Informed Consent form including information on the rationale of the treatment, the possible side-effects. All expenses should be covered by the researchers and the family should be informed of the study's outcome. √ The intervention should follow a specially designed Individual Education Plan.

4.2 Individualized Education[1]

The first and foremost component of the intervention should be the in-depth evaluation of the strengths and weaknesses of the child and, based on these, an Individualized Education Plan (IEP) should be designed. In cases where there are multiple interventions, e.g. in the school, with multiple trainers and interventions, an IEP becomes even more significant, in order to avoid selecting and applying conflicting targets and techniques which will result in the entire intervention failing. In these cases, the various IEPs must be considered together, along with the trainers who are working on these and in the presence of a central trainer who can co-ordinate the efforts. Ideally, one IEP should be formulated which includes what each of the trainers who are with the child and family are working on. This type of approach not only avoids the break-down and failure of the programme, but also reinforces the synergy between the various parts of the intervention and renders it much more effective.

An IEP is a written document, which is used to catalogue the individual educational targets and needs of each child, as well as to evaluate his/her progress. It is necessary to define *what* the child needs to learn, *how* and in what way it will be learned or which educational approach will be adopted and *when, for how long, where and by whom* the designated activities will be take place. The contribution of all the teachers and trainers who know and work with the child is necessary for designing the IEP, as is the participation of the family. The teachers or support staff who may not have an active and direct educational role but are, however, in contact with the child, should also be informed of his/her IEP.

An IEP should include the following:

- Long and short-term goals.
- Specific educational material, games or books that will be utilized.
- A list of individuals (trainers, parents, teachers, classmates) who will help and guide its application and how often the particular activities will take place.
- How much help and guidance will be provided by the adult, the type of assistance (verbal, visual, etc.) and at which point this will be reduced for independent work to be achieved.
- The type of reinforcement (verbal, material, etc.) and at which point this will be gradually reduced so reinforcement is no longer needed.
- The criteria which will be used to ascertain that the specific educational goal has been achieved.
- The period of reevaluation and redefinition of goals.

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[1] The above includes a partial reproduction of information found in a manual completed by Mrs. Areti Zakolikou in the context of EPEAEK II “Prosvasi gia olous”. The entire document (in Greek) including examples and forms can be found at http://www.noesi.gr/files/aftismos-zakolikou-odigos-daskalos.pdf.

The goals of the IEP are prioritized based on the particular needs of the child and the specific setting. They need to follow a developmental rationale, according to typical developmental, and not be based on the fragmented and non-continuous development seen in ASD. It is necessary for the goals to be limited in number and be feasible, measurable, specific and defined with regards to length of time. The long-term goals should be reduced to smaller stages, which will comprise the short-term goals, while the chain of teaching should be decided beforehand and always follow the skills which the child has already attained. The activities and educational material used to fulfill each goal are also very significant to the IEP. The style of writing in the IEP should be characterized by comprehensiveness and simplicity, and should not include scientific terms or ones that are difficult to comprehend, in order to cater not only to specialized professionals but also to the family and even the child itself. Access to the IEP should be available to all who are involved with the child. Frequent documentation of the results and three month evaluations are also necessary.

The goals should be based on the basic developmental and behavioral areas:

- Communication
- Social interactions/social skills
- Behavior
- Self-care
- Pre-number concepts/mathematics
- Descriptive abilities/writing and reading
- Higher academic areas

Consequently educational goals in the IEP should not be limited to learning, academic, or cognitive levels, since the difficulties which characterize children who are on the autism spectrum appear in various areas of development and behavior. In each of the areas, the starting point for each goal is the level of functioning of the child at the time, which is defined from the individual evaluation. For example, for children who are non-verbal, in the area of communication, goals can be limited to alternative means of communication, such as PECS, while for children on the other end of the spectrum, goals can be focused on semantics, literal understanding of concepts, etc. As far as social interaction/social skills are concerned, in some children we might teach participation in a game that requires taking turns but also the basics of creating dialogue. Even for children in special settings, a possible target could be attaining pre-number concepts, such as up/down, full/empty, number matching, and for others it could be addition and subtraction.

However, as far as the area of Behavior is concerned, the starting point of educational intervention is not so clearly defined for educators. It is not always easy to define which behaviours are inappropriate and need to be dealt with. As mentioned before, most behaviors serve a purpose. It is necessary to carefully and systematically document these in order to determine the reason the behaviors manifest themselves and the purpose they serve. Once the reason for which they manifest themselves is determined, the way they should be dealt with is most likely to include some changes in the setting and not always in the child itself. If the behaviours have a communicative role then they may be dealt with by providing communication tools.

In the event that the behaviors offer pleasure to the child, then perhaps the goal should not include their eradication, but limit their manifestation with regards to time and place. We decide to change a behavior and deem it inappropriate, when it places the child who exhibits it, or other children, in danger, when it leads to social comments or bullying, when it prevents learning, when it disrupts the educational environment or when it reinforces isolation.

Main Points

√ Intervention should be based on an Individualized Educational Plan (IEP), which begins at the child’s level of ability and follows the typical course of development.
√ The IEP should be followed co-operatively by all the individuals involved with the child: therapists, teachers and parents-family.
√ The IEP is a written document containing measurable long and short-term goals, strategies and materials which have been contributed to by ALL therapists as well as the family.
√ The various areas of the IEP include communication, social interaction/social skills, behavior, self-care, pre-number concepts/mathematics, pre-writing skills/writing, reading and higher academic areas.

4.3 General treatments

The treatment approach for ASD often results in a series of “treatments”, such as occupational therapy, speech therapy, special education, etc., for which the parents often has a vague understanding. Before analyzing the content of each one, it is important to emphasize some common characteristics:

a) All of the treatments should be integrated in and follow the child’s IEP, since there are no standard rules for type or length of interventions,

b) The goal setting of all interventions should be common to a large degree, since all of them target the same deficits which in turn interact with one another. Thus, both the speech therapist and occupational therapist can schedule common goals and activities, e.g. improving eye-contact, but also more specialized goals, such as pragmatics in the case of the speech therapist, and fine motor skills for the occupational therapist. It would be desirable for common activities to be planned which serve both areas, for example a game which requires movement and targets gross motor skills, ending with an exercise of phonological awareness. In this event, the exercise is designed by both of the therapists in the context of the common IEP.

c) Each intervention targets the child, the family and the educational setting which the child attends. Thus, the therapist also works with the parents: the IEP is made in agreement with the parents (in some settings both parties sign the document) and the parent observes many of the sessions in order to gain appropriate training which will on the one hand speed up the learning process, and on the other hand help generalize the skill/target at home and in the community (children with ASD do not automatically generalize what they learn with the educator). In rare cases where the child reacts inappropriately for many of the sessions for which the parent is present, then the solution of filming the session is brought forward. The therapist may have to visit the home in order to give instructions based on the real environmental conditions, and also watch the child’s video with the parent in order to provide appropriate feedback. Finally, the therapist needs to be in cooperation with the educator in the special or mainstream educational setting, in order to pass on instructions and collect necessary information.

d) The sessions should be structured in such a way so as to motivate the child. Materials which attract the attention of the child should be used, in the form of games, particularly for smaller children, and meaningful activities should be planned.

e) Treatment can be one-on-one or in group format. The latter case is preferable for children who have been in treatment for a long time, for older children and children who have more highly developed skills. The group sessions provide a more natural educational setting with greater chances of generalization, while the presence of other children usually increases the motivation to participate. The groups can include 6-8 children with two therapists, preferably from two different specialties so as to plan combined activities with multiple targets. The inclusion of children in the group should be guided by their age and their level of ability, but this is done in a more general manner and is based mainly on the fulfillment of the targets on the IEP. There should be an IEP for each group as well as an IEP for each child separately.

f) Often interventions need to be moved out of the therapist's office. This is extremely significant for a variety of cases: in very small children (under the age of two), in applying skills in the context of the home, playground or supermarket with the parent (for generalizing necessary skills and/or dealing with awkward behaviors) and definitely with older children, adolescents and young adults, where training in an office will almost never be of use as opposed to going out in the community and achieving hands-on learning in a natural setting.

g) The therapist who takes on the child's education may be a Speech therapist, Occupational therapist, Special Educator, Psychologist and so on. In reality though, we are in need of 'autism therapists' who, in addition to the basic training in their specialty, also have training, understanding and experience with disorders of the Autism Spectrum. Without these variables, the therapist will use his general knowledge and attempt to apply it without taking into account the specificity of the disorder. It is preferable for the parent to request from the therapist working with the child, the documents (license, special training certificates, work experience), which validates his/her adequacy to take on this role. The choice of the type of therapist depends on the nature of the child's difficulties and his/her particular needs, according to his/her IEP. Thus, a child with many sensory needs and/or dyspraxia will need an occupational therapist on the intervention team, a capable child with difficulties with pragmatics will need a speech therapist, an older child with issues with social skills or managing behaviors and matters in life outside the home, a special educator, while a child with self-esteem or anxiety/depression will require a psychologist. As has been noted previously, to a large degree, the goals that have been set are common and thus a full team of therapists is not always necessary. In some cases, special handling may be needed from time to time, but this can be done by one of the therapists under the guidance of the most suitable specialist for the matter at hand. It is very important to have one person to which all others report to, who is also responsible for the child and coordinates the IEPs and the treatments (this person could be a doctor).

Main Points

√ The type and duration of the intervention are defined in each IEP.
√ There is a common section of the IEP for the various therapists and one that is more relevant to their specialty. A single activity could target goals from various specialties.
√ The therapist works with the child, the parents, and the educational setting. The parent should observe the sessions.
√ Caution is needed when selecting materials and activities.
√Group sessions for older and more capable children are recommended.
√ It is very important for the sessions to ALSO take place outside the office, so that the training can occur in a more natural setting.
√ The therapist should ideally be an "autism therapist", irrespective of his/her basic specialty.
√ There should be a central figure to report to, who co-ordinates the entire intervention.

4.3.1 Speech therapy

Speech therapy is a scientific method aiming at preventing, diagnosing and treating verbal, speech, vocal and communication disorders. It deals with prevention, evaluation, diagnosis and therapeutic treatment, as well as the scientific study of communication, verbal and speech disorders in children and adults.

When it comes to ASD, the first goal of the speech therapist is to help develop communication (verbal or non-verbal) which is severely lacking. Thus, speech therapy begins from the moment the diagnosis is given, regardless of age, following a period of occupational therapy in order to enable the child to ‘sit’ through the speech therapy sessions. Communicative play does not in fact require a child who can remain seated, but instead a child who has developed an interest and been provided with motivation to engage in this “game” with the specialists. The parent needs to be present throughout this process since he or she has, realistically, more chances of succeeding in initiating or responding to the child’s communication game.

When communication has been developed or is already present to a large degree, the speech therapist may target the development of symbolic and imaginative play (a prerequisite for the development of language) and with language itself, that is, semantics and pragmatics, as mentioned previously. The speech therapist will need to evaluate the child’s level of pure verbal understanding with the use of certain tools, since often the child’s expressive language is at a higher level than his/her language comprehension. In other cases, the phenomenological understanding of the child is the result of the association of certain key words with specific learned routines, e.g. the child executes the instruction “put on your shoes and bring the keys so we can go for a drive” having connected the word “drive” with the latter routine, without however understanding the words. Determining the exact level of understanding is necessary in order to adjust the speech of individuals in the environment, to target improvement in the context of the IEP and so as not to misinterpret lack of understanding as being difficult, lazy, inattentive or disruptive.

Confronting difficulties in phonology or learning difficulties is of secondary importance in speech therapy for ASD. Finally, in the event of absence of speech, it is necessary to teach the child and those in his/her environment an alternative system of communication (see below) in order to prevent the development of difficult behaviors which are often the result of a poor attempt at communicating his/her needs.

Main Points

√ The primary target of the speech therapist, from the moment of diagnosis of ASD, is the development of communication (verbal or non-verbal).
√ The next goals are the development of symbolic and imaginative play and of language itself.
√ It is extremely important to evaluate the child's level of pure verbal understanding with the use of relevant tools.
√ In the event of an absence of speech it is necessary for the child and those in his/her environment to be taught an alternative communication system.
√ Dealing with problems in phonology or learning difficulties is of secondary importance for the speech therapist working with ASD.

Association of Registered Speech-Language Pathologists

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A list of speech pathologists who are members of the Association of Registered Speech-Language Pathologists in Cyprus and who have experience working with Autism, as provided by the Association of Registered Speech-Language Pathologists in Cyprus is offered below. Before making contact with any special therapist, the matter should be discussed with the child's pediatrician, developmental specialist or geneticist. Specialists who treat individuals with Autism will be more knowledgeable regarding the training of the therapists who specialize in autism.

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Callimachou Marina

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4.3.2. Occupational Therapy – Sensory Integration

The World Federation of Occupational Therapists provide the following definition: "Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement." In ASD specifically, the goals of occupational therapy are the following: a) self-care and autonomy and b) dealing with sensory difficulties.

To achieve a goal the therapist needs to work with the individual, in order for him/her to achieve the skills needed to complete certain activities, such as gross and fine motor skills, balance and coordination, behavior, self-care skills, feeding, productive skills, concentration and attention, pre-writing and pre-reading skills, organisational skills, and play skills. At the same time, occupational therapists also work on the person's environment (setting and individuals) in order to make it easier for him/her, as well as utilizing special equipment where ever necessary, such as a computer for writing. Although this should be true for every type of intervention, occupational therapy is the foremost therapy in which the activities should have a playful character, enabling the session to be pleasant and the activity to be of value and motivating for the individual.

The term **sensory integration** refers to the ability of the brain to organize and co-ordinate two or more pieces of information which it receives from the environment and the body through the peripheral sensory systems and the processing of this information enabling a rational and useful movement response. There are seven peripheral sensory systems: tactile, visual, olfactory, gustatory, auditory, vestibular (with information from the middle inner ear regarding the position of the body and head in relation to the ground, gravity, space, balance and movement) and the proprioceptive system (with information through ligaments, joints and muscles as to where each part of the body is and what they are doing)[1].

Included in the context of sensory integration is the Praxis which comprises of Ideation (forming a goal based on the awareness of the environment's abilities), Motor organisation (a plan of how to achieve the goal, including problem solving, and sensory-motor body awareness) and the Execution of the planned action.

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[1] Bundy A. et al (2002) Sensory Integration Theory And Practice. FA DAVIS COMPANY PHILADELPHIA 2002

Children with ASD often exhibit difficulties in sensory integration[1] to a rather large degree, resulting in difficulties in almost all of the aspects of adaptive, cognitive, social and academic functioning[2]. Sensory dysfunctions have been associated with higher levels of stereotyped behaviors, rigidity and repetitive behaviors, significant behavioral problems which hinder adaptation to social and academic settings, and dysfunctions in attention, interaction with others, goal-directed play and self-care. Thus, these problems need to be dealt with in order for the individual to become as adjusted to the environment as possible.

Sensory integration therapy is provided by a well-qualified occupational therapist that also has the necessary equipment. The goal of the treatment for the child with autism is improvement of sensory processing so that more sensory stimuli can be registered and formatted in a more effective way. Therapeutic techniques in Sensory Integration, when these are timed well, reinforced, and are purposeful and controlled in their application, can influence the developmental profile of the child with autism in the entire spectrum of his/her functioning. Due to the term being misused, it is best to check whether the person claiming to be applying sensory integration therapy is indeed following this method. Recently, international guidelines have been published regarding what does and what does not constitute sensory integration, as well as the prerequisites for practicing it[3].

Another important issue is whether all the professionals working with children with ASD, such as teachers, speech therapists, special educators and so on, are utilizing sensory techniques in their interventions.

The use of these techniques makes applying all other interventions much easier by removing the obstacles that are present due to the individual’s sensory dysfunction. Of course, in order to apply these techniques, it is necessary to first have the child evaluated by a qualified occupational therapist who will then recommend to the other professionals which techniques might be suitable.

We would like to note here, that the Andreas Sofocleous Centre for the Provision of Social Services “Kepaky”, in the context of social contributions, has undertaken the foundation of a **Sensory Integration Centre,** as well as providing the centre with the necessary equipment. The Centre for the Occupation of Individuals with Autism opened its doors, at a pilot level, by the Cyprus Association for Individuals with Autism, in October 2010.

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[1] Ben-Sasson A, et al (2009) A Meta- Analysis of Sensory Modulation Symptoms in Individuals with Autism Spectrum Disorders. Journal of Autism and Developmental Disorders, 39, 1-11

[2] Mailloux Z (2001) Sensory integrative principles in intervention with children with autistic disorder. In: Smith-Roley S, Imperatore- Blanche E, Schaaf RC, editors. Understanding the Nature of Sensory Integration with Diverse Populations. San Antonio, TX: The Psychological Corporation. p 365–382.

[3] Parham LD, et al (2011) Development of a fidelity measure for research on the effectiveness of the Ayres Sensory Integration intervention. Am J Occup Ther. 65(2):133-42.

The equipment and services which the Centre offers combine the classical services from specialized personnel, with the use of specially designed equipment based on Sensory Integration methods, which have to do not only with therapy but also with learning through play.

The therapists are certified in evaluation and therapeutic intervention with the Ayres Sensory Integration ASI® method. The qualification in this method was obtained through the educational programs of the Hellenic Society for Sensory Integration (ELLEAO) in Greece and the University of Southern California/Western Psychological Services in the US.

There are two specially equipped rooms at the Centre. The first, namely the Sensory Integration Room, functions as a play and activity room, in which the occupational therapist can evaluate the child, the symptoms, the responses and the way in which he/she collects information, while at the same the therapist is in a position to improve on emotional processing. The second room is referred to as the Multi-Sensory Room, which also adopts sensory techniques but also functions as a room in which to regulate anxiety. A multi-sensory environment is designed to stimulate the senses of touch, taste, vision, hearing and smell without the need for mental activity. The equipment is designed in such a way to cater for individuals from the age of 6 months through adulthood. In the remaining areas of the Centre lie the offices and rooms of the remaining specialists (one for Speech Therapy and/or Special Education and one for Music Therapy), complete with the necessary equipment.

Main Points

√ One of the goals of the occupational therapist in ASD is to improve on self-care and autonomy through cultivating gross and fine motor skills, balance and co-ordination of movement, self-care skills, feeding, concentration and attention, pre-writing and pre-reading skills and play.

√ Sensory integration is the brain’s ability to organize and coordinate two or more pieces of information it receives through the environment and the body via the senses.

√ Children with ASD frequently and to a large degree, exhibit problems in sensory integration, resulting in difficulties in almost all areas of adaptive, cognitive, social and academic functioning.

√ Sensory Integration Therapy is practiced by a suitably qualified and licensed occupational therapist that also has the necessary equipment and follows the published international guidelines.

√ All professionals working with ASD should utilize the sensory “techniques” recommended by an occupational therapist who has evaluated the child.

Cyprus Association of Occupational Therapists

P.O. Box 16202, 2087 Acropolis, Nicosia

Tel: 99351517

Website: www.ergotherapeiacy.eu

Email: cyprusot@gmail.com and info@ergotherapiacy.eu

Model Centre for Occupation, Care and Treatment which has been bestowed upon the Cyprus Association for Individuals with Autism by Kepaky

1 Ellispondou street, Ayios Nikolaos, Limassol, Tel: 25107951

A list of Occupational therapists who are members of the Council of Registered Occupational Therapists in Cyprus, who work with AUTISM, as provided by the Cyprus Council of Registered Occupational Therapists, is offered below. Prior to contacting any specialized therapist, the parent should discuss the matter with the child's pediatrician, developmental specialist or a geneticist. The specialists working with Autism will be more knowledgeable regarding the qualifications of the therapists who specialize in Autism.

Nicosia

Yianna Shiamma

81 Nikis Avenue, Office 402, 1086

Tel: 99694167

Email: yianna.shiamma@yahoo.com

Despina Kaimi

'Ergodrasi' Therapeutic Centre

12 G.Stokkou street, Dasoupoli, 2024

Tel: 99450458, 22264560

Email: dkaimi@hotmail.com, ergodrasi@hotmail.gr

Evanthia Constandinou

42 Esopou street, Aglantzia, 2113

Tel: 99676179, Fax: 22347768

Email: giannosmoti@yahoo.com

Maria Michail

Smartkids Multidisciplinary Centres

23A Laodikias street, Strovolos, 11 Archbishop Makarios III and 66 Archbishop Makarios III, Dali.

Tel: 99746485, Fax: 22482683

Email: smartkids@cytanet.com.cy

Limassol

Kristia Christou

7 Ioanni Damaskinou street

Tel: 99400388, Fax: 25336938

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Louiza Papacharalambous Kousoulidou

13A Telamona street

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Christoforos Pampakas

Model Multidisciplinary Centre

4 Aretis street, Mesa Geitonia, 4006

Tel: 99047997

Email: christosergo@cytanet.com.cy

Larnaca

Emily Theodosiou Gavrielidou

Occupational Therapist specializing in NDT-BOBATH, SI, ABA methods

84 Archbishop Paisiou street, Vergina, 7101

Tel: 99818481, Fax: 24368191

Email: e.gavrielidou@gmail.com

Paphos

Andriana Kokkali

73 Alexandroupoleos street, Andigoni Court, 8027

Tel: 99126629

Email: therapist.andy@gmail.com

4.3.3. Special Education

Often the role of the special educator is mistakenly associated only with the cultivation of school related skills, as the speech therapist is to speech (phonology, vocabulary). In reality the role in ASD is much broader, since it extends into many areas of development, in cooperation and in synergy with the speech therapist and occupational therapists.

The major areas in which a special educator works (either in individual or group sessions) is learning skills for play, social skills, recognizing and dealing with emotions, behavioral issues, self-care skills within the community (playground, super market, restaurants, etc.) organizing space and time (especially free time) by introducing a visual programme and so on. All of the above may also be included in other therapists goals, however, the distribution of goals and activities should be completed in the IEP based on the collection of the child’s needs.

The main therapist in special units for preschoolers with ASD, e.g. in TEACCH settings (see below) has a special role. In these settings, the special educator takes on the role of the preschool teacher and applies an equivalent group programme which has been adapted to the needs and skills of the child.

The area of learning is generally a secondary target in ASD, where we find deficits which have much more significant consequences in the child’s life. However, for children who are higher functioning and are coping well in mainstream schooling, this area may also receive support. Specific academic issues that may arise in children with ASD, such as dyspraxia, or in simpler terms bad handwriting-dysgraphia, are matters of concern for occupational therapists. Preschool learning skills may be the goal of the special educator, since the occupational therapists is dealing with other issues. Organizing study activities can be undertaken by the special educator who is trained in ASD, while assisting with studies can be taken on by a regular educator or with the support of an “autism therapist”. The role of the special educator is important in the event of comorbid special learning difficulties (dyslexia, dyscalculia, dysorthographia, non-verbal learning difficulties).

Main Points

√ The areas which a special educator works within are the following: skills for play, social skills, recognizing and managing emotions, behavior issues, self-care skills within the community (playground, supermarket, restaurant, etc.), space and time management (particularly free time) with the introduction of a visual programme.

√ The special educator is considered to be the main educator in special preschool settings for children with ASD

√ The area of learning is a secondary target in ASD, but for higher functioning children this area may need support from a special educator and/or teacher.

√ The role of the special educator is important in the event of comorbid special learning difficulties (dyslexia, dyscalculia, dysorthographia, non-verbal learning difficulties).

The Cyprus Association of Special Educators

P.O. Box: 28967, 2084 Nicosia

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Prior to contacting any specialized therapist, the parent should discuss the matter with the child's pediatrician, developmental specialist or a geneticist. The specialists working with Autism will be more knowledgeable regarding the qualifications of the therapists who specialize in Autism.

Koulla Pandeli

5 Paster street, 1055 Ayios Andonios, Nicosia

Tel: 99489541, Fax: 22430025

Centre for the Provision of Special Education in Limassol

Centre of Development and Support for Children and Teenagers, AASP

Tel: 97663166, Fax; 25662272

Website/email: www.cyspecialed.com, contact@aasp-cy.com

4.3.4 Psychological Support

A psychologist may often have a similar role to that of the special educator, as described above. However, he/she also holds an autonomous role in the context of interventions in ASD. More specifically:

a) The psychologist may deal with the psychotherapeutic support of a higher functioning individual with ASD, for instance, when the person begins to be aware of and feels frustrated with how different he/she is from others. The therapist may then proceed to inform the individual in a structured manner of his/her diagnosis and give advice on how to manage it. This process follows specific steps and protocols, while it also requires several meetings with a therapist whom the child knows and trusts. An experienced therapist, as well as the presence of the family, is necessary at least for the initial meetings. It is best to do this (ONLY if the individual appears to need it) before puberty and typically after the age of 8, so as the child is in a position to deal with it mentally. It is also necessary to be done with adults who suspect they may fall within the spectrum, e.g. a parent.
b) Psychotherapeutic support is necessary when the individual develops other psychiatric symptoms such as anxiety, depression or obsessive compulsive disorder. Often these are dealt with utilizing highly structured directive psychotherapy which focuses on understanding the basic difficulties that are present, teaching techniques for solving social issues, supporting development and generalizing adaptive skills. In more severe cases and if this is an option, Cognitive Behavioral Therapy (CBT) is recommended, for many issues[1], but particularly for anxiety and depression. Psychodynamic-psychoanalytic therapy is not effective for the central symptoms of the disorder neither for comorbid conditions[2]. In all cases, utilizing psychotherapy requires careful evaluation of the strengths and difficulties of the individual and specific indications that the person will benefit from it[3].

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[1] Reaven J. (2011) The treatment of anxiety symptoms in youth with high-functioning autism spectrum disorders: developmental considerations for parents. Brain Res. 1380:255-63.

[2] Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47(7):493-9.

[3] Papageorgiou V. “Therapeutic approaches to autism spectrum disorders”. Encephalos Archia Neurologias kai Psichiatrikis. http://www.inpsy.gr/Articles/HochmannGR.htm

c) The family also frequently needs support, particularly immediately following the diagnosis but also at later stages, in relation to matters that concern the child but also ones that concern the parents and the siblings of the child with ASD. While in the past, the psychodynamic approach overly focused on the family (erroneously believing it is the operative cause of the disorder), contemporary approaches focus simply on training the family. This is often inadequate, since the trauma experienced by the parent, as well as the constant pressure of the disorder (and even the intervention itself) can incapacitate the parent. Also, not addressing the psychological health of the family could lead to failure, or severe restriction, of the intervention's influence on the child.

d) Finally, an intervention may be needed which targets the functioning of the family system, where relationships are being tested, often resulting in dissolution or dysregulation of the family. The need is greater when one of the two parents is also on the spectrum (or within the broader autistic phenotype), increasing the number of difficulties. In this case, the 'neurotypical' parent should be provided with support and guidance should be given to the one with ASD[1].

Main Points

√ A psychologist will deal with the self-awareness of the individual with ASD, as well as any comorbid difficulties (anxiety, depression, etc.).

√ The psychologist will utilize structured directive psychotherapy, while the treatment of choice is Cognitive Behavioral Therapy. Psychodynamic-psychoanalytic therapy is not effective in these cases.

√ Intervention targeted at the family is very important, both on an individual level as well as to the family as a system, particularly if one of the parents is also on the spectrum.

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[1] . Aston, C.M. (2002). The other half of Asperger syndrome. Autism Asperger Publishing Company.

4.3.5 School integration

School integration (in either mainstream or special schools) should not be pursued simply for the sake of it. Many times it is a target, and even a means of intervention for children with ASD, however it cannot also become a significant obstacle if targeted prematurely, or without taking into account the needs and strengths of the child (and of the setting), or if necessary measures are not taken for the integration to be successful.

For preschoolers, integration in standard settings requires some desire for social exchange (otherwise they will simply become isolated) and the presence of imitation skills (in order for them to be "trained" by their peers). For very young children (<36 months) one can attempt integration (as long as they are no problematic behaviors which could become routine for the child) and allow some time to pass. For older children however, observation should be completed in order to ensure that their attendance covers the goals outlined in the IEP, so as not to waste time. If not, then it is preferable for the child to attend a specialized ASD preschool setting and attempts can be made there to prepare the child for being mainstreamed later on.

For children older than 5, integration in a typical setting requires appropriate preparations, at least a borderline intelligence level (IQ>70) and skills (social, communication and preschool) of at least a child of 4.5 years old (this can be assessed using certain tests e.g. the Vineland Adaptive Behavior Scales). Under the above circumstances, there should be clearly defined goals regarding the child's attendance at the school which are documented in the IEP.

For children with fewer skills, the goal of integration may simply be the development of social and communication skills. In this case, this should be agreed upon with the classroom teacher, so that there are not too many academic demands, and the achievement of the above skills is preplanned in a systematic manner. Thus, continuous or periodic cooperation with the teacher is needed to avoid the appearance of problematic behaviors, but also direct intervention will be needed to include the child in peer groups. This can be achieved by creating a "circle of friends", a technique which is affective in integration, while at the same time it is an activity which has educational value for "neurotypical" classmates. In other cases, constant presence of an individual helper for the child is needed ('shadow', parallel support), who supports the child and ensures the achievement of the IEP goals, having the role of a teaching assistant but NOT replacing the role of the teacher.

For children who have more highly developed skills, goal-setting should definitely include academic goals, while social integration should be more intensive and have deeper goals, e.g. friendship development. The above mentioned means can also be utilized in these cases (cooperation with the teacher, parallel support, "circle of friends") which should of course be adapted to the needs of the child.

It should be noted that as negative and detrimental it may be to set goals that are below the child's abilities (e.g. academic goals), it is equally as negative to set goals that are much higher than what the child is able to or needs to achieve. Often a child with lower mental abilities is required to attend a setting of a much higher academic level, which results in not covering his/her true needs (e.g. everyday skills) but also in destroying his/her self-image due to failure. This runs the risk of the individual doing less than he/she is able to and adopting challenging behaviors, while also, instead of becoming more socialized he/she falls victim to bullying or becomes isolated. If integration is decided upon for reasons of socialisation, as is the case with special classes in regular schools, active intervention is needed from the school staff in order to achieve this and not allow the child to become marginalized from the typical group of children. Finally, the outcomes of integration should be constantly evaluated and every year the benefit of continuing or discontinuing integration should be re-evaluated.

Main Points

√ Integration into mainstream schools should not be done for the sake of it, but should be constantly evaluated, along with the goals and means used.

√ In order to integrate a child, he/she must have some minimum skills which are relevant to the setting, there should be a clearly defined purpose and interventions should be applied which ensure the achievement of goals.

√ As negative as it is to set lower goals for a child it is equally as negative to set goals which are higher than the child's abilities.

4.3.6 Music Therapy

Music therapy is a clinical use of musical intervention, based on scientific research, which is aimed at achieving individualized goals via a therapeutic relationship with a suitably qualified music therapist. Through the therapeutic use of music, progress can be made in physical, psychological, mental, social and behavioral areas.

During the session, the therapist and the participants create a musical happening by either listening to music or using musical instruments which do not require musical knowledge. Throughout the music therapy process the individuals can express and process emotions via the music, explore experiences and self-knowledge, improve sociability and utilize their creativity.

In ASD, music therapy may target the basic deficits of the disorder, that is, social exchange and communication. Instead of the target of acquiring skills, music therapy provides the child with a framework within which to learn how to be part of a common story, have a common focus with others, accomplish turn taking, and regulate his/her emotions. It is necessary of course for the therapist to be knowledgeable with regards to the specifics of the disorder and set goals based on the child's IEP and not merely pursue general participation and satisfaction. The effectiveness of the specific intervention is in need of further evaluation[1].

Main Points

√ In ASD music therapy targets social interaction and communication, providing a general framework within which the child can practice these skills.
√ The therapist should be knowledgeable with regards to the specifics of the disorder.

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[1] Geretsegger M, et al (2012) Randomised controlled trial of improvisational music therapy's effectiveness for children with autism spectrum disorders (TIME-A): study protocol. BMC Pediatr. 12:2

4.4. Special treatments

As our understanding of the nature of the disorder broadens, new specialized treatments are being developed for ASD, while others are being reviewed, combined or abandoned. The list of recommended treatments is long and is constantly being added to. In order for the parent, as well as the specialist, to select an intervention for a child with ASD, he/she must follow the general rules mentioned above (§2.1) which are elaborated on in the website of the UK's National Autistic Society (http://www.autism.org.uk/living-with-autism/strategies-and-approaches/before-choosing-anapproach.aspx). Particularly for issues of description and effectiveness of an intervention we recommend the website of Research Autism, a not-for-profit company, which aims at using scientific criteria to evaluate interventions for Autism (http://www.researchautism.net/pages/welcome/home.ikml). In the following section we provide brief descriptions of the interventions which have attracted worldwide recognition and are also widely used in Cyprus.

Specifically:

a) Psycho-educational and behavioral (mainly the **T**reatment and **E**ducation of **A**utistic and related **C**ommunication handicapped **C**hildren – TEACCH and Lovaas & **A**pplied **B**ehavioral **A**nalysis – ABA) which make up the two most widely used approaches, but also the central foundation which all others have been built upon. Based on the rationale of providing a framework within which to understand and cover the needs of individuals with ASD in various settings and services, the UK's National Autistic Society (NAS) developed the programme **S**tructure/**P**ositive attitudes/**E**mpathy/**L**ow arousal/**L**inks – SPELL.
b) Augmentative/Alternative Communication aims at reinforcing communication with speech as a secondary target. The leaders in this approach are the **P**icture **E**xchange **C**ommunication **S**ystem – PECS and MAKATON which uses a combination of pictures and gestures.
c) Social skills training of higher functioning individuals is mainly achieved through group interventions and the use of visual aids, such as Social Stories by Carol Gray and Comic Strips.
d) Psychopharmacological interventions.
e) Alternative interventions: These include interventions with some support from the literature in the form of anecdotal reports from parents (such as large doses of vitamin B6 and magnesium, and casein and gluten free diets), for some of which no data is available to evaluate them (e.g. the use of stem cells, detoxification from heavy metals, and cleansing the bowel with antibiotics and probiotics) and others which have been proven to be ineffective (such as hyperbaric oxygen, facilitated communication and Auditory integration therapy).

4.4.1. TEACCH[*]

TEACCH is a special education programme which is adapted to the particular needs of the child with autism and is based on certain guidelines. The TEACCH approach is unique in that it focuses on creating a natural, social and communication environment. The environment is structured in such way so as to alleviate the difficulties of the child with autism (as well as the adult), who is trained to behave in acceptable and appropriate ways. Based on the fact that children with autism learn in a visual way, TEACCH brings visual clarity into the learning process, aiming at structuring acceptance, understanding, organisation and independence. Children work within a highly structured environment which may include the natural positioning of furniture, clearly defined activity areas, programmes based on pictures and work systems and educational clarity. The child is guided through a clearly defined succession of activities with the direct goals of becoming more organized. It is essentially a general framework of principles which makes up the foundation of most eclectic intervention programmes. The central characteristics of TEACCH (visual structure, visual schedules, analysis of behavior using the ‘iceberg’, etc.) have been integrated into many other intervention methods (including ABA) since they take into account the basic deficits and strengths of ASD, or what TEACCH refers to as ‘Autism culture’.

4.4.2 SPELL

The SPELL framework recognizes the particular and unique needs of each child and adult and emphasizes that the entire planning and intervention should be built on this foundation. A basic premise in SPELL is that a number of interrelated topics benefit children and adults who have disorders on the autism spectrum and that, building upon their strengths while reducing the negative parts of the condition, will potentially bring about progress. These topics are structure, constructive and realistic attitudes and expectations, empathy and understanding for the special way in which the individual with ASD experiences the world, mild stimulation of the individual so as not to cause anxiety and the improvement of concentration, as well as the gradual interrelation between the various areas of his/her life and the various interventions to promote consistency. SPELL is supplementary to TEACCH but it allows for the application of other interventions as well.

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[*] www.teacch.com

4.4.3. ABA[*]

The behavioral techniques were initially used by Lovaas and evolved into what we now refer to as Applied Behavior Analysis (ABA). The latter techniques follow Skinner's behavioral principles of learning and aim at improving socially significant behaviors and acquiring new skills.

All of the skills are broken down into individual steps or elements. Trainees are provided with repeated opportunities to learn and practice these skills in a plethora of situations, receiving plenty of positive reinforcement. The goals of the intervention, as well as the specific type of instructions and reinforcement used, are adapted to the strengths and needs of the specific individual. Performance is continuously measured through direct observation and the intervention is modified if the data indicate that the trainee is not making satisfactory progress. The goal of the ABA intervention is to render the individual capable of functioning as independently and as successfully as possible in a variety of environments.

These principles are integrated into more specialized interventions (Discrete Trial Training, Early Intensive Behavioral Intervention, Functional Communication Training, Incidental Teaching, Milieu Training, Pivotal Response Training, Positive Behavioral Support, Verbal Behavior Approach, Video Modeling), thus it is difficult to speak of their effectiveness in their entirety. What is certain, however, is that these programmes are intensive and require many hours a week to be applied. They have definitely exhibited effectiveness, particularly (but not limited to) the acquisition of everyday life skills, even in children who are lower functioning. The initial (Lovaas studies) and frequently mentioned effectiveness is of course overstated, while the cost effectiveness in terms of time, effort, and financial burden has not yet been fully assessed[1].

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[*] *http://www.autism.org.uk/living-with-autism/strategies-and-approaches/spell.aspx

[1] Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47(7):493-9.

4.4.4. PECS[*] (& vs. MAKATON[**])

PECS (Picture Exchange Communication System) is an incremental and alternative technique, whereby individuals with little or no verbal ability learn to communicate using picture cards. Children use the pictures to ‘verbalize’ a desire, observation or emotion. Since certain individuals with autism tend to learn visually, this type of artificial communication has proven to be effective in improving independent communication skills, often leading to benefits in spoken language as well. Through a series of steps, the child begins with the simple exchange of an object for something else he/she desires (Phase 1) moving on to looking for a card which represents what he/she wants to give it to the parent and receive the desired object (Phase 3B). This is followed by learning a simple sentence (I want…) and finally making comments and using definitions. The method is simple and effective, since it can be combined with most other interventions (TEACCH, ABA, etc.), can be used in the school environment and helps build upon the strength of the individual with ASD (visual) avoiding its weakness (action), and at the same time its use does not require special training (only for learning).

Makaton is a communication development programme. It is based upon the use of signs and/or written symbols which accompany and support verbal communication. Makaton is a programme which enables all those who exhibit a wide range of developmental difficulties in communication and speech to develop these skills and use them in a simple yet very functional way, so as to participate in social life, have fun, have choices and claim their rights.

Makaton can offer many more skills to the individual since it constitutes more of a ‘language’ than PECS. However, it lacks significantly in that it requires many skills on the part of the child, since on the one hand he/she must be able to gesture and on the other hand, have eye contact. Additionally, in order to use it, many people need to be trained, since all individuals who wish to communicate with the child must know the signs and be in a position to respond to them.

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[*] www.pecs.com

[**] www.makaton.org

4.4.5. Social Skills Training (Comic strips, Social stories)

The development of social skills constitutes a necessary field of intervention for individuals with ASD, and particularly those who are higher functioning, based on the deficits they exhibit (difficulties with theory of mind, weak central coherence, difficulty in planning and understanding sequencing, etc.). Training can be done either individually or in a group, with the latter being preferable as a more natural setting. It is best if the group is run in the context of the school, rather than at the centre only with individuals who have ASD. In the latter case, even if generalization of the learned skills is not achieved, as critics of this intervention claim, at least relationships within the school environment are normalized, where the child spends most of his/her time for many years. There are many specific techniques (mainly with the introduction of visual signs) but also educational packets which are recommended. The two techniques developed by Carol Gray[*] deserve further attention.

Social Stories are created as a response to a problematic situation, so as to explain the how and why of each person's social setting. Once the relevant information on the topic has been gathered and a conversation has taken place (to modify his/her perspective) a corresponding scenario is created including his/her needs, interests and ability but also based on the guidelines of the technique. This includes specific information regarding the facts of the situation, other people's potential reactions to it and guidelines concerning suitable and desirable social responses. This is then taught to the individual with the use of specific types of sentences which correspond appropriately to the scenario. The addition of visual elements adds to the effectiveness of this method.

Comic strip conversations are visual representations of various levels of communication in a conversation. They include what is being said in the conversation, but also what the people's feelings or intentions may be. In this way, the more abstract aspects of social communication become more specific and thus more easily understood by the individuals with ASD.

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[*] http://www.thegraycenter.org

4.4.6. Medication

Psychopharmacological interventions (table 5) target the symptoms of the disorder which hinder the general functionality but NOT the disorder itself. Antipsychotic[*] drugs, select serotonin reuptake inhibitors (SSRI's), mood stabilizers as well as medication used in ADHD, in the case of comorbidity, are known to be used in ASD. The use of medication aims at making the use of educational interventions easier but does NOT replace the need for them.

Failing to acknowledge a behavior as an 'alternative' attempt at communication and simply suppressing it, leads to over-prescription of medication in individuals with ASD. Medication may have a transient action (honeymoon phase) which is based on the drug's side effects and not on its therapeutic action. Thus, the suppression which is caused can stop the challenging behavior for as long as the suppression lasts, however, when this ceases and the reasons for the manifestation of the behavior continue to be present, then the behavior will reoccur. This wrongful approach may then continue by either increasing the dose or adding another medication, resulting in the same course.

In table 5 an algorithm regarding when one should resort to the use of medication is suggested: the only reason which warrants their use is the presence of a behavior in a consistent way (not challenging behaviors which occur only under certain circumstances, e.g. only in school) which also has consequences on the child's functionality. If not, then utilizing medication may be considered misuse. If, on the other hand, the behavior appears under specific circumstances (in the large majority of cases), then the reason and purpose of the behavior should be investigated, followed by the necessary steps to deal with it. If it is not possible to determine the cause, and it has no consequence on functionality, then it is best to ignore it. If it does impact functionality then we can resort to medication. However, this will not effective in the long-term.

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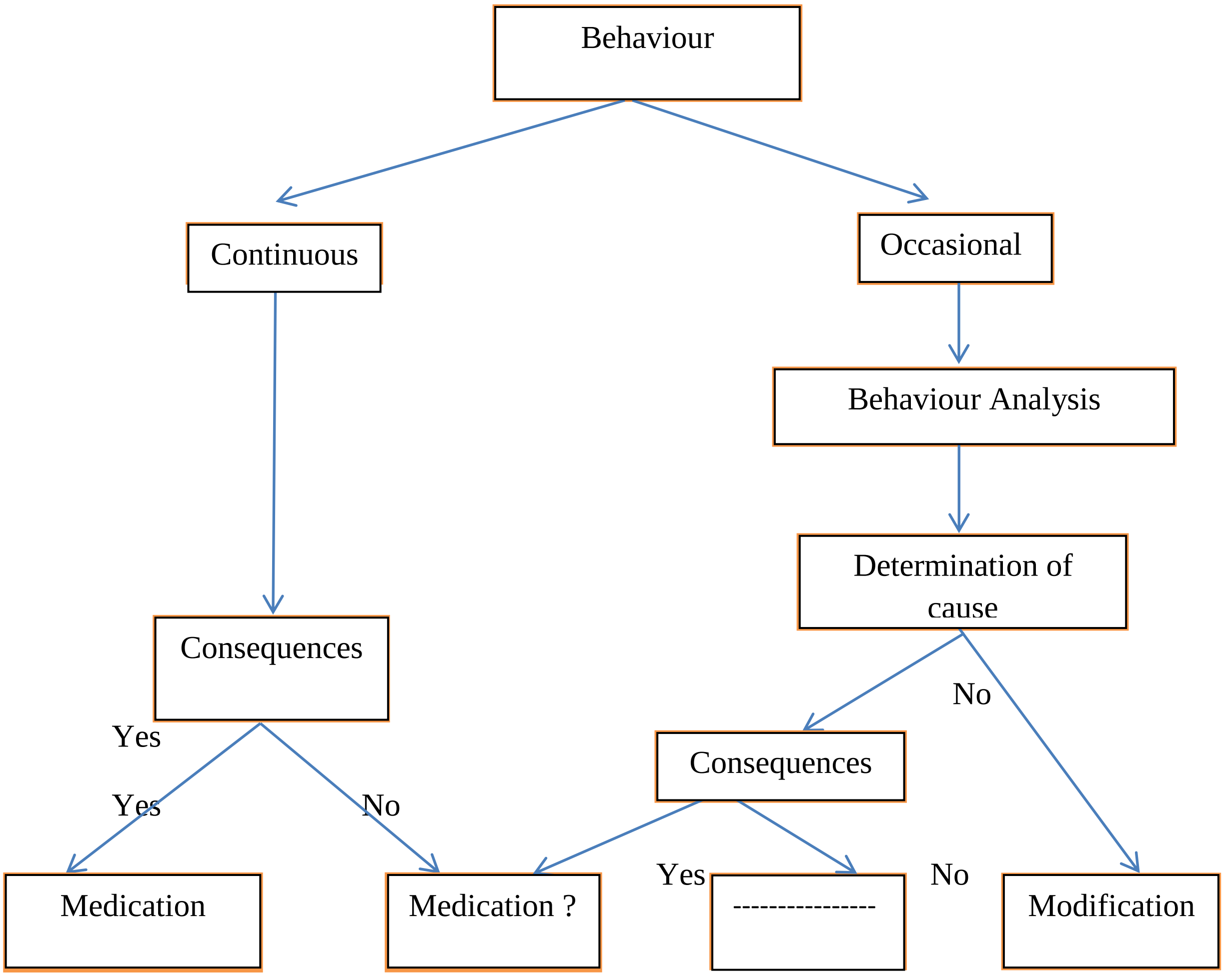
[*] The only drugs which are indicated for use in ASD are risperidone and aripiprazole.

Table 5. The medication algorithm[1]



In order for a drug (or any intervention) to be considered effective, it must be proven that its effectiveness is greater than when administering an iconic medication – a placebo (>30%). The simple, positive, reports for users of a substance or their parents, have resulted in the publication of a series of case studies and open studies. The final confirmation comes from large double-blind controlled placebo studies, where both the recipients of the medication and the researchers are unaware of whether an individual is taking the active medication or the placebo. The presence of positive results in animals is also a promising indication but of course it is not sufficient.

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[1] Francis K (2012) The projection of Autism Spectrum Disorders (ASD) in adult life. Psichiatriki 23: P66-P73

4.4.7 Alternative Methods

The lack, to this date, of an etiological treatment and the limited effectiveness of recommended interventions, leads many to turn to alternative methods of treatment. Some of these have a rational relationship to the hypothesized causes of ASD and some research evidence. However, the majority of 'treatments' are at best, simplistic approaches and at worst, attempts at exploiting the condition. When one considers such an intervention, he/she should keep in mind all that has been posited above regarding the selection process of an intervention (and the possible side-effects which are frequently suppressed) and seek evidence from scientific journals and websites (e.g. http://www.researchautism.net/pages/welcome/home.ikml). We will now refer to some of these approaches:

- Large doses of vitamin B6 and magnesium: 16 and 8mg/kg/day are administered along with other vitamins and minerals in order to aid their metabolism. It has been claimed that it helps half of children with improvements in hyperactivity, attention, learning and sleep; however, it is not clear if this is achieved to a greater degree than the placebo[1]. Improvements may occur within a few days, but usually it takes 2-3 months. The magnesium is administered to tackle the side-effects of hypervitaminosis, such as irritability, sound sensitivity and enuresis. B6 hypervitaminosis can cause peripheral neuropathy with tingling and numbing in the fingers which subsides with reduction of the dosage.
- Casein diet (dairy free) and gluten diet (grain free diet): The food in question is removed from the person's diet with the belief that their catabolic products have an adverse effect on the brain. Among the reported results are a reduction in aggressiveness and self-harming behaviors and an improvement in sociability and attention. These may occur after a transient worsening of behavior. For results from the casein diet, one may have to wait up to four weeks while for the gluten diet this may take 6 months. This diet appears to be more effective with younger children who have a history of allergies. However, the diets are difficult to follow, and the worsening of symptoms is quite great if the child consumes by mistake one of the forbidden food items. Additionally, there is an absence of the necessary scientific findings to support the effectiveness of these diets[2].
- Hyperbaric Oxygen: The use of oxygen enriched air (24-48%) with pressure greater than that of the atmosphere within special chambers (compression or hyperbaric chambers) is based on the idea that a significant percentage of children with ASD present with neuro-inflammation and decreased blood flow in the brain, conditions which can be treated by increasing the oxygenation of the brain.

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[1] Nye C, Brice A. (2002) Combined vitamin B6-magnesium treatment in autism spectrum disorder. *Cochrane Database Syst Rev* 4: CD003497.

[2] Millward C, Ferriter M, Calver S, Connell-Jones G. (2004) Gluten- and casein-free diets for autistic spectrum disorder. *Cochrane Database Syst Rev* 2: CD003498.

Side-effects occurring from this method include gravitational trauma to the middle ear (with pain, inflammation to the ear drum membrane, fluid collection, vessel rupture and/or rupture of the ear drum), pain and inflammation of the sinus cavities, nose bleeds (especially in children with allergic rhinitis and upper respiratory infection with accompanying nasal congestion, bronchospasms, worsening of asthma, hypoxemia (all fully reversible), while it also reduces the threshold for epileptic seizures, can cause reversible myopia or blurriness of the optic lens, while in children with congenital spherocytosis it causes hemolysis.

As far as the pathophysiological mechanism, two studies have failed to prove that this occurs with hyperbaric oxygen therapy[1-2]. The effectiveness of the method has been researched in two controlled studies that produced conflicting results[3-4], as well as in open studies with unequivocal results[5]. Thus, we cannot refer to this method as an effective one for ASD, as noted by the relevant Organisation, the European Committee for Hyperbaric Medicine, which in one of its guidelines published in 2004, as well as those under review, it does not accept Autism as an accepted indication[6].

- Stem cells: The use of stem cells from the umbilical cord is based on the same principle as above (inflammation and reduced blood flow to the brain). To date, there have only been three articles published in scientific journals regarding this method, and all of these suggest that it could be effective with autism as well[7]. There is a clinical study in China for the safety and effectiveness of transplanting mononuclear and mesenchymal stem cells from the umbilical cord in children with autism, which despite having been completed since October 2011, has yet to announce or publish any results. Thus, it must still be considered to be an experimental method with unknown results and consequences (www.researchautism.net/celltherapy).
- Flavonoids – Luteolin: The use of flavonoids, such as Luteolin from chamomile, follows the rationale of dealing with the neuro-inflammation. Their administration both in vitro as well as in mice has garnered positive results[8]. To date we have received positive reports from many parents, while the first series of 37 case studies has been published indicating that the

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[1] Rossignol DA, et al (2007) The effects of hyperbaric oxygen therapy on oxidative stress, inflammation, and symptoms in children with autism: an open-label pilot study. BMC Pediatr. 16;7:36.

[2] Bent S, et al (2012) Brief report: Hyperbaric oxygen therapy (HBOT) in children with autism spectrum disorder: a clinical trial. J Autism Dev Disord. 42(6):1127-32.

[3] Rossignol DA, Rossignol LW, et al (2009) Hyperbaric treatment for children with autism: a multicenter, randomized, double-blind, controlled trial. BMC Pediatr. 13;9:21

[4] Jepson B, et al (2011) Controlled evaluation of the effects of hyperbaric oxygen therapy on the behavior of 16 children with autism spectrum disorders. J Autism Dev Disord. 41(5):575-88.

[5] Ghanizadeh A. (2012) Hyperbaric oxygen therapy for treatment of children with autism: a systematic review of randomized trials. Med Gas Res. 11;2:13.

[6] Kot J. & Mathieu D. (2011) Controversial issues in hyperbaric oxygen therapy: a European Committee for Hyperbaric Medicine Workshop. Diving Hyperb Med. 41(2):101-4

[7] Siniscalco D et al (2012) Autism spectrum disorders: is mesenchymal stem cell personalized therapy the future? J Biomed Biotechnol. 2012: 480289

[8] Theoharides et al (2012) A case series of a luteolin formulation (NeuroProtek®) in children with autism spectrum disorders. Int J Immunopathol Pharmacol. 25(2):317-23

mixture is well tolerated and has good prospects. More specifically, improvement in gastrointestinal and allergic symptoms have been reported in 75% of children, attention and eye contact in 50%, social interaction in 25%, while 10% evidenced speech gains.

In order to verify the above, in December 2012, the Attikon Hospital in cooperation with Tufts University in Boston will complete the next phase of the drug evaluation in an open study of 50 children with ASD aged 4-10. The results so far are also positive, and so the final phase of evaluation is in the works, which includes a double-blind placebo controlled study, in order to verify the preparation’s clinical effectiveness.

- Chelation/heavy metal detoxification: This method constitutes an effort to remove heavy metals, particularly mercury, from the body, that is believed to have an effect on the physiology and behavior of individuals with ASD. The removal is achieved via the administration of various chemicals (the most well researched and FDA approved is DMSA), which binds to the heavy metals and expels them. Small studies (10 participants) report particularly positive results, while the larger studies are much more reserved in claiming that there is significant improvement. The method is not free of side-effects such as: loss of useful metals, worsening of mercury poisoning by it spreading to other tissues, nausea, diarrhea, anorexia, fatigue, irritability, sleep disorders, allergic reactions, and occasionally autistic regression in speech and behavior. The more serious side-effects include bone marrow suppression, damage to the kidneys and liver, toxic epidermal necrolysis, while zeolite has also been implicated in pleural mesothelioma (cancer). It should be noted that the National Institute of Mental Health in the US has discontinued DMSA studies for safety reasons.
  Thus the intervention is not considered suitable (www.researchautism.net/autism_treatments_therapies_interventions.ikml?ra=25).
- Bowel cleansing with antibiotics and probiotics: The aim of the intervention is to eliminate or reduce fungi present in the intestines, which are implicated in the worsening of autistic symptoms, including in children who do not have ASD. Antifungal medications, as well as probiotic preparations, are administered. There is no strong evidence from research which supports this method or renders it advisable[1], except for a few simple reports. Side-effects include transient deterioration for the first ten days from the circulation of the products that destroy the fungus, irritation, diarrhea, stomach disorders and itchiness from the antifungal medication, while ketoconazole can cause liver damage.

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[1] Laidler JR. DAN! (2001) Mercury Detoxification Consensus Group. DAN! (Defeat Autism Now) Mercury Detoxification Consensus Group Position Paper. San Diego, CA: Autism Research Institute

5.0 PROJECTED NEEDS OF ADULTS WITH ASD*

Children with ASD will one day become adults and face continuing difficulties. However, there will be some differences with regards to clinical picture they presented during their childhood. Indeed, during this time matters of differential diagnosis that occur, particularly in the higher functioning end of the spectrum, may lead the individual to visit an adult psychiatric setting.

5.1. Lower functioning adults with ASD

Individuals with lower or average functioning will continue to need special care and may be referred to a psychiatrist, mainly for behavioral difficulties. These difficulties may arise from the appearance of a new psychiatric condition and this possibility should not be overlooked by the clinical psychologist. However, recognizing such conditions is not easy in this sub-group, due to the restrictions in communication.

In most cases, however, the behavioral problems stem from the limitations on adaptability placed on the individual by ASD, as well the limited mental abilities of this sub-group. When the restricted skills of these individuals fail to meet their needs which become more complex in nature, this gives way to the appearance of challenging and aggressive behaviors mainly regarded as inappropriate attempts at communication. Thus, contrary to the dominant approach, the best practice in dealing with these undesirable behaviors is more often behavioral adjustments and environmental modification, and less frequently medication (see §2.4 and table 5). The latter should be chosen only in cases in which the behavior is continuous (e.g. constant irritability) which has an effect on the person's general functioning (e.g. uncooperative in educational or work environment) or in those cases where the appearance of the behavior is occasional (e.g. outbursts of anger), there are difficulties in detecting the cause and the effect is significant with regards to adaptability (e.g. dangerous for others). In all other cases, the use of medication is pointless and ineffective.

As mentioned, there is a particular risk for the development of catatonic symptoms in this group. An observed worsening in the clinical picture of the individual and loss of acquired skills is often attributed to the 'normal' course of ASD after adolescence and/or to the effects of stressful events.

However, according to more recent data, the 'normal' worsening in these ages is not universal nor does it appear to the extent previously believed, while at the same time the occurrence of a stressful event or change may simply be the trigger for the development of catatonia in ASD. Thus, in such cases the specialist should include catatonia in his/her differential diagnosis and of course investigate whether it may be

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[*] This section is based on a publication in the journal Psichiatriki

the result of a comorbid condition (e.g. depression) or simply another clinical manifestation of ASD itself.

In the latter case, in order to select a medicinal approach[1-2], it is recommended that a lorazepam challenge test is conducted (2-4mg/2ml). Initially, 1ml is injected and the situation is re-assessed in 2-5mins. In the event that it has not been successful, the rest is also injected. If the test is positive, the medication is administered in high doses per os (6-25mg/days) and once the patient has improved the treatment is continued for at least 6 months. If the test is negative or there is no improvement with the per os treatment, then bilateral electroconvulsive therapy is recommended. Also, low doses of atypical antipsychotics have been known to be used, either with or without amantadine.

Finally, a protocol of psychological and behavioral intervention has been developed, aiming at reducing stress, a common cause of the condition’s occurrence[3]. The protocol includes parent training, restructuring of the lifestyle and environment to reduce stress, provision of external stimuli and goals, in order to increase motivation and active involvement of the individual in pleasurable activities. The protocol makes use of verbal and physical prompts as external stimuli for dealing with difficulties in mobility, it maintains the element of prediction in the environment structure and routine, and offers specialized counseling for problems such as incontinence, ‘freezing’, food and episodes of stimulation.

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[1] Fink M, et al (2006). Catatonia in autistic spectrum disorders: a medical treatment algorithm. Int Rev Neurobiol 72: 233-244.

[2] Dhossche DM, et al (2006) Blueprints for the assessment, treatment, and future study of catatonia in autism spectrum disorders. Int Rev Neurobiol 72: 267-284.

[3] Shah A & Wing L. (2006) Psychological approaches to chronic catatonia-like deterioration in autism spectrum disorders. Int Rev Neurobiol 72: 245-264.

5.2 High functioning adults with ASD

Individuals with high functioning autism (HFA) are frequently referred to psychiatric settings and practices and it is estimated that approximately ¾ of the individuals with ASD who are referred are adults, while they make up 1.4% of psychiatric outpatients. These individuals may have been diagnosed as individuals with HFA in the past (usually during childhood), but frequently they consist of cases which have never received the equivalent diagnosis in the past.

Their referral may be the result of behavioral problems, emotional or psychiatric symptoms, inability to find employment, continuing difficulties in forming relationships and so on. More and more individuals seek evaluation of their own accord, having watched a relevant programme on television, gathered relevant information from the internet, or having met a person with an ASD diagnosis (frequently a relative, e.g. their own child). Many of the individuals with HFA who seek help, have (often erroneously) been treated for other diagnoses, such as obsessive compulsive disorder (OCD), schizophrenia or other psychoses, anxiety disorders, personality disorders, depression, etc.

Perhaps the most universal and characteristic deficit in individuals with HFA, even among the most capable ones, is social communication (the pragmatics of language). Individuals with HFA continue to face difficulties in recognizing the intention of communication, ensuring that the person they are conversing with understands them, being aware of the social context and the characteristics of exchange (e.g. initiating conversation and taking turns speaking). Due to these deficits, they may have difficulties conversing with others, talking only about their own interests, not taking turns, making inappropriate comments and failing to understand the concept of chatting done simply for the pleasure of those involved or due to social need. They present with difficulties in expressing and/or understanding the non-verbal aspects of communication and how to use this information to comprehend the other person’s intentions. Additional atypical characteristics of their speech include the use of sophisticated expressions, literal understanding and use of speech, unusual tone and prosody (it is frequently monotonous and does not offer any meaning or emotion to the person they are conversing with), many repetitions, constitutive use of words, inappropriate speech based on the context, obsession with conversation topics and poor regulation of the quantity of speech (too much or too little), but also the quantity of information they provide to the person they are conversing with (providing too many or pointless details or leaving out information critical to understanding the conversation).

Of course, at the core of the difficulties of individuals with ASD are the deficits in social skills and social awareness. These individuals may focus on different stimuli in the social environment, fail to understand typical social rules, give the impression or actually be somewhat ‘loners’, have difficulty distinguishing between various contexts or understanding the difference between friends and acquaintances. Also, within their marriage or relationship, they appear not to understand the expectations, responsibilities or emotions involved in them.

Individuals with ASD may also present with disordered emotional awareness, expression, including inappropriate affect (laughter, anger, etc.), deficits in the range of emotions they are able to express non-verbally, difficulty in interpreting others facial expressions or body language, while as they may also exhibit emotional reactions without realizing why they do it or what effect these may have on the person they are talking to.

The stereotyped behaviors and limited interests in adults with HFA present differently than what is seen in children and other individuals with lower intelligence. Since these individuals are aware that they are viewed as strange, they may suppress some behaviors or reactions in a public environment or perform them in a concealed way. They may have verbal rituals and pompous speech, while as they may present with a limited range of interests, lack of interests or the opposite, preoccupation and obsession with certain topics or objects.

Adults with HFA face difficulties in transitions due to deficits in executive functions (persisting in the same activity), anxiety (they cannot make predictions), mobility difficulties (difficulties in ideation), sensory difficulties (negative sensory stimuli) or a change in their routine. It becomes much easier for them when there is structure and routine in place in their daily life and workplace, however, once these are established, it is very difficult for them to change them.

The sensory dysfunctions tend to improve in adult life, they do not always disappear though, and they continue to affect their everyday life according to self-reports[1-2].

Finally, if the adults with HFA have comorbid conditions these include more frequently, depression, anxiety, OCD or Attention Deficit Hyperactivity Disorder (ADHD), while psychotic disorders are rather unusual.

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[1] Gerland G. A real person: Life on the outside. Souvenir Press, London, 2003.

[2] Grandin T, Scariano M. Emergence: Labelled autistic. Arena, Novato, CA, 1986

5.3. Diagnostic Process

The principles for the diagnosis of ASD in adults do not differ from those which are applicable for children and adolescents. A detailed developmental history of early childhood needs to be obtained, since many adults with HFA cease to fulfill the relevant criteria, at least in the way these are interpreted by the accepted tools used for diagnosis.

The difficulty of gathering reliable information for the early developmental history of the individual is overcome by gathering information from both the wider family environment and the social environment of the individual, in addition to using self-report questionnaires, such as the Autism-Spectrum Quotient. Questionnaires also constitute a means to select information for milder cases of individuals who exhibit the broader phenotype of the disorder, such as the Broad Autism Phenotype Questionnaire. The diagnosis is completed with direct observation of the individual. The latter is aided by the use of semi-structured protocols, such as ADOS.

5.4 Differential Diagnosis

The basic challenge faced by the clinician when dealing with an individual with HFA with accompanying psychiatric symptoms, is distinguishing whether these are due exclusively to ASD or if they constitute a comorbid condition. In the latter case, the comorbid disorder must be treated separately. Specific observations on the differential diagnosis of disorders are posited below, for conditions for which the symptoms are often confused with those of ASD.

5.4.1 Obsessive Compulsive Disorder

The symptomatology of obsessive compulsive disorder (OCD) may bring forth the issue of differentiating between the symptoms of limited interests and repetitive behaviors[1]. The small range of interests and the intensity they may present with in ASD may be mistaken as obsessions, while the repetitive behaviors may be interpreted as compulsions. After all, both the disorders may possibly share a common genetic substrate and pathophysiology[1]. Frequently the distinction between the two disorders is difficult, particularly due to the communicative restrictions of individuals with ASD. These restrictions hold true even in adults with HFA, who may give confused accounts, on the one hand, due to their difficulties in pragmatics, and on the other hand, due to deficits in comprehending the effect of what they say to others, and thus being able to prevent any misunderstanding on their part.

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[1] Jacob S, et al (2009). Autism spectrum and obsessive-compulsive disorders: OC behaviors, phenotypes and genetics. Autism Res 2: 293-311.

Elements which differentiate these two conditions are (a) in ASD involvement in these interests relieves anxiety, while to the contrary, obsessions and compulsions provoke or worsen anxiety, or relieve it only momentarily, (b) the content of repetitive ideas in OCD (aggression, infection, sex, religion, body, symmetry) is not a frequent occurrence in ASD and (c) the level of insight in ASD is much more limited. Finally, the symptoms of OCD typically begin after early childhood, while the developmental history of these children is normal and lacks the characteristic deviations and delays found in ASD. To the contrary, in ASD, difficulties are reported concerning development and social adjustment from almost the beginning of life. It is noted however, that it is possible for the two disorders to co-occur in which case OCD should be treated separately, typically using medication, although there are indications that cognitive behavioral therapy can also bring results.

5.4.2 Schizoid Personality Disorder

ASD and Schizoid Personality Disorder (SPD) share some common features such as lack of empathy, restricted social skills and friendships, isolation, “insensitivity” and “narrow-mindedness”. Their conceptual relationship had been stronger in the past, to the point that individuals who had previously received an SPD diagnosis are now recognized as individuals with Asperger’s syndrome or more generally people with HFA. The distinction between the two disorders is now made on the basis that the deficits in social interaction in SPD are often less severe and become apparent after the final years of schooling, the communicative deviations in SPD are mild and have a lesser effect on relationships, and there are no deficits in imagination or the presence of intense and very specific interests[1].

5.4.3 Schizophrenia – Psychosis

The real challenge as far as the clinician is concerned is the differential diagnosis of ASD and their ‘psychotic type’ presentations from schizophrenia and psychosis[2]. Hallucinations often constitute the most powerful differential diagnostic element between the two disorders. Nonetheless, their presence is not always easy to ascertain in an individual with ASD, since he/she often has difficulties distinguishing between an external voice and internal dialogue – some speak aloud to themselves, while their sensory difficulties may be present as hallucinations. Additionally, it may be difficult for such individuals to separate hallucinations from imaginary phenomena, anxiety activities, delusions, or memories (visual – photographic, flashbacks).

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[1] Scheeringa MS. (2001) The differential diagnosis of impaired reciprocal social interaction in children: a review of disorders. Child Psychiatry Hum Dev 32: 71-89.

[2] Dossetor, DR. (2007) “All That Glitters Is Not Gold”: Misdiagnosis of Psychosis in Pervasive Developmental Disorders – A Case Series. J Clin Child Psychol Psychiatry 12: 537-548

Individuals with ASD may have constitutive and stereotyped perceptions about the world around them and these may be interpreted as delirium, due to the communicative restrictions mentioned above. The disturbed, at times, speech (loose correlations, irrational thoughts and neologisms) is almost always the result of their difficulties in pragmatics. Many of their odd behaviors (stereotyped speech, echolalia, strange posture and expressions, rigor) may be part of a catatonic presentation, which, as mentioned, is related to ASD itself. Finally, the negative symptoms which may appear (lack of concentration, motivation and energy) are not specific to psychosis, while the general worsening in functioning may occur not due to deterioration in functioning itself, but from the increase in demands from the environment.

A helpful clue for differential diagnosis is the fact that the symptoms are generally confined to familiar/safe contexts (people-places), while no significant reduction in the individual's quality of life is observed. These symptoms improve with direct intervention for reducing the accompanying anxiety and protecting from social anxiety, as well as by teaching and practicing anxiety management skills. To the contrary, the condition will not improve by administering antipsychotics, except to the degree which this medication has an effect on the feelings of anxiety.

Main Points

√ Adults (already diagnosed or not) with ASD may need to visit a psychiatrist for behavior problems. More frequently these problems need to be addressed using behavioral interventions and certainly not with the use of medication.

√ In ASD catatonia requires high doses of lorazepam and in the event this is unsuccessful electroconvulsive therapy may be used.

√ In adulthood the symptoms may be more subtle thus making diagnosis more difficult in ASD.

√ In adulthood, the diagnostic process does not differ from what is recommended for younger ages, although self-report questionnaires may also be used.

√ Differential diagnosis of adults with ASD should be made in relation to Obsessive Compulsive Disorder, Schizoid Personality Disorder and Schizophrenia (psychosis).

6.0 MINISTRIES – GOVERNMENT FUNDING – PROVISION SCHEMES

(CHAPTER IS GOING TO CHANGE DUE TO THE CHANGE OF LAW. THE FOUNDATION WAIT THE RENEW).

6.1. Cyprus Ministry of Education and Culture

6.1.1. Special Education and Training in Cyprus

The Ministry of Education and Culture applies the "Special Education and Training of Children with Special Needs Law of 1999". The said Law is applicable to all children with special education needs, including children with Autism. The 113(I)99 Law ensures the provision of special education and training once a child has turned three years old. Following referral, the government provides all children with special education and training in public schools.

Any person directly related to a child who falls within the spectrum of special educational needs, such as parents, preschool teachers, special therapists, and teachers, may take action and help the child to be introduced to the educational setting, and is bound by law to notify the District Committee for Special Education and Training. Notifying the committee is done by completing a special form which bears the title: "Child referral to the District Committee of Special Education and Training" which is available at all public preschools, Primary schools, Secondary Schools, as well as at the District Education offices and the Ministry of Education website. The link for the special referral form (in Greek) is the following: http://www.moec.gov.cy/eidiki/entypa/parapompi.doc

Following the referral is the **Evaluation of Children with Special Needs from the District Committees.** The evaluation of the needs of each child who may have special needs is completed by the District Committee of Special Education and Training appointed at the time. The committee comprises of:

- One higher Education Officer from the Minister of Education and Culture who serves as president.
- A representative of the relevant education department of the Ministry of Education and Culture.
- A special education teacher.
- An educational psychologist.
- A clinical psychologist.
- A social worker.
- A speech and language pathologist.

Evaluation Process:

Within a maximum of two weeks from the date of being informed of a case of a child with special needs, the District Committee, conducts a preliminary discussion of the case and decides upon the composition of the primary multidisciplinary team from the public or private sector, which shall evaluate the child.

The multidisciplinary team can be expanded during the evolvement of the evaluation process, if deemed necessary, by decision of the District Committee, automatically or following parental request. The evaluation of the child is completed separately by each specialist who belongs to the primary multidisciplinary team, after receiving the child's history from the District Committee. After completing the evaluation, the District Committee discusses, decides and informs the parent of its substantiated conclusions as to whether the provision of special education and training is recommended for the child.

Re-evaluation Process

The District Committee re-evaluates the needs of each child with special needs every two years or more frequently, after a substantiated request by the parent or the recommendation of the key worker.

Parental rights during the evaluation

The parent has a right to be present during the evaluation and participate on his/her own or accompanied by a specialist of his/her choice, relative to the specific topic being discussed. The parent has a right to access the child's file, which is kept at the District Committee and has a right to receive copies of this report.

The decision of the District Committee

The decision of the District Committee for the provision of special education and training is sent to the child's parent within fifteen days, in which the rights regarding written objections are also made know. The District Committee discusses and then decides on its view of the parent's objections.

The child's parent has a right to submit a written objection to the Central Committee within thirty days from the date on which the District Committee's second decision was sent out.

As soon as the Central Committee receives the objection, a copy is also sent to the District Committee and the parent is notified of its receipt and of the day it shall be reviewed, which should not exceed thirty days. The parent has a right to be present during the review, along with a specialist of his/her choice.

The Central Committee's decision is made known to the parent and the District Committee within three months of the submission of the objection.

Nicosia District Committee

Mailing Address

District Committee of Special Education and Training

Nicosia District Office of Education

Corner of Kimonos and Thoukidides street Acropolis

1434 Nicosia

District Committee Contact Numbers

22800894, 22800885, 22800341

Fax: 22305503

Contact numbers of the Key Workers and Special Education Counselor

22800884/22800610

Fax: 22800660

Office of the Principal of Secondary Education

Office of Special Education

2280063/22809521

Fax: 22806326

Contact Numbers for Special Education Officers

Office of the Principal of Primary Education

22800913/22800914/22806329

Fax: 22800660

Limassol District Committee

Mailing Address:

District Committee of Special Education and Training

Limassol District Office of Education

131 Vasileos Constandinou street, Karatzis Court, 4th floor, Flat 41,

P.O. Box 56061, 3304 Limassol

District Committee Contact Numbers

25822054

Contact numbers for Special Education Key Workers

Office of Primary Education

25822034, 25822035

Contact Numbers for Special Education Key Workers

Office of Secondary Education

25820872, 25820874

<u>Larnaca/Famagusta District Committee</u>

Mailing Address:

District Committee of Special Education and Training
Larnaca/Famagusta District Office of Education
65 Eleftherias Avenue, Oikonomou Estates, 1st Floor, 7102 Aradippou
P.O. Box 45141, 7111 Aradippou

District Committee Contact Numbers

24821371

Fax: 24821380

Contact Numbers for Special Education Key Workers

Primary Education Office

24821369, 24813227

Contact Numbers for Special Education Key Workers

Secondary Education Office

24813247, 24821378, 24813202

Paphos District Committee

Mailing Address:

District Committee of Special Education and Training

Paphos District Office

Neofytou Nikolaidi street,

New District State Offices of Paphos

P.O. Box 60077, 8100 Paphos

District Committee Contact Numbers

26804535

Fax: 26306139

Contact Numbers for Special Education Key Workers

Primary School Office

26804534

Contact Numbers for Special Education Key Workers

Secondary Education Office

26804519, 26804529

6.1.2. Provision of Special Education and Training:

Via the procedure which has been described above, the District Committee of Special Education and Training, evaluates and places children with special educational needs in one of the educational settings mentioned below, on the basis of which environment is judged to be the least restrictive for their education and their specific needs.

- In a public school, in a regular class

This includes children with special needs, for whom special education and training was approved in a regular class within a public school, where according to the Ministry's educational programme, the necessary infrastructures will be available, adapted to the children's special needs and their individualized education programme. If, due to extenuating circumstances, the child is not able to attend the school in the area where he/she lives, the District Committee provides free transportation to and from that school.

- In a public school, in a special unit

For children with special needs who were approved for special education and training, this can be done in a special unit which operates in a regular school. The special units are incorporated and integrated in regular schools and function within comfortable facilities which are accessible to children with special needs. The principal of the school, where the unit is housed, is responsible for its operation. The total number of children in each unit is decided upon on the basis of age, special needs, other specific factors as well as the smooth operation of the special unit. After hearing the opinions of the principal, key worker, relevant Special Education inspector and the unit's teacher, the District Committee holds the responsibility of deciding the total number of children which will attend the special unit. It should be noted that special units operate in many Primary and Secondary Schools all across Cyprus.

- In a special education and training school

A special education and training school is defined as any private or public school which is founded and operated according to the articles of the Law for the provision of special education and training for children with special needs. These schools are staffed with suitable teaching, scientific, support and other personnel (in cooperation with psychologists, speech therapists, doctors, physiotherapists and others). They are equipped with all the modern means necessary to fulfill their mission.

Children who attend special education and training schools are placed into groups which are formed keeping in mind the age and specific characteristics of each child, as well as the special education which has been defined.

The number of pupils in each group is decided upon by a team comprising of a special education inspector, an educational psychologist, a special educator and the principal of the school, all of whom are members of the public sector. Such decisions are made based on the needs of each child. The educational policy of special education schools includes a system of frequent contact with the regular schools in the area and organizing common activities.

- Provision of services in other settings

For children of Primary and Secondary School ages, who for health reasons are, for long periods, unable to attend a regular programme in school, it is possible to obtain education by other means. Being educated outside the school is considered part of the regular class schedule of the year the child is registered in. No area other than the school is designated as a setting for the provision of special education and training, unless it has been decided, according to the provisions of the Law, and after consulting the parents, that the education defined for the child cannot be provided there.

List of Special Schools in Cyprus:

Nicosia

Evangelismos Special School
Tel: 22481081, 22571470/Fax: 22571314
Email: eid-evengelismos-lef@schools.ac.cy
P.O. Box: 24738, 1303

Nicosia Special School
Tel: 22444290, 22444289/Fax: 22305265
Email: eid-eidiko-lef@schools.ac.cy
35 Katharis street, 2103 Aglantzia

School for the Deaf
Tel: 22305422, 22305425/Fax: 22305423
Email: eid-scholi-kofon-lef@schools.ac.cy
P.O. Box: 24738, 1303

School for the Blind
Tel: 22403300/Fax: 22403340
Email: eid-scholi-typhlon-lef@schools.ac.cy
P.O. Box: 23511, 1684

Limassol:

“Apostolos Loukas” Special School
Tel: 25334175/Fax: 25385139
Email: eid-ap-loukas-lem@schools.ac.cy
P.O. Box: 51154, 3113

Red Cross ‘Paidiko Anarrotirio” Special School
Tel: 25385229/Fax: 25770694
Email: eid-paidiko-anarrotirio-lem@schools.ac.cy
P.O. Box: 55686, 3781

Larnaca:

“Ayios Spyridonas” Special School
Tel: 24637677/Fax: 24637948
Email: eid-ag-spyridonas-lar@schools.ac.cy
Olympou street, Ayios Georgios Kondos, 6046

Famagusta:

“Apostolos Varnavas” Special School
Tel: 23942133/Fax: 23942864
Email: eid-ap-varnavas-amm@schools.ac.cy
P.O. Box: 32125, 5326

Paphos:

Theoskepasti
Tel: 26962011/Fax: 26813069
Email: eid-theoskepasti-paf@schools.ac.cy
10A Amaltheias street, 8021

6.2 Ministry of Health

6.2.1 Child and Adolescent Mental Health Services

The Child and Adolescent Mental Health services target children and adolescents through age 17 who are dealing with a range of psychosocial difficulties. The following services are provided:

- Diagnostic evaluation by a child psychiatrist and/or clinical psychologist in liaison with other specialists, e.g. child neurologists, geneticists, etc. and counseling to parents on issues of how to handle their child's difficulties.
- Regular psychiatric observation of children or adolescents until they reach the age of 17.
- Occupational therapy, Physical therapy, Speech Therapy for children who are serviced by the department.
- Medication provision where necessary.
- Co-ordination and participation in regular meetings between experts who are involved with the child or adolescent, in either the public or private sector (teachers, special educators, speech therapists, developmental psychologists, occupational therapists, etc.).
- Participation of the department's clinical psychologists in the District Committees for Special Education at the Ministry of Education (See section on Special Education in Cyprus).
- Participation of the scientific coordinator of the Mental Health Services, in the Central Committee for Special Education and Training, where the type of support for challenging cases is reviewed, while the educational policy and psycho-emotional support of children with special needs is also formed, including that of individuals with autism.
- Preparation of special medical reports which are needed for the Social Welfare Services to provide monthly stipends to children and adolescents with autism.

Finally, staff at the department has already been trained in the ADOS diagnostic procedure which is internationally recognized for the accurate detection and categorization of individuals with ASD. The Mental Health Services department has already purchased the aforementioned diagnostic tool. In each district (Nicosia, Limassol, Larnaca and Paphos), a community centre is in operation, staffed by a multidisciplinary team which sees individuals on an outpatient basis.

Additionally, there is a multidisciplinary team at the Archbishop Makarios III Hospital, the Consulting-Connective Child Psychiatry Service, which provides services to inpatients and outpatients (up to 17 years old) who are being observed for a variety of medical reasons and also present with psychosocial difficulties.

The four centres accept referrals from various governmental/non-governmental services but also from the parents themselves. A prerequisite for the referrals from other services to be valid is the informed consent of both parents.

Nicosia:

Child and Adolescent Mental Health Services

Centre for Prevention and Psychosocial Intervention

4 Polykratous street, Ayious Omologites

Tel: 22378268

Fax: 22378133

Email: mchrysostomou@papd.mof.gov.cy

Consultative-Connective Child Psychiatry Services at AMH III

Tel: 22405050, 51, 85

Fax: 22405088

Email: mchrysostomou@papd.mof.gov.cy

Larnaca:

Child and Adolescent Mental Health Services

Centre for Prevention and Psychosocial Intervention

Tel: 24813164

Fax: 24532326

Email: mehelca@gmail.com

Limassol:

Child and Adolescent Mental Health Services

Centre for Prevention and Psychosocial Intervention

Tel: 25873602

Fax: 25393164

Email: paidolimassol@cytanet.com.cy

Paphos:

Child and Adolescent Mental Health Services

Centre for Prevention and Psychosocial Intervention

Tel: 26803491

Fax: 26803218

Email: paid-e@cytanet.gr

For individuals with Autism over the age of 17, the Mental Health Services can provide services to the persons themselves as well as to their families at all the Community settings, where the Adult Outpatient Clinics operate. At these settings, the staff can offer the following:

- Diagnostic evaluations by a psychiatrist and/or Clinical psychologist.
- Psychiatric monitoring and medication.
- Psychological help for the patient and the family.
- Relevant psychiatric and psychological reports.

Nicosia:

Old Nicosia Hospital, tel.: 22801618/22801519

Strovolos Outpatient Clinic, tel.: 22305723

Aglantzia Health Centre, tel.: 22444466

Kaimakli Outpatient Clinic, tel.: 22347780

Ayios Dometios Outpatient Clinic, tel.: 22302175

Limassol:

Old Hospital Outpatient Clinic, tel.: 25305333

Larnaca:

Old Hospital Outpatient Clinic, tel.: 24828768

Paphos:

Hospital Outpatient Clinic, tel.: 26803269

Paralimni:

Old Hospital Outpatient Clinic, tel.: 23815088

As soon parents receive a diagnosis for their child, it is recommended to begin the procedure of obtaining a **public hospital card,** so that all the tests and treatments provided at the hospital are covered. From what our research has indicated, in addition to the report of a private doctor stating that the child falls within the autism spectrum, it would be useful to also obtain reports from doctors in the public sector. **Specifically, parents who have taken part in our research, have mentioned that access to government services was much easier when they had provided reports from child psychiatrists, child neurologists and geneticists from the government hospital.**

Thus, as soon as the child is diagnosed as falling under the autism spectrum, parents should do the following:

- Obtain reports from the relevant doctors of the public hospital, as well as from the private sector, if they are also observing their child.
- Use the above reports to obtain Social Welfare benefits and other provisions which are available.
- Obtain the hospital card which provides FREE health care in all of the public hospitals in Cyprus.

CONTACT NUMBERS:

Nicosia General Hospital, tel.: 222603000

Nicosia Old Hospital, tel.: 22801400

Archbishop Makarios III Hospital, tel.: 22405000

Limassol Old Hospital, tel.: 25305333

Limassol General Hospital, tel.: 25801100

Larnaca Old Hospital, tel.: 24304312

Larnaca General Hospital, tel.: 24800500

Paphos General Hospital, tel.: 26803100

Famagusta General Hospital, tel.: 23200000

Kyperounda Hospital, tel.: 25532021

Polis Chrysohou Hospital, tel.: 26321431

6.3. Ministry of Labour and Social Insurance

6.3.1 Social Welfare Services

According to the Public Assistance and Services Law 95 (1)/2006, individuals with autism fall under the category of groups of people who have the right to benefit from the social provisions offered by the state based on income criteria.

At this point, it is worth noting that the laws are subject to continuous readjustment, so it is preferable that interested parties request information at the Social Welfare offices of each District.

PUBLIC ASSISTANCE:

Public Assistance (PA) is provided also to individuals with Autism. It covers their basic needs, including food, necessary clothing and shoes, water bills, electricity bills, items for healthy living, as well as any needs which are relevant to the applicant's personal comfort.

Additional benefits:

- Handicap stipend (1/2 of basic needs benefits)
- Rent stipend (1/2 of basic needs benefits)
- Stipend for purchasing disposable nappies on a monthly basis.
- Christmas stipend (20% of basic needs benefits).
  These benefits are provided based on the individual needs of each person.
- The right to apply for PA is held by each person who is a legal resident of the areas which are monitored by the Cyprus Government for a period of at least one year.

Necessary documents/reports which need to accompany the application

- The identity card numbers and exact date of birth of the applicant and the dependent members of the family. In the case of underage children, younger than 12 years old, the birth certificate should be submitted, on which the identity card number is printed.
- If there is any income from property owned by the applicant, the relevant documents should be submitted.
- A photocopy of the bank deposit booklet or bond accounts or the status of shares the applicant and the dependent members may have.
- If the applicant resides in a rented home, he/she should attach a rental agreement complete with stamp duty purchased at the Registrar as well as a receipt for the last rent paid.
- Medical confirmation (SWS form 73) from the doctor who is treating the individual, stating the medical problems/handicap of the applicant.

Note:

1. Social Welfare Services reserve the right to request additional documents or proof, where deemed necessary, in order to fully investigate an application for public assistance.
2. For purposes of assistance and the speedy review of an application for public assistance it is recommended that the applicant and spouse, or cohabitant, if relevant, submits a certificate of investigation from the land registry regarding their places of residence and origin.

Link for public assistance application (in English):

http://www.mlsi.gov.cy/mlsi/sws/sws.nsf/All/464382CFB427F75AC2256E83001BB3B1/$file/Applic.%20for%20public%20assistance%20(sws%206(a)).pdf

- **Provision of Residential Care**

  Residential care is provided to individuals who require continuous care and those whose needs cannot be met by the family, or the supportive services offered in the environment in which they live. Social Welfare Services place individuals who are in need of residential care, in state, community and private settings and homes of approved, paid carers.

- **Day Care Programmes**

  These programmes give the elderly and individuals with handicaps the opportunity to enjoy services at Nursing Homes, or Adult Centres during the day.

  The Adult Centres, which are operated by the Community Welfare Councils, are sponsored via the State Funding Scheme and provide the elderly and individuals with handicaps a variety of services during the day, such as meals, laundry, activities, entertainment and so on.

- **Home care services**

  The home care service aims at providing care in the homes of the elderly, individuals with handicaps or families with special needs. The goals of this service include the following:

- Supporting vulnerable individuals in order for them to remain in their own environment for as long as possible.
- Creating the necessary framework for a dignified lifestyle and fostering the strengths of the elderly, individuals with handicaps and other vulnerable individuals.
- Reinforcing and supporting the family to enable it to keep its elderly or handicapped members in the family home.

- Reinforcing and supporting individuals with special needs to help the family function in a smooth manner.

Social Welfare Services employ caregivers who are specially trained for work in the District Welfare Offices. The caregivers visit the homes of those who qualify for care and offer their services based on the specific needs of the individuals. These needs may also be covered by private or community caregivers, via public assistance, as long as the relevant provisions of the Law are followed.

The caregiver offers personal hygiene, house cleaning and laundry services, escort services to the hospital, provision of external jobs (e.g. payment of bills, grocery shopping etc.), as well as teaching basic tasks for taking care of the home and family responsibilities to members of the family.

The caregiver services are provided mainly to individuals who are eligible for public assistance or individuals who cannot cover the expenses for their special needs from their own income, as these are outlined in the current legislation.

Individuals who are interested in the caregiver services must fill in the special form for application for Public Assistance and submit to the District or Local Office of Social Welfare Services, based on the area in which they live in, including all relevant documentation which is listed on the guide for completing the application for Public Assistance.

In the event that the application is submitted for a caregiver:

- If the applicant is being cared for by a caregiver who is a foreigner, the necessary documents must also be submitted (passport, booklet from the Aliens and Immigration unit, work contract and proof of social insurance payment).
- If a certain person is caring for the applicant for a fee, a copy of the contract for caregiving should be submitted as well as the individual's most recent receipt of payment of social insurance fees.

CONTACT INFORMATION:

Nicosia:

Nicosia District Welfare Office

66 Ayiou Ilarionos street, 1026 Nicosia

Tel.: 22804605/Fax: 22804666

Email: lefkosia.dwo@sws.mlsi.gov.cy

Latsia Office of Social Services

34 Archbishop Makarios III street, 2020, Latsia

Tel.: 22803501/Fax: 22487640

Strovolos Office of Social Services

66 Ayiou Ilarionos street, 1026, Nicosia

Tel.: 22804605/Fax: 22804666

Lakatamia Office of Social Services

24 Pefkou and Kennedy street, Lakatamia

Tel.: 22608400/Fax: 22380853

Limassol:

Limassol District Welfare Office/Units

13-15 Grigori Afxendiou street, I.D.E Ioannou

Mesa Geitonia, Limassol

Tel.: 25811644/Fax: 25305135

Town Centre Social Services Office

73 Ayias Zonis and corner of Tyrtaiou street, 4160

Tel.: 25811776/Fax: 25305141

Polemidia Social Services Office

No. 3, 82nd street, 4153, Kato Polemidia

Tel.: 25821839/Fax: 25305760

Zakaki Social Services Office

80 Franklin Roosevelt street, 3011 Limassol

Tel.: 25804525/Fax: 25306576

Germasogeia Social Services Office

80 Franklin Roosevelt street, 3011 Limassol

Tel.: 25804523/Fax: 25804447

Larnaca:

Larnaca Welfare Office, Family and Child Services

52 Archbishop Makarios III avenue, Larnaca

P.O. Box: 40184, 6301

Tel: 24828172/Fax: 24621088

Kamares Social Services Office

23-25 Piliou street, Larnaca, 6301

Tel: 24800101/Fax: 24304876

Ayioi Anargyroi Social Services Office

54 Ayioi Anargyroi Avenue, 6301 Larnaca

Tel.: 24821047, 24821062/Fax: 24669036

Paphos:

Paphos District Welfare Office

28 Aristoteli Valaoriti & Kynira street, 8100 Paphos

Tel.: 26821600/Fax: 26306162

Email: pafos.dwo@sws.mlsi.gov.cy

Famagusta:

Famagusta District Welfare Office

134 1st of April street, 5280 Paralimni

Tel.: 23821551/Fax: 23827698

Email: ammochostos.dwo@sws.mlsi.gov.cy

Morfou:

Morfou/Evrichou District Welfare Office

11 Griva Digeni street, 2831 Evrichou

Tel.: 22870582/Fax: 22933408

Email: evrychou.dwo@sws.mlsi.gov.cy

6.3.2 Early Childhood Intervention/Liaison Service

The Early Childhood Intervention Liaison Service was formed by order of the Cyprus Cabinet on the 31/10/2001.

The complete system of services of the Early Childhood Intervention includes support and guidance services for families. These services are offered for toddlers and preschool aged children (up to 6 years old), who present with difficulties or disorders pertaining to their development (autism, syndromes, mental retardation).

The Early Childhood Intervention officer acts as a link between the family and the service providers. Once the officer is informed about a case, he/she immediately contacts the family. More specifically, the officer attends to the following:

- Investigating the child and family’s needs
- Informing parents of the services which are available in the government and private sector and by voluntary Organisations.
- Organizing and monitoring the interventions offered to the child and family.
- Promoting financial and other rights.
- Coordinating involved services to the child’s benefit.
- Arranging meetings with specialists for evaluations or to modify treatments
- Supporting and counseling parents and other family members.
- Empowering parents in order for them to assume a central role in decision making which is to the child’s benefit.

Early and timely provision of suitable services has positive consequences later on, with regards to supporting the independence of the individual with special needs and improving his/her life as an adult, as well as to relieving the family from the person’s continuous care.

The service is staffed by three psychologists and the services provided are **free and are offered** with discreteness and confidentiality.

The following departments/organisations participate in the Services work:

- Ministry of Labour and Social Insurance – Social Welfare Services.
- Ministry of Health – Child Neurology and Genetics Clinic of the Makarios III Hospital – Health Visitors Service.
- Ministry of Education and Culture – Special Education Service – Educational Psychology Service.
- Pancyprian Parents Association for People with Mental Handicaps.

<u>Referral Services:</u>

- Archbishop Makarios III Hospital
- Pediatricians from the departments of the District Hospitals
- Private sector pediatricians
- Nurses, health visitors, officers from the mental health services
- Therapists from the government and private sector (physiotherapists, speech therapists, special educators).
- Treatment centres, non-governmental organisations, voluntary organisations.
- Social Welfare Services
- Schools, preschools (public, community and private)
- Parents, parent associations

The Early Childhood Intervention/Liaison Service is provided by the Committee for the Protection of the Rights of People with a Mental Handicap, which operates under the auspices of the Ministry of Labour and Social Insurance. Participating in the Committee are representatives from the private and government sector. Specifically:

- Ministry of Labour and Social Insurance: Social Welfare Services, Department for Social Inclusion of Persons with Disabilities.
- Ministry of Health: Mental Health Services.
- Ministry of Education and Culture.
- Ministry of Finance
- Pancyprian Parents Association for People with Mental Handicaps

How the referral is made:

The referral may be done over the phone or via fax.

NICOSIA (central offices)

Tel.: 99540406 – 22871325/333

Email: cp-mental@cytanet.com.cy

Website: www.cpmental.com.cy

LARNACA/FAMAGUSTA

Aradippou Municipality

Tel.: 99540407 – 24813010/Fax: 24811072

LIMASSOL/PAPHOS

Kato Polemidia Municipality

Tel.: 99540408/Fax: 25396699

6.3.3 Scheme for the supported employment of persons with disabilities – Department for Social Inclusion of Persons with Disabilities

The aim of the Scheme is the employment in the open labour market by providing personal support through a job coach, to persons with disabilities. The Scheme provides funding to organisations which intend to apply relevant programmes to cover the expenses of the support services, which include mainly the coach's salary and some travel expenses.

The basic principles of the Scheme are the following:

- Support services should be provided on an individual basis by a trained coach.
- The support should be long-term, as needed, flexible and overall be aimed at integrating the individual into the community.
- The work position must be in the regular labor market and not in sheltered workshops.
- The employee should be employed and receive a salary on a regular basis.

The Scheme covers the employment of individuals with severe disabilities or individuals with adjustment difficulties due to their disability, which cannot be professionally or socially integrated in other ways.

Additionally, the Scheme provides funding of up to €13.500 per year to organisations which undertake the supported employment programmes, each of which must provide for the support of 3-5 people with severe disabilities or 6-8 people who do not have severe disabilities, by a trained coach.

The funding is provided by the Department of Social Inclusion of Persons with Disabilities once the relevant application has been submitted, which also provides technical guidance and supervises the approved programmes.

Prior to making decisions regarding the recipients of the funding, the relevant department considers the input from organisations for individuals with disabilities.

The scheme is financed and supervised by the Department of Social Inclusion of Persons with Disabilities of the Ministry of Labor and Social Insurance. It is has been adopted by organisations **all across Cyprus.**

For further information and details regarding the specific district you reside in, you may contact the Department at 22815015.

Department of Social Inclusion of Persons with Disabilities, 1430 Nicosia.

6.3.4. Financial assistance scheme for the provision of technical means, instruments and other aids

The above Scheme aims to support life conditions, promote independence as well as full participation of individuals with disabilities in social and economic life, by providing financial aid for the provision of suitable technical means and instruments, as well as other aids. The beneficiaries of this scheme are individuals who are citizens of the Republic of Cyprus, who have severe mobility, sensory or other types of disabilities.

Terms of Participation

- The financial assistance provided shall cover 80% of the final price of the requested technical mean and up to a maximum amount which shall be determined from time to time upon recommendation of the committee which shall examine the applications. Assistance of up to 100% of the final price shall be granted in exceptional cases of people with very low income.
- Priority should be given depending on the severity of the disability and the degree of satisfaction of both the specific objective (movement, employment, health, subsistence) and the general objective which is independence;
- Technical means, instruments etc. shall be provided on an individual basis and serve and belong to the beneficiary and not to institutions, organisations, schools or other persons. In case such instruments or means, which were purchased with the provision of financial assistance from this Scheme, are not used or in case the beneficiary passes away, they should be returned to the Department for Social Inclusion of Persons with Disabilities.
- The Scheme shall not cover the provision of orthotic and prosthetic limbs or other aids provided by other government schemes or laws.

Applications

1) Persons interested in participating in the scheme shall submit their application on a special application form, to the Director of the Department for Social Inclusion of Persons with Disabilities, together with the relevant certificates;
2) The applications shall be examined by a special committee presided by the Director of the Department for Social Inclusion of Persons with Disabilities or by an Authorised Officer of the Department for Social Inclusion of Persons with Disabilities. If necessary, representatives from other government services shall be also invited to participate in the committee.
3) During the processing of the application, the committee may request the applicant to be there in person.

6.3.5. Scheme for the management/provision of technical means, instruments and other aids

The management/provision (through lending), storage and maintenance of technical means and instruments as well as other aids returned by the beneficiaries of the “Scheme for Financial Assistance for the Purchase of Technical Means, Instruments and other Aids for Persons with Disabilities”.

Beneficiaries include Cypriot and EU citizens provided that they live permanently in the area controlled by the Republic of Cyprus for at least 12 consecutive months and they experience severe motor, sensory or other disabilities.

Terms of participation

- Second hand technical instruments are lent to the beneficiaries upon proposal of the committee that shall examine the applications;
- Priority should be given depending on the severity of the disability and the degree of satisfaction of both the specific objective (movement, employment, health, subsistence) and the general objective which is independence;
- Technical means, instruments etc. shall be provided on an individual basis and serve and belong to the beneficiary and not to institutions, organisations, schools or others. In case such instruments or means are not used or in case the beneficiary passes away, they should be returned to the Department for Social Inclusion of Persons with Disabilities.
- Following lending of the instruments and means, the beneficiary shall be exclusively responsible for their maintenance.

Applications

1) Persons interested in participating in the scheme shall submit their application together with the relevant supporting documents, to the Director of the Department for Social Inclusion of Persons with Disabilities, Ministry of Labour and Social Insurance, using a special application form;
2) The applications shall be examined by a special committee presided by the Director of the Department for Social Inclusion of Persons with Disabilities or by an authorized Officer and formed by representatives of other government services, as well as by representatives of the Cyprus Confederation of organisations of the Disabled (CCOD), where appropriate. Applications are approved by the Director of the Department for Social Inclusion of Persons with Disabilities;
3) During the processing of the application, the committee may request that the applicant to be present.

For further information please contact the Department for Social Inclusion of Persons with Disabilities, at 22815015.

6.3.6 Financial Assistance to the Organisations of Persons with Disabilities for Hiring Social Assistants for their Members

The Aim of this Scheme is the provision of Social Assistance Services to adults with severe disabilities, whose independent mobility and the exercise of their fundamental rights is not possible and is not covered by other sources, with the risk of social exclusion. By priority Social Assistants, among others, serve persons within the autistic spectrum disorder. The Social Assistance Services are provided as long as and to the extent necessary for the social inclusion of persons with disabilities. The beneficiaries are the organisations serving the individuals with disabilities.

Further Information:

Physical Location:

Department for the Social Inclusion of Persons with Disabilities,

67 Makarios III Avenue, 2220 Latsia, Nicosia.

Mailing Address:

Department for the Social Inclusion of Persons with Disabilities

P.O. Box: 12833, 2253 Latsia

Tel: 22815015, Fax: 22482310

6.3.7. Subsidization of vacations for persons with disabilities

The aim of this scheme is to subsidize the room and board of individuals with disabilities and their families or escorts at hotels/holiday accommodation of their choosing.

The amount of the grant for each overnight stay amounts to €45 for each beneficiary, €45 for the spouse or escort, €0 for each dependent child under the age of two, €23 for each dependent child over the age of two through age twelve and €34 for each dependent child over the age of twelve. A maximum of seven nights are covered by this scheme.

Approved applicants are sent a certificate with the amount of the subsidy, which they then present to the hotel/holiday accommodation of their choice. The actual payment of the hotels/holiday accommodation is arranged by the Department of Social Inclusion for Persons with Disabilities.

For further information:

22815015, 22815057

All the above documents are available on the following website (also available in English):

http://www.mlsi.gov.cy/mlsi/dsid

Link to all the relevant documents of the Department:

http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/dsipd26_en/dsipd26_en?OpenDocument

6.4. Ministry of Interior

6.4.1 Scheme for improving the housing conditions of recipients of social welfare benefits[1]

This scheme aims at providing a grant to recipients of social assistance benefits in order for them to improve their housing conditions.

General Terms:

1. It is possible to apply and receive this grant more than once, provided that the total sum does not exceed €12.000 over time. A person who has been assisted with the maximum amount of the grant may be assisted again after a period of five years since receiving the previous grant. If the grant has been given in installments, the five year period begins on the date of the last approved installment.
2. Applicants are not discriminated on the basis of gender, religion, race or nationality.
3. The scheme does not apply to recipients of social welfare benefits that have benefited from another Government scheme.

Beneficiaries:

1. Individuals who are recipients of social welfare benefits.
2. Individuals who are considered recipients of social welfare benefits, if included in their needs, as these are defined by the Public Assistance and Services Law, is the rental of a residence, as is the provision of the law itself.

Grant:

1. The grant amounts to a maximum of €12.000.
2. The grant is provided as long as the relevant application is approved prior to commencement of any work. The first installment will be granted before the work begins; while the second and last installment will be granted once the work is complete, following an inspection which will be carried out by an Officer of the relevant District Administration.

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[1] Ministry of Interior – District Administration,
http://www.moi.gov.cy/moi/da/dadmin.nsf/dmlforms_gr/dmlforms_gr?OpenDocument&Start=1&Count=1000&Expand=5
(20/06/2012)

Terms of the Grant:

1. The amount provided through the Scheme, may be used for the following purposes:

A) Improvement/maintenance of home owner’s residence.

B) Extension of the home owner’s house.

2. The grant may be bestowed to individuals who do not own their own residence, provided the following criteria are met:

A) An applicant who resides in the home of a relative must also submit a sworn statement by the owner of the residence, which is certified by the ‘Koinotarxis’ or other certifying officer, with which the home owner commits to housing the individual, for which the assistance is granted, for a period of at least seven years.

It is noted that regarding applications for individuals with low mental abilities, the application is submitted by their guardian.

B) In the event that the above agreement is violated, the owner of the residence is obligated to return the percentage of the grant bequeathed to the beneficiary, which is equivalent to the time period which remains for the completion of seven years. In this event, the applicant is entitled to reapply for the grant.

C) In the event that the individual for whom the improvements to the residence of another home owner were made, abandons the residence of his/her own accord before the completion of seven years from the date of receiving the grant, this individual is not entitled to any additional assistance from this Scheme, prior to completion of that period.

3. An individual who has been assisted with the grant’s maximum amount of 12.000 euro is entitled to further assistance after five year period from the time of receiving the first grant. If the grant has been received in installments, the five year period is calculated from the date of the final approval.

4. In the event that the applicant is not in a position to manage the grant provided, a process of co-management will be followed with a relevant officer from the Social Welfare Services.

Applications:

Applications are to be submitted by interested parties on a special form to the relevant Registrar, along with the following documents and/or proof:

A) Official confirmation from the Social Welfare Services that the applicant is a recipient of social welfare benefits.

B) A construction permit (in the event of extension or addition of a room). For improving/repairing an existing residence, a detailed appraisal should be submitted for the cost of the needed work. Depending on each case, additional documents should include either a minimum of two different tenders, or certification from a qualified individual (e.g. architect/civil engineer/surveyor) registered in ETEK.

C) A sworn affidavit regarding the accuracy of the information submitted in order to obtain the grant. Submitting false statements is liable to the provisions of the relevant law.

D) In the event that the applicant is not the owner of the residence, the owner must also submit a sworn statement stating that he/she agrees to the planned additions/improvements and that he/she undertakes the responsibility of housing and caring for the recipient of social welfare benefits who will be receiving the grant, for a period of seven years.

Application Review Committee:

The review of the applications shall be completed by the Committee, which comprises of the following:

a) the relevant Registrar or a representative,

b) a representative from Social Welfare Services

c) a representative of the relevant District Administration

Period of Validity:

The present Scheme for Improving the Housing Conditions of Recipients of Social Welfare Benefits is brought into force by the Ministry of Interior, from the date of it is approved by the Cabinet.

Application link:

http://www.moi.gov.cy/moi/da/dadmin.nsf/dmlforms_gr/dmlforms_gr?OpenDocument&Start=1&Count=1000&Expand=5

6.4.2. Scheme for improving homes which provide housing and care to the elderly and disabled who are recipients of social welfare benefits

This Scheme aims at providing government grants to families or individuals, in order for them to improve the residence which they own for the purpose of offering housing and care to the elderly or disabled members of their family, or a relative or friend, in order to avoid placing them in a Nursing Home, when they objectively are not in need of residential care.

General Terms:

1. This Scheme does not cover financial assistance of recipients of social welfare benefits who have already benefited from another Government Scheme.

2. Applicants are not discriminated based on gender, religion, race or nationality.

Beneficiaries:

1. Beneficiaries are individuals who are social welfare benefits recipients, aged 63 and over, or individuals with disabilities.

2. In the event of children with disabilities who are minors, the parents must be recipients of social welfare benefits or be borderline cases which would be welfare benefits recipients, if in their needs as these are defined by the Public Assistance and Services Law, rent or care benefits were added, as stated in the provisions of the Law.

3. Individuals aged 63 and above or an individual with disabilities, who due to his/her income is defined as a borderline case, and who would be considered a social benefits recipients, if in their needs as these are defined by the Public Assistance and Services Law, rent benefits were added, as stated in the provisions of the Law.

Grant:

1. The amount of the grant is a maximum of 12.000 euro.

2. The grant is bequeathed given that the relevant application is approved prior to commencement of any work. The first installment is granted before the commencement of the necessary work, while the second and last installment is granted once the work has been completed and following a relevant inspection to be undertaken by an officer of the relevant District Administration.

Terms of Participation:

The amount which is provided through this Scheme may be used for the following purposes:

1) Extension or addition of a room for equivalent needs e.g. bathroom, toilet, sink etc.

The grant may be given by exception to an individual who does not own his/her own residence if the following criteria are met:

2) Modifications to the residence are needed in order to serve the individual to whom care is being provided, e.g. construction of a ramp, widening a doorway, replacing a bathtub with a shower cubicle.

Grant money from the same scheme may be provided up to the maximum amount of 12.000 euro.

Priority is given to cases which have not received any aid in the past.

Applications:

Applications are submitted by interested parties on a special form to the relevant Registrar, along with the following documents and/or proof:

A) Official confirmation from Social Welfare Services that the applicant is a recipient of social welfare benefits.

B) A construction permit (for cases of extending or adding a room). For improving/repairing an existing residence, a detailed appraisal of the necessary work is needed. Depending on the case, additional documents include either at least two tenders, or certification from a qualified individual (e.g. architect/civil engineer/surveyor) registered at ETEK.

C) Sworn statement regarding the accuracy of the data/information being submitted for obtaining the grant. False statements are liable to the provisions of the relevant law.

D) Sworn statement of the owner/carer (certified by the mayor or certifying officer) with which he/she undertakes the responsibility of housing and caring for the elderly individual or person with disabilities to whom the grant is given, for a period of at least seven years.

E) Sworn statement of the person who is being cared for that he/she gives consent for the additions/improvements to be done for his/her own benefit, whenever this is possible objectively.

For extending a residence and adding a room, along with the application, a construction permit must also be submitted. With regards to improving/repairing an existing residence, a detailed appraisal of the required work must accompany the application. Depending on the case, along with the above, at least two tenders, or certification from a suitably qualified individual (architect/civil engineer/surveyor) who is registered with ETEK must also be submitted.

Application Review Committee:

The review of the applications shall be conducted by the Committee which is comprised of the following:

a) the relevant Registrar or representative,

b) a representative of Social Welfare Services

c) a representative of the relevant District Administration

Period of Validity:

The present Scheme for improving homes which provide housing and care to the elderly and disabled who are recipients of social welfare benefits is put into force by the Ministry of Interior, from the date of its approval by the Cabinet.

Application link:

http://www.moi.gov.cy/moi/da/dadmin.nsf/dmlforms_gr/dmlforms_gr?OpenDocument&Start=1&Count=1000&Expand=5

CONTACT INFORMATION:

Nicosia District Administration:

Tel: 22804304/Fax: 22804314

Limassol District Administration:

Tel: 25806403/Fax: 25806513

Paphos District Administration:

Tel: 26801101/Fax: 26306251

Famagusta District Administration:

24801002/Fax: 24304168

Kyrenia District Administration:

22867620/Fax: 22867755

6.4.3. Housing scheme for individuals with low income[1]

The Scheme covers the housing needs of households with low income which, without significant subsidization and favorable lending terms, would not be in a position to purchase their own house.

Beneficiaries:

- Natural families (including single parents, divorcees, widowers with underage children).
- The couple must be engaged with the stipulation that prior to receiving assistance they will have married.
- Unmarried individuals but only under certain circumstances
- Individuals with special needs

Income Criteria:

The income criteria have recently been reviewed by decision of the Cabinet on the 21/7/2010. In order to participate in the Housing Scheme for Individuals with Low Income families and/or individuals must have a gross annual income which does not exceed the following:

- Unmarried individuals: €13 000
- Unmarried individuals with health problems €21 500
- Single parented families with one child: €20 000
  (€2 000 for each additional child)
- Families: €22.000 (without children)
  (€2 000 for each additional child)
- Families with individual(s) with special needs: €33 000

Other Criteria

Other criteria are also taken under consideration when reviewing the applications, such as mobile and immobile assets, housing conditions and so on.

Generally, assistance is given to families and individuals, who based on their income and other property, are not in a position to resolve their housing problems on their own. The scheme is also open to citizens of the European Union member states, as well as permanent residents of Cyprus, who have continuous legal residence in Cyprus for five years.

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[1] Cyprus Land Development Corporation http://www.cldc.org.cy/gr_cldc.shtml?gr_ssxa (20/06/12)

Subsidizations

The amount of subsidy is decided upon based on the combined income of the family or individual.

Annual income	Under €18.000	Over €18.000
Assistance		
Unmarried individuals	€10.000	€---
Unmarried individuals with health problems	€18.000	€14.000
Single parent families with one child Each additional child	€20.000 €1.500	€15.000 €1.000
Families with no children Each additional child	€18.000 €1.500	€14.000 €1.000
Families with an individual or individuals with special needs	€25.000	€20.000

Assistance for families with an individual or individuals with special needs

Families with special needs are entitled to an additional subsidy of up to €5.126, in the event that the spaces in the residence which they purchase need special adaptation, in order for their special housing needs to be met.

Advance payments

The advance payment required after signing the sales document is as follows:

- For families with a joint income of under €18.000, the advance payment comes to 8% of the selling price.
- For families with a joint income above €18.000 the advance payment comes to 10% of the selling price.

Loans

The loan is arranged by the House Finance Committee or other lending companies and in the event that the buyer cannot obtain a loan, it is payable to the Cyprus Land Development Corporation with the same terms as indicated below:

- Loan repayment period of up to 30 years.
- Full repayment by the buyer’s 75th year of age.
- Floating subsidized interest.

Other Provisions

Only families who have not been assisted by any other Government Housing Scheme for building or purchasing a residence may participate in this scheme.

Application link:

http://www.cldc.org.cy/downloads/cldc_application_form2011.pdf

CONTACT:

14 Athalassas Avenue, 4th floor,

2011 Strovolos, Nicosia

Tel: 22427000/Fax: 22513143

Email: info@cldc.org.cy

7.0 NON GOVERNMENTAL ORGANISATIONS – ASSOCIATIONS

7.1. Cyprus Autistic Association

The Cyprus Autistic Association was founded in 1990 and is recognized by the state as a charitable not-for-profit Organisation. It is a member of Autism Europe and of the World Autism Organisation.

The main purpose of the Association is to work on protecting the rights of individuals with autism, aiming at securing a better quality of life.

The Association has been operating with great success in Limassol since May, 2005 and it constitutes the first specialised Intervention Centre for rehabilitation, education, treatment, protection and occupation for children and adults who present with the autism syndrome. A similar centre was created in Paphos in December 2008 to serve the children and adults with autism residing in that district.

Moreover, in December 2009, another such centre was created and put into operation in Nicosia, aiming at serving the individuals in the district of Nicosia.

Additionally, **Kepaky,** has rented, adapted and equipped the first Model Occupational Centre for individuals who fall into the spectrum of autism disorders, which among others, offers Sensory Integration treatment. The operation of this Centre was handed over to the Cyprus Autistic Association as of October, 2010.

The ambition of the Association is to create Intervention Centres in all the districts of the unoccupied areas of Cyprus, as well as “Community houses”, in order to ensure that individuals with autism lead a dignified life while being integrated in society.

The registration fee for the Association is **€8**, while the annual subscription is **€17**.

Three programmes are in operation at the Intervention Centre for Individuals with Autism in Limassol:

- Adolescents and adults programme (mornings)
- A treatment programme for preschool and school aged children with autism (afternoons)
- Occupational and care programme (afternoons)

Three programmes are in operation at the Intervention Centre for Individuals with Autism in Paphos:

- Adolescents and adults programme (mornings)
- A treatment programme for preschool and school aged children with autism (afternoons)
- Occupational and care programme (afternoons)

Three programmes are in operation at the Intervention Centre for Individuals with Autism in Nicosia:

- Adolescents and adults programme (mornings)
- A treatment programme for preschool and school aged children with autism (afternoons)
- Occupational and care programme (afternoons)

The Model Occupational Centre runs the following programmes:

- Morning and afternoon treatment programmes for preschool and school aged children including, sensory integration, and occupational therapy, special education and music therapy.

The centres operate under the scheme of state funding. The treatments and occupation provided by the Association to the individuals with autism are of fundamental importance, both to the individuals as well as to their families. All of the Intervention Centres offer treatments such as music therapy, occupational therapy, speech therapy and special education. Sensory Integration therapy is offered only in Limassol. All of the treatments are offered at special prices for members of the Association, which are in turn subsidized by the Association.

CONTACT INFORMATION:

Cyprus Autistic Association

15 Distomou street, P.O. Box. 56149, 3304 Limassol

Tel: 25343461 Fax: 25343446

Email: autisticassociation@cytanet.com.cy

Limassol Intervention Centre

15 Distomou street, P.O. Box. 56149, 3304 Limassol

Tel: 25343461 Fax: 25343446

Email: Limassol@autismsociety.org.cy

Model Occupational Centre

1 Ellispondou street, 3100 Limassol

Tel: 25107951, 99540111, Fax: 25343446

Email: Limassol@autismsociety.org.cy

Paphos Intervention Centre

4 Evrou street, P.O. Box 8028

Tel: 26221346 Fax: 26221308

Email: paphos@autismsociety.org.cy

Nicosia Intervention Centre

3 Athinodorou street, P.O. Box 16284, 2025 Nicosia

Tel: 22512262 Fax: 22512263

Email: Nicosia@autismsociety.org.cy

7.2. The Association of Parents and Friends of Children with Special Needs

The Association of Parent and Friends of Children with Special Needs was founded in Limassol in 1991. The aims of the Association was to protect and care for the special needs of these children, whether they be physical or mental, including children with autism, and promoting and resolving the difficulties faced by these children and their parents.

Today the Association operates five pioneering, for Cyprus' standards, programmes in two houses in the town centre, at number 50 Avgoustinou street, and number 12 Nicosia street.

A) **The Adult Day Centre "Marios' House"** serves 20 individuals in four groups. The education of these individuals is undertaken by permanent scientifically qualified staff, with the help of childcare assistants and other specialists via a services acquisition programme. This programme includes the following: special education, creative activities (stained glass painting, mosaic art, pottery, painting, arts and crafts), music, learning about the world through pictures and activities, movement therapy, learning how to use computers through the ministry of Education's Adult Education Programme, theatrical games, cooking, equine therapy from the volunteer organisation of the Diocese of Epistathmia, excursions, as well as educational visits to factories and other educational and vocational places.

B) **The Children's Day Centre "Panayia Pandanassa"** serves seven school aged children in two groups. Their education is provided for by permanent scientific staff with the help of childcare assistants, as well as other specialists via a services acquisition programme. The programme includes the following: special education, music therapy, movement therapy, free activities, bowling, sensory games, Puppet Theatre, creative activities, arts and crafts, cooking, entertainment, swimming and excursions.

C) **The Adult Day Centre "Panayia Pandanassa"** serves nine people in two groups. Their education is undertaken by permanent scientifically qualified staff with the help of childcare assistants, as well as specialists, via a services acquisition programme. The programme includes the following: educational games, hydrotherapy, movement therapy, care, occupation, entertainment, excursions and creative activities. The programme is gradually enriched with new activities based on their abilities.
These programmes operate with the assistance of the Social Welfare Services.

D) **The Psychological Support Programme** has been in operation since 1996 with exceptional results. Children and adults at the Day Centres are offered psychological support in an effort to avoid the development of negative behaviors.

This programme is offered at no cost to all children and adults who attend the Day Centres and to members on an individual or group basis from the Association psychologist.

E) **The Therapeutic Intervention Programme** operates in the afternoons and provides a variety of treatments (occupational therapy, speech therapy, special education and physiotherapy). Today, all children who attend the Day Centres participate in the programme, as well as an additional 40 children who are members of the Association. The programme runs with the assistance of the Radiomarathon Foundation and the Ministry of Health.

Any individual over the age of eighteen may register as a member of the Association. The registration fee is **€2** and the annual subscription is **€15**.

CONTACT INFORMATION:

Tel: 25382213, 25332245

Fax: 25822197

Email: specialneeds@cytanet.com.cy

Website: http://www.special-needs.org.cy/

Facebook: Day Centre

7.3. RADIOMARATHON

Radiomarathon is a fundraising institution which has established itself in Cyprus over a number of years. The fundraising is completed with the goal of providing financial assistance to individuals with special needs, their families and the centres which care for these individuals. Radiomarathon is an example of voluntary support by known and unknown people to individuals who are facing difficulties. Within the context of its charity work, Radiomarathon offers subsidies to individuals who need help.

Specifically it offers the following:

- Improving living conditions
- Financial support
- Speech Therapy
- Physiotherapy
- Educational assistance/Psychological support
- Medical treatment in Cyprus and abroad
- Purchase of hearing, technical equipment and wheelchairs.

In order to benefit from these subsidies, interested parties should complete the application which is available from Radiomarathon. Supporting documents must also be submitted along with the completed application form.

Applicants will need a document confirming the medical diagnosis of the condition or syndrome from which they are suffering and receipts of the treatments which they are paying for.

The application should be posted to the following address:

P.O. Box: 25743, 1311 Nicosia.

Radiomarathon Application link:

http://www.radiomarathonios.com/images/media/file/CLScan514.pdf

Applicants need to provide full details of the income of their parents/guardians, their savings, property and financial obligations. The application will then be reviewed by the Radiomarathon Managing Committee. **The amount of assistance for which the applicant is approved depends directly on his/her needs and the amount that Radiomarathon has available.**

CONTACT INFORMATION:

3 Valaoriti street, Acropolis, Nicosia

P.O. Box 28643, 2081 Tel: 22879518

Fax: 22423986

Website: http://www.radiomarathonios.com

Email: radiomarathonios@cytanet.com.cy

7.4 “To Alma” Child Development Centre

“To Alma” was founded in 1994, and is situated on the 1st floor of the Old Limassol Hospital and is **one of five programmes run by the “Theotokos” Foundation. The “Theotokos” Foundation is a non-governmental, not-for-profit organisation.** “To Alma” offers early intervention services via its **Interdisciplinary** team, to families with children aged 0-8 who are facing difficulties in various areas of their development or children who are in high risk groups (e.g. premature babies), who are may present problems as they develop. In **ALMA** special attention is paid to providing information, counseling and psychological support to parents.

With the help of the Interdisciplinary Team, parents decide and select on the most suitable therapeutic and educational approach for their child.

All the departments cooperate with and communicate with other organisations which are involved with children, including **the state Medical and Social Services, as well as Preschools** and Schools. The Centre’s services are provided to children who reside within and beyond the Limassol district.

A family may approach the centre of its own accord or following a referral from a doctor. **A medical diagnosis is not considered a prerequisite. The Centre’s activities are fully funded by the “Theotokos” Foundation and are further enriched by the Parents Association and donations.**

SERVICES

Pediatric Physiotherapy
Specialized Occupational Therapy
Specialized Speech Therapy
Special Interventions for feeding problems
Equine Therapy
Psychological support services for children and families
Services from a Social Worker
Family Activities
Educational Services
- Preschool
-Infant Department
Liaising with other specialties

The Child Development Centre ‘To Alma’ covers the following cases in the early stages of the child’s development:

Cerebral Palsy
Premature infants
High Risk Infants
Psychomotor delays
Neuromuscular Conditions
Obstetrical Palsy
Metabolic diseases
Torticollis
Genetic abnormalities
Various syndromes
Speech/Language delay
Speech/Language disorders
Difficulties in coordination and movement
Sensory processing and regulation disorders
Autism
Dysphagia
Stuttering

CONTACT INFORMATION:
P.O. Box 53098, 3300 Limassol, Cyprus
Tel: 25746804-25746828/Fax: 25746027
Email: monada@cytanet.com.cy
Website: www.theotokosfoundation.org

7.5. Horse Riding for Individuals with Special Needs at Episkopi – Riding for the Disabled Association (RDA)

Since 1985, a riding group has been operating for Individuals with Special Needs, in a luscious green area in Limassol's Episkopi, called Happy Valley.

The above Association offers individuals with special needs, including individuals with autism, weekly half an hour horse riding lessons for free. The Association's income comes from charity and other events organized by the Association itself, which enables it to offer its services for free.

The Board of Directors of the Association comprises of residents of the British Bases and serves the residents of the bases, as well as other permanent residents of Cyprus.

There are four Associations which use the specific equine therapy programme: The Theotokos Foundation, 'To Alma', the Red Cross and the Association of Parents and Friends of Children with Special Needs.

For further information: Tel.: 25933866/99481026

Website: http://www.rdacyprus.com/

7.6. Sports

7.6.1. Special Olympics Cyprus[1]

Special Olympics Cyprus was founded in 1986 and is a member of Special Olympics International and the Cyprus Olympics Committee. It is recognized from the Cyprus Olympics Committee as a sports association for individuals with mental retardation from the age of eight and above, through to adulthood. The association is not-for-profit and its activities take place through volunteer work from its members. The expenses for organizing and including athletes in various events, in Cyprus and abroad, are covered by grants from the Cyprus Sports Organisation, Cyprus Police Torch Run and private companies and organisations.

Today Special Olympics Cyprus has spread all over Cyprus. Over 400 athletes with mental retardation and severe learning difficulties are trained in classic sports, swimming, cycling, football, basketball, Olympic gymnastics, horse riding, bowling, floor hockey, skiing and Motor Activity Training Program Activities (MATP). Recently the development of unified sports has begun, with the inclusion of individuals from outside the Special Olympics in football and basketball.

Significant changes have been made over the course of the 22 year presence of the Special Olympics Cyprus, such as raising awareness in the community and creating equal opportunities conditions within the society. These changes were made possible through the tireless efforts of the Board of Directors of Special Olympics Cyprus, the sensitivity of the states, the yearly grants from the Cyprus Sports Organisation and the continuous support of sponsors and volunteers. The athletes themselves have been successful in evoking in us a strong sense of national pride in all of the events in which they have participated, by achieving European and world distinctions.

Special Olympics Cyprus is based in the Cyprus Olympic House. During a meeting we had with one of the members of the Board of Directors, Mr. Aristos Evripidou, and one of the volunteers, Mr. Varnavas Xoufarides, we were fully informed regarding their activities and goals. Their philosophy extends beyond sports and occupation, to socialisation and autonomy. The children are trained and entertained safely under the supervision of special trainers. Additionally, in all of the unoccupied cities of Cyprus there are various sports teams, in which the children can take part in. Each and every child is welcomed into the arms of Special Olympics Cyprus.

CONTACT INFORMATION:

Tel: 22449848

Email: info@specialolympics.com.cy

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[1] Special Olympics Cyprus http://www.specialolympics.com.cy/ (22/06/12)

7.6.2. Sports for All[1]

The Cyprus Sports Organisation in line with its Sports for All philosophy for providing equal opportunities for sports to all individuals, irrespective of gender, age, social status and particularly level of mental and physical health, runs special programmes for individuals with special abilities.

Trainers from Sports for All visit specific centres for individuals with special needs in each city and offer their services to the children.

To date, the programme is offered in **Limassol, Nicosia, Larnaca, Paphos and Famagusta.**

Details can be found on the organisation’s website:

http://www.ago.org.cy/special_abilities.shtm

CONTACT INFORMATION:

Tel: 22897000

Fax: 22358222

Email: info@ago.org.cy

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[1] Sports for All http://www.ago.org.cy/history.shtm (22/06/12)

8.0 BENEFITS FROM SEMI-GOVERNMENTAL ORGANISATIONS

8.1. CYTA

CYTA offers **Special Tariff Telephone Connection Packages** to individuals with low income and those with special social needs.

Provision/Usage Instructions

In accordance with the decision on setting Special Tariff Packages for low-income individuals and those with special needs (C.D. 3/2005) announced by the Commissioner of Electronic Communications and Postal Regulation (OCECPR) on 29 July 2005 and subsequent amendments, the following terms and conditions apply to Special Tariff Packages for low income individuals and those with special needs:

Eligibility

(a) Individuals with special social needs, suffering from:

- Severe motor disability (e.g. myopathy, multiple sclerosis, encephalopathy or other muscular diseases) who are wheelchair-bound or one stage prior to becoming wheelchair-bound
- Hearing and/or total speech impairment
- Blindness
- Intellectual/developmental disability

(b) Low-income individuals

- Physical persons whose annual income is less than 60% of the average income, as calculated and amended by the Statistical Service of Cyprus. As of 31/3/08 and the latest amendment by the Statistical Service of Cyprus regarding the calculation of the percentage and the amount of the average annual income of physical persons, for an individual the annual income is €7,847.61, while for each additional individual (over 14 years of age) the sum of €3,923.80 is added to the income of €7,847.61 and for every additional minor (under 14 years of age), the sum of €2,354.28 is added. The above amounts are calculated in total for each family.
- Recipients of state benefits from authorities such as the Social Welfare Services of the Ministry of Labour and Social Insurance.

(c) Minors

In cases where minors belong to one of the categories in section (a) above, their parents or guardians are eligible for the Special Tariff Package, provided that they live together in the same home, upon presentation of the following documents:

- A certificate from the District Welfare Office stating that the minor receives state benefits, together with a copy of his/her disability certificate.

- The birth certificate of the minor or a certificate from an association in which the minor’s date of birth is registered.
- The parent’s or guardian’s identity card.
- The parent’s or guardian’s signature on the application form requesting telecommunications facilities for minors with disabilities.
- Proof of guardianship of the minor (e.g. Court Order) in cases where the minor has been placed under guardianship.

(d) Individuals with Intellectual/Developmental Disability (Mental Handicap)

To be considered eligible for the specific package and its benefits, such individuals must present Cyta with a certificate from the Committee for the Protection of the Rights of People with a Mental Handicap (established in accordance with Law 117/89 and subsequent amendments) which states that he/she is included on the Committee Register and is not institutionalized.

The following documents need to be submitted:

- A certificate/booklet from the Department for Social Inclusion of Persons with Disabilities, A certificate from the responsible services of the Welfare Office (for recipients of state benefits).
- A certificate from the Committee for the Protection of the Rights of People with a Mental Handicap stating that the individual is on the Committee Register and he/she is not institutionalised (for individuals with intellectual/developmental disability).
- Applicants may also need to submit additional documentation from doctors, etc.

Call Charges for SPECIAL TARIFF TELEPHONE CONNECTION PACKAGES FOR INDIVIDUALS WITH LOW INCOME OR SPECIAL SOCIAL NEEDS, including VAT.

Based on the last update (15th of May, 2012):

Call charges to:	Charge per Unit (€)	Unit
CYTA landline	**0,01871**	1 minute
CYTAMOBILE-VODAFONE	**0,04235**	1 minute
PRIMETEL	**0,04646**	1 minute
MTN	**0,03888**	1 minute

Notes:

1. For the Special Tariff Telephone Connection Packages for individuals with special social needs, the first 100 minutes of calls to CYTA landlines each month are free of charge.
2. The charges are applied per minute.
3. The connection fee and registration is **FREE OF CHARGE.**

Terms of Provision:

i. A direct analogue fixed line (PSTN) for eligible physical persons is provided for a single home with a distinct address.

ii. Cyta will accept that eligible minors live in the same home as their parents/guardians on the basis of a signed statement by the parent/guardian in which attention is drawn to the law on false declarations.

iii. Acknowledgment that an individual is classified as having Special Social Needs will be made upon presentation of a suitable certificate and/or presentation and photocopying of a relevant identity document.

iv**. Special Tariff Packages** for low-income individuals or those with special social needs will be provided only to eligible physical persons.

v. **Special Tariff Packages** for low-income individuals or those with special social needs will apply only to individuals (members of households) whose permanent residence is in Cyprus, as determined by the Republic of Cyprus.

vi. Those eligible for Special Tariff Packages must submit a written application, either in person at one of our cytashops or by fax.

8.2 CEA (Cyprus Electricity Authority)

CEA has created the Special Tariff 08 for large and needy families. The tariff code 08 applies to the following:

- Large families with three dependent children or more, with a joint family income of up to €51.258. The income criterion of €51.258 for the annual joint family income shall be raised in intervals of €5.126 for each additional dependent child after the 4th child.
- Needy families which are receiving public assistance from Social Welfare Services.
- Families which receive the Severe Motor Disability Allowance from the Department for Social Inclusion of Persons with Disabilities.

Tariff code 08 applies to the above individuals, as long as the electricity bill is in either their own name or their spouse's name. The application should be completed by the person who is named on the bill.

The charges for electricity provision with a basic price of fuel of €300/MT for each two month period, given the present charges, are as follows:

Unit charges		Fixed tariff based on whole consumption	
Units	Cent/kWh	Total Units	€/two month period
First 100 units	11,26	0-1000	1,34
Next 100 units	12,60	1001-2000	4,28
Additional units	15,01	2001+	5,36

Fuel Clause:

Each two month period, the charges for each unit will either go up or be reduced based on the valid price of the Fuel Adjustment Clause, for each 5 cent raise or reduction in the basic price of €300 of fuel cost per metric ton, the cost of which is defined by CEA for the two month period, based on fuel price.

Note: Terms and conditions apply, which are an integral part of the tariff.

8.3 Cyprus Airways

Cyprus Airways offers individuals with autism 20% discount on all valid prices, after relevant documents are presented. The above discount does not include airport taxes or any other additional charges which need to be settled when purchasing the tickets.

Travel is subject to seat availability on the flights and aircrafts of Cyprus Airways at the time of reservation.

Reservations should be made through the Cyprus Airways Call Centre (tel. 80000008), provided there are seats in the class requested on the date of reservation. Issuing the tickets must be done directly from the Cyprus Airways Ticket Issuing Offices.

For more information visit their website:

http://cyprusair.com/

9.0 EPILOGUE

With the completion of the present Guide it became possible to form a clear picture of the Cypriot reality, regarding the issue of Autism. It arose that there are four elements involved in the matter of Autism: The government, non-governmental organisations, the society and the parents. Without a doubt since the time Kepaky was founded and began being involved in Autism a significant improvement has been observed in all four of these elements. The prevailing message through the research is that, although effort and progress has been made on all levels, more work is needed in order to safeguard the attainment of the basic principle – the right of each child and family to receive the support needed.

As far as the government services are concerned, the issue of Autism is dealt with by four Ministries (Health, Education, Labor and Social Insurance, and Finance). However, there are many cases in which resolving issues requires all four Ministries to be in agreement, resulting in issues being delayed or coming to a halt, facts which do not support the effective resolution of problems.

Furthermore, the deficits that exist, as well as the bureaucracy, could be avoided if legislation was put into effect which defines the role which each service is required to take on, or preferably, an umbrella organisation could be created which would bring together the concerns of all the relevant organisations and decide upon a united and common strategic policy regarding Autism. For instance, in Portugal, Early Intervention is based on intersectoral cooperation, including Non-Governmental Organisations (NGOs). Additionally, there is an Early Intervention Law which defines the responsibilities of each Ministry (Education, Health and Social Insurance)[1].

This organisation could be staffed with professionals, such as notable barristers, officers, financial advisers, educators, parents and others. Ideally, this organisation could ensure that all actions taken are correct, the most suitable and effective, as well as providing guidelines so as to avoid certain actions, to utilize all experience and continuously lend perspective regarding this issue. It would also be desirable for this organisation to encourage the state to create government settings which will offer all necessary services, for individuals of all ages who have Autism.

Regarding the area of intervention, ideally there should be a team of specialists comprised of a child neurologist, child psychiatrist, psychologist, special educator, speech therapist and others, who will work with the child continuously and on a regular basis. These individuals would track his/her progress both in the school and home environment, as is the case in other countries.

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[1] European Agency for Development in Special Needs Education: www.european-agency.org

There are significant concerns regarding the education of children who fall into the autism spectrum and some examples are given in this guide which have been picked up on after reviewing the relevant literature, in the hope that in the near future, the best will also be offered to these individuals and they will be provided with the appropriate help using the most suitable approach.

The review of the research and available sources concerning individuals with autism, has indicated that more than anything, their education requires specialization. Unfortunately, frequently our education system does not have sufficient sources of support and services for children with autism. Therefore, it is recommended that the Ministry of Education allows selected staff to receive relevant training and acquire specific skills which will guide them in their work. In Queensland, Australia, there are Advisory Visiting Teachers for children with Asperger's Syndrome. The specific special teacher may visit the class to observe the child and act as a source of support, providing explanations, strategies for dealing with difficulties and training to teachers. Wherever distance is an obstacle, then technology assists the process through the use of video and teleconferencing. It is compulsory that the personnel and management staff of the various private Centres which care for children with special educational needs for the purpose of treatment are trained so as to achieve greater results.

Regarding NGOS, the fundamental importance they hold and the meaningful role their efforts have in contributing to social affairs have now become apparent, particularly due to the fact that the activities and way of operating of these organisations is more flexible in comparison to the state. Besides, both individuals with autism and their parents or environment find themselves in a worse position when they are not integrated within a special Intervention centre of the Cyprus Autistic Association of the Limassol, Nicosia and Paphos districts. Additionally, via the integration of these individuals in a NGO they are able to benefit both financially and socially, since they will have the opportunity to socialize and avoid the social exclusion which they may be up against. At this point, it is important to underline the lack of specialized centres in Larnaca and total absence of provision of services in the villages.

Through contacting the parents it was understood that their main concern, particularly for those with adult children with Autism is what lies ahead. Specifically, there are very few cases in which parents have been able to secure special housing and care for their children outside institutions and nursing homes, when they themselves are no longer able to care for them. One suggestion would be to create Centres with Dormitories, in each of Cyprus' larger cities staffed with trained personnel, where children with these disorders can reside. This would provide both the parents and the children with a sense of security and autonomy

An important finding from our research regards the way in which parents accept the fact that their child falls in the autism spectrum. The psychological state of a parent who first encounters the word ‘autism’ is undoubtedly very negative. During the course of the diagnostic process, some parents essentially cannot see the reality and try with every possible way to rule out the possibility that their child may fall in the autism spectrum. At this point, the timely intervention by special staff that will approach the parents in a professional manner can play an important role. Approaching parents in a correct and appropriate manner with regards to their psychological wellbeing is unfortunately a part of the process which is not given the necessary attention in our country.

Beyond psychological support, it is imperative to offer parents training, through which they will feel empowered, develop a more enjoyable way of communicating with their child, and in turn they will also be able to train their child regarding acceptable behaviors in his/her own environment. Unfortunately, parent training is essentially nonexistent in Cyprus. This service is only offered in a very small number of private centres and comes at a very high cost, a fact which renders it inaccessible to most families.

At this point it is worth mentioning one mother’s advice: “As a mother of a child with autism, I would like to emphasize how important it is for parents to read about autism, understand it and accept their child along with his/her problems. The sooner they do that, the more able they will be to help their child. They know their child better than anyone”.

Another important issue that arose from our research is the prejudice and ignorance that exists in Cypriot society concerning the topic of Autism. In the absence of informed awareness, merely by hearing about it, autism evokes fear. It is therefore, necessary to raise awareness and sensitivity so as to promote acceptance of the particularities of these individuals and their smooth integration into society.

Generally, it would be ideal if it becomes possible to create a welfare state, as well as a common policy for each action, on which governmental and non-governmental organisations can follow led by what is in the best interests of children with Autism and all children with special needs in general.

In closing, it is emphasized that this guide is a piece of work which needs constant revision, since different information regarding autism is constantly brought forth. Kepaky wishes to continue to gather updated information and recommends to all those involved with Autism that with their help, and with the help of other relevant individuals, we keep these efforts alive.

10.0 A FEW MORE THOUGHTS

“It was with great pleasure that I read the Practical Guide for Individuals with Autism in Cyprus: rights and provisions from Governmental and Non-Governmental Services. As I read it, I was mentally transported back to the years we went through as parents since the day we heard the word autism and didn’t know what it meant or where to turn to for help. All parents who struggled blindly to go down this difficult path can appreciate today what a great value this Guidebook will have for parents who are just receiving the diagnosis and are literally lost. Our journey is long and hard. Let us gather the right tools which will help us make our children’s and our family’s life a better one”.

Mother of a child with Autism

“Parents are the top experts in relation to their children and their concerns regarding their child’s development, particularly regarding communication, behavior and socialisation must be taken seriously immediately by the health professionals dealing with children. Early intervention is important to early therapeutic intervention, which will lead to a better quality of life for the family and child.”

Dr. Christos Christofi, Pediatrician- Specialised in developmental disorders

“You have the right to smile, laugh, be happy, be sad, cry, hurt, think, hear, touch, smell, feel beautiful and you definitely have the right to love in whichever way you want as long as it is beautiful! The beauty of the soul is the greatest power of your existence! Be one of the ones to continue the above feelings!

Maria Kyriakou, Educator-Psychologist

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12.0 APPENDIX

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22 Chr. Kalaitzi street, Dasoupoli, 2015 **Nicosia**

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Margarita Liasidou Foundation for Handicapped Children

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Website: www.margaritafoundation.net

The Good Samaritan Foundation

11 Thermopylon street, Acropolis 2008, **Nicosia**

Tel.: 99618836/Fax: 22496067

Cyprus Red Cross Society

Cyprus Red Cross, 2063 Strovolos

P.O. Box:25374, 1309 **Nicosia**

Tel.: 22666955, 22668177/Fax: 22666956.

Youth Department: 22665166

Email: admin@redcross.org.cy

Website: www.redcross.org.cy

Cans for Kids

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