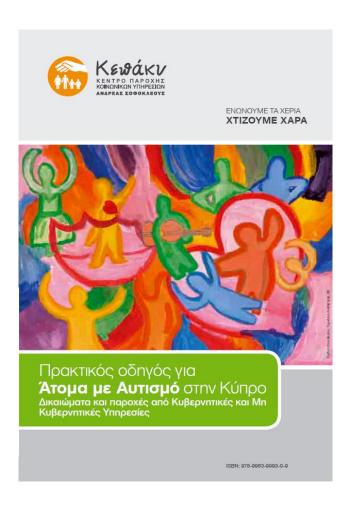
A Practical Guide for Individuals with Autism in Cyprus: Rights and Provisions from Governmental and Non-Governmental Services.



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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 Sophocleous And the President of the Board of Directors, Azucena Sophocleous

Gregorio Marañón (1887-1960) médico y escritor español

[&]quot;Joining hands, creating joy"

[&]quot;Vivir no es sólo existir, sino existir y crear, saber gozar y sufrir y no dormir sin soñar..."

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 Autistic Association and has been by our side in every practical way to this day. One part of this practical support is the establishment of the Specialized 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 Autistic Association 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.

Limassol 2013

Tasoula Georgiadou President of the Cyprus Autistic Association

ACKNOWLEDGMENTS - FIRST 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 - 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.

ADDITIONAL ACKNOWLEDGMENTS - THIRD EDITION 2018

In addition to the aforementioned individuals, we would like to thank Mrs. Cleanthous, president of the Cyprus Autistic Association, for her participation in this edition. We would also like to thank attorney Marina Pericleous, Mrs. Maria Evripidou, Special Education officer, Secondary

Education; Mrs. Maria Shiakalli, psychologist; Mrs. Marina Payiatsou, officer at the Committee for the Protection of Rights of People with a Mental Handicap; Mrs. Eleni Dimitriou, Early Intervention officer; and the ladies from the Department for Social Inclusion of Persons with Disabilities, deputy senior officer, Vaso Frangaki and officer Maria Toumazou. We would also like to extend our appreciation to officers in governmental, semi-governmental and non-governmental organizations and associations who have assisted us in gathering information. In closing, we would like to express our appreciation and admiration to all the parents of children with autism, and particularly the very socially active Mrs. Tasoula Georgiadou, Mrs. Athena Constandinou and Mr. Apollon Kapodistrias, who have shared with us their valuable experiences. The parents are the unsung heroes who battle on a daily basis to ensure their children can live with dignity. Finally, we would like to thank Nicholas Pavlou, psychologist and officer at KEPAKY for his contribution to this project.

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1.0 INTRODUCTION

The Andreas Sophocleous Centre for Provision of Social Services "Kepaky" was founded in 2008, registration number 268. The centre is a not-for-profit organization directed by a nine member board and aims at improving the living conditions of individuals who need support, contributing to awareness regarding social topics and values, such as volunteering, social inclusion and solidarity.

Kepaky activities focus on four main areas:

- Protection and support to individuals with Autism and their families
- Financial aid and vouchers for young people with socioeconomic difficulties as a means of prevention of a range of social problems
- Seminars and professional services to organized entities, such as psychological support in schools
- Campaigns and other projects aiming to cultivate social and environmental consciousness

In the context of its continuing support to individuals with Autism and their families, Kepaky has taken the initiative to create this informative guide for people with autism.

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, continuing financial support up until 2013. The inauguration of the centre, organized by Kepaky in 2012, was led by then Minister of Health, Mr. Stavros Malas, in the presence of 'Theofilestatou Horepiskopou Amathoundos' Mr. Nicolaou.

Following this, and having recognized the need for informing parents regarding legislation, services, subsidies and other rights, Kepaky took the initiative to create an informative guide. Specifically, the present guide includes useful information, focusing particularly on treatments, services, legislation, European Union documents, the rights of these individuals and the procedures necessary in order 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 re-checked was obtained from reliable, scientific sources.

In 2012, 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 this point it is worth noting the valuable contribution of child psychiatrist, Dr. Costa Fransi, whose scientific knowledge has significantly enhanced the guide. The material regarding the theoretical background, up to and including the presentation of Autism Spectrum Disorders in adulthood comprises Dr. Fransi's contribution.

In this latest revision of the Guide, some changes have been made to the chapters Classification-Criteria, Prevalence – Comorbidity. At the same time, with the intention of maximizing the improvement of the guide, the professional writing style was combined with a simpler one, via tables which include the Key Points of each subsection. The aim of this modification was to ensure that the guide is useful and accessible to parents and professionals who encounter individuals with these disorders. Armed with the valuable cooperation of officers from governmental and non-governmental services and the valuable contribution of parents of children with autism, we have succeeded in producing the new and enriched version of our guide.

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.

BRIEF SUMMARY OF KEPAKY ACTIVITIES FOR AUTISM

- ✓ Based on Kepaky's initiative, a television show was produced featuring autism. The purpose was raising awareness and sensitivity to this issue.
- ✓ Funding and part of organizing the seminar "The hyperbaric chamber method in autism" from doctor CEM KINACHI in 2009.

- ✓ Funding of fees for three families to participate in the seminar "Parent Teacher Trainings (Autism Assessment Support Practice)".
- ✓ Covering the expenses of a seminar titled "Recognition and Intervention of Sensory symptoms in autism" which took place on May 15th and 16th, 2010 at hotel "Curium" in Limassol. The main speakers were known MA, OTR trainer, Mrs Anna Sampsonidou, from Thessalonica, and Mrs. Despina Kaimi, OT therapist.
- ✓ Development of the Model Centre for Occupation, Care and Treatment for individuals with autism, which was officially handed over to the Cyprus Autistic Association in October 2010, and financially supported until 2013.
- ✓ Conducting sociological research, creating and printing "A Practical Guide for Individuals with Autism in Cyprus: Rights and Provisions from Governmental and Non-Governmental Services. The presentation of the book took place on October 20th, 2011. We were especially honored by the serving Minister of Social Insurance, Mrs. Sotiroula Charalambous.
- ✓ Organizing the inauguration ceremony for the Model Centre for Occupation, Care and Treatment for individuals with autism which took place on January 22, 2012 from the honorable minister of Health at the time, Mr. Stavros Malas.
- ✓ As of 2012, through the programme "Lending a hand to the young", food and/or clothing vouchers are provided to families with children with autism at Christmas or Easter.
- ✓ Funds for hiring two psychologists to provide group support of parents of children who are on the autism spectrum. The programme took place in Limassol and Nicosia from February July 2013.
- ✓ Participation in Light it Up Blue (World Autism Awareness Day). Joining this worldwide initiative, the building housing the foundation's offices was lit up with blue headlights during the night of the 2nd of April 2017 & 2018.
- ✓ Subsidized treatments for children with autism, whose parents have financial difficulties.

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 Contact¹. 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's²⁻³ 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 disorder⁴.

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

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

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

⁴ 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.

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. 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.

Key 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.

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. With regards to Autism, these two systems (ICD and DSM) are extremely close in the classification and criteria which they utilize (Table 1).

As of 2013, the fifth revision of the Diagnostic and Statistical Manual has been adopted, as well as the 11th revision of the International Classification of Diseases⁵. The new diagnostic criteria refer to "Autism Spectrum Disorder" and all 'types' of Autistic disorders, such as Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified, are abolished. Severity levels are based on the degree of support the individual will need in terms of the difficulties he or she faces with regards to social communication, restricted interests as well as repetitive behaviors.

The following criteria are specified in the DSM-V for Autism Spectrum Disorder⁶:

- 1. Persistent deficits in social-emotional reciprocity as manifested by 2 out of 3 symptoms mentioned in the DSM-V.
- 2. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by 2 out of the 4 symptoms mentioned in the DSM-V.
- 3. Symptoms must be present in the early developmental period.
- 4. Symptoms cause significant impairment in the individual's functioning
- 5. These disorders are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

⁵ Applied Pedagogy, Electronic Version of the *Hellenic Institute of Applied Pedagogy and Education (HELIAPED)*, Issue 6. ISSN 1792-7587

⁶ https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria

Table 1. Autism Spectrum Disorders (ASD) in the classification systems:

ICD-10	DSM-IV-TR	DSM-V/ ICD-11
F84.0 Childhood Autism	299.0 Autistic Disorder	
F84.3 Other 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	Autism Spectrum Disorders
F84.8 Other Pervasive Developmental Disorders		
F84.9 Pervasive Developmental Disorder unspecified		
F84.2 Rett Syndrome	299.80 Rett Syndrome	
F84.4 Overactive disorder associated with mental retardation and stereotyped movements		

Key Points

- ✓ The disorders are classified using descriptive criteria of World Health Organization, International Classification of Diseases and the American Psychiatric Association, Diagnostical and Statistical Manual.
- ✓ In the new classification of DSM-V (2013) all cases fall into one category and are referred to as Autism Spectrum Disorders (ASD).

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 the 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 typically, an 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.

Key Points

 $\sqrt{}$ There is great variability in the clinical presentation of ASD, which renders each individual's profile unique.

 $\sqrt{\text{Socially}}$, an individual with ASD may be withdrawn, passive, energetic but also odd or very ritualistic.

 $\sqrt{}$ 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.

 $\sqrt{}$ They have difficulties in non-verbal communication: limited hand gestures, limited facial affect, and an odd tone of voice.

 $\sqrt{}$ 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.

 $\sqrt{}$ Other characteristics include self-harm, attachment to objects, resistance to change, odd posture and gait and unusual fears.

 $\sqrt{}$ 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 and thus should be granted appropriate attention.⁷

Table 3*. Behaviours of a child with ASD, which may frequently be a concern for parents, divided into subcategories⁸.

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

Behavior	Absolute indications for further assessment	
• Tantrums	No babbling by 12 months	
• Is hyperactive/uncooperative or	 No gesturing (pointing, waving bye- 	
oppositional	bye etc.) by 12 months	

⁷ Ozonoff S, et al (2009) How early do parent concerns predict later autism diagnosis? J Dev Behav Pediatr. 30(5):367-75

⁸ 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.

- 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 single words by 16 months
- No 2-word spontaneous (and not just echolalic) phrases by 24 months
- Demonstrating any loss of skills relating to language or social interaction (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)

Key Points

√ Parents are usually concerned about a delay in speech

 $\sqrt{}$ 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

 $\sqrt{\text{Certain symptoms (table 3)}}$ 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.

The diagnosis can be made reliably from the ages of 2-2.5 years old⁹ 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, one 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 which may be achieved. ¹⁰

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

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

¹⁰ 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^{11·12}:

- A good neurological assessment since often these children present with milder symptoms (soft signs).
- A hearing assessment, even if clinically there doesn't seem to be any impairment
- 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. Testing in Cyprus can be performed by the Institute of Neurology and Genetics in Nicosia. Fragile X syndrome is the second most common form of inherited mental retardation, following Down's syndrome. It causes learning and behavioral problems which vary from mild to severe and are found more frequently in boys.
- 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.) 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).

¹¹ 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.

¹² 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

- 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 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.
- The possibility of a metabolic disease (including mitochondrial disorder) in ASD is <0.5% and thus standard testing¹³ 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)

Key Points

 $\sqrt{}$ There is no absolute point that needs to be reached which is either necessary or sufficient for giving a diagnosis.

 $\sqrt{}$ The diagnosis is given with confidence at around the age of 2-2.5 years old. In younger children it is given as a provisional diagnosis.

 $\sqrt{\text{Assessment includes taking a detailed developmental history, clinical observation,}}$ and naturalistic observation (e.g. at the child's school).

 $\sqrt{}$ Following the diagnosis, a detailed assessment of the child's difficulties is needed in order to develop his/her Individualized Educational Plan for intervention.

 \sqrt{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.

 $\sqrt{}$ Any other examination should be conducted only if the child's clinical presentation indicates it is necessary.

¹³ 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 Prevalence - Comorbidity

In recent years, the number of reported incidents of autism have rapidly increased in all countries in which scientific studies have been conducted.

According to Autism Europe, recent studies in Europe indicated that Autism Spectrum Disorder affects approximately 1 in 100 people, while according to studies conducted in the U.S. (Autism Speaks) the ratio is 1 in every 68 people^{14·15}.

ASD is 4 times more frequent in boys than it is in girls.

The rise in prevalence is attributed, at least in part, to the following ¹⁶:

- Knowledge with regards to the disorder, which has increased among health professionals, parents and the broader population.
- Broadening of diagnostic criteria.
- Diagnoses made at younger ages.
- Demographic and geographical variables.
- It is also possible that environmental factors contribute to the rise in prevalence of autism, however, that requires further investigation.

Rates of prevalence vary in the literature, with some studies finding higher rates and others lower. This is to be expected, based on the fact that prevalence studies vary with regards to the chosen scientific method and most are based on a restricted sample of a country's population, rather than national data.

It has been known for many years that autism coexists or is intertwined with other medical conditions, either from the outset, or within the course of the life of the individual with ASD. These may include physical-organic conditions or psychiatric disorders. The most common conditions are the following¹⁷:

Hearing impairment

¹⁴ www.autismeurope.org (03/04/18)

¹⁵ www.autismspeaks.org (03/04/18)

¹⁶ http://www.autismeurope.org/about-autism/prevalence-rate-of-autism/ (03/04/18)

¹⁷ http://www.autism.org.uk/about/what-is/related-conditions.aspx (03/04/18)

Vision impairment

Down's Syndrome

Fragile X Syndrome

Sleep disorders

Dyslexia

Dyspraxia

Anxiety

Mental retardation

Epilepsy

Gastrointestinal disorders

Key Points

- ✓ According to Autism Europe, recent studies indicated that Autism Spectrum Disorder affects approximately 1 in every 100 people, while according to studies conducted in the US, the ratio is 1 in every 68 people.
- ✓ Autism Spectrum Disorder coexists or is intertwined with other medical conditions, either from the onset or through the course of the life of the individual with ASD, e.g.:

Hearing impairments

Vision impairments

Down's Syndrome

Fragile X Syndrome

Sleep disorders

Dyslexia

Dyspraxia

Anxiety

Mental retardation

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 in a family with one child who already has ASD is estimated at around 18,7% ¹⁸. 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 reaches 32,5%. The severity of ASD in the child does not appear to be related to the degree with which it 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^{19·20}. 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.

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

¹⁸ Hallmayer J, et al (2011) Genetic heritability and shared environmental factors among twin pairs with autism. *Arch Gen Psychiatry*. 68(11):1095-102.

¹⁹ Grafodatskaya D, et al (2010) Autism spectrum disorders and epigenetics. *J Am Acad Child Adolesc Psychiatry*. 49(8):794-809

²⁰ Helt M, et al (2008) Can children with autism recover? If so, how? *Neuropsychol Rev.* 18(4):339-66.

- 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.

It should also be noted that none of the existing neuropsychological theories can independently explain all the particularities which collectively constitute ASD.

Key Points

 $\sqrt{}$ The etiology of ASD has a very strong genetic substrate – predisposition, a result of the interaction of many different genes.

 $\sqrt{}$ 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.

 $\sqrt{}$ 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.

 \sqrt{A} s in all psychiatric disorders, there is an interaction between genes and environment.

 $\sqrt{}$ 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 are clearly very different from those used in contemporary times (many innovative methods – very early intervention).

Researchers agree that 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 exist²¹. These individuals are typically high functioning with less severe symptoms and higher mental abilities. However, clinical observations limit the percentage of individuals whom are "cured" to less than 5%.

As far as long-term prognosis is concerned, results from 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.

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 have positive prognosis themselves).

²¹ Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47(7):493-9.

In recent years a significant percentage of children with ASD attend regular schools, on the one 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 typical 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.

Key Points

 $\sqrt{}$ The progression of ASD and the level of functioning that can be accomplished varies from person to person.

 $\sqrt{}$ The percentage of individuals who are "cured" is less than 5%.

 $\sqrt{}$ 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.

2.9 Autism from the perspective of Psychoanalysis

Psychoanalysis is a field in Psychology which focuses on examining the psychological state of the individual based on stimuli which are received during his/her lifetime, from childhood onwards. It was used extensively by Austrian psychologist Sigmund Freud, known as the 'father of psychoanalysis', who laid the foundation for Analytical Psychology.

According to Dr. Michalis Papadopoulos, through cases encountered in his practice, he can overturn approaches which consider Autism the result of biogenetic certainty²².

Specifically, in his book "The Suicide of Psychiatry" he refers to an example where a young girl with a clear diagnosis of Autism was completely cured. The child was two and a half years old when doctors in both Cyprus and London, announced to the parents that she had severe mental retardation and they should "make sure they have another" child. Dr. Papadopoulos disagreed and claimed the child had Autism.

He created a therapeutic intervention with high expectations, with the confidence that the prognosis for this case could be optimistic. His therapeutic strategy comprised of 3 axes:

- Psychotherapeutic support for the child
- Psychotherapy and counseling for the parents
- Early integration of the child into a school unit and not a special school

Within the first weeks of the child attendance at nursery school, a dramatic development was observed in terms of adjustment and behaviour. The psychosocial development, social integration and sufficient functioning of the girl continued for the years that followed. Today she is married with two children and works in a large private company.

Given the above, we conclude that each individual is different and assessment and management of cases should be approached in a wider context (family, genetic predisposition, social environment)

²² Papadopoulos M. (2017). "The suicide of Psychiatry" (p.73-86). Athens: Nisos publishings

3.0 LEGISLATION AND RIGHTS

3.1 The rights of individuals with autism

CHARTER FOR PERSONS WITH AUTISM

At its 4th Congress in Hague, on May 10th, 1992, the European Federation of Associations of Parents of individuals with autism, 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)²³ and the Rights of Handicapped Persons (1975)²⁴ 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.

²³ 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.

²⁴ 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.²⁵

3.2 Legislation:

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

²⁵ Reproduced from the Autism Europe website "Charter of Rights" http://www.autismeurope.org/blog/1996/12/11/charter-for-persons-with-autism-1996/ (4/6/2018)

begin with, individuals with autism present with a type of handicap, since often transportation and self-care is not feasible. This of course is directly dependent 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 diagnoses conferred 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 obstacles naturally 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.²⁶

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).

²⁶ European Committee "Justice and Citizens Rights" http://ec.europa.eu/news/justice/101115_el.htm (15/06/12)

• 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, was signed in a plenary session of the Cyprus Parliament in 2012.

Guiding principles of the Convention

There are eight guiding principles that underlie the Convention and each one of its specific articles:

- 1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- 2. Non-discrimination
- 3. Full and effective participation and inclusion in society
- 4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- 5. Equality of opportunity
- 6. Accessibility
- 7. Equality between men and women
- 8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Conceptualizing the social model for disability as an institution

In relation to older documents of the United Nations, the Convention is characterized by many groundbreaking and innovative recommendations. However, three new points are of definitive importance:

- It is considered a *binding* document for the countries which sign and ratify the Convention
- It introduces the *social approach* to disability, as opposed to the outdated medical approach
- It introduces the *Rights based model* for disability, in contrast to the opportunistic and charity type approaches

Article 1 of the Convention, introduces the view that there is an interaction between individuals with disability and the barriers found in the environment, suggesting a holistic approach to the

definition of disability. It distances itself from the historically prevalent medical model, while introducing the social dimension in approaching disability.

Article 1 states the following: "Persons with disabilities include 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."

Among the legislative modifications in favor of individuals with disabilities on an international level is the **SUNDBERG Declaration**²⁷ 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), Convention on the Rights of the Child (UN 1989), the Declaration on the Rights of the Disabled Persons (UN 1975) and the Declaration on the Rights of the Mentally Retarded Persons (UN 1971), it underlines the following ^{28·29·30·31}:

"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."

According to the principles of the SUNDBERG declaration:

²⁷ UNESCO Sundberg Declaration. Final report of the International Conference of UNESCO and the Spanish Government, Malaga, Spain, 2-4 November, 1981.

²⁸ 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.

²⁹ 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

³⁰ 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

³¹ 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

- **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 1989³² 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.

Basic Rights of Individuals with Mental Retardation:

³² L.117/1989

- (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 ³³.
 - (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.
- (3) The provisions of this paragraph do not relieve the parents of their own duties towards their children.

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³³ L.113 (I)/1999 EDUCATION AND TRAINING OF CHILDREN WITH SPECIAL NEEDS LAW 1999

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.

The Individuals with Disabilities Law of 2000 is issued through publication in the official Gazette of the Republic of Cyprus, in accordance with Article 52 of the Constitution³⁴.

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

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³⁴ L.127(I)/2000

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.
- (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.

Note: The aforementioned law also includes further articles which relate to the following: equal treatment and prohibition of discrimination in the workplace, provision of goods, services and facilitations, transportation of individuals with disabilities with the public transportation system, telecommunication and disseminating information.

Additionally, it specifies the presence of a committee, namely the "National Committee for Individuals with Disability".

Key Points

✓ At its 4th Congress in Hague, on May 10th, 1992, the European Federation of Associations of Parents of individuals with autism, Autism Europe, voted for the implementation of a Charter of the rights of people with autism, according to which people with autism should enjoy the same rights and privileges enjoyed by all citizens of European countries.

- ✓ The European Union has put into action the scheme "Europe Without Obstacles to People with Disabilities". The specific European strategy aims at helping these individuals live their daily lives in the same manner as everyone else and enjoy their rights as citizens of the E.U.
- ✓ In Cyprus there are two laws that pertain to Individuals with Autism Spectrum Disorder:
 - 1. The Mentally Retarded Individuals Law of 1989 which was issued through publication in the official Cyprus Gazette according to Article 52 of the Constitution.
 - 2. The Individuals with Disabilities Law of 2000 which was issued through publication in the official Gazette of the Republic of Cyprus, in accordance with Article 52 of the Constitution.

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 support³⁵. 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 the latter case, we cannot have evidence of the treatment's effectiveness, however, the attempted intervention should be rationally related to the data on the disorder, provide some experimental data and information regarding 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).

³⁵ Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47 (7):493-9.

Key Points

- $\sqrt{\text{To date}}$, there is no etiological treatment for ASD
- $\sqrt{\rm All}$ treatments to date target aspects of the disorder, aiming to improve functionality.
- $\sqrt{}$ In order to select a treatment, we need to weigh the expected results, consider whether the rationale 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.
- $\sqrt{}$ In research based interventions all involved must sign an Informed Consent form including information on the rationale of the treatment and the possible side-effects. All expenses should be covered by the researchers and the family should be informed of the study's outcome.
- $\sqrt{}$ The intervention should follow a specially designed Individual Education Plan.

4.2 Individualized Education Programme³⁶

The first and foremost component of the intervention should be an 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, by the trainers who are working on these and in the presence of a key 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.
- ➤ The educational strategies which will be employed
- > 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.

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³⁶ This section (translated into English) is republished in part from the relevant manual authored by Mrs. Areti Zakolikou in the context of the Operational Programme for Education and Initial Vocational Training "Access to all". The full manual with examples and handouts (in Greek) can be accessed at http://www.noesi.gr/files/aftismos-zakolikou-odigos-daskalos.pdf.

- ➤ 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.

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 development, and should 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 and specific and it should be possible to define these with regards to length of time needed. 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 basic developmental and behavioral areas:

- Communication
- ➤ Social interactions/social skills
- Behaviour
- > 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 focus 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, most likely, is to include some changes in the setting and not always require changes in the child. 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 limiting 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 negative social comments or bullying, when it prevents learning, when it disrupts the educational environment or when it reinforces isolation.

Key Points

 $\sqrt{}$ Interventions 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.

 $\sqrt{}$ The IEP should be followed co-operatively by all individuals involved with the child: therapists, teachers and parents-family.

 $\sqrt{}$ 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.

 $\sqrt{}$ 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 have only 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 can be 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).

Key Points

 $\sqrt{}$ The type and duration of the intervention are defined in each IEP.

 $\sqrt{}$ 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.

 $\sqrt{}$ The therapist works with the child, the parents, and the educational setting. The

parent should observe the sessions.

- $\sqrt{\text{Caution}}$ is needed when selecting materials and activities.
- $\sqrt{\text{Group sessions for older and more capable children are recommended.}}$
- $\sqrt{}$ 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.
- $\sqrt{}$ The therapist should ideally be an "autism therapist", irrespective of his/her basic specialty.
- $\sqrt{}$ There should be a key 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.

Key Points

 $\sqrt{}$ 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.

 $\sqrt{}$ It is extremely important to evaluate the child's level of pure verbal understanding with the use of relevant tools.

 $\sqrt{}$ 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.

 $\sqrt{}$ Dealing with problems in phonology or learning difficulties is of secondary importance for the speech therapist working with ASD.

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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)³⁷.

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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³⁷ Bundy A. et al (2002) Sensory Integration Theory And Practice. FA DAVIS COMPANY PHILADELPHIA 2002

Children with ASD often exhibit difficulties in sensory integration to a rather large degree, resulting in difficulties in almost all of the aspects of adaptive, cognitive, social and academic functioning^{38·39}.

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 it⁴⁰.

Another important issue is the use of sensory 'techniques' by all the professionals working with children with ASD, such as teachers, speech therapists, special educators and so on. 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 provision, undertook the task of creating and equipping a **Sensory Integration Centre.** The Centre for the Occupation of Individuals with Autism opened its doors, on a pilot level, by the Cyprus Autistic Association, in October 2010. The equipment and services which the Centre offers combine the typical services provided by

³⁸ 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.

³⁹ 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.

⁴⁰ 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.

specialized personnel, with the use of specially designed equipment based on Sensory Integration methods, which relate not only to therapy but also to 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 as 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 other specialists (one for Speech Therapy and/or Special Education and one for Music Therapy), complete with the necessary equipment.

Key points

- $\sqrt{}$ Children with ASD present with sensory integration problems with a higher frequency and to a much larger degree than other children, which results in difficulties in almost all areas of adaptive, cognitive, social and academic functioning.
- $\sqrt{}$ 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.
- $\sqrt{}$ 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.
- $\sqrt{\text{All professionals working with ASD should utilize the sensory "techniques"}}$ recommended by an occupational therapist who has evaluated the child.
- $\sqrt{}$ 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.

 $\sqrt{\text{An additional goal for occupational therapists in ASD}}$ is to address sensory difficulties through sensory integration.

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

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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 school-based learning is generally a secondary target in ASD, due to the fact that there are deficits inherent in the disorder 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 therapist 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).

Kev Points

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

 $\sqrt{}$ The special educator is considered to be the main educator in special preschool settings for children with ASD

 $\sqrt{}$ 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.

 $\sqrt{}$ The role of the special educator is important in the event of comorbid special learning difficulties (dyslexia, dyscalculia, dysorthographia, non-verbal learning difficulties).

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

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 issues⁴¹, but particularly for anxiety and depression. Psychodynamic-psychoanalytic therapy is not effective for the central symptoms of the disorder neither for comorbid conditions⁴². 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.
- 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.

⁴¹ 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.

⁴² Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47(7):493-9.

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 ASD⁴³.

Key points

 \sqrt{A} psychologist will address the self-awareness of the individual with ASD, as well as any comorbid difficulties (anxiety, depression, etc.).

 $\sqrt{}$ The psychologist will utilize structured directive psychotherapy, in the event that a choice of type of treatment is available, Cognitive Behavioral Therapy is recommended. Psychodynamic-psychoanalytic therapy is not effective in these cases.

 $\sqrt{}$ Intervention targeted at the family unit 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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Psychologists Licensing Board http://www.seps.org.cy/registers/

⁴³. 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) is often 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, and simultaneously constitutes an activity which has educational value for "neurotypical" classmates. In other cases, the 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. At the same time, 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 harmful and detrimental it may be to set goals that are below the child's abilities (e.g. academic goals), it is equally as harmful 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 each year the benefit of continuing or discontinuing integration should be re-evaluated.

Kev Points

 $\sqrt{}$ Integration into mainstream schools should not be done simply for the sake of it, but should be constantly evaluated, along with the goals and means used.

 $\sqrt{}$ In order to integrate a child in any setting, he/she must have some minimum skills which are relevant to the setting in question, there should be a clearly defined purpose and interventions should be applied which ensure the achievement of goals.

 $\sqrt{}$ As harmful as it is to set lower goals for a child, it is equally as harmful to set goals which are much 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, therapist and participants create a musical happening by either listening to music or using musical instruments which do not require prior musical knowledge. Throughout the music therapy process the individuals can express and process emotions via 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 evaluation⁴⁴.

Key Points

 $\sqrt{\text{In ASD}}$ music therapy targets social interaction and communication, providing a general framework within which the child can practice these skills.

 $\sqrt{}$ The therapist should be knowledgeable with regards to the specifics of the disorder.

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⁴⁴ Geretsegger M, et al (2012) Randomized 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 upon on 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.

- a) Psycho-educational and behavioral (mainly the Treatment and Education of Autistic and related Communication handicapped Children TEACCH and Lovaas & Applied Behavioral Analysis 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 Structure/Positive attitudes/Empathy/Low arousal/Links SPELL.
- b) Augmentative/Alternative Communication aims at reinforcing communication with speech as a secondary target. The leaders in this approach are the Picture Exchange Communication System 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. TEACCH⁴⁵

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 include 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.

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.

⁴⁵ www.teacch.com

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 46.

4.4.4. PECS⁴⁷ VS MAKATON⁴⁸

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).

⁴⁶ Francis K: Autism interventions: a critical update. Dev Med Child Neurol. 2005;47(7):493-9.

⁴⁷ www.pecs.com

⁴⁸ www.makaton.org

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 is significantly lacking 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. This renders the method more time consuming and more difficult to apply on a practical level in relation to PECS.

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 Gray⁴⁹ deserve further attention:

(a) Social Stories: *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.

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⁴⁹ www.carolgraysocialstories.com

(b) Comic strip conversations: *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.

Key Points

- ✓ TEACCH is a special education programme which is adapted to the needs of each child with autism and is based on certain general guidelines. It brings visual clarity into the learning process, aiming at structuring acceptance, understanding, organisation and independence. Children work in 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.
- ✓ SPELL is supplementary to TEACCH but it allows for the application of other interventions as well. It includes the principles of structure, constructive and realistic attitudes and expectations, empathy and understanding of the special way in which the individual with ASD experiences the world, mild stimulation of the individual so as not to cause anxiety and encourage the improvement of concentration, as well as the gradual interrelation between the various areas of his/her life and the various interventions in the interest of consistency.
- ✓ Behavioral techniques have evolved into what we refer to today as ABA—Applied Behavior Analysis. The techniques in question, aim at improving socially significant behaviors and facilitate the acquisition of new skills. The goal is to render the individual capable of functioning as independently and successfully as possible in a range of different environments.
- ✓ PECS is an incremental and alternative technique whereby individuals with little or no verbal ability learn to communicate using picture cards.
- ✓ Makaton is a programme which helps develop communication. It is based on the use of signs or graphic symbols which accompany and support verbal communication.
- ✓ The developmental of social skills constitutes a necessary field of intervention in individuals with ASD, given the deficits they present with, and this holds true particularly for those who are higher functioning. Two techniques developed by Carol Gray are worth noting: Social Stories and Comic strip conversations.

4.4.6 Alternative treatments

The absence, to date, of an etiological treatment and the limited effectiveness of suggested interventions, has resulted in a shift towards alternative methods of intervention. Some of these have a logical relationship with the causes of ASD and are accompanied by some research data. However, most of these "treatments" are at best simplistic approaches and at worst, attempts to take advantage of the issue at hand. When one is considering such an intervention, it is important to keep in mind what was aforementioned regarding the way in which an intervention should be selected (and the possible side effects which are often obscured) and to seek data in scientific journals and sites (e.g. http://www.researchautism.net/). We will mention some of these treatments below:

- 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 accidentally consumes one of the forbidden food items. Additionally, there is an absence of the necessary scientific findings to support the effectiveness of these diets⁵⁰.
- 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. 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 fail to prove that this is achieved with

⁵⁰ 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.

hyperbaric therapy^{51·52}. The effectiveness of the method has been researched in two controlled studies that produced conflicting results, as well as in open studies with unequivocal results^{53·54·55}. 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 indication⁵⁶.

- Stem cells: The use of stem cells constitutes a promising new method with applications in regenerative medicine. The stem cells which are used currently in cell treatments originate from placental umbilical cord blood and bone marrow and are termed Hematopoietic stem cells and from the tissue of the umbilical cord and the fat which are known as mesenchymal stem cells⁵⁷.
- 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 results⁵⁸. To date we have received positive reports from many parents, while the first series of 37 case studies has been published indicating that the 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.
- Chelation/heavy metal detoxification: This method constitutes an effort to remove heavy metals, particularly mercury, from the body, which are believed to have an effect on the

⁵¹ 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.

⁵² 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.

⁵³ 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

⁵⁴ 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.

⁵⁵ Ghanizadeh A. (2012) Hyperbaric oxygen therapy for treatment of children with autism: a systematic review of randomized trials. *Med Gas Res.* 11;2:13.

⁵⁶ 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.

⁵⁷ Siniscalco D et al (2012) Autism spectrum disorders: is mesenchymal stem cell personalized therapy the future? *J Biomed Biotechnol.* 2012: 480289.

⁵⁸ 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

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 advisable⁵⁹, 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.

Key Points

- ✓ The absence, to date, of an etiological treatment and the limited effectiveness of suggested interventions, has resulted in a shift towards alternative methods of intervention. When one considers such an intervention, he/she needs to seek evidence in scientific journals, and sites.
- ✓ Casein-free and gluten-free diet: The foods in question are removed from the diet with the rationale that the catabolic products have a negative effect on the brain
- ✓ Hyperbaric Oxygen: The use of oxygen enriched air at pressures higher than that of the atmosphere inside special chambers (decompression or hyperbaric chambers)

⁵⁹ Laidler JR. DAN! (2001) Mercury Detoxification Consensus Group. DAN! (Defeat Autism Now) Mercury Detoxification Consensus Group Position Paper. San Diego, CA: Autism Research Institute

- ✓ Stem Cells: The use of stem cells constitutes a new and very promising method which has many applications in regenerative medicine.
- ✓ Flavonoids Luteolin: The use of flavonoids, such as Luteolin from chamomile, follows the rationale of dealing with the neuro-inflammation.
- ✓ Chelation/heavy metal detoxification: Comprises of the effort to remove heavy metals, particularly mercury, from the body, which are considered to have effects on the physiology and behavior of individuals with ASD.
- ✓ 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.

5.0 ASD IN ADULT LIFE⁶⁰

Children with ASD will one day become adults and face continuing difficulties. However, there will be some differences with regards to the clinical picture they presented during their childhood. Indeed, matters of differential diagnosis that occur during this time, 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, who should collaborate with the psychiatrist in order to treat the individual.

In most cases, however, the behavioral problems stem from the limitations on adaptability placed on the individual by the ASD itself, as well as his/her limited mental abilities. When the ever more complex needs of the individual exceed his/her abilities, the opportunity arises for challenging and aggressive behaviors, mainly as inappropriate attempts at communication. Consequently, contrary to the predominant approach in these cases, the main method in dealing successfully with these undesirable behaviors is more often behavioral adjustments and environmental modification, and less frequently medication.

Finally, a protocol of psychological and behavioral intervention has been developed, aiming at reducing stress, a common cause of the condition's occurrence^{61.62}. 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.

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 ³/₄ of the individuals with ASD who are referred are adults, comprising 1.4% of psychiatric outpatients. These individuals may have been

⁶⁰ This section is based on a relevant article in the journal "Psychiatriki"

⁶¹ 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.

⁶² Shah A & Wing L. (2006) Psychological approaches to chronic catatonia-like deterioration in autism spectrum disorders. *Int Rev Neurobiol* 72: 245-264.

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.

The 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. Additionally, they do not understand the expectations, responsibilities or emotions involved in marriage or relationships.

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^{63·64}.

Finally, if the adults with HFA have comorbid conditions these include more frequently, depression, anxiety, OCD or Attention Deficit Hyperactivity Disorder (ADHD), and more rarely psychotic disorders, which are considered unusual in this group.

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 collect 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.

⁶³ Gerland G. A real person: Life on the outside. Souvenir Press, London, 2003.

⁶⁴ Grandin T, Scariano M. Emergence: Labelled autistic. Arena, Novato, CA, 1986

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, specifically 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 behaviors⁶⁵. The small range of interests and the intensity individuals 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. 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.

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 achieve positive 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

⁶⁵ Jacob S, et al (2009). Autism spectrum and obsessive-compulsive disorders: OC behaviors, phenotypes and genetics. *Autism Res* 2: 293-311.

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 interests⁶⁶.

<u>5.4.3 Schizophrenia – Psychosis</u>

The real challenge as far as the clinician is concerned is the differential diagnosis of ASD and their 'psychotic type' presentations from schizophrenia and psychosis⁶⁷. 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).

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.

⁶⁶ Scheeringa MS. (2001) The differential diagnosis of impaired reciprocal social interaction in children: a review of disorders. *Child Psychiatry Hum Dev* 32: 71-89.

⁶⁷ 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

- ✓ 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 adulthood the symptoms may be more subtle thus making a diagnosis of ASD may not be easy.
- ✓ In adulthood, the diagnostic process does not differ from what is recommended for younger ages, although self-report questionnaires are 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

6.1. Cyprus Ministry of Education and Culture

6.1.1. Special Education and Training in Cyprus

The Ministry of Education and Culture adheres to the "Special Education and Training of Children with Special Needs Laws of 1999-2014". Said laws, refer to all children with special needs, including children with Autism. The above laws have provisions with regards to special education and training after the child has turned three years old. The Ministry of Education offers all necessary means and accommodations for children who attend public schools, as these are defined in the law itself and the decisions of the District Committees of Special Education (DCSE). Before the referral to the DCSE, the New Procedure for Intervention for children with possible emotional or other difficulties must be followed by the school. The mechanism for Identification and Support can be found on the Ministry of Education website and has been enforced since September 2014, after the relevant decision of the Minister of Education. http://www.moec.gov.cy/eidiki_ekpaidefsi/en/gen_info_evaluation.html

Any individual, directly related to a child – e.g. parents, nursery school teachers, special therapists, teachers – or in a different field, that falls into the category of special educational needs, and who identifies learning difficulties, may refer the child to the DCSE. The referral is made by completing a special form titled "Referral of a child to the District Committee of Special Education" which can be obtained from all public nursery schools, primary schools, middle schools, as well as from all the District Education offices or the Ministry of Education website.

Referral form link:

http://www.moec.gov.cy/eidiki_ekpaidefsi/entypa.html

Following the referral, the next step is the **Evaluation of Children with Special Needs from the District Committees**.

The evaluation of each child who may have special needs is completed by the equivalent District Committee of Special Education. This Committee consists of:

A Ministry of Education and Culture Chief Education Officer who presides the committee

A Ministry of Education and Culture representative of the relevant educational level

A special education teacher

An educational psychologist

A clinical psychologist

A social worker

A speech 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. Additionally, the parent has a right to access the child's personal file, which is kept at the District Committee and to receive copies of this report after submitting a small fee.

<u>District Committee decisions – Right to appeal</u>

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 it also informs of the rights regarding written objections. The District Committee discusses and then decides on its view of the parent's objections.

The child's parents have a right to submit a written objection to the Central Committee within thirty days of 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.

Nicosia District Committee

Mailing Address

District Committee of Special Education

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

22800632/22809521

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

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

25822054/22822179

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

Larnaca/Famagusta District Committee

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

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

- ✓ The Ministry of Education offers all necessary means and accommodations to children with special needs who attend public schools, as these are specified within the law and via the decisions of the District Committees of Special Education (DCSE)
- ✓ Any person directly related to a child who may fall into the spectrum of special educational needs, who detects any learning difficulties, may refer the child to the District Committee of Special Education for evaluation.

- ✓ The evaluation of the child is completed independently by each specialist who is part of the primary multidisciplinary team. The parent is allowed to be present during the evaluation and to participate on his/her own or accompanied by a specialist.
- ✓ The child's parent has the right, within 30 days of the date of the second decision of the District Committee, to submit a written appeal to the Central Committee.

6.1.2. Provision of Special Education and Training:

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

- In a public school, in a regular class

Children with special needs for whom special education was determined are entitled to free attendance at a public school where special education will be provided in a regular classroom. According to the educational programme of the Ministry, the necessary infrastructures will be available, adapted to the children's special needs and their individualized education programme.

In the event that the special education is provided, fully or in part, in a regular school classroom, the District Committee determines the public school and classroom, the number of children in the classroom in which children with special needs are placed (which can be reduced based on the degree of severity of the difficulties of the children who are placed in it), the exclusions, exemptions, adaptations or modifications to the curriculum, the type of support provided to the child, the necessary structural and environmental changes to the school, the teaching hours of the educational staff responsible for the class in which the child is placed and the key worker who will have direct responsibility for the child.

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 the designated school.

- In a public school, in a special unit

Education for a child for whom special education has been determined, may be provided in a special unit operating in a regular school. 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. Children in a Special Unit, register at the school as other children, and where possible are included in the roster of the class that matches their age. 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 efficient 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 collaboration 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 for each of them.

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 at times the organization of 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. (http://www.moec.gov.cy/eidiki_ekpaidefsi/eidiki_agogi_ekpaidefsi.html)

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

- ✓ Children, for whom special education has been determined are entitled to free attendance at a public school, in a regular classroom, where suitable provisions will be offered, according to the educational programme of the Ministry and adapted to their special needs and individualized education plan.
- ✓ Children for whom special education has been determined may attend a special unit which operates within a regular school.
- ✓ Children who attend special education schools are integrated into groups based on their age and special attributes as well as the special education which has deemed necessary.
- ✓ Children in Primary or Secondary Education, who cannot attend school for long periods due to health reasons, may have access to education through other means.

6.2 Ministry of Health

6.2.1 Child and Adolescent Mental Health Services

Child and Adolescent Mental Health Services are accessible to children and adolescents up to the age of 17 who are facing a range of psychosocial difficulties. An exception to this age limit is the Centre for the Prevention and Treatment of Eating Disorders which treats children and adolescents up to the age of 19.

The services provided consist of the following:

- 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 assessment and provision to children and adolescents seen at the centres
- Medication services when deemed necessary
- Counselling –Liaison Child Psychiatric Services, offers its services to children, adolescents and their families who are referred during inpatient treatment at Archbishop Makarios III Hospital or hospital E.R. treatment
- The Centre for the Prevention and Treatment of Eating Disorders (CPTED) offers services to individuals who are on the Autism Spectrum and suffer from eating disorders
- Coordinating and participating in meetings, at regular intervals, with other specialists involved with the child or the adolescent in the public or private sector (teachers, special educators, speech therapists, developmental psychologists, occupational therapists etc.)
- Participation of clinical psychologists in the District Committees of Special Education of the Ministry of Education (see Special Education in Cyprus section).
- Participation of the Scientific Coordinator of Mental Health Services in the Central Committee of Special Education, which assesses the assistance needed for difficult cases, and furthers policies for educational and psychoemotional support of individuals with special needs, a group which includes individuals with autism.
- Preparation of relevant medical reports requested by Welfare Services in order for children and adolescents with autism to be granted a monthly stipend.

Finally, staff in 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.

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

Child and Adolescent Mental Health Services run 4 community centres which accept outpatients, one in each district (Nicosia, Limassol, Larnaca and Paphos). The 4 community centres accept referrals from various Services, state and private, but also from the parents themselves, and offer diagnostic assessment and treatment on an outpatient basis. In order for referrals from other services to be considered valid, consent is needed from 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: kepsypa1@gmail.com

Website: www.moh.gov.cy

Consultative-Liaison Child Psychiatry Services

Archbishop Makarios III Hospital 6 Korytsas street, 2012, Strovolos

Tel: 22405053, 86

Fax: 22405051

Email: cals@mhs.moh.gov.cy
Website: www.moh.gov.cy

Centre for the Prevention and Treatment of Eating Disorders (CPTED)

Archbishop Makarios III Hospital

6 Korytsas street, 2012, Strovolos

Tel: 22405053, 86

Fax: 22405051

Email: caedc@mh.moh.gov.cy
Website: www.moh.gov.cy

Inpatient Unit for Adolescents (IUFA)

Archbishop Makarios III Hospital 6 Korytsas street, 1474 Nicosia

Tel: 22405052, 83 Fax: 22405088

Email: <u>iufa@mhs.moh.gov.cy</u> Website: www.moh.gov.cy

Larnaca

Child and Adolescent Mental Health Services Centre for Prevention and Psychosocial Intervention

2 Argolidos street, 2nd floor, Court 11, Aradippou, 7101 Larnaca

Tel: 24813164, 174 Fax: 24532326

Email: mehelca@gmail.com Website: www.moh.gov.cy

Limassol

Child and Adolescent Mental Health Services Centre for Prevention and Psychosocial Intervention 17 Miltonos street, Ayios Spyridonas, 3051 Limassol

Tel: 25873602, 618 Fax: 25393164

Email: paidolimassol@cytanet.com.cy

Website: www.moh.gov.cy

Paphos

Child and Adolescent Mental Health Services Centre for Prevention and Psychosocial Intervention Paphos General Hospital

Tel: 26803275, 491 Fax: 26803218

Email: paid-e@hotmail.gr
Website: www.moh.gov.cy

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

6.2.2. Medical cards

According to a decision by the Cabinet of Ministers on 3/12/16, individuals with mental disability are exempt of any financial contribution to healthcare, and do not need to pay any fees for their medical expenses as long as a medical card, with the indication "ALL FREE", is presented.

Official confirmation that the individual has a mental disability can be obtained by the Committee for the Protection of the Rights of People with a Mental Handicap.

For more information, individuals may contact the relevant department of the Ministry of Health: Medical Card Division 22605349/ 22605474/ 22605727/ 22605465/ 22605468

- ✓ Child and Adolescent Mental Health Services target children and adolescents up to the age of 17, who present with a variety of psychosocial difficulties, with the exception of the Centre for the Prevention and Treatment of Eating Disorders which accepts children and adolescents up to age 19.
- ✓ At Archbishop Makarios III Hospital there is a child psychiatry multidisciplinary team which covers the needs of inpatients and outpatients (children and adolescents up to age 17) who are receiving services for a variety of medical reasons and also present with psychosocial difficulties.
- ✓ With regards to people with Autism over the age of 17, the Mental Health Services can offer services to the individuals themselves and their families in all of the Community Centres, where Adult Outpatient Services are provided.
- ✓ As soon as a child is diagnosed as belonging on the Autism Spectrum, the parents should do the following:
- Arrange to obtain medical reports confirming the diagnosis from doctors from the public hospital, in addition to any doctors from the private sector who are involved in the child's care.
- Use the medical reports so as to claim all the resources which are available.
- Obtain a medical card which allows FREE medical coverage at all the public hospitals in Cyprus.

6.3. Ministry of Labour and Social Insurance

6.3.1 Social Welfare Services

Social Welfare Services aim to ensure conditions of social cohesion and social solidarity, to provide social protection, succeed in achieving social integration, promote equal opportunities for all citizens of the Republic of Cyprus, combat poverty and social exclusion and promote the interests of individuals, families and communities.

Care services scheme

The aim of the Scheme is to improve quality of life and promote social integration of individuals who can benefit from services of social care based on the provisions of the Guaranteed Minimum Income and other Social Provision Laws, through subsidizing their confirmed needs for care services.

The types of care included in this scheme are the following:

Home care from an approved physical individual or legal entity or domestic worker: Home care covers a range of care services, including personal care and domestic help. The home care services are provided by approved physical entities and/or legal entities or from a domestic worker, according to the terms specified by the Director of Social Welfare Services. A subsidy of a maximum of ϵ 400 per month per family unity is granted, except in cases of cohabitation, where the amount is distributed accordingly.

Residential care: 24 hour care is provided by approved programmes which may be operated by physical or legal entities (NGOs, Local Government Authorities, private sector) to individuals who are in need of constant care and whose needs cannot be met by their families, nor by the supportive services offered in the environment in which they live. In the event that it is established that individuals need to be admitted into a residential care facility, the subsidy includes only room and board expenses. The subsidy offered ranges **between €625-€745 per month, depending on the individual's condition.**

Day care: This is offered via approved Adult Centres which provide services to individuals (e.g. the elderly, individuals with disability) during the day and may be operated by physical and/or legal entities (NGOs, Local authorities, private sector). Among others, care services, recreation activities and entertainment are offered during the day. For this type of care, transportation/escort services of the individual to and from the Adult Centre may be subsidized pending an assessment based on specific tools. The subsidy is a maximum of €137 per month.

Respite care: This consists of a temporary care service to the individual which allows his unofficial carer to have some respite/a break from the responsibility of his/her care. The service supports the unofficial carer in his invaluable role and at the same time allows the individual to

remain at home. Respite care can also be requested by individuals who live alone and at times feel unable to care for themselves and are in need of help. Respite care is defined, as much as possible, based on the needs and preferences of the individual and the family, and is provided on the basis of the above mentioned types of care (home care, residential care, day care) and additionally may be provided through child care (only via infant care and nursery schools and centres for protection and child care).

Child care: Consists of caring, protecting, entertaining and teaching children via approved infant care centers, approved child care providers at home, as well as approved centres for protecting and occupying children, and nursery schools approved by the Ministry of Education and Culture. A subsidy of a **maximum of €102 is provided per month.**

The provision of care services is covered via payments and/or with the provision of the services themselves towards beneficiaries. Individuals who can benefit from social care services (e.g. the elderly, individuals with disabilities, infants) who are in need of infant/adult diapers will need to complete and submit Special Form EEE.11 which is available on the Social Welfare Services website, at the Benefit Management Service, as well as at all the Social Welfare Services Offices. Contact Social Welfare Services for additional information

(http://www.mlsi.gov.cy/mlsi/sws/sws.nsf/All/51950D3157907F4AC2256E7700387B35?OpenDocument)

- ✓ Social Welfare Services aim to ensure conditions of social cohesion and social solidarity, to provide social protection, succeed in achieving social integration, promote equal opportunities for all, to combat poverty and social exclusion and promote the interests of individuals, families and communities.
- ✓ The aim of the care services Scheme is to improve quality of life and promote social integration of individuals who can benefit from services of social care based on the provisions of the Guaranteed Minimum Income and other Social Provision Laws, through subsidizing their confirmed needs for care services.
- ✓ Care services are provided either through submission of payments and/or through the provision of the services themselves to the beneficiaries.

6.3.2. Welfare Benefits Management Service

Guaranteed Minimum Income

On July 10th, 2014, the Parliament voted for legislation put forth by the Ministry of Labor, Welfare and Social Insurance (MLWSCI) titled "The Guaranteed Minimum Income and Social Provisions Law of 2014", which concerns the implementation of a new system of social welfare, in order to ensure a minimum quality of life for each family which meets certain criteria.

Specifically, individuals with disabilities, former recipients of public benefit are entitled to GMI regardless of age.

In order for someone to be entitled to receive GMI, the following criteria need to be met:

- The total value of property belonging to the individual and his/her family unit must not exceed 100,000 euro based on the land and property register evaluation (2013). The house in which the individual and his/her family reside in, is except from the assessment of property value, if the size of the house does not exceed 300m², when the entire property, or most of it cannot be utilized due to a mortgage or memo.
- The bank deposits of the applicant and the members of his/her family must not exceed the total amount of €5.000 plus €1.000 for each additional person belonging to the family unit. From the calculation of bank deposits, extra financial elements up to €20.000 are except, providing they fall into one of the following categories:
 - o The amount is on hold for purposes of a loan (and was obtained before 11/7/2014)
 - The amount is in the name of minor children (arranged prior to 11/7/2014)
 - The amount relates to student loans and scholarships
 - The amount is necessary for an individual with a disability because of his/her disability
 - The amount is in the name of minor children as a result of inheritance or fund raising or other extenuating reasons.
 - o The amount is in a joint account with an elderly/retired parent (and was established before 11/7/2014) and the money can be proven to belong to the parent, then it is not calculated.
 - The total value of stocks, bonds, insurance contracts, bill payments and other similar elements, which the members of the family unit are in possession of must not exceed the amount of €5.000.
 - The total income of the members of the family unit, must be lower than the cost of the entire needs assessed on the basis of GMI (480 for the applicant, 240 for the

spouse and every member of the family over 14 years old, 144 for every member of the family under the age of 14)

Housing benefits are also provided as well as benefits for the purpose of covering the interest of a housing loan (for more information contact the Welfare Benefits Management Service). It should also be noted that since the application of the GMI scheme individuals with disabilities have retained all their rights. Additionally, all the benefit and grant schemes for individuals with disabilities remain unchanged. Finally, the various disability stipends are not included in the calculation of income with regards to the GMI.

For more information contact the Welfare Benefits Management Service.

CONTACT INFORMATION:

District Welfare Services offices and phone numbers are provided below:

- Nicosia District Welfare Office

66 Ayiou Ilarionos street, 1026 Nicosia, Tel.: 22804607

- Limassol District Welfare Office

80 Franklin Roosevelt street, 3012, Limassor or P.O. Box 71032, 3840 Limassol, Tel: 25 804452

- Larnaca Welfare Office

23-25 Piliou street, 6301 Larnaca, or P.O. Box 40184, 6301 Larnaca, tel: 24800209/24 800211

- Paphos District Welfare Office

28 Aristoteli Valaoriti & Kynira street, 8100 Paphos or P.O. Box 60018, 8100 Paphos, Tel.: 26821630/26821602

- Famagusta District Welfare Office

170 1st of April street, 5280 Paralimni or P.O. Box 33065, 5310 Paralimni, Tel.: 23821720

- On July 10th, 2014, the Parliament voted for legislation put forth by the Ministry of Labor, Welfare and Social Insurance (MLWSCI) titled "The Guaranteed Minimum Income and Social Provisions Law of 2014", which concerns the implementation of a new system of social welfare, in order to ensure a minimum quality of life for each family which meets certain criteria.
- ✓ As far as individuals with disabilities are concerned, former welfare benefits

recipients are eligible for GMI regardless of age.

✓ In order for individuals to qualify for GMI, they need to meet certain criteria concerning property owned, income and bank deposits.

6.3.3 Early Childhood Intervention Liaison Service

What is the Early Childhood Intervention Liaison Service (ECILS)

ECILS is a specialized service, within the Committee for the Protection of People with a Mental Handicap, for children with developmental disorders and mental retardation. It operates under the auspices of the Ministry of Labour and Social Insurance following the relevant decision of the Cabinet of Ministers in 2001. It is staffed by one co-ordinator and 3 officers with qualifications in psychology, and services families in Nicosia, Limassol/Paphos and Larnaca/Paralimni.

Services offered, scope and goals

The basic responsibility of ECILS is coordinating all professionals/services involved and supporting the family with the ultimate goal of creating favorable conditions for the development of the child who has a developmental disorder and/or mental retardation. As research has shown, early and timely provision of suitable services has positive consequences on the individual's ability to become independent, the quality of life in adulthood while also offering relief to the family.

Specifically, the Early Intervention Officer's (EIO) responsibilities are the following:

- Investigating and helping to meet the needs of the child and family
- Psychological support and counseling to all members of the family (e.g. counseling with regards to the diagnosis, guidance on how to manage the children, acceptance of the diagnosis by the parents.
- Cooperation of all services involved in the interest of the child.
- Organizing and observing the interventions the child needs (immediate referral to therapists, special professionals, associations and others, with whom ECILS continues to stay in touch with throughout the intervention).
- Provision of detailed information to the parents about services provided in the public, private and voluntary sector (ECILS has detailed databases with a list of professionals of all specializations organized by district).
- Empowerment and psychological support of the parents, especially with regards to accepting the problem and becoming as effective as possible in their role.
- Promoting the rights of the family (assistance with the various benefits and stipends, providing information sheets and applications, monitoring procedures etc)

• Making appointments with specialists in order to evaluate and/or revise the intervention

The officer does not provide therapy to the child, however, he/she pursues the above actions, having the best interest of the family in mind. These services are provided with discretion and confidentiality.

ECILS collaborates with the following services:

- Ministry of Labour, Welfare & Social Insurance: Social Welfare Services and the Department for Social Inclusion of Persons with Disabilities
- Ministry of Health: Child Neurology Clinic at Makarios III Hospital, Clinical Genetics Clinic at Makarios III Hospital, Child and Adolescent Mental Health Services & Health Visitors Service
- Ministry of Education & Culture: Special Education & School Psychology Services
- National Association for Parents of Individuals with Mental Disability
- Professionals/therapists from the private sector and Non-Governmental Organizations

Who can get help from ECILS

ECILS is available to families of children aged 0-7 years old who have difficulties in their developmental or developmental disorders. Many times however, the officers support families who have older children. Usually the cases that ECILS handles regard children with the following conditions:

- Mental disability
- Global developmental delay
- Autism Spectrum Disorders
- Genetic or chromosomal syndrome (Down's, Angelman, Prader-Willi etc)
- Speech delay or communication difficulties
- Attention Deficit disorder with or without hyperactivity
- Difficulties due to prematurity
- Physical disorders
- Social/financial difficulties which may lead to a delay in mental and emotional development
- Children who have a high risk factors to develop the above problems or a combination therein.

Referrals

There is no time-consuming process for referrals; parents or professionals who are interested may contact ECILS directly to refer a case. Within a week of the referral, the officer responds and arranges a meeting with the family. ECILS is provided free of charge, and in the interest of a holistic intervention, the officer aims to make house visits.

Referrals to ECILS can be made via phone, fax or email using the contact details below

Nicosia

CPPMH Central Offices

Tel: 99540406 & 22871325, Fax: 22429544

Limassol/Paphos

Kato Polemidia Municipality

Tel: 99540408 & 25396699, Fax: 25396699

Larnaca/Paralimni

Aradippou Municipality

Tel: 99540407 & 24813010, Fax: 24813010

Email: earlyintervention@cytanet.com.cy

- ✓ ECILS is a specialized service, within the Committee for the Protection of People with a Mental Handicap, for children with developmental disorders and mental retardation.
- ✓ The basic responsibility of ECILS is coordinating all professionals/services involved and supporting the family with the ultimate goal of creating favorable conditions for the development of the child who has a developmental disorder and/or mental retardation.
- ✓ ECILS is available to families with children aged 0-7 who present with difficulties in development or developmental disorders.
- ✓ Parents or professionals who are interested in these services can contact ECILS directly to make a referral. ECILS is provided free of charge, while in the interest of a holistic intervention, officers aim to make house visits.

6.3.4 Department of Social Inclusion of Persons with Disabilities - Schemes

The main goal of the Department of Social Inclusion of Persons with Disabilities is promoting social protection, social inclusion and employment for individuals with disabilities. The responsibilities and projects of the Department are organized into four basic divisions: The division of Assessment of Disability System management, the division of Social Provisions, The division of Employment Rehabilitation, and other supportive services, and the division of implementation of the UN convention for the Rights of Individuals with Disabilities, whereby the department acts as a central point with regards to the procedures of modulating national plans, strategies and legislation with the values and articles of the Convention.

Multidisciplinary Centre of Assessment for Autism⁶⁸

Currently in Cyprus there is a significant gap with regards to mechanisms of screening, identifying, assessing and providing interventions to children with developmental disorders, including children with ASD. In cases where a possible diagnosis of ASD is suspected, a cumbersome process begins for the child and the parents, where the child is subjected to endless assessments and visits to various specialists. This process often has many psychological, physical and financial consequences.

Additionally, until the need for assessment is identified, many times valuable time is lost which could have been utilized for immediate intervention, an element that is internationally recognized as the corner stone for the positive prognosis of children with ASD.

As far as parents are concerned, until the age of mandatory schooling, there are no specialized and/or suitable facilities to which they can entrust their children. Unfortunately, as a consequence to the lack of services, some parents are forced to abandon their jobs and stay at home to care for their children.

Having the above in mind, the Department of Social Inclusion of Persons with Disabilities moved forward with a plan for developing and operating a Centre of Multidisciplinary Assessment for Autism. The development and implementation of the Centre was approved by decision of the Cabinet of Ministers on the 27/09/2017. The Centre will operate via Public Contract by assigning services to a concessionaire, with the Department of Social Inclusion of Persons with Disabilities as the Assignment Authority. For the selection of the concessionaire, the Department proclaimed an open public contest via eprocurement. The projected date for

⁶⁸ https://www.eprocurement.gov.cy

signing the contract is June 21st, 2018, with a duration of 24 months from the day of implementation and the right to renew for an additional 12 months.

The contract constitutes a legal commitment within the project "Expanding the implementation of the new Systems for Assessing Disability and Functionality" which falls under the framework of the Operational Programme "Employment, Human Resources and Social Cohesion" 2014-2020 of the European Social Fund.

The aim is to cover the aforementioned gaps and relates to children from 0 up until the age where schooling is mandatory (4 years and 8 months).

The Centre will provide the following:

- A) Assessment of the individual needs and strengths and the establishment of a specialized programme of rehabilitation, education and care. Staff at the centre will include: Child psychiatrist/Child Neurologist, Pediatrician, Clinical Psychologist, Special Educator, Speech Therapist, Occupational Therapist.
- B) Provision of specialized Services of support and counseling to families of children with ASD, so as to ensure their psychological health and the quality of life of the members of the family. The services will be provided for by: a Psychologist and 2 Social Workers
- C) Day care services with will operate five days a week and cater to a maximum of 20 children. The services of the Day care will include additional staff, such as occupational and speech therapists, who as group Leaders will take on matters such as education, development of social skills and recreation. The services will also be further enhanced by Group assistants who will be in charge of matters such as feeding and hygiene, in addition to a nurse who will be responsible for health issues, including administering medication to children (where necessary).

Scheme for the supported employment of persons with disabilities (SSEPD)

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 individual 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.

<u>Financial assistance scheme for the provision of technical means, instruments and other aids</u>

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 based 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 Authorized 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.

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, who 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.

<u>Financial Assistance to the Organisations of Persons with Disabilities for Hiring Social Assistants for their Members</u>

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.

Professional Development Scheme for individuals with disabilities

The aim of the Scheme is to broaden the opportunities for professional education and development of individuals with disabilities based on individual programmes in professional development centres or businesses in the private and public sector. The professional development/education programmes must aim to facilitate employment or professional advancement of individuals with disabilities.

The scheme covers expenses of up €1708,60 in a suitable professional centre or business on the basis of a special programme which is put forth by the applicant alone or in collaboration with the Department.

Applicants eligible to apply include individuals with disabilities who are having serious difficulties finding employment or advancing in their profession, regardless of their education level. Priority is given to individuals with severe disabilities, who are inactive and underemployed.

Parking Permit for Individuals with disabilities

This Permit allows holders with disabilities to park in advantageous parking spaces, in spaces with parking meters where parking is free and with no time limit, and in specified points in streets with a single or double yellow line where the right to park is specified on a special sign.

Eligibility for parking permits:

- (a) Individuals with disabilities who receive Benefits for Severe Mobility Disability. It is implied that individuals with disabilities who would have been eligible for the aforementioned benefit, had they not reached the prescribed age limit are also eligible for the parking permit.
- (b) Individuals who are blind based on the Student grant Law and the Special grant for the blind Law.
- (c) Individuals with disability who are recipients of financial aid for acquiring a car, according to the relevant Scheme for the Provision of Financial Aid to Individuals with Disability for acquisition of a car. It is implied that individuals with disabilities who would have been eligible for the aforementioned benefit, had they not reached the prescribed age limit are also eligible for the parking permit.
- (d) Individuals whose disability consists of amputation or severe weakness of the upper or lower limbs, due to any cause, which resulted in a disability assessed as beyond 39%
- (e) The disabled based on the provisions of the Relief of Adversely affected Persons.
- (f) Individuals with mental disability
- (g) Organisations providing care to individuals with disability, which belong to one of the aforementioned groups and use a vehicle to transport these individuals.

All of the above can be found on the following website: www.mlsi.gov.cy

For more information:

Address:

Department of Social Inclusion of Persons with Disabilities

67 Makariou III Avenue, 2220, Latsia, Nicosia.

Tel: 22815015, Fax: 22482310

6.3.5 Child Benefits

Application forms for child benefits are available from the offices of the Department of Grants and Benefits, the Citizen Service Centres in Nicosia, Limasson, Famagusta, Larnaca, Paphos, Polis Chrysochous and Pelendri. Also application forms can be found on the website of the Ministry of Labor, Welfare and Social Insurance

http://www.mlsi.gov.cy/mlsi/mlsi.nsf/All/2D5E79C8F6C6D032C2257F77002B8C8C

Candidates are informed that according to the provisions of the relevant Law which was voted by the Parliament, child benefits will be granted on the basis of income and property ownership. Specifically, child benefits will be granted to families providing that their annual gross salary in the previous year does not exceed:

- a) €49.000 for families with 1 depended child and
- b) €59.000 for families with 2 or more dependent children

In addition, and regardless of the number of dependent children, the total value of property belonging to the family, based on current estimates, should not exceed €1.200.000.

Table A. Child Benefits rates

No. of children in the family	Basic annual benefits for families with 2 or more dependent children with an income of €49.000,01 − 59.000 (per dependent child)	Basic annual benefits for families with an income of up to €49.000 (per dependent child)	Additional annual benefits for families with an income up to €19.500,00 per dependent child	Additional annual benefits for families with an income from €19.500,01 to €39.000,00 (per dependent child)
Families with one (1) child	0	€380	€95	€45
Families with two (2) children	€345	€380	€190	€140
Families with three (3) children	€690	€760	€285	€235
Families with four (4) or more children	€1.135	€1.260	€415	€265

Table B. Benefits rates for Single Parent families

Family income	Monthly Benefits for each dependent child
€0 -39.000,00	€180
€39.000,01-49.000,00	€160

Key Points

- ✓ The purpose of the Supported Employment of Persons with Disabilities Scheme is the employment of persons with serious disabilities, as well as other groups of individuals with disabilities, in the open labour market by providing personal support through a job coach.
- ✓ The aim of the Financial assistance scheme for the provision of technical means, instruments and other aids is 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 purpose of the Scheme for the management/provision of technical means, instruments and other aids is 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".
- ✓ 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.
- ✓ Professional Development Scheme for individuals with disabilities: The aim of the Scheme is to broaden the opportunities for professional education and development of individuals with disabilities based on individual programmes in professional development centres or businesses in the private and public sector.
- ✓ Parking Permit for Individuals with disabilities: The permit allows the holder to park in advantageous spaces for individuals with disabilities
- ✓ Child Benefits are granted based on income and the value of property owned

6.4. Ministry of Interior

6.4.1 Scheme for the Protection of Primary Residence⁶⁹

Basic Principles

- The Scheme is intended to help vulnerable groups of the population
- The right to participate in the scheme is reserved for those who have received a housing loan, with a mortgage for the primary (permanent) residence.
- The Scheme is open only for housing loads obtained for building or purchasing the applicant's primary home, as well as business loans which were obtained for business development. The Scheme does not cover outstanding debts for current accounts, credit cards, investment and consumer loans, tax debts towards the state, debt towards Social Insurance and any private debts or fines.
- The Scheme provides for the subsidy via the Cyprus Land Development Corporation (CLDC) of the interest on the loan of applicant, with the purpose of eradicating the danger of divestment of the home.
- The maximum length of the Scheme is four years. The length of the application of the Scheme will be re-evaluated by CLDC in collaboration with the Ministry of Finance, three months before the end of the first two year period, based on the development of Cyprus economy.
- A basic prerequisite for inclusion in the Scheme is the completion of the procedures set forth in the Central Bank's Directive on Arrears Management of 2015 regarding debt restructuring, as well as the mediation procedures with a mediator appointed by the Financial Ombudsman. Additionally, the applicant must have contacted the Insolvency Services.

Criteria for inclusion

1. "Primary residence is considered to be the private dwelling used as the residence of the debtor or in the event of leasing, the contractor as per the leasing agreement, for a period of 6 months each year. The estimated market value of the principal residence shall not exceed €250 000 while the outstanding amount of the loan to be repaid shall not exceed €300 000.

⁶⁹ Cyprus Land Development Corporation http://www.cldc.org.cy/cgibin/hweb?-A=641&-V=schemes (03/03/2018)

- 2. Eligibility for the Scheme will be determined based on strict income and property criteria, with the following criteria with regards to annual income:
- Families without children €22 000
- Any additional child plus **€2.000**
- Single Parent families with one child €20.000
- Any additional child plus €2.000
- Families with one or more disabled person €33.000
- Singleton €13.000
- Singleton Disabled €21.500
- 3. The total market value of the other property owned by the applicant and his family unit cannot surpass $\in 100.000$, The residence in which the applicant and his family reside is exempt from this estimate as long as the estimated market value of the principal residence does not exceed $\in 250.000$.
- 4. The minimum period of residence in the house must exceed 5 (five) years.
- 5. To be considered for the Scheme, the applicant should be a resident in the Republic of Cyprus or reside legally in Cyprus for the last ten (10) years.

Conditions for participation in the Scheme

- 1. The principal residence shall be under mortgage or have a collateral agreement by a financial institution licensed by the Central Bank of Cyprus as guarantee
- 2. Completion of the procedures set forth in the Central Bank's Directive on Arrears Management of 2015 regarding debt restructuring, as well as the mediation procedures with a mediator appointed by the Financial Ombudsman. Additionally, the applicant must have contacted the Insolvency Services.

Application Process

The applicant should contact a Insolvency Consultant who will know beforehand the criteria and condition for entry into the Protection of Primary Residence scheme. If based on the personal financial information, the consultant finds the debtor eligible for the scheme, he/she submits a letter to the Organisation with all the necessary documents (see

http://www.cldc.org.cy/cgibin/hweb?-A=641&-V=schemes - Appendix 1)

Based on the information received from the Consultant, the Organization examines the case and responds if initially the individual appears to be eligible and recommends the submission of an application.

Remaining and exiting the Scheme

The CLDC will submit the interests of the loan the Lending institution for a maximum of 4% rate of interest. For instance:

Loan: €100.000

Interest: 3,5%

Grant: €3.500

In the event that applicants are recipients of GMI and receive an amount to cover their interest in part, the amount they receive from the Organisation will be factored into so that the subsidy does not exceed the maximum interest of 4%.

CONTACT INFORMATION:

14 Athalassas Avenue, 4th floor, 2011 Strovolos P.O. 23928, 1687 Nicosia

Tel. 22427000,

Email: info@cldc.org.c

Key Points

✓ The Scheme for the Protection of Primary Residence operates based on certain principles and criteria. The applicant must contact a Insolvency Consultant who will now beforehand the criteria and conditions for inclusion in the Protection of Primary Residence Scheme. If, based on the personal financial information the debtor is considered eligible for the Scheme then the Consultant sends a letter to the Organisation will all the necessary documentation.

7.0. BENEFITS FROM SEMI-GOVERNMENTAL ORGANIZATIONS 7.1. CYTA

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

Provision Guidelines:

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, Ministry of Labor and Social Insurance (e.g. individuals with severe mobility disability, the hard of hearing and the blind).
- A report from the Audiology centre at Makarios Hospital or from an ear, nose and throat specialist, confirming that the individuals has loss of hearing to the degree that even with auditory support, he/she cannot hear and thus cannot communicate with hearing individuals using spoken word (hard of hearing) or a report from the School for the Deaf which confirms the inability to use spoken language with hearing people or an auditory disability equal to or greater than that specified for severe hearing loss, as this is defined by International Organisations (e.g. World Health Organisation, WHO).
- Confirmation from the National Organisation for the blind, stating that the individual has sight, using corrective lenses, one tenth (1/10) of that which is typical (blind).
- Medical report from a specialist ophthalmologist stating that the individual has sight, using corrective lenses, one tenth (1/10) of that which is typical (blind).
- Medical report from a doctor at the Institute of Neurology and Genetics, or from a special neurologist, stating that the individual is suffering from the specific disease and are confined to a wheelchair or at a stage just prior to full confinement to a wheel chair (individuals with multiple sclerosis or other myopathies)
- A certificate from the relevant services of Social Welfare Services (welfare benefits recipients)
- Certificate from the Income Tax Department (low income individuals)

- Certificate from the department of Social Insurance in which the amount of income/pension is confirmed (low income individuals)
- 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).

The Special Priced Phone Packages are offered to individuals with low income or special social needs

SPECIAL PRICED TELEPHONE PACKAGES FOR INDIVIDUALS WITH LOW INCOME

Description	Tariff	Payment period
Connection Cost	€ 25,00	in whole or in 12 monthly installments
Subscription	€ 8,28	Monthly
Transfer cost	€ 12,50	in whole or in 12 monthly installments

SPECIAL PRICED PACKAGES FOR INDIVIDUALS WITH SPECIAL SOCIAL NEEDS

Description	Tariff	Payment period
Connection Cost	Free	-
Subscription	Free	-

Notes:

- 1. Prices include VAT
- 2. For individuals with low income calls will be priced with the <u>current costs of the service</u>.
- 3. For individuals with special social needs the first 100 minutes of National calls towards landlines, mobile phones and the internet are free each month.

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 photocopy 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 entities.
- 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.

7.2 CEA (Cyprus Electricity Authority)

CEA has created the Special Home Tariff 08 for Specific Categories of Vulnerable Consumers, including the following:

- Large families with three dependent children or more, who receive Child Benefits from the Welfare Benefits Management Service of the Ministry of Labor, Welfare and Social Insurance 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.
- Recipients of public assistance from Social Welfare Services of the Ministry of Labor, Welfare and Social Insurance
- Recipients of GMI which is provided by the Welfare Benefits Management Service of the Ministry of Labor, Welfare and Social Insurance
- Families which receive the Severe Motor Disability Allowance from the Department for Social Inclusion of Persons with Disabilities of the Ministry of Labor, Welfare and Social Insurance.
- Recipients of Care Benefits for Quadriplegic Individuals provided by the Department for Social Inclusion of Persons with Disabilities of the Ministry of Labor, Welfare and Social Insurance.
- Recipients of Care Benefits for Paraplegic Individuals from the Department for Social Inclusion of Persons with Disabilities of the Ministry of Labor, Welfare and Social Insurance.
- Individuals who are on dialysis for kidney diseases, and who receive Transportation Benefits from the Department for Social Inclusion of Persons with Disabilities of the Ministry of Labor, Welfare and Social Insurance.
- Individuals who suffer from multiple sclerosis who are registered members of the Cyprus Multiple Sclerosis Association.

In order to qualify for code 08 the necessary application needs to be submitted by a client of EAC at any of the Customer Service Centres. The application can also be found on the EAC website, in the section customer service/applications (www.eac.com.cy)

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	11,26	0-1000	1,34	
units				
Next 100	12,60	1001-2000	4,28	
units				
Additional	15,01	2001+	5,36	
units		 		

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.

Key Points

- ✓ CYTA offers Special Tariff Telephone Connection Packages to individuals with low income and special social needs, minors and individuals with mental retardation, under certain terms and conditions. Eligible individuals will need to submit a written application either during a visit to one of the CYTA shops or via fax.
- ✓ CEA has created Special Home Tariff 08 for Specific Categories of Vulnerable Consumers. In order to qualify for the 08 Tariff, the necessary application needs to be submitted by the CEA client at any of the Customer Service Centres.

8.0 NON GOVERNMENTAL ORGANISATIONS – ASSOCIATIONS

8.1. 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, 2004 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 goals of the Association are to create the following:

- Intervention Centres in all districts of the unoccupied areas of Cyprus
- Centres for the provision of treatments for younger children (speech therapy, occupational therapy, etc)
- "Houses in the Community" in order to ensure that individuals with autism live with dignity within the society
- Afternoon programmes for adults for entertainment and socialization
- Creation of a garden nursery for professional rehabilitation of moderate and high functioning individuals.

The registration fee for the Association is $\mathbf{\epsilon}3.50$, while the annual subscription is $\mathbf{\epsilon}8$.

<u>Three programmes are in operation at the Intervention Centre for Individuals with Autism in Limassol:</u>

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

The Intervention Centre for Individuals with Autism in Paphos runs the following programme:

Adolescents and adults programme (mornings)

<u>The Intervention Centre for Individuals with Autism in Nicosia operates three programmes:</u>

- 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, occupational therapy, special education, speech therapy 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. All of the treatments are offered at special prices for members of the Association, which are subsidized by the Association. As of January 2018, the Association also operates a Counseling and Support Programme for Individuals with Autism which is staffed by 2 Social Workers for the whole of Cyprus, who make home visits to families.

CONTACT INFO:

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: <u>Limassol@autismsociety.org.cy</u>

Model Occupational Centre

1 Ellispondou street, 3100 Limassol

Tel: 25107951, 99540111, Fax: 25343446

Email: <u>Limassol@autismsociety.org.cy</u>

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

8.2. Limassol Association of Parents and Friends of Children with Special Needs

The Limassol Association of Parents and Friends of Children with Special Needs was founded in 1991 and aims to protect and care for children with special needs as well as bring awareness to and resolve issues that are faced by children with special needs and their parents.

There are two Day Care Centres in operation in rental houses in the centre of Limassol, one at 50 Avgoustinou street and another at 12 Lefkosia street, at which 4 programmes are run:

- A) The Adult Day Care Centre "Marios' Home" is in operation since 2001 and today services twenty five (25) individuals in five groups from 7.00 until 15.00, Monday to Friday. Training has been undertaken by five qualified trainers along with the help of two child minders and the guidance of a Director, who is a social worker. The programme includes special education, creative activities (drawing, arts and crafts), music, getting to know the world through images and activities, dance/movement therapy, theatre games, cooking, equine therapy, gardening, excursions and educational visits.
- B) The "Panagia Pantanassa" Adult Day Care Centre has been in operation since 2007 and today services twelve (12) individuals in two groups from 7.00 to 14.00, Monday to Friday. Training has been undertaken by a qualified trainer, aided by three child minders under the guidance of the Director who is a psychologist. The programme includes educational games, hydrotherapy, dance/movement therapy, music therapy, care, entertainment, excursions and creative activities.

Both Adult Day Care Centres operate according to the Adult Centres Law 38(1)97 passage (3) of article 4 and the regulations issued based on it.

C) The Psychological Support Programme has been in effect since 1996, with excellent results. Psychological support is offered to children and adults at the Day Care Centres in an effort to prevent the development of negative behaviours.

All three programmes operate with the financial support of Social Welfare Services

- D) The Therapeutic Intervention Programme operates in the afternoon with the collaboration of qualified therapists and offers all therapies (occupational therapy, speech therapy, special education and physiotherapy) at very low rates.
- E) The need to raise funds was the inspiration for the creation of a workshop named "Creations of Love". The staff and children, alongside a group of volunteers, lovingly create unique handmade crafts which are then offered for sale, such as Christmas and Easter goods, wedding, birthday and christening favors as well as beautiful crafts suitable to give as gifts.

F) "DESMOS" Cultural group was approved by the Registrar of Societies and Institutions on March 18th 2015, registration number 4257. Seeing as the children have many abilities in dance, singing and in theatre it was decided that their own Cultural Group should be created, named "Desmos" ('bond'). Its purpose is to enable individuals to have an active role in the culture and traditions of Cyprus, to be given the ability to develop their skills and at the same time have fun.

Any individual above the age of 18 can become a member of the Association. Registration costs $\in 2$ and the annual subscription is $\in 15$.

CONTACT INFORMATION:

50 Avgoustinou street, 3086 Limassol

Tel: 25 382212, Fax 25 822197

Email: specialneeds@cytanet.com.cy

8.3. "To Alma" - Child Skills Development Centre

"To Alma" was founded in 1994, is located on the 1st floor of the old Limassol hospital and is **one of five programmes implemented by "Theotokos" Foundation. "Theotokos" is a nongovernmental, not for profit organization.** "To Alma" offers Early Intervention Services, in the mornings and afternoons, through its multidisciplinary team, to children aged 0-6 who have difficulties in various aspects of their development or children who are in a high risk group (e.g. premature), which may develop problems later on in development. At **ALMA** special attention is also given to providing information, counseling and offering psychological support to parents.

Aided by the Multidisciplinary Team, parents decide and select the most suitable therapeutic and educational approach for their child.

All departments collaborate and communicate with other services related to the child, including **state Medical and Social Welfare Services, as well Nurseries and Schools.** The services of the Centre are offered to children both within and outside of the district of Limassol.

Families can contact the Centre on their own accord or following a doctor's referral. A medical diagnosis is not a prerequisite. The Centre's work is funded entirely by "Theotokos" and is enhanced significantly by the Parents Associations and donations.

SERVICES

- Pediatric Physiotherapy
- Specialized Occupational Therapy
- Specialized Speech Therapy
- Special Intervention for feeding problems
- Play therapy
- Music Therapy
- Psychological support to children and families
- Services from a Social Worker
- Family activities
- Education Services
 - Nursery
 - o Infant Unit

- Collaboration with other specialists

Additionally, Alma provides services in the early stages of development for the following conditions:

- Cerebral Palsy
- Prematurity
- High Risk Infants
- Psychomotor delay
- Neuromuscular Diseases
- Obstetric Palsy
- Metabolic Diseases
- Torticollis
- Genetic anomalies
- Various syndromes
- Speech delay
- Language and communication disorders
- Difficulties in organizing and coordination of movement
- Disorders of sensory function and regulation
- Autism
- Dysphagia
- Stuttering

CONTACT INFORMATION:

P.O. Box 56473, 3307 Limassol, Cyprus Tel: 25746804-25746828/Fax: 25746027

Email: monada@cytanet.com.cy

Website: www.theotokosfoundation.org

8.4. Riding for the Disabled Association (RDA)

A riding group for individuals with Special Needs was established in 1985, in Happy Valley, in Episkopi, Limassol.

The Association offers free 30 minute riding sessions on a weekly basis for individuals with special needs, including those with autism. The Association's funds are raised through donations and a variety of events, organized by the Association itself, enabling it to offer these services free of charge.

The Board of Directors of the Association comprises of residents of the British Bases and offers services to other residents at the bases, as well as any permanent resident of Cyprus.

There are four Associations which use this particular Equine therapy programme: Theotokos Foundation, Alma, the Red Cross and the Association of Parents and Friends of Children with Special Needs.

For more information please call 25933866/99481026

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

8.5. "Apostolos Louka" Association of Parents of Adults with Mental Disability

"Apostolos Louka" Association of Parents of Adults with Mental Disability has operated a Day Care Centre since 2000, in which individuals with mental disability over the age of 18 take part from 7.45-15.45. The parent pays a monthly fee which includes the cost of the programmes, meals and transportation.

The aim of the staff and directors is to continually upgrade the quality of the programmes they offer to participants. At this stage, the centre offers many alternative and innovative programmes such as:

- ✓ Scouts
- ✓ Theatre
- ✓ Dance
- ✓ Music and singing
- ✓ Arts and crafts
- ✓ Decorating-Baking
- ✓ Swimming
- ✓ Bread making
- ✓ Sewing
- ✓ Music Therapy
- ✓ Fitness and sports
- ✓ Bowling
- ✓ Taking classes once per month at the Ayios Andonios Lyceum
- ✓ Education, self-care
- ✓ Computers
- ✓ Employment
- ✓ Psychological support
- ✓ Social outings and regular excursions
- ✓ Afternoon and evening outings

CONTACT INFORMATION

Tel: 25738768

Fax: 25384044

Facebook page: apostolos loukas protipo kentro

8.6. Prosvasi

Prosvasi is a non-governmental organization with the main aim of promoting social inclusion of people with disabilities. The vision of the organization is to create a social environment within which equal opportunities will be available to all, with an emphasis on accessibility, overturning prejudice, and inequality.

As part of its action in this field, Prosvasi NGO operates a Day Care Centre for individuals with disabilities.

PROSVASI Day Care Centre

PROSVASI Day Care and Training Centre for Individuals with Disabilities was founded in Limassol by friends of people with Special Needs who were sensitized to the issue and aimed to provide holistic care for these individuals. In 2005, with a lot of love and willingness to offer to others, a welcoming space was created, in which people with disabilities have the opportunity to receive high quality training so as to maximize their abilities.

The Day Care Centre constitutes a comprehensive, flexible, contemporary and multifaceted programme which is designed according to the principles of the Lisbon Summit and the UN convention for the rights of Individuals with Disability.

Staff is comprised of special professionals with the goal of providing quality services aimed at enhancing the autonomy of their patients and improving the quality of their life. Groups of volunteers, who are trained and offered support, are also involved in the activities of the programme.

Within the protected environment of PROSVASI Day Care Centre, members have the opportunity to take part in a person-centered, individualized programme, to receive training in conventional and unconventional types of learning and training in a plethora of skills. Additionally, individuals have the opportunity to take part in a range of social, cultural and sports activities, always keeping in mind their own needs and wishes.

Target Group

The services of Prosvasi target individuals above the age of 16 who have mental retardation, autism, pervasive developmental disorders, syndromes and psychiatric disorders. The main prerequisite for admitting a new member is the ability for self-care and the absence of serious mobility, vision or behaviour problems (aggression)

Programme

The Centre operates five days a week, Monday to Friday from 8.00 until 15.00 and offers the following services:

Training Services

Learning computers, educational kitchen, budgeting, theatre games, maintenance and/or enhancement of knowledge.

Skills Services

Craft workshop, arts and crafts, drawing

Therapy Services

Speech therapy, counseling, enhancement of emotional intelligence, adapted sports, music therapy, psychomotor education.

Socialization Services

Visits, road education, shows

Self care Services

Training and/or enhancement of personal hygiene skills and personal care skills.

Autonomous Living Services

Organized trips (two-day, five-day trips) in Cyprus and abroad with the aim of promoting the autonomy of individuals with disabilities and practicing skills needed to meet their personal needs.

These services are further enhanced by a plethora of scheduled activities such as swimming during the summer months, and other impromptu activities such as fun outings.

CONTACT INFORMATION

Tel: 25877080

Email: prosvasi@hotmail.com
Website: www.prosvasi.net

8.7. Red Cross Children Therapy Centre Stella Soulioti

The Cyprus Red Cross (C.R.C) Children Therapy Centre Stella Soulioti (former Child Infirmary), was founded by the C.R.C. in Kyrenia, in 1957 and aimed at providing special treatment for ill and disabled children. It is the oldest and largest C.R.C. project and its development has undergone four phases. The first phase was the period up until the Turkish invasion in 1974 (1957-1974) when the Centre operated in its own building with a boarding house, so as to service ill and disabled children coming from all communities, in all areas of Cyprus. The second phases was during 1980-1994 when it began operating in the same way in their own facilities in Limassol. The third phase began in 1994 when the Centre began operating providing only day care services, while the fourth phase began after 2012 when it was renamed C.R.C. Children Therapy Centre Stella Soulioti and renovations were initiated.

The Centre cares for about 75 children aged up to 18, with multiple serious physical disabilities such as cerebral palsy, muscular dystrophy, various syndromes and other severe developmental and motor difficulties. In addition to medical and nursing care, children are offered physiotherapy, hydrotherapy, speech therapy, occupational therapy and are provided with special aids which can help them move around with greater comfort. Importance is given to suitable entertainment for the children, creating a family atmosphere, integrating them into society and generally ensuring a better quality of life. The services offered at the Centre are constantly upgraded. General medical care is offered by a pediatric specialist, while the Centre collaborates closely with the Limassol General Hospital and specialists from abroad. The dedicated therapy personnel and the comprehensive equipment – which is always added to – contribute to offering high quality specialized medical and therapeutic services.

In collaboration with the Ministry of Education and Culture, the Centre operates a Special School for children which offers expert special education, therapies, psychological supports, and more. There is also a close collaboration with the Ministry of Health and the Limassol General Hospital, which offers the services of a child neurologist and orthopedic doctor on a regular basis, while also offering other expert medical services on an emergent basis. In collaboration with St. James University Hospital in Leeds, UK, a new treatment for children with cerebral palsy was introduced to Cyprus, namely Botulinum Toxin. After success using this new treatment over a period of several years with children at the Centre, it is now offered to children who are inpatients in state hospitals. New collaborations are also formed continuously with other organizations, such as state services, other schools and institutions with children with disabilities, Parents, the British Bases which offer equine therapy programmes to the children, international organizations, charities and other voluntary organizations.

CONTACT INFORMATION

Tel: 25334024

Fax: 25333466

Email: home@redcross.org.cy

Website: www.redcross.org.cy

8.8 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 aids, 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. Additionally, it is necessary to fully disclose the income status of parents/guardians, any savings, property owned and any financial obligations. Once this information is submitted the application will be examined by the Radiomarathon Board of Directors. The amount approved for the applicant depends directly on the determined needs and the funds available by Radiomarathon.

The application should be posted to the following address:

P.O. Box: 28643, 2081 Nicosia.

CONTACT INFORMATION:

P.O. Box: 28643, 2081 Nicosia

Tel: 22879518 Fax: 22423986 8.9. "Mazi" Association of Relatives and Friends of individuals with Autism

"Mazi" Association of Relatives and Friends of Individuals with Autism was officially registered with the state on April 30th 2012, in alignment with the Societies and Institutions Laws of 1972

and 1997 and the Regulations of Societies and Institutions 1973 to 1998. It was created by

families and friends of individuals with autism with the following main goals:

> Raising societal awareness about ASD

> Ensuring the rights and welfare of individuals with ASD

Ensuring the care, welfare, and quality of life of individuals with autism and occupying

them in creative ways

> Integrating these individuals into society

> Supporting and offering assistance to their families

> Creating homes in the community for adults with ASD

➤ Creating Centres for Pre-Professional Training of adolescents and adults.

CONTACT INFORMATION:

P.O. Box 24096, 1701 Nicosia

Tel: 96904717

Email: <u>mazi4autism@gmail.com</u>

Website: www.mazi4autism.com/

Facebook page: Syndesmos Mazi

8.10 Ayios Georgios- Christakis Hasapis Association of Parents and Friends of children with special needs

The Ayios Georgios-Christakis Hasapis foundation has been operating in Larnaca since 1992 as registered Charity organization, registration number 1137. For 17 years it has been housed in a prefabricated building of the old retirement home of "Iera Mitropoli Kitiou".

It initially began as a day care service however, due to demand, as of February 2000 it began offering 24 hour services.

Three programmes are in operation:

- The Day Care Centre which accepts children with special needs aged 3 and over, regardless of gender and operates from 7.30 until 4pm, Monday to Friday.
- The Children's home which accepts children aged 3 to 18 for boarding, regardless of gender.
- The Adult Home which accepts individuals aged 18 and over for boarding, regardless of gender

Currently the three programmes service 18 individuals. The aim is to care for children with severe physical and mental disabilities. The services of the foundation offer great relief to the families of the children from the psychological and physical toll that caring and protecting them on a daily basis takes. The individualized programmes offer opportunities to develop and maximize their physical and mental abilities, to learn self-care and social integration.

Transportation is offered via the Association's bus.

CONTACT INFORMATION:

P.O. Box 42356, 6533 Larnaca, Cyprus

Tel: 24642144/ Fax: 24660196

Email: stgeorgeidrima@cytanet.com.cy

8.11 Margarita Liasidou Foundation for Handicapped Children

The Margarita Liasidou Foundation is the only approved foundation in Paphos for adults with special needs. It was founded by Ismini Liasidou Saul as permanent and eternal memorial service for her child, Margarita, and as permanent source of help for fellow sufferers.

It was built in the village Koloni, on a plot of land bequeathed by the Holy Metropolis of Paphos, with the financial support of the founder, as well as donations from others. The foundation began operating on September 15th, 1992.

The purpose of the foundation is to house, care for, train, protect, offer exercise, entertain and rehabilitate individuals with special needs. The individuals reside in an environment of love, understanding, respect and acceptance where a specially tailored programme is applied according to their needs and abilities.

A Day Care Centre is offered from 7.30 to 3pm, Monday to Friday and services individuals over the age of 18 from the entire district of Paphos. The individuals attending the programme depart by bus at 2.30pm. There are currently 27 individuals with special needs attending the programme.

<u>SERVICES – PROGRAMMES</u>

- Provision of Specialized Services delivered by Professional staff comprised of Psychologists, Speech Therapists, Occupational Therapists, Physiotherapists, P.E. instructors, Social integration trainers.
- Training and development of social skills and self-care skills to maximize independence
- Provision of programmes with activities that help the individuals cultivate self-confidence, self-respect and to develop their skills. These include different practices and creative activities (computers, art, dance, music, gardening, woodwork, home economics, etc).
- Occupation in protected workshops producing handmade crafts for sale.
- Provision of services from Paphos Adult Education Centres, Ministry of Education
- As of 2001, implementation of the Supported Employment Scheme for employing individuals with disabilities in the labor market with the aim of achieving social integration. Individuals from the foundation are employed in different businesses. The Scheme is subsidized by the Department for Social Inclusion of Persons with Disabilities.

- Exercise programme to improve physical condition. Participation in the Special Olympics in Cyprus and abroad.
- Participation in a range of other sports such as riding, bowling, golf, football and basketball.
- Participation in the Cyprus Festival of Special Arts
- Organizing educational and recreational excursions for socialization

ACTIVITIES-EVENTS

- Opportunities are also provided for participation in events and activities outside the foundation with the aim of social adjustment and easing social integration.
- The Foundation organizes a range of different events with the purpose of sensitizing the public and to raise funds to cover its needs. These include markets, afternoon tea, fashion shows, annual fair of love, Christmas event, bingo, dances, concerts, etc.
- Seminars and lectures

CONTACT INFORMATION:

17 Margarita Liasidou street, 8310 Koloni, Paphos

Tel: 26962533 Fax: 26963331

Email: mliasidouhome@cytanet.com.cy

8.12 "Apostolos Pavlos" Centre

"Apostolos Pavlos" Centre functions as a Day Care Programme, caring for individuals, aged 18 and over, with special needs and other accompanying problems from all over the district of Famagusta. The goal of the Centre is to offer healthy ways to care for the individuals, develop personal, social and professional skills, avoid any type of institutionalization or social isolation, provide care and safety, and overall ensure a better quality of life to individuals with special needs. As a continuation of the work of the centre, two homes in the community are in operation where individuals whose parents are unable to care for them or are deceased can reside.

At the Centre, individuals are involved in many creative activities such as fishing, Ju Jitsou, exercise, and drawing. Additionally, individuals take part in five creative workshops which are supported and enhanced by funds raised from the sale of the products produced.

Specifically the following workshops are in operation:

Woodwork
Baking
Basket weaving
Crafts and jewelry
Recycling

Also specialized staff offers the following services:

Music Therapy Physiotherapy Speech therapy Special education

CONTACT INFORMATION:

19 28th October street, 5320 P.O. Box 32116, 5326 Liopetri Tel: 23942650 / Fax: 23943220

Email: kentro.apostolos.pavlos@cytanet.com.cy

Facebook: "Apostolos Pavlos" Centre

8.13 Faros Zois Association

Faros Zois Association is made up of parents and guardians of children with special needs and is based in Paralimni. In order to cater to the problems and needs of children in a scientific-rational way, Faros Zois has been operating a special school for some years. The school provides speech therapy, occupational therapy, Movement therapy and anything else each child may need.

Children attending the Faros Zois school this year exceed one hundred. The school is housed without charge at the KEPA building. Beyond offering the building, KEPA also provides free electricity, heating and water and takes part in the Association's board of directors.

Services:

Psychological interventions
Special Education
Music Therapy
Physiotherapy
Occupational Therapy
Speech Therapy
Hydrotherapy-Swimming
Summer and Winter activities

CONTACT INFORMATION:

P.O. Box 33770 5317 Paralimni Tel: 23 828844

Fax: 23 730548

8.14. Sports

8.14.1. Special Olympics Cyprus⁷⁰

Special Olympics Cyprus was founded in 1986 and is a member of Special Olympics International and the Cyprus Olympics Committee. It is recognized by 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.

As of 01/01/2015 Special Olympics Cyprus has been renamed Cyprus Federation of Special Olympics.

Today Special Olympics Cyprus has spread all over Cyprus. Over 450 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, as well as the Young Athlete programme, targeting children aged 2-7.

Thanks to the tireless efforts of the Board of Directors, the sensitivity of the state, the annual grants from CSO and the continued support of sponsors and volunteers, Special Olympics Cyprus have achieved some important changes, both in sensitizing society as a whole, as well as creating conditions for equal opportunity in society. On their part, the athletes have made Cyprus proud in all the competitions they have taken part in, achieving European and World distinctions.

Special Olympics Cyprus is based in the Cyprus Olympic House. In addition to sports and providing activities for children, this institution also aims to promote socialization and autonomy. Exercise and entertainment is provided safely under the supervision of special trainers. Additionally, there are groups for different sports, in all the towns of unoccupied Cyprus, in which children can take part. Each and every child is welcomed into the arms of Special Olympics Cyprus.

CONTACT INFORMATION:

Tel: 22 449848/9

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⁷⁰ Special Olympics Cyprus http://www.specialolympics.com.cy/ (19/03/18)

Email: info@specialolympics.com.cy

8.14.2 Sports For All $(SFA)^{71}$

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.

SFA trainers visit specific foundations in each city and offer services to the children.

Currently the programme is offered in Limassol, Nicosia, Larnaca, Paphos, and Famagusta.

All members participating in the Programmes have the following benefits:

Insurance

• Free transportation for the children to the Programme's sporting events

• The programme supplies its sports centres as well as primary schools with sports

equipment

• Free transportation to swim centres for the programme "Children and Swimming"

For applications:

http://ago.org.cy/archiki-selida/dilosis-dikeomata/dilosis/

Further information is available on the organisation's website: http://www.ago.org.cy/

CONTACT INFORMATION:

Tel: 22897000 Fax: 22358222

Email: info@ago.org.cy

⁷¹ Sports for All http://www.ago.org.cy/ (19/03/18)

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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 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 support, integration, and assurance of the health and education needed, as any other European citizen.

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.

A higher Organization could be created which would bring together the concerns of all involved in order to reach a comprehensive and common policy for addressing the issue of Autism. For instance, in Portugal, Early Intervention is based on intersectoral cooperation, including Non-Governmental Organisations NGOs. Additionally there is legislation for Early Intervention which defines the responsibilities of each Ministry (Education, Health and Social Insurance)⁷².

This organisation could be staffed on a professional basis with notable specialists, such as 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. It has been observed that equal opportunities are not available for all Individuals with Autism, since comprehensive, equivalent services are not offered in all parts of Cyprus.

⁷² European Agency for Development in Special Needs Education: <u>www.european-agency.org</u>

Regarding the area of intervention, best practice consists of having 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. For this reason, we welcome the initiative of the Republic of Cyprus to create a Multidisciplinary Assessment Centre for Autism which will cater to 100 children annually⁷³.

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 Autism⁷⁴. 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, technology is utilized to enable 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, are suitably trained and qualified so as to maximize results.

Additionally, the state cannot forgo its responsibility towards legislation which it is obligated to monitor and enforce. As much as we often overlook the application of certain practices, we must consider that the wrong approach to such problems, will not only have repercussions on a state level, but will also have huge consequences on family bonds. The fact that Autism has an effect not only on the individual, but also the immediate environment, results in families being unable to find solutions on their own, which means in the long term we must find fundamental solutions. For instance, often funds given to families with Individuals with Autism who are in financial trouble, are forced to be allocated to cover other needs, which results in a temporary, ineffective solution to the problem. Additionally, having studied the legal framework which is followed in Cyprus, we have noted that there is an absence of legal safeguards in terms of work matters for parents of children with Autism. It should have been possible for them, for instance, to retire early as it is very likely that their children are especially in need of their care.

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

⁷³ https://www.eprocurement.gov.cy/epps/cft/prepareViewCfTWS.do?resourceId=3101351 (29/03/2018)

⁷⁴ European Agency for Development in Special Needs Education: <u>www.european-agency.org</u> (29/03/2018)

state. Until state facilities and programmes are created, which are ideally needed for caring for Individuals with Autism, NGOs are essential. In addition to the Services offered, some centres raise awareness and sensitivity around the issue of Autism. NGOs contribute to developing a social conscience, changing the mindset of our country and bringing forth ways of harmonious co-existence.

In our opinion the role of voluntary organizations in all social issues is very important, however, each time a voluntary organization responds to a social deficit, it shines a light on the need for the system itself to resolve issues using suitable policies, strategies and facilities.

There is also room for improvement with regards to raising awareness and training professionals, as well as society, on the diagnosis of Autism in children in the early stages (e.g. parents, doctors, educators etc.). All involved with Autism, should adopt a active role so that no individual with Autism remains without early intervention and the necessary support.

On another level, the psychological situation of a parent who is faced with the term "Autism" for the first time is clearly very difficult. During the diagnostic process, some parents are in essence not able to face the reality and try in every possible way to reject the possibility that their children may fall in the spectrum of autism. At this point, the early intervention of specialized staff which will approach the parents is very important. The right and appropriate psychological approach to parents is unfortunately a part of this process to which our country does not give appropriate attention. Additionally, all members of a family which has a child with Autism should receive specialized help, psychological support and guidance, in order to contribute to the effective integration of the child in the family and in society.

The diagnosis should not become a "label" for the child, since it does not define the limits of where he/she can go but instead constitutes the starting point from which we can build upon intervention strategies aiming to maximize the child's abilities and offer learning opportunities. Acceptance of the diagnosis of Autism is not equivalent to a passive attitude, instead it indicates that the child is seen with objectivity and that a commitment exists to making the best choices for his/her development. At this point it is important to share the advice of a mother: "As a mother of a child with autism I would like to emphasize how important it is for parents to study about autism, understand it and accept their child with his problem. The sooner they do that, the more able they will be to help their child. They are the ones who know their child the best." Through training, parents can become empowered, develop a more effective way of communicating with their child and by extension become more able to train their child to display more acceptable behaviors within its natural environment. Unfortunately, parent education is essentially nonexistent in Cyprus. This service is offered at a few private centres and comes with a high cost, a fact which renders the training inaccessible to most families.

We have realized that some parents and siblings of adults with Autism have valuable experience in the area of Autism and this should be actively utilized. A suggestion for review is the possibility of parents and siblings engaging in **round table discussions** and programmes regarding Autism so that they can share their experiences with others. In this way they can become extremely useful and "escape" from their own problems by offering to others. In relation to the above, through training, parents could become members of a **supervisory committee** for their children's rights, in which services for individuals with Autism are involved. In both cases these services could be offered for a fee and not be regarded simply as a charitable contribution.

Through contact with parents with adult children with Autism, it has become apparent that their main concern is what the future holds. Specifically, there are very few cases in which parents have managed to obtain special housing and care for their children outside of institutions or homes for the elderly, when they are no longer able to care for them. One suggestion would be to create "Homes in the Community" in every city and community of Cyprus, which have suitably qualified staff, where children with these disorders can live. This could provide socialization, security and autonomy to parents and children alike. Plans and strategies are needed for these cases in order to avoid institutionalization. Within the context of social conscience, we need to acknowledge that 50% of individuals face an obstacle in some phase of life, either temporarily or permanently, and thus we must view each social issue as our own. We are all building a future for everyone.

In closing, it is emphasized that the Guide is a work which requires constant renewal, since different changes with regards to Autism are constantly brought to the forefront. It would a good future step to attempt to compare good practices for the various issues and services offered in Cyprus in relation to that offered abroad, in the interest of Individuals with Autism and their families. Kepaky wishes to continue to bring together updated information and reaches out to those involved with the issue of Autism, so that with their help, and the help of all those responsible, the efforts around this issue continue to thrive.

Overall, it would be a blessing to create a welfare state and a common policy for each action, which state and nongovernmental organizations can follow, always keeping in mind the welfare of children with Autism and those of all children with special characteristics. As far as society is concerned, there is still a long road ahead of us, since it needs to gain awareness, learn to accept what is different, learn not to fear it and learn not to isolate it. It is necessary for all of us to strive, wherever we may find ourselves, to respect the right of each of our fellow human beings for a life of dignity, a life where each individual has a role and something to offer society. We need to have a deep knowledge of our rights as well as our obligations towards other human beings.

Accepting a child who is different constitutes a confirmation and a revelation regarding the deeper meaning of humanity. Interaction with the child will reveal the mystery of life and provide us with an opportunity to develop both personally and spiritually.

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

Committee for the Protection and welfare of the child Famagusta's District

170 1st of April street, 5281, Famagusta **Paralimni**

Tel.: 99465596 / Fax: 23822641

Email: papaloucass@cytanet.com.cy

Committee for the Protection of the Rights of People with a Mental Handicap

10 28th October street, Acropolis

Mailing address: P.O. Box 23292, 1680 Nicosia

Tel.: 22871333 / Fax: 22429544 Email: <u>cp-mental@cytanet.com.cy</u> Website: <u>www.cpmental.com.cy</u>

Theotokos Foundation

1 Dimitri Lagiou street, 3113

P.O. Box 56473, 3307 **Limassol**. Tel.: 25-338948 / Fax: 25-387848 Email.: theotokosf@cytanet.com.cy

Foundation for the Protection of People with a Mental Handicap "Agios Stefanos"

84 Georgiou Neofytou street, 4006 Mesa Geitonia

P.O. Box 51212, 3502 **Limassol** Tel.: 25725136 / Fax: 25715614 Website: www.agiostefanos.com.cy

Portage Cyprus Foundation

P.O. Box: 20590, 1660 **Nicosia** Tel.: 22481666 / Fax: 22485331 Email: <u>csgfound@spidernet.com.cy</u>

Website: www.cyprusportage.tripod.com

Saint Christopher Foundation

3 Steliou Ioannou street, 2032, Strovolos, Nicosia

Tel: 22570095 / Fax: 22570099 Email: stegi@spidernet.com.cy Website: www.saintcristopher.org.cy

Elikas Foundation

22 Chr. Kalaitzi street, Dasoupoli 2015, Nicosia

Tel.: 22491032 / Fax: 22660881

Margarita Liasidou Foundation for handicapped children

17 Margaritas Liasidou street, Koloni 8310 Paphos

Tel.: 26962533 / Fax.: 26963331

Email: mliasidouhome@cytanet.com.cy
Website: www.margaritafoundation.net

The Good Samaritan Foundation

11 Thermopylon street, Acropolis, 2008, Nicosia

Tel: 99618836 / Fax: 22496067

Cyprus Red Cross Society

Red Cross street, 2063 Strovolos P.O. Box 25374, 1309 **Nicosia**

Tel.: 22666955, 22668177 / Fax: 22666956.

Youth Department: 22665166 Email: <u>admin@redcross.org.cy</u> Website: www.redcross.org.cy

Cans for Kids

3 Kolokotroni street, 2369 **Nicosia** Tel.: 22781828 / Fax: 22781848 Email: <u>caracal@cytanet.com.cy</u> Website: <u>www.cansfor-kids.org</u>

Family Guidance Centre

Panagia Pantanassis Church courtyard

4152 Limassol

Tel.: 25341785 - 25341894 / Fax: 25342083

Research Unit in Behavior and Social Issues - RUBSI

46 Makedonitissas street, 24005, Nicosia

Tel.: 22841638 - 22841557 / Fax: 22841557

Email: phellas@cytanet.com.cy, constac@cytanet.com.cy, loizou@rubsi.org

Website: www.rubsi.org

Youth Board of Cyprus

6 Evgenias & Theodotou street, P.O. Box 20282, 2150 Nicosia

Tel.: 22402600 / Fax: 22402700

Email: <u>info@youthboard.org.cy</u>
Website: <u>www.youthboard.org.cy</u>

Pancyprian School of Parents, P.O. Box: 27298, 1643 Nicosia.

Tel.: 22754466 - 99614807. / Fax: 22345103

Email: scholigoneon@cytanet.com.cy Website: www.scholigoneon.org.cy

Multi-thematic Therapeutic Centre Right to Life

9 Ilia Venezi street, Strovolos 2042 Nicosia

Tel.: 22518767 / Fax: 22518768

Email: dikaiomazois@cytanet.com.cy

Agios Spyridonas School Parents Association

Olympou street, Agiou Georgiou Kondou, 6046 Larnaca

Tel.: 24637948

Email: scholioagiosspyridonas@cytanet.com.cy