

# **Rights & Services**

## **for Children with Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder in East Jerusalem**

**A study conducted for  
Diakonia**

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## Executive Summary

The goal of this study is to assess the status of educational and therapeutic services provided to children with Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) in East Jerusalem. Israeli studies (Raz, Weiskopf, Davidovitch, Pinto & Levine, 2015) show that the percentage of children that the National Insurance Institute recognises as suffering from ASD is one tenth compared to their percentage in Jerusalem. The recognised percentage did not surpass 0.001%, while according to the data of the Israeli Ministry of Health, the percentage of children in Israel suffering from ASD stood at 0.01%. Concerning children with ADHD, this phenomenon is yet to be addressed in East Jerusalem. Furthermore, clear data and statistics on the prevalence of ADHD among Palestinians is not available.

The study primarily utilised a qualitative approach, where meetings were held with educational and therapeutic service providers in East and West Jerusalem, as well as with parents of beneficiaries. Israeli legislations and governmental policies relevant to children's rights were reviewed. Finally, the rehabilitation programmes of East Jerusalem colleges targeting teachers working in the fields of ASD and ADHD were examined.

The semi-structured interview was used as a primary research tool. Each category of respondents (parents of ASD and ADHD children, principals of ordinary schools, principals of special education schools, directors of the Child Development Centres, director of National Insurance Institute and coordinators of the service development unit for people with disability of the Israeli Social Welfare Ministry) was asked specific questions. A guide was developed for assistance in the interviews. This method in data collection is comparably good to other tools since it enabled us to delve deeply into different pre-assigned topics relevant to legislations, services and challenges facing each category of the study (Abeidat, Abu Nassar and Mbeiden, 1999). Focus group discussions were also used to collect data from teachers in ordinary schools working with ADHD children, as well as with teachers in special education schools working with ADHD children in East Jerusalem. The contents and main issues were identified and analysed in accordance with the content analysis method (Braun & Clarke, 2008).

The sample was chosen purposefully (available sample) in a non-probable snowball sample. This approach was adopted because we had to convince the respondents to partake in the interviews. A total of 5 principals from East Jerusalem schools and 2 principals from West Jerusalem schools were interviewed. Parents, teachers, directors of Child Development Centres and service providers in East Jerusalem were met; children with ASD and ADHD were not interviewed in light of contextual difficulties and limited research duration.

**The study concluded a number of results in different areas, most importantly:**

- 1 The presence of a large gap between the percentages of children diagnosed with ASD and ADHD and their actual number in Jerusalem.
- 2 The presence of a clear gap in the quality of services provided to children and the awareness of parents to these services and their access to them between East and West Jerusalem. These gaps did not appear in the process of obtaining recognition from the National Insurance Institute and particularly among children with ASD.
- 3 The available educational and therapeutic services do not cover the real needs of the children, particularly children with ADHD.
- 4 The infrastructure available in East Jerusalem, such as room size and environment, is predominantly unsuitable to work with children who have ASD and ADHD.
- 5 The presence of challenges that face parents when they have the desire to access specialised services, such that they have to access these services in West Jerusalem, which not only forms a financial burden on them but there is also the language barrier.
- 6 The number of therapists in different specialisations working in the Child Development Centres and in private education schools does not meet the real needs of the students. Also, the quality and quantity of the services remains basic, as they do not meet all the educational and therapeutic needs of the students.
- 7 There is significant scarcity in the number of specialised doctors and neurologists. This increases the difficulty of accessing therapeutic services, and extends the time to access these sometimes to several months.
- 8 It was clear from the study that teacher rehabilitation to work in schools with ASD and ADHD children is insufficient to fully prepare teachers.
- 9 It was clear that the vast majority of the educational and therapeutic services are available inside the Wall, especially in the case of ASD services.
- 10 Regarding legislation, the Israeli law guarantees the rights of all children irrespective of whether they are Jewish or Arabs. However, for reasons relevant to culture, acceptance of disability, level of awareness of parents of their rights and complications induced by the political situation and place of residency, there is a large number of children whose status of suffering from ASD or ADHD goes unacknowledged, and therefore they do not access their rights and educational and therapeutic services.

The researchers suggested a large number of recommendations on the policy, ministerial, municipal, university and international organisations' levels. In the executive summary we outline the most important recommendations, classified in accordance with the type of disorder.

## **1 ASD Recommendations**

### **■ On the Level of Ministry of Health**

Increase the number of neurologists and therapists working with children who have the ability to diagnose and provide psychological and medicinal treatments. This comes within the context of the increasing scarcity of specialists, which consequently increases waiting time to access services and decreases the number of children identified at the Ministry of Health and the National Insurance Institute as ASD children, as well as delays the receipt of therapy for children and obtainment of necessary medical reports.

### **■ On the Level of Ministry of Education**

Open educational and therapeutic frameworks and centres outside the Wall: the study reflected the absence of educational frameworks providing educational and therapeutic services outside the Wall, with the exception of one small centre in Kufr Akab that attempts to provide services to Jerusalemite and West Bank children.

### **■ On the Palestinian Policy Level**

Work towards the enactment of legislation that provides basic protection to ASD children and regulates the role of the State towards these children on the medical, educational and rehabilitation levels.

### **■ On the Level of Palestinian Universities**

Since the study demonstrated a gap between the rehabilitation teachers and therapists receive and the current situation in working with ASD children, universities should provide more specialised programmes, as well as specialised training frameworks for special education professionals and teachers. Additionally, there is a need for clinical supervision frameworks based on case studies.

### **■ On the Level of Funding Organisations**

There is a severe scarcity in clinical and educational ASD research in Palestine and Arab countries. Therefore it is important to commence in supporting the undertaking of studies to develop educational knowledge that contributes to raising the level of

education in colleges and universities. It is possible to examine the undertaking of one Palestinian university of a number of studies in the field or in the establishment of a research specialising in ASD.

## 2 ADHD Recommendations

### ■ On the Level of Ministry of Health

Provide professional cadre for diagnosis and treatment: the study clearly demonstrated a quantitative scarcity in the number of Child Development Centres in East Jerusalem. There is also a large shortage in the human resources that can diagnose ADHD, as the number of Arab diagnosticians in East Jerusalem and outside the Wall are insufficient to deal with the cases professionally, in addition to a small number of Arab therapeutics that can provide treatments to these groups of students.

### ■ On the Level of Ministry of Education

Rehabilitation of teachers and educational counsellors: the results of the study show that teachers and educational counsellors are insufficiently prepared to work with ADHD cases. Furthermore, the solutions and tools they utilise are predominantly improvised and based on their own analysis instead of utilised systematic programmes to work with ADHD students.

### ■ On the Palestinian Policy Level

It is important to shed light on cases of learning difficulties instead of congregating it with the remaining forms of disability. It is important that the Palestinian Ministry of Education provide attention to the diagnosis of this group of children and provide appropriate educational frameworks and teacher rehabilitation to enable them to meet the educational needs of this group of students.

### ■ On the Level of Palestinian Universities

Improvement of the university rehabilitation programme: it was evident from the teachers who studied in Israeli higher education universities and college that their studies enables them to acquire theoretical knowledge but does not qualify them or enables them to acquire necessary tools to deal with ADHD children. Furthermore, teachers from graduate from Palestinian universities graduate with simply knowledge in the field that does not qualify them to understand the needs of ADHD students and deal with them. Therefore it is important that universities and education colleges develop a course that brings together theory and practice to ensure proper rehabilitation to understand and succeed in working with ADHD students in the future.

### ■ On the Level of Funding Organisations:

Support relevant initiatives and community organisations that work on raising the awareness of parents and the local community on the rights of these children and the need to integrate them in schools and the society.

### Intervention Priorities

**Based on the current study several priorities can be put forward to commence in their realisation within the next few years:**

- 1 On the level of international organisations: it is important to support civic and civil society initiatives demanding the improvement of the situation of Jerusalemites in general, and children with disability and their families in particular, as well as the realisation of equality in provided services at the therapeutic, educational, infrastructural and funding levels. It is important to forge partnerships between various organisations and allocate tasks in accordance with the organisations' mandates and strengths.
- 2 Create innovative ways to increase the number of therapeutics, neurologists and paediatricians by creating a scholarships programme for those who want to specialise in these areas inside Israel and outside the country. This comes within the context that the shortage of professionals is one of the main variables that have adversely impacted the provision of services to Palestinians and the low acknowledgement rates.
- 3 Develop a clinical rehabilitation programme for teachers in ordinary schools and particularly those working with ADHD students in cooperation with the Education Directorate in East Jerusalem and one of the Palestinian universities. The programme should increase the level of knowledge among teachers in the field of disability and learning difficulties in general and ADHD in particular. Additionally, current programmes and courses at universities should be supported and developed to raise their level.
- 4 The continuation of support by Diakonia and other international organisations to support organisations that provide services in East Jerusalem, particularly emerging organisations in areas outside the Wall. It is important to support any intervention by these organisations through mobilisation and rights-based support to enable it to provide much needed scarce services.

## Scientific Methodology of the Study

The study primarily utilised a qualitative approach, where interviews were conducted with educational and therapeutic service providers in East and West Jerusalem, as well as with parents of beneficiaries. Israeli legislations and governmental policies relevant to children's rights were reviewed. Finally, the rehabilitation programmes of East Jerusalem colleges targeting teachers working in the fields of ASD and ADHD were examined.

To understand the experience of parents in services provided to them and their children in schools, kindergartens, offices of social affairs and identify any present gaps in accessing rights, a comparison was undertaken between East Jerusalem and West Jerusalem through meetings with parents and school principals.

### Study Tools

The semi-structured interview was used as a primary research tool. Each category of respondents (parents of ASD and ADHD children, principals of ordinary schools, principals of special education schools, directors of the Child Development Centres, director of National Insurance Institute and coordinators of the service development unit for people with disability of the Israeli Social Welfare Ministry) was asked specific questions. A guide was developed for assistance in the interviews (annex 1). This method in data collection is comparably good to other tools since it enabled us to delve deeply into different pre-assigned topics relevant to legislations, services and challenges facing each category of the study (Abeidat, Abu Nassar and Mbeiden, 1999).

The sample was chosen from the study community: the group of individuals benefiting from therapeutic and educational services and service providers in East and West Jerusalem.

### Study Sample

The sample consisted of the following:

- 1 Parents of ASD and ADHD children in East and West Jerusalem: 18 families of children in primary schools were chosen from both parts of the city.

- 2 Principals of ordinary schools and special education schools in East and West Jerusalem. Principals of private schools working in the field of ASD, one kindergarten principal working in the field of ADHD and 3 principals of ordinary schools that have ADHD students were chosen. Additionally, the principal of the Princess Basma School, which brings together children with various developmental disorders with ordinary children (an integration school) was interviewed. Also, communication via telephone to clarify some points was undertaken with the principal of an ASD school and the principal of an ASD kindergarten in East Jerusalem.
- 3 Directors of Child Development Centres in East Jerusalem: a meeting was held with the director of the Child Development Centre of the Clalit Health Fund. Also, an interview was conducted with the director of the Child Development Centre in Shufat, a private centre that provides services to all Health Fund members.
- 4 Jerusalemite organisations and treatment centres in East Jerusalem and provide services to ASD and ADHD children. Interviews were undertaken with the director of the Jerusalem Autism Children Association (Kufr Akab) and the director of the Warm House Centre.
- 5 Governmental organisations: interviews were held with the director of the National Insurance Institute in West Jerusalem, social worker in the Social Welfare Office in East Jerusalem, coordinator of the disability unit in East Jerusalem and the ex-director of the service unit for people with disability in East Jerusalem. The study sample can be found in table (1).

The sample was chosen purposefully (available sample) in the non-probable snowball sample. This approach was adopted because we had to convince the respondents to cooperate with the researchers. Communication was also undertaken with the social worker of the social welfare office of the Jerusalem Municipality in East Jerusalem, who suggested families living inside the Wall and others outside the Wall. The researchers also approached private education schools who were asked to facilitate communication with parents who are willing to meet with us. In addition to consulting the lists of students, one of the researchers worked and diagnosed them in the past years. Communication with parents living in areas outside the Wall was undertaken directly and interviews times were met. In West Jerusalem, we commenced with an interview with the principal of an ASD school, who suggested to the research assistant to communicate with the families coordinator in Eilat Association, where she interviewed parents. Parents were also reached through an announcement in the David Yellin College to conduct interviews with mothers of ASD and ADHD children. These were the methods utilised to reach principals and families.

Also, due to the specificity and limitations of the topic, representatives of organisations and service providers were chosen in both sides of the city. This was undertaken by identifying provided services and the members we should communicate with in order to receive the necessary information. Also, communication was undertaken with the directors of centres, social workers and coordinators of services provided for children.

**Table 1: Details of Individual Interviews**

Type of Disorder	Category	Details
ASD	Parents	(9) parents from various parts of the city. Some inside the Wall, others outside the Wall. 6 from East Jerusalem and 3 from West Jerusalem
	School Principals	(3) school principals: 2 in East Jerusalem and 1 in West Jerusalem
	Shati Centre/ Jerusalem Municipality	(2) Director of the centre and ex-director of the centre in East Jerusalem. and director of ASD Services in West Jerusalem.
	Jerusalem Autism Children Association (Kufr Akab)	(1) Director of the centre
	Princess Basma Organisation	(1) interview with the principal of the school and director of rehabilitation division
	Directors of educational framework that provide services to 3-6 year old children	2 clarification phone calls
	National Insurance Institute	Director of National Insurance Institute in West Jerusalem

ADHD	Parents	(9) parents from various parts of the city: some inside the Wall, others outside the Wall. 6 from East Jerusalem and 3 from West Jerusalem
	School Principals	(3) school principals: 2 in East Jerusalem and 1 in West Jerusalem
	Social Affairs in East Jerusalem	(1) the employee responsible for the follow up of ADHD children
	Warm House Centre	Main social worker and the director of the organisation

In addition to individual interviews with parents, school principals, directors of centres and municipality service providers, the research team interviewed two officials in the Child Development Centres that provide diagnosis and treatment services to ADHD and ASD children; these centres are: Clalit Health Fund and the Development Centre in Shufat, a private centre that provides services to all Health Fund patients. Also, two focus groups were undertaken, comprising teachers working with ASD and ADHD children in East Jerusalem schools, as clarified in table (2). Teachers working in private schools were approached through the training programme of the David Yellin College of Education, in addition to individually approaching some teachers and inviting them to partake in the focus groups in a snowball approach.

**Table 2: Details of Focus Groups**

ASD	Teachers	(6) teachers working in private education schools. An occupational therapist from one of the schools participated in this group.
ADHD	Teachers	(6) teachers working with ADHD students.

## Study Procedures

The research team conducted interviews with parents, officials and teachers individually or in the form of focus groups. The goals of the study were explained to them, and they were assured that any shared information will be used solely for the purposes of the study. They were also given the choice to refrain from answering questions, and choose whether to share the names of their sons or daughters. It was also clarified to them that the study will never refer directly to their names and the names of their schools. Furthermore, the respondents were asked for their consent to record the interviews, and the researchers contended with written documentation in the cases of those who refused. The recordings were later inscribed.

The recorded interviews of different research categories (parents, principals, civil servants, directors of Child Development Centres) were inscribed and later analysed thematically. This method was designed to understand and deduce the most important content of the interview (Braun & Clarke, 2008). Focus was on the themes that the study was concerned with, including provided services in East Jerusalem, gaps between rights and services that parents receive and service providers give and any differences between East and West Jerusalem. In accordance with Braun and Clarke's methodology, we connected the content of the interview with various available literature and reports; points of intersection were identified and the contents and major themes were presented. Quotes were used from the interviews to verify the content.

## Study Limitations

In this current study a purposeful sample was chosen that was limited to 18 parents of children who have ASD or ADHD and who receive therapeutic and educational services in educational and treatment frameworks available in East and West Jerusalem. The sample also included teachers working in recognised and unrecognised Arab schools in East Jerusalem. Only 7 schools from those present in East and West Jerusalem, including Princess Basma School, were chosen to undertake interviews with their principals. Special education schools outside the Wall were not chosen because they are non-existent. Also, interviews were conducted with directors of only two Child Development Centres in East Jerusalem. The study was undertaken in the end of the first semester of 2017 and utilised the qualitative method to collect and analyse data.

In addition to the aforementioned limitations, this study was restricted to focusing on services provided for parents and challenges that parents face from themselves and from education and therapeutic service providers. The study did not include the concerned children.

**Part 1:**

# **Autism Spectrum Disorder (ASD)**

# 1 Definition and Data

Autism Spectrum Disorder (ASD) is defined as a disorder whose causes are hard to determine and that appears during the early stages of child development. It is also defined as a disorder that impacts basic social behaviour, such as ability to interact socially, ability to communicate feelings and ideas, imagination and creation of relationships with others (Ashbi and Musleh, 2015).

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders differentiates three levels of ASD severity that reflects in an individual's occupational performance. The manual focuses on two components of ASD; the first is a difficulty faced by the individual in building social interaction with his/her environment, and the second is the emergence of repetitive typical behaviour or actions involuntarily, in addition to unsuitable reactions to sensory stimuli (appendix 2).

ASD does not discriminate between different social groups, whether they are rich or poor. It is, however, more prevalent among males compared to females with a 4 to 1 ratio (Werlinga & Geschwind, 2013). The difference between males and females is primarily associated with the higher levels of performance, such that the prevalence of the phenomenon between males and females in higher performance is 1:6, while in average and low performance it stands at 1:7 (Fombonne, 1999). In the United States, due to the increasing awareness of the phenomenon and development of diagnosis tools of higher accuracy, the percentage of its prevalence there reached 1 in every 68 births (Christensen, Baio & Braun, 2016). Since most children are diagnosed after the age of four, the proportion of children diagnosed before the fourth year reached 13.4 per 1000 births (Christensen, Bilder, Zahorodny, Pettygrove & Durkin, 2016). According to the findings of the Israeli Ministry of Health, one in every 100 children is diagnosed with ASD (Israeli Ministry of Health, D.T), while in the West Bank, statistics are not available on the percentage of Palestinian children suffering from ASD (Dababnah & Bulson, 2015).

A study undertaken by Raz and others reveals that the percentage of Arab children with ASD in Israel is lower than that of Jewish children (Raz, Weiskoph, Davidovitch, Pinto & Levine, 2015). Despite increasing awareness of the phenomenon and openness of families to accept their children, acknowledge the presence of the problem and take steps to address it, cultural factors still prevent many parents, as is the case in other Arab states, such as Egypt, Jordan and others, from acknowledging that their children have ASD (Hussein, Taha & Almanasef, 2011; Raz et al, 2015). In another study on the prevalence of the phenomenon in Israeli society, the percentage ranged

from 3 cases for every 1000 Arabs, 2.5 cases for every 1000 religious Jew and 9 cases for every 1000 secular Jews (Shertz, Tamir, Genizi & Ruth, 2016). This study does not attribute the large discrepancy to lack of acknowledgement and cultural factors, but to early childbirth in both societies compared to the secular Jewish society. Another study, undertaken by Clalit Health Fund in 2014 on a group of ASD children in Haifa, revealed that the percentage of Arab children with ASD reflected their percentage in the areas that were researched, such that the percentage of Arab children with ASD reached 35.5%, while the percentage of Jewish children reached 64.5% (Mahajnah, Sharkia, Shalabe, Terkel-Dawer, Akawi & Zelink, 2014).

Irrespective of the differences in interpretations that researchers attribute their results to, this phenomenon is still a contentious issue among some Arab and religious Jewish families, whose details are hard to delve in. Many cases of ASD are unknown and undocumented in Ministry of Social Affairs for many reasons, particularly in East Jerusalem among Arab families and religious Jewish families (from an interview with AA, ASD coordinator and social workers supervisor in the autism frameworks in the rehabilitation service unit for people with special needs in West Jerusalem; from an interview with MM, a social worker responsible for the autism division in the rehabilitation unit of people with special needs in East Jerusalem).

In an interview with AS from the rehabilitation of people with special needs unit, he revealed the presence of an acknowledged 200 cases of ASD in the Ministry of Social Affairs in the East Jerusalem area. It is important to note here that the findings of the Ministry are mostly accurate as every child is required to go through the process of the Ministry to access their rights as recognised by the law in different governmental institutions. According to the statistical book of the Israeli Central Bureau of Statistics, the number of Palestinian residents in East Jerusalem reached 319,000 (37.5%), while that of Jewish citizens 520,700 (61.3%). According to these statistics, the percentage of Palestinians with ASD in East Jerusalem who are registered with social affairs reached 0.6 for every 1000 Palestinian Jerusalemite. In case we make the calculations until the age of 24, on the basis that awareness of diagnosis and development in the field of autism in East Jerusalem commenced in the early 80s (interview with RB, a special educational school principal and AS, previous citation), the percentage of Palestinian Jerusalemites until the age of 24 according to the statistical book reaches 58% of the total Palestinian population in Jerusalem. Hence, if we calculate the percentage of individuals with ASD who should have been acknowledged and registered since the development of awareness, tests and special education frameworks, we get the statistic of 1 in every 1000 case, a large deviation from the statistics of Israeli institutions (Israeli Ministry of Health, D.T) and statistics of previous studies. When these data were communicated to the director of rehabilitation of persons with

special needs unit in East Jerusalem, he attributed the gap to two main reasons. The first is relevant to the awareness of parents of the phenomenon, as many consider it a form of mental disability and their fear to acknowledge the disorder that his/her child suffers from. The second reason is associated with the shortage in the number of diagnosticians and social workers. This predicament is not limited only to autism divisions, but extends to include all social welfare divisions in East Jerusalem.

## 2 Summary of Israeli Legislation Relevant to Rights of Children with ASD

### 2.1 Special Education Law

The Israeli Special Education law, enacted in 1998, regulated the rights the State is responsible to provide for people with special needs between the age 3 and 21 in accordance with their disability in both private and public frameworks. The law sought to develop the skills and capacities of people with special needs; improve their physical, mental, psychological and behavioural performance; and facilitate the acquisition of necessary knowledge, competencies and traditions that would enable them to integrate in the society and labour force (Special Education Law, 2008, Ministry of Education Website). Additionally, the law emphasised the need to integrate capable children into ordinary educational frameworks, such that the integration law applies to all children with special needs who are entitled to free education in accordance with the compulsory education law, enacted in 1949. As such, the child is integrated into the ordinary framework after the Placement Committee undertakes all necessary tests, which incurs an obligation on the Ministry of Education to cover the cost of additional hours and services that meet the special needs of the child, thus facilitating an optimal integration in the ordinary framework (previous source). Children with special needs, according to the integration law, receive one of two budgets; approximately 90% of children with special needs who are integrated into ordinary schools are given statistical finance, which translates into an additional 1.85 hours/ week. The remaining 10%, who suffer from severe developmental difficulties, are given differential finance, which translates into an additional 2.7 hours/ week (Faisplay, 2015).

## 2.2 ASD Diagnosis

The report of the general director (number 13/15 of 10 November 2013) conditions that the diagnosis of a child with ASD include physical, neurological, developmental and psychological tests. As such, doctors capable of diagnosing ASD are either psychiatrists specialising in childhood and adolescence, a development doctor with a minimum of 3 years of experience in a known Child Development Centre, a neurologist, or a child development doctor. In addition to the medical diagnosis, a psychological diagnosis can be undertaken by a clinical psychologist in the field of childhood, evolutionary psychologist (intern under supervision), an educational psychologist, or a rehabilitation psychologist specialising in the diagnosis of ASD. Following the diagnosis of the child as one suffering from ASD, the child has to register in the community centre (social affairs bureau in area of residency) to be able to access all entitlements relevant to the disability.

## 2.3 National Insurance Institute Allocations

According to the regulations of the National Insurance Institute on allocations to ASD individuals, the allocated finances for the year 2017 are 2561 ILS per individual (interview with the director of National Insurance Institute in West Jerusalem). In the cases where there is more than one ASD child in the family, each child is entitled to a 50% raise on the amount allocated to each child. Irrespective of the level and severity of the disorder, each ASD child, according to the regulations of the Institute, is considered a child that suffers from a "special disorder," and therefore receives the same allowance. In the case where a 3-18 year old child is completely dependent on another individual to meet his basic needs, including food, dress and hygiene, that child gets an additional 1927 ILS.

In order for the child to access the allocations, he/she has to fill in the questionnaire dedicated to children with disability and attach the diagnosis that was determined in the report of the general director of the Ministry of Health (look section 2.2 above). The disability application is submitted by the parents, guardian or caretaker of the child. If the medical committee does not acknowledge the status of the child, the parents can appeal the committee's decision. Furthermore, and in accordance with the law, in cases of appeal the parents can access free representation before the court from one of the legal assistance offices of the Ministry of Justice. In addition to the financial allocations, the child, and in accordance with the regulations of national

insurance, is entitled to the receipt of a disability badge that enables him/her to buy a car that is exempt from licensing fees, employ a foreign worker, receive daily rehabilitation care, reduction in phone fees, reduction in house tax fees, entitlement points with income tax, reduction in electricity rates for those entitled 5 points or more, reduction of water fees, exemption from waiting lines and exemption of assistance fees (summary from website of National Insurance Institute, D.T).

In an interview with the director of the National Insurance Institute, she clarified that the child needs to pass two tests; the first is the pathology test and the second is the reliability test. The financial allocation is based on the results of these two tests.

## **2.4 Accrued Tax**

The parents of ASD children are entitled to request tax exemptions from the Collection Department at the Ministry of Finance. Irrespective of the income of the father or the mother, one of the parents is entitled to a tax reduction that can be distributed among both parents if they desire. In this context, the parents have to fill the Request for a Tax Entitlement 116-A form, as well as questionnaire 127, which is the medical form filled by specialists. Additionally, the parents need to attach 100% disability entitlement report from the national insurance.

# **3 Available Services in East Jerusalem for Children with ASD**

This part of the study will present social, therapeutic and educational services available to ASD children in East Jerusalem. This presentation relies on available documentation and interviews conducted with service providers.

## **3.1 Rehabilitation Unit for Children with Disability of the Israeli Ministry of Social Welfare**

The interview with social worker MH, who specialises in the follow-up of autistic children in East Jerusalem clarified a set of services provided by the rehabilitation unit of the family and society services unit. This clarification took place through

the presentation of regulations, rules and laws that were determined by the Israeli Ministry of Social Welfare following interaction with people who suffer from ASD and their families.

The first step undertaken by the social worker inside the rehabilitation unit is the provision of psychological and emotional support to the family, in addition to the preparation of reports and necessary and required tests by the Ministry so as to be passed to the inspector of the autism service section inspector, who in turn refers the report to the psychiatrist of the Ministry. The final decision on whether to acknowledge the case as a case of ASD lies with the psychiatrist of the Ministry. A decision that the child is autistic incurs a set of services provided by the Ministry, including:

- Nursery: children between the ages of 6 months and 3 years who received recognition. In East Jerusalem there is one nursery called Rand in Beit-Hanina for ASD children. It is the only nursery for this age group for ASD children.
- Help and assistance for ASD individuals through the provision of an escort in coordination with the family.
- Convalescent homes: there is the Ayat Al-Quds centre in Ras Al-Amoud area that hosts individuals with ASD for 15 days per year that are renewable in needed cases.
- Summer camps that include ASD individuals whose ages range from 3-21 years and their families. These services are activated by associations and organisations.
- A daily therapeutic centre for individuals above 21 years of age activated by Aloen association.
- Referrals of ASD individuals to internal organisations. There are not any organisations in East Jerusalem that provide services to children; as such, cases are referred to houses in the Northern area.

Also, the families are supported during the different stages of their child's development to acquire the various rights entitled to their children from all organisations, including the National Insurance Institute and the National Health Funds...etc. Additionally, psychosocial counselling services are available to families.

It is worth noting that the diagnosis of ASD individuals takes place over two periods, as follows:

**First:** early childhood period, where the child acquires a temporary entitlement until the age of 6 years.

**Second:** above the age of 6 years, the entitlement is re-conferred based on new

reports and examinations. If the entitlement is acquired it is usually given for life. There are attempts to integrate ASD individuals, including ASD children, in recreational activities in East Jerusalem, whether through the community centres in Wadi Al-Joz or the community centre in Beit-Hanina. However, these experiences are still preliminary (interview with AA, coordinator of the special needs rehabilitation unit in West Jerusalem).

In relation to adults, the unit provides them with protected and semi-protected employment. There is only one organisation in East Jerusalem who follows up cases of the kind (Aloen) that has 9 registered ASD adults, as per social affairs. The unit also provides the service of protected residency. However, there aren't any protected residencies in East Jerusalem for ASD individuals; and Shakel organisation provides services only to people with mental disability and who are associated with the rehabilitation division.

In comparison with West Jerusalem, the presence of nurseries and kindergartens is not a new thing. According to the statistics of the rehabilitation unit, the number of Jewish children acknowledged as ASD children in 2008 reached 300 children, compared to only 4 acknowledged Palestinian ASD children (interview with Mr. Mohammad Abu Sway, ex-director of the rehabilitation unit of persons with special needs). The issue of diagnosis and acknowledgement is continuously increasing. However, a large gap remains between East and West Jerusalem in the identification of and provision of services to ASD children.

AA, coordinator of the rehabilitation unit for people with special needs in West Jerusalem, clarified that there is only one house that serves religious and non-religious Jews, administrated by a religious Jewish organisation in the French Hill in Jerusalem. Additionally, there are hundreds of university students and others who provide household support services in West Jerusalem, when only 60 children in East Jerusalem receive this service. AA attributes the lack of utilisation of Jerusalemite Palestinian parents of these service to the lack of desire of parents to host strangers in their houses in late hours and during the weekend, as well as for other cultural and social reasons. Regarding recreational activities and events, there are numerous Israeli organisations that provide services to these groups in the afternoon through 3 main centres: Alot organisation and Variety centre in West Jerusalem and Tshma' organisation for religious children (website of Ministry of Social Welfare, DT).

## 3.2 Diagnostic and Therapeutic Services

The first Child Development Centre in East Jerusalem opened in 1996 in Sheikh Jarrah neighbourhood. Then, the Israeli organisation Shakel administered the centre, while a social worker from the social welfare office worked at the centre to follow-up cases. Before 1996, parents had to undertake diagnosis in West Jerusalem. After that, the Ministry of Health took charge to manage and fund Child Development Centres. In 1998, National Health Funds commenced in establishing Child Development Centres, followed by the creation of placement committees to direct children to rehabilitation and educational organisations, including for ASD children (interview with MAS from the rehabilitation of people with special needs unit). Nowadays, all Child Development Centres in East Jerusalem are supervised by the Ministry of Health, which grants them requisite licenses.

In an interview with MA, a director of one Child Development Centre in East Jerusalem, he elaborated on the presence of 3 centres that provide services to children in East Jerusalem:

- 1 Clalit Child Development Centre provides its services to the children of the fund and has a branch in Kufr Akab neighbourhood. The centre provides services to the children of the fund as well as specialised services.
- 2 Maccabi Child Development Centre is a relatively small centre compared to the size of the fund in East Jerusalem.
- 3 Child Development Centre in Shu'fat area provides services to all National Health Funds (Clalit, Maccabi and Meuhedet), as well as to individuals who are not affiliated with any of the funds.

Additionally, the Jerusalem Children Association for Autism, a small association in Kufr Akab in its final licensing stages provides therapeutic services (music therapy, occupational therapy and communication therapy) to Palestinian children who are not necessarily Jerusalemites.

According to the Israeli National Health Laws No. 43 and 48, every ASD child is entitled to weekly therapeutic care that decreases as the child gets older, whose expenses should be covered by the National Health Fund without delay. Furthermore, every ASD child is entitled to dental care with full anaesthesia, with an exemption of payment of fees when visiting specialised doctors (Alot, 2015). Table (3) reflects the refundable amounts that parents receive if they receive special care from an accredit source (previous source).

**Table 3: Costs of Basic Treatment**

Treatment	Refundable Amount
Meeting with Social Worker	151 ILS
Speech Therapy	198 ILS
Occupational Therapy	198 ILS
Physiotherapy	215 ILS
Psychiatric Treatment	240 ILS

Child Development Centres generally provide services to children until the age of 9, where children receive unlimited sessions until the age of 3 based on the medical and performance needs of the child in accordance with the medical reports that vindicate this. Between the ages of 3 to 6, each child is entitled to 27 therapeutic sessions in each field annually. Each child, until the age of 9, is entitled to annual therapeutic sessions (interview to MA, a director of the child development centre in Shu'fat).

Regarding somatic children, who do not demonstrate any significant progress during treatment and who suffer from the disorder all of their life, they are entitled to therapeutic services until the age of 18, including ASD, cerebral palsy and Dawn syndrome children. The parents of ASD children pay an average of 30 ILS for every treatment their child receives after the age of three; this amount is non-refundable irrespective of the number of the weekly sessions. The fund covers the gap in the cost of the therapeutic sessions. This sometimes poses as a financial burden on the families (previous source).

Regarding medical and psychological diagnosis, MA thinks that the time required to run the tests depends on the fund itself. Whereas it takes a maximum of 1 week to run the tests in Clalit Health Fund, it takes several weeks in Meuhedet Health Fund and more than a month in Maccabi Health Fund. He attributes this to the presence of integrated tests in Clalit Health Fund, whereby the family can meet more than one specialist or can meet a physician specialising in one more than one aspect, compared with the other National Health Funds.

In comparison with West Jerusalem, we found 3 main differences. According to MD from Clalit Child Development Centre and NS a director of one of the ASD frameworks in East Jerusalem, Jewish families are more aware of their rights compared to Palestinian Jerusalemite families, and hence they are more successful in accessing and

benefiting from available services. Furthermore, the number of Child Development Centres in West Jerusalem far exceeds that in East Jerusalem compared to the number of residents, in addition the presence of all National Health Funds, including Leumit. In light of the presence of more specialised therapeutic and professional cadre and in higher numbers, the cadre can complete diagnosis more efficiently and effectively, compared with East Jerusalem, such that in East Jerusalem, the number of specialised doctors is very little compared to the needs. For example, there is only 1 neurologist who provides services to the patients of the Clalit Health Fund only. Also, there is a shortage in the number of clinical psychologists, compared to West Jerusalem, who are capable of diagnosing ASD and writing necessary reports.

MA, a director of a Child Development Centre, adds that the number of specialised therapists in physiotherapy, occupational therapy, arts therapy, music therapy, communication therapy and other types who hold Israeli licences has been rising over the past years. Nonetheless, there is still a gap between the number of therapists in this field and the real need on the ground. The report submitted to the research and information centre in the Knesset (Israeli legislative body), reflects a clear shortage in the number of Palestinian therapists, amid religious Jews in different fields working with children with special needs, whether in schools or Child Development Centres, including with ASD children (Faisplay, 2015).

### 3.3 Educational Services

The predicaments facing special education schools in East Jerusalem do not differ significantly in many aspects between primary and secondary schools. Our visits to organisations and schools revealed that all ASD schools under the administration of the Jerusalem municipality are rented schools that were originally designed as residential instead of educational buildings. While all educational services for ASD children are provided inside the Wall, not one educational organisation is accredited outside the Wall in Kufr Akab, Shu'fat refugee camp and Beit Ounah, such that all children classified as ASD children have to commute to inside and outside the Wall to access educational services, or alternatively have to give up this burden in search for virtually non-existent alternatives in the West Bank. It is worth noting that more than 55 thousand Palestinian Jerusalemites live outside the Wall (Abu Arafah, 2016).

Table (4) presents the names of educational organisations working with ASD children and those suffering from communication disorders, as well as some physical and professional information in East Jerusalem.

**Table 4: Accredited educational organisations that provide educational services to ASD children**

Name of School and Real Estate Status	Number of Children and Age	Cadre	Number of Classes
Basma School; rented house that was renovated to accommodate the needs of the children	100 children; 7-21 Years	70 Employees (45 educator and complementary teacher; 20 assistant, administrative employees, occupational therapists and communication therapists)	9 Classes
Basmat School; rented house; residential house	28 children in first grade; 6-8 years	10 teachers and 4 therapists (2 occupational therapists and 3 communication therapists). 10 assistants and supportive staff	4 Classes
Sanabel Kindergarten for Special Education; rented house and small rooms	59 children; 3-6 years	75 employees (27 educator and complementary teachers; 32 assistants; 4 communication therapists; 4 occupational therapists; 3 behavioural guides; 1 social worker; 1 psychiatrist; 1 music therapist; 1 motion therapist; and 1 neurologist) in addition to the administrative staff	13 classes

<p><b>Princess Basma Organisation;</b>  an owned organisation and a wide physical environment suitable for work compared with other frameworks</p>	<p>19 students;  6-9 years;  some of them integrated in the ordinary framework</p>	<p>24 employees (2 educators; 2 complementary teachers; 4 assistants; 16 occupational therapists, physiotherapists and communication therapists; water therapy; music therapy; and psychological therapy); in addition to the administrative staff. There is a rehabilitation centre in the Princess Basma organisation that provides a large set of therapies to children from inside and outside the organisation</p>	<p>2 classes</p>
<p><b>Rehabilitation Kindergarten Rand (private house);</b> previously used as a maternity hospital</p>	<p>12 children (6 months-3 years)</p>	<p>11 employees (2 teachers, 2 assistants; 5 therapy specialists: speech therapy, physiotherapy, occupational therapy, nutritionist and behavioural therapy; in addition to the administrative staff)</p>	<p>2 kindergartens</p>
<p><b>Al-Zaytouna Kindergartens;</b>  rented building</p>	<p>30 children;  3-6 years</p>	<p>30 employees (8 educators and complementary teachers; 5 therapists; 20 assistants; 1 psychiatrist; and administrative staff)</p>	<p>4 kindergartens</p>

The number of children studying in ASD schools in East Jerusalem far exceeds the number of registered children in the social affairs bureau. When asked about the reasons, school principals and coordinators of rehabilitation units clarified that there is a number of students who are still at the different levels of their classification and are yet to be considered ASD children, in addition to that there are communication classes in ASD schools for children with communication and language problems.

In addition to both official and non-official organisations in the table above that are accredited by the Israeli Ministry of Education, a number of additional organisations that work on the development of the situation of ASD children, provide therapeutic services, work on increasing the awareness of the society in ASD issues and provide alternative services to those provided by the government were identified, including:

- **Jerusalem Autistic Child Care Organisation:** is a non-profit organisation established last year to facilitate the integration of autistic children into society, raise the awareness of the society towards ASD, create participation opportunities for ASD children in social events and activities and integrate in the business world following the preparation of the society (from the website of the organisation). It is an emerging organisation that is diligently striving to provide services to ASD children, their families and the Jerusalemite community needs (interview with Mr ST; a founder of the organisation).
- **Jerusalem Children Association for Autism (Kufr Akab):** is an Israeli accredited institution (according to the director of the organisation in an interview with the researcher) that commenced work in Kufr Akab (outside the Wall) in 2015. It lies in the first floor in an old apartment building and consists of two therapy rooms, an entrance, lobby and small non-rehabilitated garden. The status of the institution is poor according to the assessment of the researcher, with weak lighting and cold, humid and unorganised atmosphere. This organisation works 5 days a week in specified hours. 3 therapists licensed by the Ministry of Health provide music therapy, occupational therapy and communication therapy for children living in Kufr Akab, Am'ari refugee camp and the Ramallah area. The association currently provides services to 16 children (7 children from East Jerusalem and 9 from the West Bank). The parents sometimes cover the expenses of the therapy, while in other times some benefactors cover the therapy expenses, especially for those coming from the West Bank. The association also raises the awareness and provides guidance to parents in working with their children and complementing the therapy within their households.
- **Alot Association:** is an association established by the parents of autistic children in Israel. It provides services to autistic children, teenagers and adults. It provides services to more than 12,000 families and works in helping children and their parents access their rights, develop new services that help individuals and their parents and encourages scientific research and dissemination of knowledge in the field of autism. Alot association contributes to the development of 3 aspects in the schools of the Ministry of Education: develop the knowledge and skills of staff working in the field of ASD through trainings, counselling through

workshops and provision of a supportive framework for parents through trainings and educational workshops, and through the provision of therapeutic hours and provision of therapy for children in these frameworks (website of the association).

- **Kul Al-Haq:** is a non-profit Israeli organisation that seeks to disseminate legal knowledge to citizens through the provision of an information bank that facilitates acquisition of knowledge of rights and methods of accessing them. The organisation translates necessary legal material in the field of ASD, as well as other fields, to Arabic for the benefit of those who need this information. Note: translation of introductions and interfaces is available in Arabic; however, the majority of the presented documents on the Arabic page are in Hebrew (website of the organisation).

Compared to West Jerusalem where ASD and special education schools are eligible schools to provide services for people with special needs, ASD schools in East Jerusalem are schools located in buildings that were built for residential purposes instead of for educational purposes, such that the infrastructure of these building compromises their eligibility to provide optimal services. The rooms are small; also, these isn't a safe and healthy space for playing and movement, in addition to the absence of yards to transform and make use of them in a better way and limited rehabilitation rooms for therapy, is a striking difference to the situation in West Jerusalem. The Jerusalem Municipality prefers to rent residential buildings and rehabilitate them to function as schools, rather than build schools in East Jerusalem, unlike the reality in West Jerusalem.

The children commute between both parts of Jerusalem through special transportation, but children coming from outside the Wall suffer from difficulty and the burden of transportation. This comes within the context of the absence of any educational or therapeutic frameworks for ASD children outside the Wall, in a direct reflection of the indifference of the Ministry of Health, Ministry of Education and the Jerusalem Municipality towards these areas (Hijazi, 2016).

## 4 Results and Conclusions

### 4.1 Major Challenges Facing Educational and Therapeutic Organisations

#### 1 Physical (Spatial) Environment

Through the observation of schools and kindergartens visited by the researcher, and based on the interviews with schools principals and parents, it is clear that the educational and therapeutic frameworks do not meet best standards to work with ASD children, particularly since they have enormous needs and the work environment constitutes a major component in the success of any educational or therapeutic programme. As indicated before, all ASD frameworks in East Jerusalem are rented residential buildings, except that of the Princess Basma organisation.

Despite the relative satisfaction of the parents regarding the performance of the teachers and the therapists in the majority of the educational frameworks, the vast majority of them do not consider the frameworks their children study in as healthy ones that meet the needs of their children **“let me tell you the truth; when I go to visit them I feel that the place is similar to a prison. They are 8 children and their number is not big; there are curtains, heating, carpets, pictures, cards and individual therapy rooms, but not like this: the rooms are small and have teachers and assistants in them. Imagine if the social worker or therapist enters, not to mention the closets of the children in the same room.”** Another mother, whose child studies in an ASD kindergarten, adds **“despite the presence of sound insulation, curtains and visual and audio presentations, there is need for development. Autism children do not need to do mathematics...they need to jump and move freely, and they cannot do that because the class is small in size.”** **“The environment is unsuitable; the teachers work within their capabilities; God bless them; but really the size of the classroom does not exceed 2 meters by 2 meters; they need larger classes and a richer class environment.”**

#### 2 Rehabilitation of teachers and therapists

To measure the suitability of the rehabilitation component that teachers who graduated from universities and colleges and who work in ASD schools and frameworks in East Jerusalem, academic programmes and courses were examined,

and focus groups were conducted with teachers working in these frameworks. All education colleges and universities that rehabilitate teachers for special education (Al-Qasimi, David Yelen College, Al-Quds University, Al-Quds Open University) teach one course on autism and mention the phenomenon in the introduction to special education course. When we analysed the content of these courses, we found that students acquire general information in this course about the phenomenon, as well as theoretical diagnosis tools and work strategies. One teacher who participated in the focus group discussions and reflects the opinion of more than one teacher, said **“The course only helped me by 20%, because autism is very vast and general. Each student is a special case and we in the kindergarten teach each student something different. I have 6 students in my class but they are not of the same level.”**

Furthermore, complementary teachers in special education do not receive any specialised clinical course in ASD, irrespective of the college they are affiliated with. All of those working in colleges are graduates of special education colleges, psychology and related specialisations; however, there is not one teacher who specialises in working with ASD children. School and kindergarten principals working with ASD children face immense challenges in working with special education college graduates **“If I want to compare between the rehabilitation that I received as a person who studied in an Israeli institution and undertook my training in an Israeli organisation, and recalled the vast amount of knowledge and experience that I received there, I emerged from this period strong and with rich knowledge in this field, in addition to that I continuously worked and developed myself...until today there is not any new book in the field that I did not read.”**

Principals suffer from the new orientation method. Principals claim that inspectors abide by the law in designating teachers to schools in accordance with precedence instead of competence. Hence, many teachers arrive to the school with limited experience, and sometimes no experience at all in the field; **“The teacher arrives after the designation of the inspector because no other jobs are available. We as a school and they as teachers find it difficult to deal with this. Most of those referred work for a short period of time and leave the job or finish one year of work one way or another and are transferred to other categories of special education.”** Newly appointed teachers agree with their principals on this and attribute their knowledge in the field to the training and continuing education they received during their work years in the schools; **“I did not apply concepts relating to ASD in college to fully understand what autism is. When I entered the school I thought I’ll find every child in a corner, in their own special world. But when I saw the situation I found that it was opposite of what I have imagined. The situation is different there; there is communication there but it is difficult; the situation was not clear to me previously.”** When the teachers

presented their needs in order to improve their professional performance in the field of ASD, it was clear that professional supervision over their work and acquisition of clinical experience through discussion of cases in a multidisciplinary framework is the optimal strategy to real knowledge; **“There are children, despite the long times that I interact with them, who I find it difficult to deal with...it is not like I do not accept them, but there remains something that decreases my professionalism with them. I feel that I should work on myself first, which is far more important than theoretical knowledge, so that I can accept all autistic children equally and at all levels...so I want to add that there is a need to discuss cases that we work with, each time focusing on one child, and to undertake a multifaceted discussion. There should be a law that forces schools to do this, just like in West Jerusalem.”**

## 4.2 Major Challenges Facing Parents in East Jerusalem

### 1 Guidance, Counselling and Social Support:

One of the biggest challenges that face parents is their emotional preparation for when they discover that their children suffers from ASD. Parents explained that they were familiarised by the rights of their children through various sources, including Child Development Centre, social worker in the school, Matia centre, social affairs office, neurologist and the medical committee. It was also clear that the period between the visit to the family doctor to undertaking the diagnosis and publishing the report took between a couple of weeks to a month at the latest. This reflects a similar period taken to complete the administrative work of determining and writing the diagnosis in East Jerusalem compared to clarifications given by Jewish families in West Jerusalem.

There was not sufficient guidance and counselling by specialists who diagnosed the case in its early stages **“At the beginning, the child development centre was good in terms of diagnosis, but in my perspective as a mother, the centre did not give sufficient counselling to parents. I believe that they have to prepare parents to accept that their children has a problem, clarify the nature of the problem and increase their awareness as they were the ones who diagnosed the child. They should also ask for the parents to have another member of the family, so that the mother and father are not alone, since the news poses as a big shock to the parents.”** Another mother says that the explanation was very shocking to her and that the committee did not present the situation to her as they should have. There was not sufficient explanation about the situation of her son for example; **“They told us about the situation generally...that our son had autism and was different**

from other boys of his age, that he requires medication. This was because they considered it a normal thing and they asked us to have faith in God and they tried to lift our spirits. But in reality, regarding the report, we were told about the situation without giving recommendations, even though this was a new situation to us and we would hold tight to every word they told us to know how to act, since it was a new situation and we did not have experience in it." Another mother talked about this predicament "...they did not explain anything to us...I went by myself and looked on the internet to know how to help and act with my daughter; they left us to the wind without explaining anything to us or raising our awareness to enable us to absorb the shock. This situation leaves us to determine how to act based on this information after the shock fades off, instead of telling us what we should do and what we should not do...they have to put counsellors to parents to guide them in how to act."

## **2 Small number of treatments available in schools and their cost that poses sometimes as an economic burden on parents:**

Schools in East Jerusalem do not receive the upper limit of any entitlement in any of the frameworks, which stands at 3.4 therapeutic weekly hours. Also, the number of therapists and specialists is insufficient in some of the specialisations, such as behavioural therapy, animal-assisted therapy and physiotherapy to cover all of the hours. Even though the therapy hours came close to reaching the upper limit in some frameworks (interview with 2 school principals and a conversation with NH, the principal of a kindergarten in East Jerusalem), the Princess Basma school, and due to external support, is the only one that exceeds the upper limit of therapy hours to reach five hours a week or more, according to AMJ, director of rehabilitation at the school. He also added that it is the only school that provides water therapy, as it has a special pool inside the building. One mother says **"They give them speech, occupational, behavioural, motor and animal-assisted therapy... but it does not matter...every 3 to 4 months they ask us to come and attend a session of our boy, provided that the time works for us and the circumstances allow us...these issues need continuity...you cannot just give them for a short period of time and without continuity."** Another mother talked about her satisfaction with the intensity of the treatment **"They receive treatments but the period between one treatment and the next is two weeks which is very far...they also receive small amounts and there is not any continuity or satisfaction...they need at least two to three treatments per week. They take behavioural, motor, animal-assisted and alternative communication treatments, and they send in the communication notebook that the child received their treatment...I ask my daughter and she**

tells me that she received her treatment...but still, what is wrong with increasing the number of treatment sessions?" It was clear that the majority of the parents consider treatment hours given to their children as insufficient, especially that some treatments, like the horseback riding treatment and other treatments are only available in West Jerusalem and costs the family very high costs, including the time they spend with their children and the cost of transportation "One speech therapy session every two weeks, one music therapy session every two weeks, behavioural therapy sessions barely once a month...this is very little for children with autism who need diligent continuous work. But like I told you, this is what the school provides, and what I can provide to my son I do it from external sources." "Doing tests in West Jerusalem requires the presence of the father, which requires him to take the day off from work...the same thing applies if the child needs to take treatment there."

Treatment costs pose as a burden to parents, such that they pay 2000 ILS annually in return for the treatment that the child receives from Alot Association, in addition to the personal contribution to every treatment (an average of 30 ILS per session), as well as the additional costs of complementary special therapy whose costs are sometimes completely covered by the parents "You know even though we live in the camp, I looked for a long period of time for a speech therapist and I finally found one. He used to take 200 ILS per session and the child used to take 3 sessions per week; that's 600 ILS per week and approximately 2,400 ILS per month only for speech therapy, which is not available in the camp. This is also putting aside referrals, each of which costs 29 ILS and does not cover transportation or anything else. When I am late to get back home sometimes I bring ready-made food with me and I leave my four children at my sister in law's house."

Compared to West Jerusalem, it was clear the level of satisfaction of interviewed parents from West Jerusalem that they were more satisfied about the provided services and physical environment, compared to their East Jerusalem counterparts "The framework is very good...parents are asked to meetings with counsellors and educators to discuss individual work plans; there is an ordinary kindergarten close to the school where my son integrates...I am satisfied with the quality and quantity of treatment that my son receives: communication therapy, occupational therapy, music therapy..." another mother says in the same framework "The school does everything they can possibly do; there is a weekly meeting in the school to examine and review the case of the child...I am completely satisfied with the physical environment that my son studies in."

### **3 Lack of special treatment in East Jerusalem: the time problem and language barrier:**

Reports are given to parents in Hebrew; therefore, many of them need for the report to be translated to Arabic **“when the report arrived, it was in Hebrew...I could not understand a thing...my husband read it and explained that our son has autism and has allocations now, and that we should contact the Child Development Centre or Matia organisation.”**

Going to West Jerusalem sometimes causes problems for some families, because of the language barrier and personal variables of the difficult economic situation **“Doing tests in West Jerusalem requires the presence of the father, which requires him to take the day off from work...the same thing applies if the child needs to take treatment there,”** or due to personal circumstances resulting from the political security situation **“I go to Variety centre every Monday, which is 4 times a month, because it is most intensive and to try a new approach...the problems that face us include the language barrier, difficulty in leaving my children at home by themselves, fear because of the political situation, the long distance, the pressure because the child takes three sessions in a row and I pay for all of them because my husband had to leave his work to help his mom and because we don’t have any other choice.”**

In West Jerusalem, the interviewed mothers express their satisfaction at the level of additional treatments available that their children receive. One mother says **“My son receives animal-assisted therapy, external therapy and therapy through horseback riding.”** Even though the level of satisfaction of available services is high, one mother says **“The provided services are less than what is required and the State has much to do.”**

### **4 Lack of specialised doctors and long waiting periods for tests**

There is a real problem in the availability of specialists to treat autism issues, including neurologists and evolutionary medicine specialists, among others. Parents clearly suffer from the lack of specialists, which poses as a main hindrance in the provision of timely treatment and receipt of documents that parents need to follow-up the entitlements of their children **“Sometimes appointments are delayed for months to receive treatments...sometimes I miss school deadlines to provide medical reports that should be submitted to official institutions...I do not have a choice but to submit them until the appointment is made according to their timetable...they do not take into consideration that we are in a hurry or that our children have special circumstances...no concessions at all.”** Another mother talks about her despair at the scarcity of specialists **“There are very long waiting lines; when you schedule**

**an appointment with a specialists you have to wait 7 months, or when you ask for the neurologist appointment to get the report, we are not referred due to the waiting line that requires months to complete...even though these periodic tests are important to our children."**

Jewish mothers in West Jerusalem did not mention or talk about this challenge, as they have not mentioned in their interviews any difficulty in accessing medical services. They mentioned that there were some problems in the initial acknowledgement stage, but no problems were mentioned with governmental institutions and National Health Funds after this stage.

## **5 Checkpoints and Movement Difficulties**

The issue of military checkpoints and the Wall, as well as the absence of medical services and ASD specialised schools outside the Wall renders a truly tragic situation for ASD children and their parents. One mother says **"My biggest problem is that my house is in the camp outside the Wall and is far from the main street...there is not any infrastructure and the roads are not paved. I go out to take my son to the main road at 6 in the morning when it is still dark and I have to carry him on my shoulder because he is still sleeping. The situation is particularly difficult if it was raining as we get wet and dirty...the child might also get cold and sick so in the winter I always send with him extra clothes so that they will change his clothes for him when he reaches the school."** Also, the lack of therapeutic services in areas outside the Wall makes parents that we've met contend with what is available at the school even though they know that their sons require a bigger quantity of therapy. This is attributed either to the presence of more children in the family that require the mother's attention or because of movement difficulties. One mother says **"Because we live outside the Wall like I told you, we are happy with the services provided in the school. My son registered in an educational class and receives treatments from Alot organisation, so I will have to pay for the additional treatments...I personally do not know what is available and I don't know Hebrew and would rather not leave my children or ask my husband to leave his job and take me and my child there."** Another mother says about the same problem **"I am not doing enough because I have other children at home and I live in Kufr Akab and there is not anyone to help me to stay with the boys...so I either have to take all the children with me or I have to give up some sessions...especially that they do not provide transportation for us so we have to go in the very difficult public transportation."** These are the challenges mentioned by the director of Jerusalem Children Association for Autism, where she expressed her knowledge as a teacher in the Beit Hanina area that parents

living in Kufr Akab prefer to find solutions in their area, because commuting to West Jerusalem is like "hell."

In an interview with the director of the National Insurance Institute, she clarified that there is a real challenge in areas outside the Wall in terms of provision of services, such that provision of evidence of the centre of life and the absence of the post office play a major role in delaying access of individuals to entitlements. Furthermore, Jerusalemites living outside the Wall need to prove their Jerusalemite identity in order to access entitled services.

## **6 Cultural Dimension**

This dimension did not emerge sharply in the interviews conducted with the parents, such that the interviewed families discovered the phenomenon during the first two years of the child's life, and the medical consultations and diagnosis commenced at an early stage. But in some cases, the predicament of accepting a child with special needs in the family and the social stigma pose as a hindrance for parents to provide services to their children. One mother says about her husband who does not want to provide treatment to their daughter and acknowledge that she has autism **"We receive the entitlements of her disability...but my husband does not even want to believe that his daughter is autistic...but we receive a reduction in the property tax. If my husband knew that we are entitled to tax refunds he would not want to take it...he is affected mentally that he is getting money for his daughter! He keeps saying that we'll save this money so that when she grows up she will be able to take care of herself."**

This dimension emerged in an interview with the school principals, when they discussed the issue of social integration of ASD children **"on the level of Jerusalem, I have been working on the issue for 3 years in guidance and counselling to Jerusalemites about this group of students...what is most important today is the medical centres...it is very upsetting for parents to see the reaction of the doctor or the people in the waiting area when they ask them "why did you bring this child with you?" which is embarrassing for mothers."**

## 5 Recommendations

### 1 On the Policy Level

#### 1-1 On the Israeli Policy Level

##### 1-1-1 On the Level of the Israeli Ministry of Health

- 1 Provide professional cadre for diagnosis and treatment: the quantitative shortage in the number of Child Development Centres in East Jerusalem was evident in the study; also, there is a severe shortage in the human cadre that has the ability to diagnose ASD, such that the preparation and rehabilitation of Arab diagnosticians residing in East Jerusalem and outside the Wall is insufficient to address these medical cases professionally. Furthermore, there is a very small number of Arab therapists and specialists who are able to provide treatments to this group of students.
- 2 Provide additional Arabic language speaking frameworks in East Jerusalem that provide complementary treatments to ASD children (horseback riding treatments, art therapy...etc) to facilitate access of parents to these services and to solve the language barrier and transportation predicament that sustain parents a high economic load.
- 3 Provide licenses to open Child Development Centres in areas outside the Wall as the Centre present in Kufr Akab is a branch of the Clalit Child Development Centre in Shu'fat, and does not provide all the services that ordinary Child Development Centres provide; furthermore, there is not a Child Development Centre in Shu'fat refugee camp.
- 4 Increase the number of neurologists and therapists working with children who have the ability to diagnose and provide psychological and medicinal treatments. This comes within the context of the increasing scarcity of specialists, which consequently increases waiting time to access services and decreases the number of children identified at the Ministry of Health and the National Insurance Institute as ASD children, as well as delays the receipt of therapy for children and obtainment of necessary medical reports.
- 5 Increase supervision and inspection: there are policies related to the number of treatment hours entitled to an autistic child; these policies require monitoring and follow-up in terms of degree of applicability by the Child Development

centres, National Health Funds, individual specialists and therapists and schools, in order to ensure the quality of the provided service and the duration.

### **1-1-2 On the Level of the Israeli Ministry of Education**

- 1** Rehabilitate special education teachers working with ASD children, as well as new therapists and educational counsellors working in the field: the results of the study shows that teachers and therapists lack sufficient practical experience in working with this group of children. The same applies to educational counsellors who do not acquire sufficient knowledge within their university qualification to work with ASD individuals; therefore, it is important to complement and bridge their knowledge in this field.
- 2** Optimal utilisation of the treatment hours provided by the Ministry of Health. This requires increasing the number of therapists especially in the complementary treatments fields and provide treatments in school. It is important as well that there is communication and coordination about the treatments received by the child in the school and the treatments received in the Child Development Centre.
- 3** Work with the Jerusalem municipality and oblige them to provide appropriate infrastructure to work with this group of children, and provide between treatment and learning environment compared with West Jerusalem.
- 4** Open educational and therapeutic frameworks and centres outside the Wall: the study reflected the absence of educational frameworks providing educational and therapeutic services outside the Wall, with the exception of one small centre in Kufr Akab that attempts to provide services to Jerusalemite and West Bank children.

### **1-1-3 On the Level of the Israeli Ministry of Social Welfare**

- 1** Increase the awareness of parents of rights and services: in addition to the intervention undertaken by the social workers in the social welfare office in Jerusalem following the arrival of children for acknowledgement of their condition, they can increase awareness about the possibility and importance of early diagnosis and provide the necessary information to parents about their rights.
- 2** Encourage parents to make use of available social services, including participation in awareness-raising workshops, enrolling their children in social clubs and activities, and benefit from the services provided by the service development for

people with special needs unit, such as safe and private houses in East Jerusalem.

- 3 Increase working hours with parents towards accepting the idea of welcoming professional assistants into their homes to relieve them off the burden in caring for their children in afternoon hours and the weekend, as well as recruit university students and relatives to do the work (provided that the work is financially remunerated).
- 4 Provide sufficient professional cadre of social workers: the study, alongside other studies, demonstrated that the number of social workers does not cover the bare minimum to meet the needs of Jerusalemites. This is the case in the service development for people with special needs unit. Therefore, it is important to provide a higher number of social workers to follow-up the needs of acknowledged ASD children, and help a bigger number of parents in getting recognition and accessing their rights.

## **1-2 On the Palestinian Policy Level**

- 1 Work towards the enactment of legislation that provides basic protection to ASD children and regulates the role of the State towards these children on the medical, educational and rehabilitation levels.
- 2 Enact laws that oblige and facilitate the rehabilitation and integration of ASD individuals in the society and labour market.
- 3 Open specialised centres to diagnose and treat ASD in East Jerusalem, particularly in areas outside the Wall, to provide services to Palestinian Jerusalemites carrying a blue identity card on one hand and Palestinians living outside the Wall on another hand.

## **2 On the Level of the Israeli Jerusalem Municipality**

- 1 Build more suitable schools than those where ASD children currently study, which do not meet the bare minimum of the legal standards and in comparison with the schools in West Jerusalem.
- 2 Rehabilitate current schools to meet the needs of the students, whereby parents and teachers have clarified their lack of content and satisfaction with the current status of the schools and the unsuitable physical environment that students learn in.

### 3 On the Level of Palestinian Universities

- 1 Improve university rehabilitation programmes: the results of the study show that students learn about ASD either through general specialisation courses or as part of a general course in the introduction to special education. It is therefore important to develop these courses and their content to become more specialised and enable students to become more familiarised in the areas of diagnosis, treatment and methods of work.
- 2 Since the study demonstrated a gap between the rehabilitation teachers and therapists receive and the current situation in working with ASD children, universities should provide more specialised programmes, as well as specialised training frameworks for special education professionals and teachers. Additionally, there is a need for clinical supervision frameworks based on case studies.
- 3 Create a research unit to develop the ASD field in terms of diagnosis, intervention, programmes and awareness-raising, as is the case of Israeli universities including Ben-Gurion University of the Negev and the Hebrew University of Jerusalem.

### 4 On the Level of Funding Organisations

- 1 There is a severe scarcity in clinical and educational ASD research in Palestine and Arab countries. Therefore it is important to commence in supporting the undertaking of studies to develop educational knowledge that contributes to raising the level of education in colleges and universities. It is possible to examine the undertaking of one Palestinian university of a number of studies in the field or in the establishment of a research specialising in ASD.
- 2 Support Palestinian universities that teach courses in this field to raise their clinical knowledge and capacity, since the university teachers of ASD courses are predominantly specialised in special education and do not have sufficient specialised knowledge in ASD.
- 3 Provide support in developing or opening a specialised multidisciplinary centre to diagnose and provide treatments to ASD students.
- 4 The study demonstrated the lack of content of the parents and school principals of the rented buildings and small classrooms used, as they are not suitable to provide optimal services. Therefore, it is important to intensify work with

the parents' committees, mobilise and guide them to demand their rights in providing better learning environments for their children. Additionally, it is necessary to undertake advocacy to build schools for Jerusalemites that meet their demographic proportion, as well as increase the number of Arab specialists working in National Health Funds.

- 5 In this regard the absence of official services in areas outside the Wall was clear and that Jerusalemites suffer from difficult commuting and access to services. Therefore it is necessary to consolidate efforts and advocate to provide necessary services outside the Wall, as well as specialised schools, kindergartens and therapeutic frameworks to support children and parents.
- 6 There are two organisations that provide therapeutic and awareness-raising services to ASD Jerusalemite children, as well as to children outside the Wall. It is important to support grassroots organisations and help them to deliver and develop services in marginalised areas. It is also possible to support schools and organisations to increase grassroots awareness on social integration through the development of written, computerised and televised awareness-raising sources.

**Part 2:**

# **Attention Deficit Hyperactivity Disorder (ADHD)**

# 1 Definition and Data

Attention-Deficit Hyperactivity Disorder (ADHD) is defined as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterised by mild, moderate and severe levels of severity. (DSM5)

The classification of ADHD within the framework of progressive neurological disorders is considered a major shift in the perceptions of specialised authorities towards the disorder. This comes within the context that the previous classification of mental disorders by the American Psychiatric Association's diagnostic scheme (DSM-IV-TR) classified the disorder at a behavioural level. More recently, extensive research and studies of ADHD have yielded a recommendation to revise the DSM-5 index and classify this disorder under developmental disorders. This change recognises that the disorder experienced by the individual directly affects his/her performance, where sometimes his/her behaviour is out of control and could last a lifetime.

The majority of teachers, (interviewed in the ADHD focus group from East Jerusalem), also agree that children with ADHD do not necessarily have low IQs. The intelligence of people with ADHD ranges from average to high, and their low academic achievement is not a result of their mental abilities but the disorder, and this is consistent with numerous studies (Yehudit, Aldor, 2013; Sharon, Asef and Others, 2008). Children with ADHD are intelligent, have arguments for everything, they are sometimes mature and precede their generation (from interviewing the mother of a child with ADHD from West Jerusalem).

In children with ADHD, there are difficulties in executive functions, which includes difficulties in self-control, curbing impulses and reactions, working memory, balance of breath, organisation and planning, solving problems and developing strategies (Barkley, 1997; Willcutt, 2005).

Worldwide prevalence rates of ADHD vary between 5-10% (Lecendreux, Konofal, & Faraone, 2011; Akinbami et al., 2011). In Israel, the percentage of people diagnosed by the physician, as individuals suffering from this disorder, ranges between 6-10% (Cohen, 2013). School principals, both in East and West Jerusalem, believe that percentages can be as high as 20-40%; however, due to lack of diagnoses, only 10-15% of school students are diagnosed. **"The educational staff believe that there are many students who suffer from ADHD, but many are not diagnosed"** (from an interview with ShH, a school principal in West Jerusalem), while in East Jerusalem only 1% of students are diagnosed (interview with a school principle in East Jerusalem). There is a significant problem in diagnosing this disorder as well as being recognised by the

National Insurance Institute (interview with the head of disability at the National Insurance Institute in West Jerusalem).

The prevalence of the disorder by sex between males and females in childhood is 1: 3, while the ratio in adolescence is 1: 6. The higher ratio of males with ADHD is due to the visibility of hyperactive-impulsive symptom among males (Or Noy, 2009).

The symptoms of the disorder in teenage years are less common in 65% of people who have been diagnosed as children with ADHD in their childhood. Although not all symptoms disappear, adolescents have acquired skills to cope with this disorder, which in turn increases their performance and their ability to control certain symptoms. (Faraone, Biederman & Mick, 2006). The symptoms of hyperactive are often declined, while inattentive and impulsive symptoms remain the same (Kordon, Kahl & Wahl, 2006).

60% of those diagnosed as children with ADHD in their childhood, they experience difficulties in adapting to work, driving, interpersonal relationships, and emotional difficulties as adults (Bernardi et al., 2012; Able et al., 2007).

The failure of parents to seriously deal with this disorder in children leads to the development of other behavioural-emotional disorders; which consequently negatively impacts their children on education, life skills, and work levels. Therefore, it is important to immediately conduct a proper diagnoses if there is a suspicion of symptoms of ADHD, and to start the implementation of the therapeutic plan to avoid any negative consequences.

A person may experience other disorders alongside ADHD such as anxiety, depression and falling behind academically (Larson et al., 2011). The same study showed that 46% of children who suffered from ADHD had learning difficulties.

Due to the overlap between ADHD and other disorders and the consequent results on the diagnosis and treatment later, the Ministry of Health issued the Director-General's publication (2010/40) requesting the attention of all diagnosticians to cases of ADHD alongside other disorders and requiring that the diagnostician carefully examine the various disorders before diagnosing the child as having ADHD.

If necessary, the child should be referred to consult with specialists in specific disorders. If the diagnosis is made by a specialised psychologist, he/she must act in accordance with the policies set out in the Director-General's publication (2010/40) and transfer the child to a doctor specialised in diagnosing and treating children with ADHD, in order to rule out other disorders and give the best medical treatment (Ministry of Health, publication 2010/40).

Emphasising the need for caution during the diagnostic process, one of the mothers

shared her son's personal story of how the doctor diagnosed her son and followed the required procedures to confirm the diagnosis **"They referred us to see the psychologist clinic within a month of the accident and then they referred us to the clinic in West Jerusalem for Hyperactivity. It took a year and eight months for the doctor to confirm that my son had hyperactivity and prescribed him a medicine. The doctor said: It was necessary to monitor the case to confirm whether the behaviour is from the accident or it will continue. When the diagnosis was confirmed after monitoring my son's case, his condition was identified as hyperactivity and he needed to take medication"** (from an interview with AH, a mother in East Jerusalem).

### **Types of ADHD**

Three presentations of ADHD are defined in DSM-5™ based on the predominant symptom pattern for the past 6 months:

- 1 Inattentive Type Predominately.
- 2 Predominately Hyperactive-Impulsive Type.
- 3 Combined type: the most common type, with 50-70% of people suffering from the combined type (Takahashi et al., 2007; Kutcher, 2010).

### **Diagnostic Criteria for ADHD**

According to DSM-5, the predominant symptom patterns are as follows:

- 1 Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years.
- 2 Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g., at home, school, or work; with friends or relatives; in other activities).
- 3 There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.
- 4 The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication or withdrawal).
- 5 Symptoms do not fall under developmental disorder such as PDD or ASD.

Additionally, a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development:

### **A. Inattentive Type:**

- 1 Six or more symptoms of inattention for children up to age 16, or five or more for adolescents 17 and older and adults. (Appendix 2)
- 2 Symptoms have been present for at least 6 months, and they are inappropriate for developmental level.
- 3 Negatively impacts directly on social and academic/occupational activities.
- 4 The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility or failure to understand tasks or instructions.

### **B. Hyperactive-Impulsive Type**

- 1 Six or more symptoms of inattention for children up to age 16, or five or more for adolescents 17 and older and adults. (Appendix 2)
- 2 Symptoms have been present for at least 6 months, and they are inappropriate for developmental level.
- 3 Negatively impacts directly on social and academic/occupational activities.
- 4 The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility or failure to understand tasks or instructions

The **current severity** of ADHD should also be specified:

- **Mild** – few, if any, symptoms in excess of those required to make the diagnosis are present, and symptoms result in no more than minor impairments in social or occupational functioning.
- **Moderate** – symptoms or functional impairment between ‘mild’ and ‘severe’ are present.
- **Severe** – many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present; or the symptoms result in marked impairment in social or occupational functioning.

## 2 Summary of Israeli Legislation Relevant to Rights of Children with ADHD

### 2.1 Special Education Law

According to the provisions of the Israeli Special Education Law of 1988, a child suffering from ADHD only is not classified within the framework of children with special needs, and therefore is not entitled to special education entitlements.

However, a child who suffers from ADHD coupled with a learning difficulty is classified as a student with special needs, and is therefore entitled to special education services: a set of services that might provide for the child some treatments, based on the need of each child, such as: speech therapy, occupational therapy, arts therapy, music therapy and motion therapy. In case these services are not provided by the school, the child can receive them through the National Health Fund (Ministry of Education, Ministry of Health 2017). In addition to these treatments, children can receive remedial education classes, which is given in small groups by special education teachers (interview with ND, integration coordinator and special education teacher in an East Jerusalem school; interview with ShH, a school principal in West Jerusalem), or in classes of their own (interview with principal of integration school in Princess Basma Organisation).

### 2.2 ADHD Diagnosis

According to the Public Health Insurance Law, National Health Funds have to give children until the age of 6 years to diagnose ADHD, in accordance with the conditions and standards set by the Ministry of Health (Director-General's Publication, Ministry of Health, 2010).

According to the previous source, the diagnosis is undertaken by one of the following:

- 1 A specialised doctor who acquired experience in the field of ADHD, including: paediatric neurologist, evolutionary paediatrician, child and adolescent psychologist, paediatrician with at least 3 years of experience in child development, specialised paediatrician who was rehabilitated to work in the ADHD field, adult neurologist, or adult psychologist.

- 2 A specialised psychologist who acquired rehabilitation and experience in the treatment of ADHD, provided that the child is directed to a licensed specialised doctor to diagnose ADHD, and in order to clarify any concurrent disorders and the need for medicinal treatment.

The specialised therapists mentioned above can seek assistance from other specialists, such as social workers, academic diagnosticians, occupational therapists, physiotherapists and communication therapists. Nonetheless, they are the only one authorised to diagnose the condition (Director-General's Publication, Ministry of Health, 2010).

Also, if students in primary school have a suspicion that one of their fellow students as someone who suffers from ADHD, the school's administration can guide the child to educational psychological services of the school to undertake educational psychological tests in order to issue an accurate diagnosis of the child and determine the required intervention accordingly.

Interviews have demonstrated to us that there is a discrepancy in the provision of this service between East and West Jerusalem. In West Jerusalem, a thorough and complete psychological-educational diagnosis is undertaken for free by the psychological education services based on the school's referral. The diagnosis can take 6 sessions as certified by an Israeli mother (from the interview with Yehudit, a mother of an ADHD child who also suffers from learning difficulties in West Jerusalem). However, in East Jerusalem, in light of the scarcity of budgets to employ psychologists, psychological services usually undertake specific psychological assessments that do not exceed 45 minutes, whose predominant purpose is to refer the case to the placement committees (from the interview with RM, special education coordinator and special education class teacher in an ordinary school in East Jerusalem).

### **Requirements of Diagnosis:**

To reduce the margin of error in diagnosing children and adults with ADHD, the (Ministry of Health, 2010) specified in leaflet 23/2002 the requirements of the diagnosis and its content, in line with internationally agreed-upon standards and based on the 5<sup>th</sup> edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5™)

The inclusion of the following in the diagnosis of children and youth with ASD is conditioned:

- 1 A clinical assessment, including:
  - Detailed historic background about the child and family
  - Complete assessment in accordance with the standards of DSM-5TM

- An assessment of other possible disorders
  - A detailed clinical test.
- 2 Diagnosis questionnaires for parents and teachers (Conners Questionnaire for example), but not follow-up questionnaires.
  - 3 Additional diagnosis tools: as needed the doctor of diagnosing psychologist could recommend the completion of the diagnosis with the use of additional tools, such as continuous performance test, psychological tests, assessment of mental abilities, assessment by a psychiatrist and assessment of learning capabilities.
  - 4 Medical examination: the diagnosing psychologist should recommend finalising the diagnosis process by referring the child to a neurologist and/or a psychiatrist qualified in the diagnosis of ADHD.

### **Questionnaires used for children:**

- 1 Conners' Rating Scales
- 2 Achenbach's Child Behaviour Checklist.
- 3 Strengths and Difficulties Questionnaire

### **Computerised Diagnostic Tests and the Economic Situation:**

Research shows that there is a direct relationship between taking the necessary steps to diagnose ADHD and the family's economic situation, such that families with a high economic status go to take the necessary tests compared with families who have a low income. As such, National Health Funds try to provide computerised diagnosis for ADHD in Child Development Centres or through an authorised provider by the funds.

Computerised tests are not free of charge in the basic health insurance but are included in specific deductions within the complementary insurance of different National Health Funds. These include the TOVA diagnosis, which consists of two components: the first to examine the presence of ADHD and the second to measure the effectiveness of a medicinal intervention. Other tests included are the BRC test, which measures different mental performances that include ADHD; the MOXO test, which examines ability to concentrate, impulsivity and hyperactivity; NeuroTax, which consists of several tests that examine mental performance such as memory, listening, concentration, eye and arm association and speech abilities. The costs of diagnosis depends on the type of the National Health Fund and the type of card held by the insured person as can be seen in table (5).

**Table 5: Comparison between Different National Health Funds and their Coverage of the Cost of Computerised Tests**

Clalit Health Fund	Maccabi Health Fund	Meuhedet Health Fund	Leumit Health Fund
<p>Those with a "Clalit Moshlam Gold" insurance are entitled to two tests from TOVA, BRC, MOXO and NeuroTrax and with a personal contribution of 220 ILS for the two tests without a waiting period.</p> <p>For those with "Clalit Moshlam Platinum" and with a personal contribution of 50 ILS, the entitlement is for 2 tests carried out at an authorised provider with a waiting period of up to 6 months.</p>	<p>Those with a "Megen Gold" or "Megen Silver" are entitled to a BRC or TOVA test with a personal contribution of 300 ILS for the two tests, with or without medicinal intervention, and without a waiting period.</p> <p>Those with a "Maccabi Shelley" insurance are entitled to TOVA, BRC, MOXO, NeuroTrax with a personal contribution of 21 ILS for each test at an authorised provider and with a waiting period of 6 months. Applies for one time that is non-renewable.</p>	<p>Those with a "Meuhedet Adif" insurance are entitled to a TOVA or BRC test with a personal contribution of 212 ILS for each test.</p> <p>Those between the ages of 5-18 are entitled to a TOVA test followed by a BRC test or a BRC test followed by a TOVA test without a waiting period.</p>	<p>Those with a "Leumit Silver" Insurance:</p> <p>TOVA Test with a cost of 300 ILS MOXO Test with a cost of 298 ILS From ages 6-35</p> <p>Those with "Leumit Gold" Insurance:</p> <p>TOVA Test with a cost of 175 ILS MOXO Test with a cost of 244 ILS From ages 6-35.</p>

(Dan, 2014; internet websites of the different National Health Funds)

In an interview with the director of the Warm House Centre, the centre provides free diagnosis for all National Health Funds. All that is needed is a referral and a financial commitment by the fund (form 17) to cover the costs of the diagnosis.

Since ADHD is often associated with learning difficulties, some National Health Funds provide academic and psycho-academic tests to reinforce the diagnosis process and address educational and emotional aspects side by side with ADHD.

Parents sometimes pay large sums of money because they lack awareness of their rights or they do not have the appropriate insurance, such that some of them go to the Marah Centre in the Collège des Frères or to Spaford Centre to undertake an academic or psycho-academic diagnosis, instead of going to the National Health Funds. One mother adds **“the cost varies between 900-1800 ILS paid every time by the parents from their personal accounts.”** Another mother adds **“I recently went to West Jerusalem to a centre to diagnose my son but the costs were very high and reached 3,350 ILS.”**

And here it emerged that the contribution of the National Health Funds to cover these academic and psycho-academic diagnosis tests depends on the type of complementary insurance that the person has, as demonstrated in table (6).

**Table 6: Comparison between Different National Health Funds and their Coverage of Academic and Psycho-Academic Examination Costs**

Clalit Health Fund	Maccabi Health Fund	Meuhedet Health Fund	Leumit Health Fund
<p>“Clalit Moshlam” insurance: Academic test with a personal contribution of 950 ILS; and a psycho-academic test is a personal contribution of 1550 ILS.</p> <p>“Clalit Moshlam Platinum” Insurance: Academic test with a personal contribution of 550 ILS; and a psycho-academic test is a personal contribution of 950 ILS.</p> <p>One academic or psycho-academic diagnosis for one time during the enrolment period at authorised providers between the age of 6-17 years.</p>	<p>“Maccabi Shelley” insurance: Academic test with a personal contribution of 643 ILS; and a psycho-academic test is a personal contribution of 1287 ILS.</p> <p>One academic or psycho-academic diagnosis for one time for a period of 4-6 hours at an authorised provider for those above the age of 6.</p>	<p>“Meuhedet C” insurance: Academic test with a personal contribution of 550 ILS; and a psycho-academic test is a personal contribution of 950 ILS for ages between 6-26 years for one time only.</p>	<p>“Leumit Silver” Insurance: Academic test with a personal contribution of 794 ILS.</p> <p>“Leumit Gold” Insurance: Academic test with a personal contribution of 492 ILS.</p> <p>Academic test for one time during enrolment period at an authorised provider between the ages of 6-18 years.</p>

(Dan, 2014; internet websites of the different National Health Funds)

## 2.3 National Insurance Institute Allocations

In an interview with the head of disability and the director of the National Insurance Institute in West Jerusalem, she clarified that the diagnosis of ADHD persons is a contentious issue, in light of the absence of allocations from the National Insurance Institute for children with ADHD or learning disabilities, such that these disorders are not considered a disability. This was confirmed by MV (from an interview with an ADHD mother from West Jerusalem) who said that adults with ADHD can submit a request to the National Insurance Institute to receive disability allocations. This can be carried out through the submission of a valid psycho diagnostic that determined the degree of disability, that elaborately explains the impact of the disorder on the individual's work ability and social adaptation capacity (Skolski, 2011). The individual's work ability and social adaptation capacity is assessed following the provision of the treatment process; for example, the individual's capabilities are assessed while the individual is under medication. If the individual is going through a therapeutic period that is yet to finish, he/she is given a temporary disability status (Skolski, 2011).

## 2.4 Accrued Tax

Income tax department provides a two-degree exemption on the income of parents of children with special needs who have received a decision from the placement committee. These two degrees incur a reduction in the taken income tax applied to the salary. The value of these two degrees changes in accordance with the cost of living (Tax Authority, 2012).

One of the parents of children who suffer from ADHD and learning difficulties who have a decision from the placement committee on the education of their child in a special education framework, including in a therapeutic kindergarten, developmental class in an ordinary school, a student in a 07 track in a secondary school or a special education school are entitled to income tax deduction, but not both.

To acquire the points that lead up to the income tax deduction the parents go to the income tax office that is close to their residency and present the following to one of the employees:

- 1 Application number 16A
- 2 The latest report of the placement committee.

The decision is valid for a period of 3 years from the day of issue (Tax Authority, 2012). Parents sometimes fear dealing with the tax authority and hence lose a fundamental right. In an experience of a Jerusalemite family that reflects their limited knowledge and awareness of their rights, one mother relays to us **“My son had a placement committee and they put him in a special education class in an ordinary school in the last year. The head of the placement committee, Matia, gave me a tax refund paper. I gave the paper to my husband but he refused to follow-up, saying that it is useless and that eventually we will not get a refund, adding that he does not have the time to go to submit it and follow-up. I tried to explain to him what the head of the committee told me but he replied forget about it”** (from an interview with AH, the mother of a child with ADHD and learning difficulties).

As noted above, parents are entitled to a tax refund if they have not received one for up to 6 years from the day of the submission of the application, date of the child's birth, or the day of the diagnosis with the addition of benefits. Parents of children with ADHD and a learning difficulty are entitled to a tax refund from 2003.

## **3 Available Services in East Jerusalem for Children with ADHD**

We will present in this section of the study the various medical services available for people with ADHD, including medication used in the treatment of the disorder and supportive developmental treatments, with a presentation of the cost of treatment and waiting periods and diagnosis of different relevant services. We also present available educational services with a focus on the counselling of parents.

### **3.1 Therapeutic Intervention**

The governmental health law of 1994 forces the Ministry of Health to provide multidisciplinary treatment until the age of 6 (occupational therapy, physiotherapy, speech therapy, psychological/social therapy) for students with ADHD, as well as for students with learning difficulties. This does not include remedial education. Medicinal treatment, on another hand, is provided until the age of 18 years (economy and health insurance division, 2012, page 20).

## **Medicinal Treatment:**

According to the governmental health insurance law, the National Health Funds have to provide medicinal treatment to all persons diagnosed before the age of 18 with ADHD (Director-General's Publication, Ministry of Health, 2010).

## **Medication used in the treatment of ADHD:**

- 1 Ritalin- 10 mg; effective for up to 4 hours.
- 2 Slow Release Ritalin- 20 mg; effective for up to 6 hours.
- 3 Long Release Ritalin- 20-40 mg; effective to up to 8 hours.
- 4 Concerta- 18-54 mg; effective to up to 12 hours.

According to the governmental health insurance law, the National Health Funds have to provide the first two medications as they are the only ones present in the medicine basket of the Ministry of Health. The National Health Funds are not obliged to provide the third and fourth medications, as well as other medications (Adderall, Amphet Mix, Strattera, Focalin, Daytrana and Vyvanse). Some of these medications are available to patients through complementary health insurance only (Levi, 2010).

It is worth noting that some children are not responsive to specific kinds of medications, such is Ritalin, and the cost of changing the medication to another type falls on the shoulder of the parents. Another option would be to obtain additional complementary insurances, which are usually highly expensive (Levy, 2010). Generally, the medication is changed based on the medical follow-up that the physicians do and the responsiveness of the child to the medication **"The doctor gave our son Ritalin 12 mg, but it was not helpful as he lost his appetite and had continuous headache. Then he changed the medicine to another type of Ritalin, but no improvement was observed. Finally, the doctor changed the medicine to Concerta and that was when the situation of the child improved...until today he is still taking this medicine."** (From an interview with Yehudit, a mother of an ADHD child from West Jerusalem). For more information on the cost of medication and reduction rates of different National Health Funds, see annex (3).

It is worth noting that the medicinal treatment does not include persons diagnosed with ADHD after the age of 18, as the governmental health insurance law does not include this group in the medication basket. As such, they are not entitled to medicinal treatment from the National Health Funds. Additionally, the National Health Funds are not responsible for various supporting treatments. Despite this, some National

Health Funds tend to provide medicinal and other treatments of their own accords, but they are not forced to do that by the law.

## 3.2 Supportive Developmental Treatments

The governmental health insurance law obliges the State to provide child development services for those who need treatment for developmental and therapeutic problems from birth until the age of 18. The law ensures for them diagnosis and treatment until the age of 9 years via a multidisciplinary staff for children (Ministry of Health, 2010). The multidisciplinary staff includes: a neurologist specialising in children, or a specialised paediatrician with experience in child development; a psychologist; a social worker; a speech therapist; and an occupational therapist. Compulsory insurance provides the following basic treatment (occupational therapy, physiotherapy, communication therapy and psychotherapy), as demonstrated in appendix (5).

### Waiting periods for diagnosis and treatment

The waiting period for diagnosis and treatment depends on the age of the child, as follows:

- 1 From 0 years to 1 year: up to 3 months of waiting from the date of referral until the receipt of the service in the Child Development Centre.
- 2 More than 1 year: up to 4 months of waiting from the date of referral until the receipt of the service in the Child Development Centre (Ministry of Health, 2010).

Interviews with parents have shown that diagnosis appointments with the neurologist in East Jerusalem in the Clalit Child Development Centre in East Jerusalem in the Shu'fat division (for example), can take up to 6 months or sometimes even more if the referral took place through the Clalit Health Fund. **"The biggest problem or difficulty I face is taking an appointment for tests and translating the reports from Arabic to Hebrew; especially National Health Funds, which takes a lot of time, and sometimes even months"** (from an interview with AH, a mother from East Jerusalem). The same applies to the case of child H, who says **"Waiting for appointments with specialists in the National Health Funds takes between 1 to 6 months, which poses as a big obstacle for me...this forced me to do all of the tests on my own expense."** This is also in line with what specialists told us in the Warm House Centre **"If the referral is done via the National Health Funds it takes many months that sometimes reach up to a year."**

The acquisition of a computerised ADHD diagnosis or a psycho-educational diagnosis depends on side approached. If specialists are personally approached the period takes between 1 week to 1 month; however, if the referral is through a National Health Fund, it can take up to a year (from an interview with TS, a mother from East Jerusalem). Alternatively, specialists at the Warm House Centre have informed us that they welcome children from all National Health Funds with a referral and a financial commitment to cover the costs of the diagnosis (Form No. 17), and that the waiting period there does not take more than two weeks, provided that the parents directly ask the National Health Fund to direct the referral to the house. In addition to diagnosis sessions, parents are given 10 counselling sessions, renewable as needed (from an interview with the director of the Warm House Centre in East Jerusalem).

The results of the interviews have also showed as that there is a disparity in how National Health Funds deal with ADHD, in terms of ease of obtainment of a referral and approaching specialised bodies, and even in the awareness and interest of the funds with ADHD. The biggest National Health Fund in East Jerusalem in terms of number of members is Clalit, with approximately 70% of people insured there, followed by Meuhedet, then Leumit and finally Maccabi (from an interview with the Warm House Centre in East Jerusalem). The remarks of the specialists at the Warm House Centre indicate that Clalit attempts to reduce the number of referrals and to keep referrals internal to their Child Development Centres to reduce the costs, while those insured at Meuhedet Health Funds receive quick, easy, unconditioned and unrestrained referrals, and provide parents with a large number of meetings. They also have an Arab social worker who is in charge of the mental health of children, and therefore focuses on this aspect with them, which is not available at other National Health Funds. In Maccabi Health Fund parents receive unlimited meetings due to a small number of members. Leumit do not have sufficient awareness in the mental health field (from an interview with a specialist at the Warm House Centre in East Jerusalem).

The lack of commitment of National Health Funds to provide appointments within the timeframe as specified by the law incurs damages on the child due to a delay in service delivery on the one hand. On another hand, it could lead to the despair of parents, such that they stop following-up the procedures of the National Health Funds, thus waiving treatment for their child or alternatively seek diagnosis and treatment individually and at their own expense **“The National Health Funds deliberately give distant appointments that take up to a year to reduce the financial burden of covering the diagnosis and treatment costs, thus hindering parents from accessing services. They could also tell parents that there is no need for a diagnosis and that the child is fine”** (from an interview with a specialist at the Warm House

Centre in East Jerusalem).

Alongside medicinal treatment, several other treatments are recommended by specialists for ADHD patients, such that in the last few years witnessed increased awareness that the treatment of ADHD is not restricted only to medicinal treatment but extends to include behavioural, social and cognitive...etc treatments. A study undertaken in Norway in 2011 and published in the Journal of Alternative and Complementary Medicine demonstrates that therapeutic horseback riding is effective and has a positive impact on children with ADHD, particularly on the behavioural and social aspects, quality of life and motor performance. There are also some additional treatments provided by the National Health Funds, including therapeutic horseback riding, therapeutic swimming, art therapy and animal-assisted therapy.

Appendix (6) reflects the cost of additional treatment in various National Health Funds and the reduction percentages the insured person is entitled to (therapeutic horseback riding, therapeutic swimming, art therapy and animal-assisted therapy).

## 3.2 Educational Services

Professor Uri Bar Noi clarified in the education session of the Knesset in 2010 that the findings of the inter-ministerial committee, formed in 2009 to examine the effectiveness of the medicinal treatment on ADHD, revealed that medicinal treatment is only part of the treatment, and that the other components are equally important, including: parents' guidance, school staff guidance and emotional and sentimental support for the child. The task of counselling and guiding parents and school staff was assigned to the Ministry of Education (education, culture and sports committee in the Knesset, Protocol No. 321, 7 December 2010).

The Ministry of Health- Child Development Centre in West Jerusalem in cooperation with the Brookdale Institute has preceded the results of the inter-ministerial committee, such that it implemented in 2008 a therapeutic programme for ADHD children in four non-Arab schools in West Jerusalem. The programme examined the effectiveness of early detection, diagnosis, treatment of behavioural symptoms of the disorder, in addition to improving the educational and social situation of the students. Interviews were conducted with ADHD students, their parents, teachers and classmates. The research results indicated a significant improvement in the behavioural and educational aspects among the students. Additionally, two thirds of the parents indicated that the programme contributed to the acquisition of mechanisms of addressing the disorder; while 90% of the teachers introduced changes

and appropriated their teaching methods to meet the needs of this group of the students. Also, 50% of the parents indicated an improvement in their relationship with the school and educational staff (Sharon, Asef and Others, 2008).

In light of the recommendations of the inter-ministerial committee, the learning difficulties and ADHD department in the Ministry of Education adopted school intervention plans to equip teachers with the knowledge and skills to work with ADHD children (Education, Culture and Sports Committee in the Knesset, Protocol Number 321, 7 December 2010). The Ministry of Education also opened complementary courses in ADHD to empower teachers, educational counsellors and psychologists to acquire tools to work with ADHD students and create an educational environment that suits their needs (Aldor, Yehudit, 2013).

Treatment of ADHD requires an intervention at the level of the educational system as a whole, alongside counselling and guidance of parents, and direct work with the child to with emotional, sentimental and educational support, if necessary.

The opinions of interviews principals, teachers and parents were in line with this, as all of them support the integration of ADHD children in ordinary classes, as they have the capacity to interact in ordinary classes, while the school has to adapt itself to meet their needs **“All ADHD students are normal and present in all classes; sometimes they are leaders in their classes”** (from an interview with ShH, a school principal in West Jerusalem). He adds that for every child an individual therapeutic plan is put; the plan does not depend solely on medication, instead it consists of **“therapeutic strategies based on analysis and thinking, and the contribution of school staff in the development of the plan.”**

The proposed model of action requires a comprehensive intervention from the Ministry of Education that extends beyond medicinal treatment. It is imperative to adopt educational, psychological and behavioural plans for children, as well as accompany and counsel parents. It is also important for parents to discuss and consult the diagnostician to become partners in decision making relevant to later treatment.

The intervention process by educational bodies and authorities in working with student cases can be seen in annex (8), as provided by the Ministry of Education.

## 4 Results and Conclusions

### 4.1 Main Challenges facing Educational and Therapeutic Organisations in East Jerusalem

#### 1 Physical Environment

The observations of the researcher of the visited schools, as well as the sayings of interviewed school principals and teachers, revealed that the educational frameworks consist of small classes. Therefore, it is difficult for teachers to work with ADHD students, as they naturally need significant space for movement and the utilisation of non-conventional teaching methods, including indoctrination (from an interview with RM, special education coordinator and special education teacher in an ordinary school in East Jerusalem; from an interview with TS, a mother of an ADHD child in East Jerusalem). The situation somewhat differs in West Jerusalem, where students in one class are divided into small groups that facilitates the containment of ADHD students. Furthermore, the physical environment is comfortable (from an interview with the mother of an ADHD child in West Jerusalem). The optimal solution for ADHD children is **“for classes to contain a smaller number of students, such that each student receives special attention”** (from an interview with ShH, a school principal in West Jerusalem).

#### 2 Technological Capabilities

There is no doubt that ADHD students get bored from conventional methods of teaching that are primarily based on indoctrination. The adaptation of teaching methods to their needs, such as through the use of computers and other technological tools effectively contributes to overcoming their difficulties. Interviews with school principals in West and East Jerusalem, excluding special education schools, which are indirectly affiliated with the Jerusalem municipality, revealed that the majority of the schools are equipped with computers and smart boards in some of them (from an interview with school principals in East Jerusalem; from an interview with ShH, a school principal in West Jerusalem). The qualitative addition in West Jerusalem is the provision of smart tablets that are distributed among the students and are used in classes (from an interview with the mother on an ADHD child in West Jerusalem).

### 3 Teacher Rehabilitation:

To measure the suitability of the rehabilitation component that teachers who graduated of universities and colleges and who work in East Jerusalem, academic programmes and courses were examined, and focus groups were conducted with teachers working in these frameworks. All education colleges and universities that rehabilitate teachers in special education (Al-Qasimi, David Yelen College, Al-Quds University and Al-Quds Open University) introduced in recent years to the rehabilitation programme a special course on ADHD; in some cases ADHD is addressed through other courses, including definitions, causes and detection indicators. Content analysis of the courses reveals that the student receives general information about ADHD and theoretical work strategies with students. One teacher who participated in the focus group discussions and reflects the opinion of more than one teacher, said **"I took a course in ADHD, but I started working in the field I discovered that the course had nothing to do with the reality, it was full of theories that I did not benefit from, as there was not a practical component when I was studying."** All teachers in these colleges are graduates in special education, psychology and related disciplines, but none of them is specialised in working with ADHD children and accompanying learning difficulties. Principals of ordinary schools face a big challenge in working with college and university graduates, such that teachers of special education have a specific background in ADHD, while teachers of education and other classes, such as mathematics, English and science lack knowledge and awareness about ADHD (from an interview YH, a resource room teacher in an ordinary school in East Jerusalem) **"Our teachers are not sufficiently rehabilitated to diversify teaching methods to meet the needs of ADHD student, where students can be occupied with tasks that rely on his/her strengths."**

A teacher revealed that they need **"Increased applications with ADHD students, and learning new methods to work with them...strategies that are especially designed for them, because many times we classify them with the group with learning difficulties or as a person with an emotional or behavioural disorder...we need to learn mechanisms especially designed for them."**

The opinions of the teachers were in line with those of the school principals in East Jerusalem, emphasising that teachers are not sufficiently qualified. In an interview, the principal of a school in East Jerusalem HG said **"No they are not sufficiently qualified to determine the needs of this group of students; they work with them in an arbitrary manner and based on their own decisions, instead of in a systematic manner. Teachers need rehabilitation courses on how to work with this group of students."**

Interviewed school principals also pointed out that rehabilitation courses for teachers are not given in ADHD. School principals and teachers have indicated that teachers do not have sufficient knowledge on working with ADHD, as a direct result of an educational deficiency in the types of courses given to them in the university. Even in cases where ADHD is mentioned, it is only limited to the theoretical aspect. One teacher explains **“Schools in East Jerusalem have recently been included within the self-management programme that enables principals to decide the types of courses and programmes needed for the school...not one time a course in ADHD was given, and the school counsellor does not guide the students on working with ADHD students”** (from an interview with RM, special education coordinator and special education teacher in an ordinary school in East Jerusalem).

Interviewed school principals have indicated that some of the adaptations given. On the teaching level, students are given intra-class assignments, such as helping their classmate or in extracurricular activities. On the level of exams, the student is given a different exam that meets his level; sometimes the exam might be an oral exam. Also the time of the exam is changed to be in one of the morning classes. The adaptation of examinations mentioned in this section are yet another indicator on the need to raise the awareness of schools and staff in means of working with ADHD children, as some of these adaptations, such as changing the content of the exam or doing a verbal examination, contravenes ministerial laws in this area.

#### **4 Accompaniment of teachers in the field**

Parents and schools have indicated that the competent authorities do not accompany teachers when they receive the diagnosis of an ADHD child, as this depends on the sole efforts of the school. Most of the time, parents seek assistance from the special education staff in the school, as the majority of the teachers in specialised topics have knowledge deficiency in ADHD.

Compared with schools in East Jerusalem, a school principal in West Jerusalem told us **“Our teachers do not feel that they are alone in working with ADHD students, because we as a school give them all the support needed. We sometimes bring professional therapists for observation. There are weekly follow-up sessions between the teacher and the psychologist, educational counsellor and remedial education teacher to discuss and talk. Sometimes specialists from other fields are brought in to provide advice and guidance.”**

In some cases, where necessary, the school brings in the specialists who undertook the diagnosis of the child to counsel the school staff on how to work with the case (from an interview with SHH, a school principal from West Jerusalem). This accompaniment

of the teachers in the field and providing guidance for them after the diagnosis was not present before (from an interview with MH, a school principal in East Jerusalem; from another interview with the director of a Child Development Centre in East Jerusalem).

## **5 Absence of treatment in the majority of the schools**

School principals have emphasised to us the absence of treatments for ADHD inside schools, including art therapy, music therapy, movement therapy, social therapy and other types of therapy (from an interview with AZ, a school principal in East Jerusalem). Instead of providing treatments, schools organise and conduct extracurricular activities in their own individual capacities. This is considered a major challenge to the school's capacity to work with this group of students. This is further verified by the mother of one of the children **"There is a major challenge resulting from the absence of educational and therapeutic services in East Jerusalem schools"** (from an interview with TS, the mother of an ADHD student from East Jerusalem). This is the prevalent situation with the exception of the Princess Basma school, which has a rehabilitation centre that provides therapeutic services for children with disability, including ADHD students that study in the integration school.

The situation differs in West Jerusalem. Parents and teachers talked about a set of treatments that schools attempt to provide from social and emotional support groups. These include art treatment, among other treatments (from an interview with ShH, a school principal in West Jerusalem; from an interview with VM, a mother of an ADHD student in West Jerusalem).

## **6 Scarcity of educational counsellors in schools**

School principals in East Jerusalem that the scarcity of educational counsellors who are completely aware of the problems that this group of students face poses as an obstacle to working with them. Alternatively, in West Jerusalem schools there is always an educational counsellor who has complete knowledge in these fields (from an interview with ShH, a school principal in West Jerusalem).

## **7 Limited allocated budgets to psychologists in schools:**

There are 7 centres in Jerusalem that provide psychosocial counselling services, distributed as follows: 5 in West Jerusalem and 2 in East Jerusalem. Until last year, there was only 1 centre in East Jerusalem. The aim of the psycho-educational services

provided by these centres is to improve the mental health of these students. In many compulsory kindergartens and primary schools, there is a designated psychologist assigned there, while schools receive a small partial service in light of the limited budgets allocated to East Jerusalem (psycho-educational services website, Jerusalem Municipality).

## **8 Lack of coordination between various treatments of the child**

By law, the National Health Funds are required to provide only in Child Development Centres, Child Development Units, or at a service provider accredited by the fund, by are not required to do so inside schools. Here, the special education law provides the treatment inside the school, whose costs are covered by the Ministry of Education but not the Ministry of Health. Hence, sometimes the child receives the same treatment within more than one framework and without coordination.

## **4.2 Main Challenges facing Parents in East Jerusalem**

### **1 Guidance, Counselling and Social Support**

One of the major challenges facing parents is their lack of knowledge about ADHD, as the majority of them do not have sufficient knowledge, nor are equipped with the tools to work with their children. They have significant fears towards the diagnosis and medicinal treatment; one teacher tells us **“there is a mother who hates her son because he has ADHD; she wants to send him to a boarding schools. The parents are not accepting his situation and think that their son cannot improve...the biggest challenge is the lack of acceptance of parents”** (from an interview with RM, special education coordinator and special education teacher in an ordinary school in East Jerusalem).

There are disparities among parents in identifying the level of difficulty they their son/ daughter faces, and the explanation of their behaviour. Sometimes, parents do not find anything noteworthy, and consider his/her behaviour appropriate for his/her age. They sometimes claim that the problem is only in the school and that their son’s behaviour is completely different inside the house, where he is calm and can focus on things **“there are some parents who do not even believe that their son acts differently in the school, and other parents who have listening and concentration problems that they do not even realise the situation of their son”** (from an interview with AK, a personal escort of an ADHD student in an East

Jerusalem school). Also, parents sometimes do not accept the idea that their child has ADHD and consequently do not cooperate with the school (from an interview with RM, special education coordinator and special education teachers in an ordinary school in East Jerusalem).

Concerning social support, interviews with parents in East Jerusalem revealed to us that they feel that they do not receive sufficient support, counselling and guidance to work with their children's cases. One mother shares with us **"we do not receive any guidance from the school, Child Development Centre, or the neurologist."** Alternatively, those interviewed in West Jerusalem reflected higher confidence in the health and educational system and their capacity to provide guidance, support and whatever is needed for the benefit of the child. One mother says **"I have faith that the health insurance will provide to us any support that we need. The same applies to schools...I know they will help as much as they can, whether inside the class or through increasing individual support hours from the Ministry of Education."** One mother from West Jerusalem also pointed out that the Shaare Zedek Medical Centre organises study days in Hebrew about ADHD that span over a period of 3-4 days. One mother said that she participated in these study days and that they had an immense impact on her and the way she treats her son (from an interview with Yehudit, the mother of an ADHD child who also suffers from learning difficulties in West Jerusalem).

On another hand, all interviews with parents reflect that parents in East Jerusalem are not aware of the services provided by social affairs, which are quite vast for children who suffer from ADHD, as the social worker in the Wadi Al-Joz social affairs office explained (KhS, coordinator of the counselling programme for ADHD). She explains that the office provides services, instructions and guidance as per the capabilities of the department and its allocated budget. These services include: guiding and referring parents to competent authorities to undertake necessary tests, individual or group counselling for families, integration of the child in an therapeutic camp for children from the ages of 6-10 years, integration of children in curricular and extracurricular activities, provision of financial/ monetary support once or twice a year to facilitate procurement of medicine or partially contribute to the costs of the psycho-educational test to diagnose learning difficulties and the possibility of providing accompaniment with the aim of improving and impacting the behaviour of the child, support his personality and help in social, behavioural and educational aspects (from an interview with KhS, social worker in Wadi Al-Joz social affairs in East Jerusalem).

## **2 Small number of treatments available in schools and their cost that poses sometimes as an economic burden on parents:**

Interviews have demonstrated disparities in how schools work with ADHD children. One mother shared with us **“We received the diagnosis that our son has ADHD and a therapeutic plan was developed with the educational staff in the school. The plan included a free behavioural therapy programme provided by the school and the integration of our son in a social group in the school for 50 ILS/ month. The organisers of this group guided parents and the educational staff on how to work with ADHD students, and this group had a significantly positive impact on all of the participants, parents, teachers and students alike, in developing mechanisms to working with the disorder”** (from an interview with one of the mothers of an ADHD child in West Jerusalem). In East Jerusalem, for reasons relevant to the awareness and rehabilitation of teachers on one hand and the infrastructure on another people, school administrations attempt to direct and guide parents to treatments available outside the school, such as registering their children in swimming courses or in different sports. These suggestions are met with rejection because of the limited time remaining after the long school day, the high costs and scarcity of therapeutic centres in East Jerusalem. **“The challenge is the response of the parents that there is not enough time after school, the lack of therapeutic activities in Jerusalem and the financial situation of the parents”** (from an interview with ND, integration coordinator and special education teacher in an East Jerusalem school). In the case of another child, the mother says that she has to go to West Jerusalem for her child to receive a specific treatment that costs 180 ILS/ hour, in addition to the costs of the translator accompanying her son, the transportation and other expenses (from an interview with TS, a mother of an ADHD child from East Jerusalem).

## **3 Lack of special treatment in East Jerusalem: the time problem and language barrier:**

In one interview that reflected the absence of complementary services in East Jerusalem and the challenges families face in going to West Jerusalem to access services, one mother tells us **“Yes sometimes I have to take my son and his siblings to West Jerusalem. Regarding my son I went o the Child Development Centre even though it was in Hebrew, but I tried to manage myself. Getting to the Centre was easy, as I asked pedestrians about the place and they showed me the way. But after the political events it became very difficult to take public transportation because they would curse and hit us and I was afraid for my children, so I started taking a private taxi, which increased the financial burden on me, but I only want what is best**

**for my child. So the difficulties are the language barrier and the political situation** (from an interview with AH, a mother of an ADHD child from East Jerusalem). The mother of another child tells us **“the language is the biggest barrier; if my son knew Hebrew I would have taken him to many organisations. He can communicate in English in the organisations that he goes to now in West Jerusalem, and there is not an alternative in East Jerusalem”** (from an interview with TS, a mother of an ADHD child from East Jerusalem).

#### **4 Forms are only available in Hebrew**

The directives of the Ministry of Health to the National Health Funds clearly state that the funds have to adapt themselves for service recipients on the cultural and language levels. This includes the provision of documents in Arabic and the availability of translation in cases where Arabic doctors or physicians are not available (Jemzo, 2011).

The directives of the Ministry of Health are in line and verify that sentiments felt by Arabic families who do not know Hebrew. One mother explained that her biggest difficulty was translating the reports from Hebrew to Arabic or translating the forms from Arabic to Hebrew (from an interview with AH, a mother of an ADHD child from East Jerusalem). A specialist from the Warm House Centre explained to us **“the simplest example is that parents in East Jerusalem are not aware of their rights. They go to a lawyer and pay approximately 700 ILS to fill the forms in Hebrew.”**

#### **5 Lack of specialised doctors and long waiting periods for tests**

There is a clear scarcity in the availability of competent specialists in East Jerusalem. In East Jerusalem, there are 5 neurologists, 4 of which are general neurologists, while only one is a specialist paediatric neurologist. He works in the Clalit Child Development Centre and is therefore only accessible to Clalit clients. Clients in other National Health Funds are referred to doctors in West Jerusalem. Furthermore, the number of accredited Arab psychologists in East Jerusalem does not exceed 4 (see appendix 4).

#### **6 Type of tools used in diagnosis**

Despite the directives of the Ministry of Health (Director-General’s Publication 23/2002), the diagnosis process requires several tools, including a clinical assessment, diagnosis questionnaires for parents and teachers, the use of additional diagnostician

tools such as computerised tools and a medical examination (see diagnosis tools section). However, the diagnosis does not cover all required fields, and therefore it might be incomplete in many of the times.

Since the symptoms of ADHD is similar to symptoms of other disorders, such as behavioural or emotional disorders (see coinciding of ADHD with other disorders section), one cannot rely only on the child and parents' interview, or the completion of a preliminary examination questionnaire by the teachers and parents.

### **7 Availability on information about the student to be diagnosed (by parents, teachers and clinical observations)**

Some of the questionnaires filled by the parents, teachers and children themselves rely on personal assessment and are not objective. Therefore, there is a tendency to depict the child in the best or worst possible picture; this depends on the respondent. Furthermore, according to Diagnostic and Statistical Manual of Mental Disorders the filling of the questionnaires requires observation for six months to ensure that the symptoms are continuous and not merely symptomatic symptoms. In cases where the questionnaires are filled in a certain temporal point without continuous observation and follow-up of the child's behaviour, this could lead to a faulty diagnosis.

### **8 Family background of the child, their acceptance of the diagnosis and their concern of societal perceptions**

Some indicators require the referral of the child to diagnosis. However, sometimes parents do not cooperate for a number of reasons: lack of awareness of parents, and consequent denial of any difficulties that their child may have; their fear of societal perceptions, particularly in cases of girls; shortage of diagnostic competent and professional authorities in East Jerusalem; difficulty of reaching West Jerusalem as a result of transportation to undertake diagnosis; language barrier; and security situation. This became evident to us when we interviewed parents of ADHD children who refused to divulge their names, but said that they have an ADHD child.

### **9 Extent of acceptance of parents of the visitation of a neurologist to complete the diagnosis procedure**

Sometimes parents are convinced in the beginning and go to undertake necessary tests for their child. However, they become hesitant when they are asked to go to a neurologist to complete the diagnosis procedure, as the neurologist is the one

authorised to give a categorical diagnosis, as well as give a recommendation for medicinal treatment. This comes within the context of the association between the neurologist and psychiatrist with psychological diseases, and therefore parents refuse to complete the diagnosis from fear of the social stigma. Furthermore, and since the psychiatrist is authorised to provide a recommendation for medicinal treatment some parents fear giving medicine to their children and believe that there are negative side effects, **“parents fear the stigma associated with medicinal treatment, as they see children who take medicine as crazy, and therefore they refuse to try it”** (from an interview with a specialist in the Warm House Centre in East Jerusalem).

### **10 Conditioning of medicinal treatment by schools:**

Despite the content of the Director-General’s publication (2011), on the abstention of schools from giving recommendations or forcing medicinal treatment on parents, Yitzhak (2013) indicated that numerous parents complain about the recommendations and insistence of teachers on giving medicinal treatment; they sometimes even condition continuing the teaching of the child on the provision of medicinal treatment. The same thing was observed in West Jerusalem but not with the same severity. One principal in West Jerusalem (from the interview of ShH) said **“We do not put it as a condition and try to exhaust all means before guiding the parents towards medicinal treatment, and in cases where parents refuse, we do not insist and never condition it.”** In the case of another child in West Jerusalem, a mother told us that the homeroom teacher forced parents to give medicine to children even on trips **“I tried to point out to the homeroom teacher that I was okay with giving medication to the child on school days but not to force it and even reduce it on trips as much as possible; he replied that a child without medication is not a healthy child”** (from the interview of Yehudit, a mother of an ADHD child in West Jerusalem).

### **11 Lack of organisations that provide therapeutic services in East Jerusalem**

There is only one private organisation in Jerusalem that provides services to ASD and ADHD children. The organisation provides music therapy, water therapy and other conventional therapies through their rehabilitation centre. In addition to Spaford centre, which provides communication and other conventional treatments for children with communication problems, it seems that the total number of treatments available is insufficient to cover the real needs of residents. Parents, teachers and employees of the Warm House Centre talked about how parents seek specialised complementary treatments in West Jerusalem. A mother talked about the experience of her child in receiving therapeutic services in West Jerusalem, where they cover the

cost of the treatment by themselves. The mother expressed her satisfaction at the level and quality of the services, saying that her son benefited from these services. She complained about the lack of such organisations in East Jerusalem. Also, a social worker in an East Jerusalem school clarified the importance of the presence of such frameworks in the city **“We as counsellors need to know how to guide teachers and students; many times we need to guide parents to centres and organisations, but they are not available in East Jerusalem...we need frameworks and organisations that provide services to ADHD children.”**

The interview with the Warm House Centre in East Jerusalem revealed to clear disparities between East and West Jerusalem, in terms of the parents awareness of their rights and provided services there, such that there is a larger number of therapeutic centres and access to services is easier. Also, training courses, parents’ groups and children’s groups are available there (from the interview of the Warm House Centre).

## **12 Inaccurate diagnosis**

According to one teacher, psycho-educational diagnosis of her students seem to be inaccurate (from an interview with RM, special education coordinator and special education teacher in an ordinary school in East Jerusalem). She mentioned a case to us of receiving an identical diagnosis for two different persons; the only difference was changing the name of the student. In another case, a student was given by the placement committee an ADHD diagnosis, even though he only had listening and concentration difficulties but did not have any learning difficulties. One principal in East Jerusalem said to us **“The diagnosis today depends on the testimonies of the parents, the questionnaire filled by the school and the conversation with the child... based on this the child is given a medicine. This is far from professional and accurate and leads to faulty diagnosis”** (from an interview with HG, a school principal in East Jerusalem).

## 5 Recommendations

### 1 On the Policy Level

#### 1-1 On the Israeli Policy Level

##### 1-1-1 On the Level of the Israeli Ministry of Health

- 1 Enact a special law for parents with ADHD children: the presence of an ADHD child in the family places several big challenges on parents and requires comprehensive treatment. Therefore, we recommend direct contact with Arab members of Knesset to enact a law that reduces daily working hours, to enable parents to spend quality time with their children and accompany them to complementary treatments, which usually take place after school.
- 2 Rehabilitation of diagnosticians and therapists in the ADHD field: ADHD has undergone several updates during the past few years, the most recent of which in May 2013 in light of the content of the 5th edition of the Diagnosis and Statistical Manual of Mental Disorders, as well as the introduction of a number of computerised diagnostic tools that accompany the diagnosis process. These changes and updates should require the Ministry of Health the conduction of training rehabilitation courses to facilitate the acquisition of knowledge of these changes by the diagnosticians on the one hand, and prompt them to support their diagnosis with objective tools alongside the questionnaires filled by the beneficiaries on another hand. The same should apply to therapists, as physiotherapy is not the only affective therapy working with ADHD students; as such, the Ministry of Health should conduct rehabilitation courses that introduce therapists to additional treatments (aside from medicinal treatment) that have the effectiveness to improve the situation of students, and facilitate the acquisition of tools to work with this disorder.
- 3 Provide professional cadre for diagnosis and treatment: the study clearly demonstrated a quantitative scarcity in the number of Child Development Centres in East Jerusalem. There is also a large shortage in the human resources that can diagnose ADHD, as the number of Arab diagnosticians in East Jerusalem and outside the Wall are insufficient to deal with the cases professionally, in addition to a small number of Arab therapeutics that can provide treatments to these groups of students.
- 4 Make National Health Funds provide basic and complementary treatment on a

larger scale and in a multidisciplinary manner in East Jerusalem, both inside and outside the Wall.

- 5 Establishing a specialised centre in East Jerusalem: East Jerusalem is in dire need for a specialised centre to provide professional diagnosis and various treatments within a singular centre under one roof. This would enable parents to access services from a singular destination instead of going to multiple destinations, most of which are located in West Jerusalem, where services are provided in Hebrew.
- 6 Increase monitoring and inspection: the Ministry of Health has numerous publications and policies relevant to working with ADHD, methods of diagnosis, qualifications of diagnosticians, expected timeframe for receipt of services and others. However, these policies require a higher degree of activation by the Ministry of Health in terms of monitoring and inspecting extent of their application by the Child Development Centres, National Health Funds and individual therapists and specialists to ensure the quality of provided services and timeframe and avoid the occurrence of mistakes in diagnosis and treatment.
- 7 Integrate computerised diagnosis and treatment tools into the Israeli Health Law: the past few years have witnessed the development of several computerised diagnosis and treatment tools that serve as a milestone not only in diagnosis but also in treatment. However, these services are not included in the Israeli Health Law. Instead, parents will have to cover their financial costs by themselves; in some cases there is partial coverage by complementary health insurance, which costs the family an additional amount of money on a monthly basis.

### **1-1-2 On the Level of the Israeli Ministry of Education**

- 1 Rehabilitation of teachers and educational counsellors: the results of the study show that teachers and educational counsellors are insufficiently prepared to work with ADHD cases. Furthermore, the solutions and tools they utilise are predominantly improvised and based on their own analysis instead of utilised systematic programmes to work with ADHD students.
- 2 Provide professional cadre consisting of psychologists and educational counsellors in schools: the study has demonstrated the presence of two centres that provide psycho-educational services in East Jerusalem. The number of psychiatrists/psychologists present in schools is very little, in addition to the complete absence of educational counsellors in the primary level. This poses as a hindrance before schools from creating professional teams inside schools to work with this group of

students, and provide them, their teachers and parents with necessary guidance and instructions.

- 3 Provision of integration programmes and therapies inside schools: there is a clear deficiency in the availability of educational programmes and specialised therapies inside schools in East Jerusalem. Hence, the Ministry of Education should integrate specialised intervention programmes that are similar to those provided in the Hebrew language to work with this group of students. Additionally, the Ministry of Education should expand the basket of specialised treatments that could be provided inside schools.
- 4 Reduce the number of students in class: working with ADHD students poses as a major challenge to teachers and the educational system as a whole. Therefore, in order to accommodate ADHD students and integrate them into ordinary schools, the Ministry of Education should work on reducing the number of students inside classrooms to enable teachers to reach every single student and address his/her special needs.
- 5 Emphasise the importance of integrating students in ordinary frameworks: some schools, as a result of immense challenges in working with ADHD students, tend to remove ADHD students from ordinary educational frameworks and place them in special education frameworks, despite the distinctive mental abilities that the majority of them possess. This leads to the deprivation of the student from studying with his/her peers and fosters a sense of social isolation. This could also lead in some cases to a complete a radical change in the course of his/her academic life.
- 6 Improve the infrastructure and technical capacities of the school: working with ADHD students requires teachers to change their teaching styles, utilise more creative and enjoyable teaching methods and reduce conventional teaching that predominantly relies on indoctrination. As such, schools should be provided with the technological techniques that effectively contribute to the integration and engagement of ADHD in the learning process.

### **1-1-3 On the Level of the Israeli Ministry of Social Welfare**

- 1 Increase the awareness of parents and students in ADHD: the results of the study have revealed that parents' decision to undertake diagnosis and treatment depends on their extend of awareness of the disorder and its causes on the one hand, and their awareness of their rights and the obligations of service providers on another hand. Furthermore, the disorder significantly impacts the family, and

usually causes clashes between parents and ADHD children and among parents themselves, who argue about the best method of upbringing the children. This impacts their marital relationship and reflects on the children and family as a whole. Therefore it is important that the Social Affairs bureau of the Ministry of Social Welfare to create social support groups for the families and students alike.

- 2 Provision of a professional cadre of social workers: the results of the study have reflected a limited intervention from social affairs with families with ADHD children. The number of social workers qualified to accompany families and children is very little. As such social affairs should provide a specialised and trained cadre in the area of ADHD to create social support groups for the children and their families.

## **1-2 On the Palestinian Policy Level**

- 1 Rehabilitate a cadre to diagnose and treat ADHD
- 2 In Ministry of Education and Higher Education: create a separate department than the special education department, such that this one is specialised in learning difficulties and ADHD.
- 3 In Ministry of Education and Higher Education: open specialised programmes in learning difficulties and ADHD in Palestinian universities, as develop existing programmes.
- 4 In Ministry of Education and Higher Education: develop a compulsory course in ADHD in all education programmes.
- 5 Open specialised centres for diagnosis and treatment in East Jerusalem, especially in areas outside the Wall.

## **2 On the Level of the Israeli Jerusalem Municipality**

- 1 Improve services in East Jerusalem: the Jerusalem municipality is responsible for opening psycho-educational service centres, employment of psychologists inside schools and provision of appropriate technological tools and means to schools.

### 3 On the Level of Palestinian Universities

- 1 Improvement of the university rehabilitation programme: it was evident from the teachers who studied in Israeli higher education universities and colleges that their studies enables them to acquire theoretical knowledge but does not qualify them or enables them to acquire necessary tools to deal with ADHD children. Furthermore, teachers from graduate from Palestinian universities graduate with simply knowledge in the field that does not qualify them to understand the needs of ADHD students and deal with them. Therefore it is important that universities and education colleges develop a course that brings together theory and practice to ensure proper rehabilitation to understand and succeed in working with ADHD students in the future.
- 2 Develop complementary courses or a diploma programme for teachers in primary education stage to impart and facilitate the acquisition of knowledge and experience and research-based work methods to work on the difficulties students face in schools, and help them control their disturbances, improve their academic achievement, improve their behaviour and increase the level of acceptance of other students of their peers.

### 4 On the Level of Funding Organisations

- 1 Financing specialised studies in the effective treatment of ADHD. This could be undertaken in cooperation with Palestinian universities.
- 2 Provide support in the development of university programmes and the rehabilitation of teachers who teach relevant courses, since, as mentioned earlier all of those teaching these courses lack specialised clinical experience in working with these students.
- 3 Provide support in developing or opening a specialised multidisciplinary centre to diagnose and treat ADHD students.
- 4 Support relevant initiatives and community organisations that work on raising the awareness of parents and the local community on the rights of these children and the need to integrate them in schools and the society.

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## Appendices

### Appendix 1:

### Interviews Questionnaires

#### Parents' Interview Questionnaire

1. Name: Optional
2. Age of child: \_\_\_\_\_
3. Does your child study in a school or in any particular educational framework? What is this framework? \_\_\_\_\_
4. How did you discover the problem your child is experiencing, and at what age?
5. What was the role of the family doctor?
6. How did you know about your rights as people who could get help from Israeli institutions?
7. How was your experience with Israeli institutions?
8. What process did you go through with your child? Who referred you to get this diagnosis? Where was the diagnosis? How much was the cost?
9. Do National Health Funds contribute to the diagnosis's cost? If yes, what was the coverage? Was it conditional coverage depending on the type of health insurance the child to be diagnosed has?
10. How much does it cost you per month to treat your child?
11. Do you receive disability benefits, what percentage? Do you think this percentage is the right percentage for your child's situation?
12. In the event that your child is placed in the framework of a special kindergarten, special education classes in a regular school, or a special education school, have you received entitlement points from the Ministry of Finance?
13. How long did the diagnosis process take from your referral appointment until the actual diagnosis taking place?
14. Did you receive a written report of the results of the diagnosis? How long after the diagnosis did you receive the report? Did you get an explanation of the results

of the diagnosis? Did the report include practical recommendations for you on how to deal with your child or for the teaching staff?

15. What services does your child receive now? What institutions help your child improve and develop?
16. How satisfied are you with the educational services that your child receives? Please Explain? What is your role in the institution's programs?
17. How satisfied are you with the treatment services your child receives? Please Explain? What is your role in the institution's programs?
18. How do you evaluate the educational staff working with your child in school expertise/qualification in helping your child's needs?
19. Do you think that the classroom environment is designed to accommodate students with special needs (soundproofing, curtains for the room, individual work space, use of smart board, audio-visual teaching methods, etc.)
20. Does the school provide any type of treatment for your child (remedial education, art therapy, music therapy, alternative communication, sensory-motor therapy, behavioural therapy, animal therapy, etc.)?
21. Do you need to take your child to West Jerusalem for treatments? What are the challenges you face?
22. Kindly share with us the daily obstacles and challenges you face with your child?
23. What are the most important problems you have faced or encountered in dealing with the official authorities (child development centres, health funds, hospitals, schools)?
24. What are your concerns, if any, regarding the future of your child?
25. Does your child receive certain special teaching methods? what are they? (Learning in small groups, more practical lessons, getting breaks more than other students, the material explained with visual support, motivating students and stimulating them mentally and emotionally ... etc.).
26. Does your child receive special examination methods? What are they? (Breaks during the exam, getting more time, submitting the exam in a special room without distractions, non-complex questions format, enlarging exam papers, etc.).
27. Did the school ever happen to force you to give pharmacotherapy to your child? How did you deal with this issue?

28. Is it possible to buy medical devices or programs for ADHD at a reduced price or with a certain tax exemption?
29. What are the available technologies to help students with ADHD?
30. As parents, have you received guidance and counselling on how to deal with your child by the official authorities? What kind of counselling did you get?

### **ASD Directors Interview Questionnaire** .....

1. School Name: \_\_\_\_\_ Location: \_\_\_\_\_
  - Age Groups in the school: \_\_\_\_\_
  - Director Name: \_\_\_\_\_
  - Years of teaching experience: \_\_\_\_\_
  - Years of management experience: \_\_\_\_\_
2. How many students are at your school, and what are the levels of autism?
3. What services do you provide at your school for students with ASD?
4. Do you think teachers are qualified enough to deal with this group of students, what is their qualification? What are their needs to better enable them to work with this group of students?
5. How many students, assistants, therapists, and psychologists ...you have in the school?
6. What are the challenges your school teachers face in working with this group of students?
7. How much money does the school receive for each student, and how is the entitlement calculated?
8. What is the role of the parents and their participation with the school and teachers?
9. How do you assess the diagnostic process of children in West Jerusalem up until referring them to schools?
10. Do your teachers pursue continuing professional development? What type of continuing professional development has your teachers' pursuit in the last three years? What are the topics?

11. How do you evaluate your experience with the Ministry of Education and the Ministry of Health in meeting students' needs? Is there an average (time) taken by each activity?
12. How ready is the school and classroom environment to accommodate students with ASD, and what would you recommend?
13. What technologies are available to help students with autism?
14. What are the challenges and difficulties you face in helping this group of students?

### **ADHD Directors Interview Questionnaire** .....

1. School Name: \_\_\_\_\_ Location: \_\_\_\_\_
  - School Stage: \_\_\_\_\_
  - Director Name: \_\_\_\_\_
  - Years of teaching experience: \_\_\_\_\_
  - Years of Management Experience: \_\_\_\_\_
2. What do you think is the percentage of students with ADHD in your school?
3. What is the percentage of students, who have been professionally diagnosed with ADHD out of the total number of students in your school?
4. What is the academic background of teachers who teach students with ADHD?
5. Do you think teachers are qualified enough to deal with this group of students, what is their qualification? What are their needs to better enable them to work with this group of students?
6. What are the steps taken before parents are advised to pursue a diagnosis for their child because there is suspicion that he/she has ADHD?
7. In case the school receives a diagnosed student with ADHD, what are the procedures?
8. Do the school staffs receive guidance and counselling on how to deal with the diagnosed child?
9. Is an individual development plan prepared for a student with ADHD? Who prepares it?
10. Are budgets designated by the municipality and / or the Ministry of Education to deal with students with ADHD? What do those budgets include?

11. How much money does the school receive for each student, and how is the entitlement calculated?
12. Did the school staff receive a special training course to help students with ADHD? What are the results?
13. In the case there is an educational counsellor in the school, what is his/her role in helping students with ADHD?
14. What are the treatment services provided by the school to students with ADHD?
15. Do you think pharmacotherapy is a compulsory for treating students with ADHD, why?
16. What is the most appropriate framework for helping students with ADHD? Why? (Regular classes, special education classes, special education schools, etc.)
17. Does your school provide certain special teaching methods for students with ADHD? What are they?
18. Does your school provide special examination methods for students with ADHD? What are they?
19. How ready is the school and classroom environment to accommodate students with ADHD, and what would you recommend?
20. What technologies are available to help students with ADHD?
21. What are the challenges and difficulties you face in helping this group of students?

### **Child Centres Directors Interview Questionnaire** .....

1. How many child development centres are available in East Jerusalem? Are there centres outside the Wall?
2. For what ages does the centre offer its services? Are there other centres providing services for other ages, name the centres?
3. When you receive a family with the suspicion of a child with a disorder, what are the procedures and tests you conduct?
4. What papers and previous reports should the mother bring to start working with her child at the centre?
5. Can parents approach you directly or do they have to get a referral from their National Health Fund? If yes, what are the qualifications of the doctor authorized to give this referral? Up to what age is it applicable?

6. What services are provided to this group by your centre?
7. What is the qualification of people who provide these services?
8. Is there psychological support for children and parents in the centre, who provides it?
9. Does the Centre provide educational support for children? If yes, what type of support?
10. For children with ADHD, is there a quota in terms of medication provided to beneficiaries? Or other treatments? (such as Ritalin SR is partially covered by the National Health Fund and Ritalin LA is almost completely covered, so there may be a difference between the number of diagnosed cases and the number of cases treated with medication or non-medication due to certain quotas 10%, 20% ... etc.)
11. Do you have a diagnostic service for those groups? If yes, what are those tools? If the answer is no, what are the institutions that you refer parents to?
12. Are diagnoses free or paid?
13. Who covers the costs of tests (what is the contribution of National Health Fund, and is there a difference between funds in the percentage of coverage?)
14. Who covers the costs of follow-up and treatment (what is the contribution of the National Health Fund, and is there a difference between funds in the percentage of coverage?)
15. How long does it take to write a report explaining the child's situation, and what are the components of this report, especially if it has instructions to help the educational framework?
16. Is there a relation between the Child Development Centre and the Ministry of Education, (Case and Referral committees, special education teachers in schools, psychologists...) what is the relation? Is there a connection between the centre and the schools? What is the structure of this relation?
17. Are residents referred to other services, whether in East or West Jerusalem? What are those services?
18. What is the centre's role in working with parents? What are the Centre's activities in this area?
19. What are the challenges parents' face in receiving a diagnostic, follow-up and treatment services both in the centre or other places in East Jerusalem or West Jerusalem?

20. What are the challenges parents' face, in your opinion, since their child diagnosis up till receiving treatment and follow-up services at the centre?
21. Do you think that workers in your centre are qualified enough to diagnose of ASD and ADHD? What are their needs / the centre's needs to provide the best service to parents?
22. In comparison to the services provided by Israeli child development centres, do you think there are differences in terms of the services provided, the budgets received for diagnosis, treatment, service to parents, etc.?

**Shati Centre "Development Unit for Services for People with Special Needs" Interview Questionnaire** .....

1. Branch \_\_\_\_\_
2. Name of person interviewed: \_\_\_\_\_
3. Please share the services provided in general by the Centre to people with special needs?
4. What services does the centre provide for children with ASD?
5. What challenges do parents of children with ASD face in accessing these services?
6. What services does the centre provide for children with ADHD?
7. What challenges do parents of children with ADHD face in accessing these services?
8. What are the institutions you communicate with to provide services?
9. Please share the process of your work by presenting a case of parents who sought your service?
10. How many of the institutions you work with require parents to speak or understand Hebrew?
11. What is the relationship between your centre, National Insurance Institute, and Social Affairs?
12. What challenges do you face in providing these services?
13. Are there differences between the services provided in East and West Jerusalem, if the answer is yes, what are these differences?
14. What should the municipality do to improve services for people with ASD / ADHD in East or West Jerusalem?

## National Insurance Interview Questionnaire .....

1. Do you have data and statistics on ASD and ADHD in general and particularly in Jerusalem?
2. How are children recognized with special needs ?What are the procedures and forms requirements?
3. What is the criteria by which benefits are calculated?
4. How do you explain the low level of recognition among Arabs compared to Jews? Is there an increase in cases submitted?
5. We have found a great difference in the services provided outside the Wall compared to areas inside the Wall, how do you explain this?
6. What are the services provided by the National Insurance Institute to raise awareness of the rights of Palestinians living in East Jerusalem to access services and entitlement?

## Appendix 2:

### Diagnostic Criteria for ADHD

#### DSM-V Diagnostic Criteria that raise suspicion of ADHD

Inattentive Symptoms	
1	Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g., overlooks or misses details, work is inaccurate).
2	Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).
3	Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of any obvious distraction).
4	Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily side-tracked).
5	Often has difficulty organising tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganised work; has poor time management; fails to meet deadlines).
6	Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).
7	Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, and mobile telephones).
8	Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).
9	Is often forgetful in daily activities (e.g., doing chores, running errands, for older adolescents and adults, returning calls, paying bills, keeping appointments).

## Hyperactivity and Impulsivity Symptoms

1	Often fidgets with or taps hands or feet or squirms in seat.
2	Often leaves seat in situations when remaining seated is expected (e.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place).
3	Often runs about or climbs in situations where it is inappropriate. (Note: In adolescents or adults, may be limited to feeling restless.)
4	Often unable to play or engage in leisure activities quietly.
5	Is often "on the go," acting as if "driven by a motor" (e.g., is unable to be or uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with).
6	Often talks excessively.
7	Often blurts out an answer before a question has been completed (e.g., completes people's sentences; cannot wait for turn in conversation).
8	Often has difficulty waiting his or her turn (e.g., while waiting in line)
9	Often interrupts or intrudes on others (e.g., butts into conversations, games, or activities; may start using other people's things without asking or receiving permission; for adolescents and adults, may intrude into or take over what others are doing).

### Appendix 3:

## A comparison between the costs of pharmacotherapy for ADHD among different National Health Funds

Medication	Leumit Health Fund	Meuhedet Health Fund	Maccabi Health Fund	Clalit Health Fund
LA-Long Release 30 mg pill	All members 75.30 ILS (50%) discount	"Meuhedet Adef" or "Meuhedet C" members 75.30 ILS(50%) discount	"Maccabi Sheli" or "Maccabi Gold" members 86.5 ILS(43%) discount	150.60 ILS No discount
concerta 18- 30 mg pill	All members 268.69 NIS "Leumit Gold" members 133.80 NIS	All members 268.69 ILS "Meuhedet Adef" or "Meuhedet C" members 134.35 NIS	All members 268.69NIS "Maccabi Sheli" or "Maccabi Gold" members 134.35 NIS	All members 268.69 ILS "Mushlam" or Platinum" members 131.66 NIS
Adderall	Not Available	"Meuhedet C" 50% discount	A contribution of 15% of the price, after passing through the Exceptions Committee. It can also be purchased independently for members of "Maccabi Gold" or "Maccabi Sheli" up to 360 NIS	Not Available

Medication	Leumit Health Fund	Meuhedet Health Fund	Maccabi Health Fund	Clalit Health Fund
Amphet	<p>"Leumit Gold" members</p> <p>10 mg 30 –pill 133.38NIS</p> <p>20 mg 30 – pill 173.30NIS</p> <p>30 mg 30 – pill 206.51NIS</p>	Not Available	Not Available	Not Available
Strattera	Not Available	<p>10 mg -60 mg28 pill 464.47 NIS.</p> <p>80mg582.23 NIS.</p> <p>"Meuhedet Adef" or "Meuhedet C" 50% discount</p>	With a contribution of 15% in complex and exceptional medical cases	Not Available
Daytrana	Not Available	Not Available	With a contribution of 15% in complex and exceptional medical cases	Not Available
Vyvanse 30 pill	<p>All members</p> <p>30 mg1031.21 , NIS.</p> <p>50 mg1165.82 , NIS.</p> <p>70 mg 1380.81 ,NIS</p> <p>"Leumit Gold" members</p> <p>30 mg 309.37 ,NIS</p> <p>50 mg 349.75 ,NIS</p> <p>70 mg 408.24 ,NIS</p>	Not Available	Not Available	The medication can be purchased independently, to be reimbursed 311 NIS, after exhausting alternative medications available in the basket of medicines and obtaining prior medical approval.
Focalin	Available	Not Available	Not Available	Not Available

(Dan, 2014), (visiting the websites of different National Health Funds)

(دان، 2014)، (مواقع الإنترنت لصناديق المرضى المختلفة)

List of medications given to students with ADHD without deduction from the Healthcare funds

Medication	Dosage	Number of Pills	Cost (ILS)
Ritalin LA	10 mg	30 pill	115
	20 mg	30 pill	149
	mg	30 pill	200
	40 mg	30 pill	278
Ritalin	10 mg	30 pill	31
Ritalin SR	20 mg	30 pill	133
Concerta	18 mg	30 pill	203
	27 mg	30 pill	219
	36 mg	30 pill	241
	54 mg	30 pill	277
Strattera	10 mg	30 capsules	439
	18 mg	30 capsules	439
	25 mg	30 capsules	414
	40 mg	30 capsules	422
	60 mg	30 capsules	422
	80 mg	30 capsules	590
	100 mg	30 capsules	590
	4 mg	Liquid	522
Vyvanse	30 mg	30 capsules	467
	30 mg	100 capsules	1,556
	50 mg	30 capsules	467
	50 mg	100 capsules	1,556
	70 mg	30 capsules	467
	70 mg	100 capsules	1,556
Focalin XR *	10 mg	100 capsules	1,477
	15 mg	100 capsules	1,597
	20 mg	100 capsules	1,713
Focalin XR HGC *	30 mg	100 capsules	1,883

## Appendix 4:

### Comparing the number of specialists between East Jerusalem and West Jerusalem

Comparing the number of specialists between East Jerusalem and West Jerusalem by National Health Fund

National Health Fund	West Jerusalem				East Jerusalem			
	Psychologist	Psychiatrist	Neurologist	Social worker	Psychologist	Psychiatrist	Neurologist	Social worker
Clalit	18	32	11	17	1 Ya'ad Ghandary	3 Naser Srouf Suhail Khalayleh Wael Jadallah	3 Adel Misk Muhannad Da'na Suhair Khoury	5 Ghaida Rabah Rana Azayzeh Duaa Munazal Fatina Hlahel Siham Assali
Maccabi	0	5	10	0	0	1 Suhail Khoury	3 Muhannad Da'na Salim Khoury Suhair Khoury	0
Meuhedet	2	13	12	9	0	0	2 Suhair Khoury Adel Mist	0
Leumit	0	5	3	0	0	0	2 Adel Misk Nour Eddin Yaghmour	0

## Appendix 5:

### Basic treatments provided by compulsory insurance

#### Number and Cost of Treatment Sessions

Age	Number of Sessions	Cost by Compulsory Insurance
0-3 years	Not limited	Free of charge On the condition that treatments are conducted in National Health Funds' Centres or private Centres referred by the National Health Fund
3-6 years	Up to 27 treatment sessions per year for each types of treatment A maximum of 54 treatment sessions/year for all types of treatment More treatments are provided at the expense of parents or complementary insurance.	Personal contribution of 27 ILS per therapy session  If parents receive National Insurance benefits, they are exempted from contribution fees.
6-9 years	Up to 9 treatment sessions including physical therapy, functional treatment, speech therapy. No more than 18 treatment sessions per year for all treatments mentioned above. More treatments are provided at the expense of parents or complementary insurance.	Personal contribution of 27 ILS per therapy session  If parents receive National Insurance benefits, they are exempted from contribution fees.

(Kaisher Association, 2010, Ministry of Health, 2010)

(جمعية كيشير، 2010؛ وزارة الصحة، 2010)

## Appendix 6:

### Additional Treatment Services provided by the National Health Funds

#### Different National Health Fund Treatments, Costs and Insurance Type

Leumit Health Fund	Meuhedet Health Fund	Maccabi Health Fund	Clalit Health Fund
<p>"Leumit Silver" members Up to 30 treatment sessions at 76ILS per session</p> <p>Up to 100 treatment sessions per membership period.</p> <p>"Leumit Gold" members Up to 30 treatment sessions at 45 ILS per session</p> <p>Up to 100 treatment sessions per membership period.</p> <p>Additional treatments such as therapeutic Horseback riding Up to 30 treatments per year with 80% reimbursement (up to 60ILS)</p>	<p>"Meuhedet C" members 0-12 years old= 24 treatment session per year with 75% reimbursement (up to 103ILS)</p> <p>Up to 100 treatment sessions per membership period.</p> <p>Additional treatment sessions are provided at your own expense</p> <p>Swimming Therapy at 41ILS Art, music, movement therapy at 52 ILS</p> <p>Waiting period (entitlement) = 6 months</p>	<p>"Maccabi Gold" members 3-12 years old with ADHD= up to 30 treatment sessions at 67ILS per session</p> <p>"Maccabi Sheli" members 3-12 years old with ADHD= up to 50 treatment sessions at 67ILS per session</p> <p>Unlimited treatment sessions per membership period</p> <p>Waiting period (entitlement) = 12 months</p>	<p>Members of "Mushlam" or Platinum" members 3-9 years old = up to 30 treatment sessions per year at a starting cost of 45 ILS</p> <p>10-18 years old= up to 30 treatment session at a starting cost of 45 ILS</p> <p>Up to 100 treatment sessions per membership period.</p> <p>Waiting period (entitlement) = 6 months</p>

## Appendix 7:

### Child Growth and Development Units

#### 1. National Health Funds' Child Growth and Development Units and Centres

Name	National Health Fund	Location	Phone Number
Child Development Centre Shu'fat	Clalit	Shu'fat- Behind the Mosque	02-5453300
Al-Mustaqbal Centre for Child Development	Clalit	Kufr Akab	02-6288055
Child Development Centre	Macabbi	Jerusalem, 8 Asfahani Street	02-6281255
Child Development Centre	Meuhedet*	Jerusalem, 13 Kenvi Nisharem Street Beit Anbar, Kiryat Shaul	02-6302222
Child Development Centre	Leumit**	Jerusalem, 3 Trambildor Hjadim Street	02-5675104/6

\* They do not have centres in East Jerusalem, and the service is provided in Arabic.

\*\* They do not have centres in East Jerusalem, and some services are provided in Arabic.

#### 2. Child Growth and Development Centres- Private

Name	National Health Fund	Location	Phone Number
Warm House Centre	All Funds	Al-Nuzha Building, Jerusalem	02-5470775
Child Development Centre	Macabbi Meuhedet Clalit	East Jerusalem, Shufat. Behind the Mosque. Abu Khdeir Building	02-5815060
Child Development Unit- MEODI	Meuhedet Clalit Leumit	Jerusalem, Leef Yaffe Street, Arnona	02-6516727
Variety Unit		17 Diskin Street, Jerusalem	02-5666608 02-5391968

### 3. Community Centres

Name	Location	Phone number
Palestinian Counselling Centre*	Beit Hanina	02- 6562272
Spaford Centre*	Jerusalem/Old City- AsSadeyeh Neighbourhood next to Abna' Al-Quds	02-6284875
Princess Bassma Centre*	Mount of Olives- Opposite Al-Maqassed Hospital	02-6283058 02-6264536

\* Computerised ADHD diagnosis are not available

### 4. Centres inside Hospitals

Name	National Health Fund	Location	Phone number
Hadassah Mt. Scopus Hospital for children	All funds	Mt. Scopus	02-5844903 02-5328963
Hadassah Ein Karem	All funds – personal contribution	Ein Karem	02-6779308
Sha'are Zedek	All funds	Sha'are Zedek Hospital	02-6555999 02-6555414 02-6666641

### 5. Educational Psychological Service Centres - through school referrals

Name	Location	Phone number
Beit Hanina Centre	Beit Hanina	02-5850332 02-6563207
Bab As-Sahera Centre	4, Al-Rasheed St., Jerusalem	0544692055

## Appendix 8:

### The Process of Intervention for students with ADHD in Educational Settings

The diagnosis and treatment of ADHD is a complex and multi-step process, typically involves the comprehensive evaluation of information gathered from a number of sources relevant to the child's life.

Qualified healthcare professionals, who have the knowledge and tools to diagnose and treat ADHD, collect and process the gathered information, then determine the child's difficulties and how to manage it. (Ministry of Education, 2009).







