

# First National Public Opinion Survey: Palestinians Knowledge and Understanding of Autism, 2014

Prima indagine nazionale di opinione pubblica:  
conoscenza e comprensione nella popolazione  
palestinese sull'autismo, 2014

Sami Basha / Palestine Ahliya University / Bethlehem – PA

When considering the current status of inclusive education in the Palestinian Authority it is clear that a great deal needs to be done to improve not only the quality, but also the accessibility of education for children with special needs. Key initiatives developed from various conferences have helped to ensure improved training and awareness about inclusive education among all teachers, parents and support staff. At the present time there are many challenges that need to be addressed for the inclusion policy in Palestine to be successfully implemented, particularly in view of the current way in which universities in Palestine are staffed and resourced and the type of links they have with the institutions who are offering services. This is why awareness initiatives are so important to build the bases for any future intervention, especially in the field of special and inclusive education, and in more specific way in the Autism field.

This study was created to be a pilot study wherein for the first time in the PA (Palestinian Authority) national research is done on the Palestinians knowledge and understanding of Autism. This study was implemented based on the recommendations of the Second National Conference on Autism, which was held on the 2nd and 3rd of April 2012 in Bethlehem<sup>1</sup>.

The survey was developed by the researcher and was evaluated by four experts in the field of sociology and psychology. It includes eight demands and was sent to men and women, 18 years old or older, randomly selected from throughout the Palestinian governorates. 718 people from twelve different regions responded to the questionnaire. The purpose of this study was to explore the knowledge and attitudes about Autism spectrum disorders among the Palestinian populations. Significant differences were found between individuals when it came to conclusions and results demonstrate an urgent need to increase awareness, influence policies and provide families with effective strategies for dealing with their children. Equally urgent is the need to assist parents, policymakers and educators to understand the extent of the problem of lack of awareness about in the Autism community and be prepared to intervene in the future.

abstract

**Key-words:** Autism Knowledge, Awareness, Palestinians, Palestinian Authority.

© Pensa MultiMedia Editore srl  
ISSN 2282-5061 (in press)  
ISSN 2282-6041 (on line)

## III. Esiti di ricerca 87

- 1 The conference aimed to create a thinking space between all institutions, bodies, and individuals concerned with Autism on a local and international level, and combine efforts with the international institutions to develop recommendations and realistic plans for the care and treatment, rehabilitation, education, and training of autistic children and to care and empower their families. It was thought to open new possibilities for potential intervention for autistic individuals, especially children.

## Introduction and conceptual framework

There has been a significant shift in attitudes toward Autism over the past decade. In general, people appear to be far more tolerant and understanding than in the past and this is a positive development considering that Autism spectrum disorders (ASDs) have risen to epidemic proportions in many parts of the world. And while we are still struggling for a more positive attitude in Palestine Authority (PA), so individuals with ASDs are equal citizens who take part in everyday life, in various community and recreational programs including school and university.

Yet, in spite of the rise in ASDs and the various attempts to integrate people with invisible disability into all aspects of the community in our Palestinian society, there still seems to be a lack of basic knowledge accessible to the public on Autism. This is why I believe such research is so significant and important. People with everyday lives need to know a minimum of information about ASDs to give them a better understanding of their fellow citizen. All questions in the questionnaire were meant to provoke curiosity to learn more about ASDs and may encourage individuals to dedicate time to learn more about this issue. I hope that this research will be a positive and constructive instrument to invite more people to be involved with children who have ASDs whom we want to have as full citizens in our country, well treated and considered in any future governmental projecting.

For the last decade, discussions on Autism have become more commonplace in the Arab World. This means that while many steps have been taken to make a difference in the ASDs children, still more needs to be done. Though there is currently no specific explanation for why this syndrome exists, or any new findings about treatments, many seem to be interested in continuing to explore this issue. The lack of understanding about the origin of Autism makes it difficult for many people in the community to understand Autism itself. There considerable effort is required in order to follow the manner in which Autism is discussed openly in other communities, especially Europe and United States. Another reality that we need to consider is that the population of people with ASDs is much like the general population; some of us have special talents, some of us are geniuses, and some of us are retarded. But most of us are just average earthlings (Grandin 2004). Therefore, many people have the difficulty to accept that some ASDs children are talented and could live almost a normal life and could be enrolled in a normal school with support from educators.

This type of research has never before been conducted in the PA and therefore all previous initiatives about Autism have not been based on scientific research. These previous initiatives have, therefore, failed to address the complexity of Autism and how it is viewed in the community. Most people want to look for initiatives that give quick answers and rapid results, but may not always be entirely accurate. I believe that it is important to encourage more researches to better understand the ASDs situation in the PA and developing an Autism surveillance system (BASHA, 2010).

In her speech at the workshop organized by the Najah National University in 2001, Ms. Rima Kilani, Director of Special Education (Kilani 200 (of the Ministry of Education spoke about the importance of ordinary teachers to deal with peo-



ple with special needs. She affirmed that many calls have been made for a serious work on teacher's rehabilitation to deal with various difficulties and disorders, but we still need to actually implement what we have declared. She explained that it is hugely importuned to have experts not only in the field of special education, but also with a concrete understanding about the best methods for addressing the knowledge level of the Palestinian community.

It should be noted that in 2003-2004, the number of private educational institutions was 134 centers, distributed in 13 Special Education Directorates of Education (Ministry of Education /high Education 2005). The number of such institutions and centers has increased in the past few years. This is a clear indication of the increased demand for the special education services in the PA, thought as of yet there is still no center that focuses on Autism. This demonstrates the low level of awareness about ASDs. Through this research, an effective strategy for intervention and early diagnosis will be implemented to improve the lives of many autistic children. Additionally, it would work to provide the support for parents to become more aware of working with their children to uphold the hope that with, among other things, a shift of mentality in the community will bring about a better and more integrated future for their children.

## 1. Method

Participants in this survey completed a demographic information report on age, region, gender, and job, as well as years of work experience. Participants also responded to a question regarding their prior awareness of Autism (i.e., "what is Autism?). The Autism Awareness Survey was constructed based in part on questions used in previous studies (for example, British Social Attitudes Survey, Staniland, 2009; Questions about Disability Survey, Graf et al., 2007; and the survey for Americans' Knowledge and Understanding of Autism, 2008) as well as questions reflective of commonly held attitudes and understandings concerning Autism that usually people ask when we meet them during our training course in the PA. The survey is composed of eight questions and addresses people's understanding of key characteristics or behaviors associated with Autism, exposure to people with Autism, awareness and attitudes toward health causes, role of the national media, responsibility, and accommodations for ASDs children in PA.

## 2. Statistical analyses

A primarily exploratory analysis of the data was completed. A reliability analysis was conducted and used to create four scales. First, a scale was created to address the participant's perceived knowledge about the symptoms and etiology of Autism. The scale was composed of three question as follows; what is Autism; what causes Autism; and do you know individuals with Autism. Next, a scale was created to examine roles of the national media in the awareness and media coverage. A third scale was used to investigate perceived negative attitudes toward people with Autism and barriers to accessing resources and health care; ques-

tions were related to this scale were as follows; Who bears responsibility for autistic children? And what is the most appropriate place for the autistic? The fourth scale examined the sense of responsibility and what people think should be done to meet this challenge. In order to help answering this question, five options were given; the existence of early detection programs for Autism; Autism among the priorities of the government; organize national awareness campaign; prepare qualified cadres and finally the option to add what was not mentioned.

### 3. Results

In the first question, the sample was largely male (52%) and female (48%). The education showed the participation of 47% undergraduates and 32% postgraduates and the rest (21%) with less formal education. The main areas as answered by the survey were divided as follows: 68% from the main cities; 21% from villages and 11% from refugee camps. Levels of education ranged as followed: academics (23%), students (20), employees (30%) and others (27%): In terms of specializations status: medical field (12%), psycho-social (36%), others (52%). Fifty six percent of the participants have less than 10 years of experience in their field of specialization and the rest go for more than ten years.

Answer Options	Biological illness	Psychological Disorder	Behavioural Disorder	General growth disorder	I do not know	Response Percent
Biological illness	37	0	0	0	0	5.2%
Psychological Disorder	0	135	0	0	0	19.1%
Behavioral Disorder	0	0	249	0	0	35.3%
General growth disorder	0	0	0	250	0	35.4%
I do not know	0	0	0	0	35	5.0%

#### Q2: What is Autism?

To understand the answers and give significant analyses we need to develop our understanding of the origin of Autism. The first to release the name of Autism and to describe its conditions was the American psychiatrist Leo Kanner (Leo Kanner 1943). He described it as a lack of ability to develop relationships with others and the delay in the acquisition of speech. Later on, all definitions were affected by what Kanner has described. Dr. Abdullah Alzeriqat from the University of Jordan linked the definition of Autism in childhood to the developmental disruption that affects the normal growth and affects social communication and stereotyped behavior characterized by specific and iterative definition (Alzeriqat 2004) Another position is the one Dr. Adel Mohammed Abdul Agllah from Zagazig University in Egypt interested in the Music treatment for autistics, where he define it as a pervasive form of mental disability, and therefore mental disability related to social complex (Mohamed, Adel Abdullah 2008).

The World Health Organization defines this syndrome as an evolutionary disorder diagnosable in the first three years of the child's life. It revolves around



three main areas that we consider as the characteristics of the autistic; the area of communication with others and the social and behavioral area (WHO / ICD-10, 1994). Based on what was mentioned, we can say that the reason why 35.3% answered that it was behavioral disorder was because behavior is what we see first especially in Mediterranean cultural context. Additionally, significant differences between responses of individuals with high knowledge was seen when 35.4% answered that Autism is a general growth disorder, and with those who added more values to the behavioral aspect. The 19.1% who have answered that it was a psychological disorder could be added to the same cultural context where behavior and attitude prevails on the depth of the disorder.

### *Q3 Do you know individuals with Autism?*

Those who answered with yes, were 42% while 58% said no. 28% of those who know individuals autistic were from both sex, while 57% were male and 15% were females. In terms of ages, who have answered the survey considered that 63% are less than 12 years old, while 21% are more than 13 years old and represent all ages arrived to be 16% only.

To understand answers for this question, it is important to mention that there are no medical tests for the Autism diagnosis; accurate diagnosis depends only on the direct observation of the behavior of the individual and his relations with others and the rates of growth. In some cases it is important to refer to medical tests because there are certain behavioral patterns occurring in disorders other than Autism. People sometimes tend not to discuss their opinion when it deals with disability, due to a cultural and mentality attitude. The majority of the answers gave negative knowledge of Autism in the area of living, while less number mentioned knowing autistic children. Sixteen percent of people confirmed that they know more boys with Autism than girls.

International reports have estimated that Autism occurs in as many as 3 in 300 individuals (Kira, 2004), but we do not have a real panoramic of this syndrome in the Mediterranean area that can calculate the number of cases and how far it is spread. Many of the researchers refer to the continuously increasing rates in all parts of the world, including within the PA, these disorders affect males more than females still this ratio is not anymore endorsed! (?)

In the mentality of the people in the WB, many that parents see the diagnosis of Autism for their children, regardless of if it is a boy or a girl, to be a huge shame on the family. This might bring shame on the family and for many it is considered as a curse or bad omen for the family. In the past, people were hesitant about applying a label because they felt that the label of Autism was permanent and signified that there was no hope for that person. Accordingly, this is the reason behind the fear of people declaring that they know people with Autism.

Q4 What Causes Autism?

Answer Options	Biological illness	Psychological Disorder	Behavioural Disorder	General growth disorder	I do not know	Response Percent
Other	0	1	1	2	0	0.6%
Vaccination	1	2	17	13	1	4.9%
Medicine	5	1	18	19	1	6.3%
Heredity	12	24	51	64	7	22.6%
Wrong Education	2	45	35	14	2	14.0%
Family relation	3	47	43	18	2	16.2%
Unknown	12	24	118	142	4	42.9%
I don't know	5	36	36	24	19	17.2%
other	4	7	22	34	1	9.7%

Autism is seen widely as a neurological disorder linked to brain genetic factors (genes) and there is no specific or direct cause linked to Autism (Greenspan, 2006), although there are many theories and research in this domain. There has been a lot of research on this puzzling syndrome in all parts of the world and still the scientists and researchers cannot give an accurate interpretation to the causes of Autism, though there are many theories. In the fifties, the psychoanalytic theory was mainly behind many explanations of Autism and did not take into account the complexities of the human body. It only blamed the wrong education on parents who did not give enough love and affection for their children. In many Arab countries, where the “shame” is a slogan, many kids are likely not given the correct the diagnosis, instead they become part of what the family has to hide. Nowadays, the situation has started to change and awareness campaigns are made to help parents go further with their autistic kids to be able to understand the “Why” and give opportunities for specialists to conduct more explorative research. Nowadays, researchers have begun to explore a different interpretation based on all human components related to physiology, cognitive, psychological, genetic, neurological, and biochemical factors. All of these individual aspects require a lot of research and effort in the coming decades. In the results given, 42.9% accepted that the main reason for Autism is unknown, while the 22.6% agreed on the heredity as the cause of Autism. This second position links to the mentality and cultural context that would like to see the family behind any disability. This is to be confirmed by the 14.00% who responded that it is the wrong education. At the end, 9.7%, in the other item, discussed the cause of Autism and there were 68 persons who were involved in this discussion.



Q5 The role of the national media in the following aspects:

Answer Options						Rating Average
Awareness						
Excellent	1	4	4	3	1	2
Good	2	6	10	4	2	3.5
Accepted	5	22	29	30	5	13
Weak	15	57	86	101	8	38.5
Very Weak	12	45	118	108	16	43

Media Coverage						
Excellent	1	1	2	4	2	2
Good	0	11	12	4	2	4.5
Accepted	3	19	16	16	0	8.5
Weak	10	45	78	82	7	35.5
Very Weak	14	45	119	117	14	49.5

In this section, it is clear that the majority agree that national media do not support the awareness through their programs, with 81% in favor of this position. A small number would say that it is accepted and good, while a very small number of persons supported positively their media coverage and their awareness work.

Q6: Who bears responsibility for autistic children?

Ministry of Education	0	6	9	3	3	3.0%
Ministry of Social Affairs	5	25	27	18	1	10.9%
Ministry of Health	2	11	14	17	1	6.4%
NGO's	4	3	13	12	1	4.7%
All mentioned	19	64	169	174	18	63.4%
I don't know	2	14	6	12	10	6.3%
other	3	11	9	13	0	5.1%

It is so clear that most of those who answered the survey are not specifically aware of who is exactly responsible for the disability issue. Accordingly, their main answer was "all mentioned". The Ministry of Social Affairs was at the top of the list of those who are responsible for working to increase awareness and offering services. In the list of others, one interesting issue was raised, and that is the lack of specialized institute, center or a school that is concerned about autistics in the PA.

Q7: What is the most appropriate place for the autistic?

Home	1	20	16	14	2	7.6%
School	1	8	13	10	2	4.9%
Special Institution	15	45	78	78	15	33.2%
All mentioned	18	60	139	147	14	54.3%

For many families with a family member on the Autism spectrum, the best place to live is where they can access different educational, medical and recreational resources without having to drive to another city or country. I know personally that many people from PA had to take their children to Jordan, US or some European countries hoping to find a better place for their treatment. Many parents would ask themselves their child will be able to live independently? To read and write? To hold a job? To get married? This is why parents want their children to have the best therapy program, accordingly, they would prefer to trust specialists who can deal with the child better than the parents. Unfortunately, this is what many parents think and act without considering the important role of their parenthood. Those who answer 33.2% for special institutions were faced by 54.3% who highlighted the importance of dividing the responsibility.

*Q8: What can be done in Palestine to meet this challenge?*

Existence of early detection programs for Autism	20	78	157	167	20	63.1%
Autism become among the priorities of the government	13	44	103	121	16	42.4%
Organize national awareness campaign	16	62	137	132	18	52.1%
Prepare qualified cadres	17	64	155	160	23	59.8%
other	4	6	14	26	4	7.7%

Today there are more opportunities for inclusion of autistics in daily life, but still many would probably be wondering and worrying about what comes next. No parent is ever prepared to hear that a child is anything other than happy and healthy, and a diagnosis of Autism can be particularly frightening. Unfortunately, the last decades have been a disaster for Autism, especially with those who pretend to diagnose Autism in PA, accordingly, parents and children were victims of quick evaluation with final report that categorize the child as autistic, and in most cases were given psycho pharmacy to calm them down without serious pedagogical intervention. The culture and the local mentality find it difficult to bring the child into a shared world and foster attention and engagement. People are in front of how to coop with new challenges related to Autism. It is so clear that all answers give the impression that people want changes in this sector and see real and concrete steps toward serious intervention especially on official levels.

## 4. Final remarks

I thought to start working on this research in order to highlight the growing need for concern and awareness about Autism in the PA, and as a way to educate the public about Autism and issues within the Autism community. I remember when I launched the survey many people said that there was no need to ask the public opinion about Autism because it is unknown disorder. When I went ahead with my idea I felt that it was necessary to do it, simply because answers given shown the need for such provocative survey. It is an important indicator when 22.6% says that Autism is caused by heredity, while the majority of 42.9% says that it is





unknown, furthermore, 63.1% said that there is a need for early detection for Autism, while 58.9% pretended the need for the preparation of qualified cadres. All other answers showed a positive opinion about Autism in the Palestinian Authority, in spite of their sufficient knowledge.

## Key points

1. There are sufficient levels of public awareness of Autism in the PA, taking into consideration the cultural and mentality aspects.
2. There was a good and representative gender participation in the survey, where there was largely male (52%) and female (48%).
3. The research showed worrying data about what people know about Autism, 35.3% thinks that it is a behavioral disorder, while 19.1% believes that it is under the psychological disorders. I admit that it is really worrying to have such number of people supporting this theory in the PA. The final 5% which declared their ignorance in the field is classic percentage in most researches, while the 35.4% see it as a general growth disorder.
4. Most respondents (42%) would feel comfortable declaring to know an individual with Autism.
5. The majority of respondents (42%) said that the cause of Autism is unknown.
6. There was considerable support for pedagogical interventions from all who are related to the autistic child, especially at home, in school and special institutions.
7. The public is unclear and uncomfortable about media coverage in supporting and highlighting the needs of individuals with Autism.

## References

- Edward A. Polloway (2008). *Strategies for teaching learners with special needs*. Pearson USA.
- Scot Danforth (2007). *Cases in behavior management*. Pearson USA.
- Libby G. Cohen (2011). *Assessment of children and youth with special needs*. Pearson USA.
- Alan R. Tom (ed.) (2002). *Rethinking Standards Through Teacher Preparation Partnerships*. State University Of New York Press.
- Al-Ramahi N., Davies B. (2002). Changing Primary Education in Palestine: pulling in several directions at once. *International Studies in Sociology of Education*, 12, (1), 59-76.
- Jafari R. (2006). *Engaging Teacher Educators in Inclusive Education Discourse*. Unpublished MED Dissertation, University of Manchester.
- Karlsson P. (2004). *Towards Inclusive Education for All in Palestine 2004*. Diakonia/Nad Rehabilitation Program.
- Khalidi M., Wahbeh N. *Teacher Education in Palestine: Understanding Teachers' Realities and Development* – Chapter ten of an edited book.
- Lifshitz H., Glaubman R., Issawi R. 'Attitudes towards inclusion: the case of Israeli and Palestinian regular and special education teachers'. *European Journal of Special Needs Education*, 19 (2), 171-190.
- Balshaw M., Farrell P. (2002). *Teaching Assistants: Practical Strategies for Effective Classroom Support*. London: Fulton.
- Lewis A., Norwich B. (2005) (Eds.). *Special Teaching for Special Children? Pedagogies for Inclusion*, Buckingham: Open University Press
- Mittler P. (2000). *Working Towards Inclusive Education: Social Contexts*. London: David Fulton.

- Nind M., Rix J., Sheehy K., Simmons K. (2005) (eds.). *Curriculum and Pedagogy in Inclusive Education. Values into Practice*, Abingdon: Routledge Falmer.
- Rix J., Simmons K., Nind M., Sheehy K. (2005) (eds.). *Policy and Power in Inclusive Education. Values into Practice*. Abingdon: Routledge Falmer.
- Thomas G., Vaughan M. (2004). *Inclusive Education: Readings and Reflections*. Maidenhead: Open University Press.