



***Enhancing public services for
individuals with autism in Saudi
Arabia***



**World Autism
Awareness Day**

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Introduction

Autism is a lifelong condition and a "developmental" "social and communication disorder" that makes the person suffering from it experience the world differently from how typical people experience it (Parker, Jones and Wheatcroft, 2008; Frith, 2008). It is often associated with sensory issues, as Jackson indicated (2011). The individual can be hypersensitive or hyposensitive to environmental stimulations such as, light, sounds and touch. Without the appropriate accommodation, these sensory issues, together with difficulties in communication and socialising can significantly and negatively affect the individual and his or her family life. Therefore, the particular needs of the sufferers and their families have to be understood by typical people in order to help them live a fulfilling life in a community that is inclusive to all individuals, where their differences are respected and their abilities appreciated (Parker, Jones and Wheatcroft, 2008; Frith, 2008).

Although during recent years recognition of the condition of autism has gradually increased, this has not yet been reflected in practice and in the development of services that can meet the complex needs associated with the condition of autism (Parker, Jones and Wheatcroft, 2008).

As part of the teaching staff at King Saud University, I aim for this small-scale study to clarify the current state of public services and support for children and adults with autism, as well as their families, in Saudi Arabia by monitoring the satisfaction of parents with regards to public services and the support provided for them. The study will examine six areas of support as follows: the diagnosis services, level of awareness among services providers and the public, education, employment, the role of autism charities and funding and finally the amount of information available in Arabic and the quality of research conducted. The information will be collected from parents in different regions of the Kingdom of Saudi Arabia.



Literature Review

The economic impact of autism in Saudi Arabia is still unknown. However, according to Jordan and Knap's (2011) study, the lifetime cost of raising a person with autism in the UK exceeded 2.4 million pounds. As services have gradually developed, the need for funding has had to increase in order to cover the therapist and intervention costs, otherwise the quality of life of parents and children will be negatively impacted. In addition, parents have the right to access the information and knowledge that allows them to have a better understanding of their children's needs. However, this might be an issue for Saudi families because the majority of information is in English. Therefore, autism associations and universities have to perform their role in providing Arabic sources for parents and service providers in the community by translating guidance and advice for parents, in addition to ensuring that their training programmes are up to date (Tree of Knowledge, 2010 and Riddick, 2006).

With regard to the right of accessing diagnosis services, diagnosing autism is still an issue in Saudi Arabia. The process is not yet clear and teachers in mainstream schools still lack understanding of the characteristics of autism, as well as parents, especially if the child is at the higher end of the autism spectrum. Thus, educators in collaboration with health professionals have to increase their knowledge of the early signs of the condition of autism (Ravet and Taylor, 2008). Although parents may have concerns about their child's development, most children are diagnosed by the age of 3 or older, as Rogers (2004) indicated. Misdiagnosing autism means that the child and his family do not receive the right help and support they need. In terms of diagnosing Asperger syndrome and high-function autism, this can also be



difficult due to the high cost of the diagnosis if it is not being funded. In addition, it needs to be made by people who are highly qualified and experts in the field. Neglecting these children and not meeting their needs can greatly affect the quality of their life and limit their opportunities on a day-to-day basis (Simone, 2010).

Receiving follow-up advice and support after diagnosis is the simplest right for individuals with autism and their family members. They have to be guided to the most appropriate services available for them in the community. These services and support include: the appropriate school for them, social services, support for family members, benefits and support groups (The National Autistic Society, 2009).

With regard to their rights in education, there is no doubt that appropriate education can make a great difference regarding the individual's development and opportunities in life. Thus, teachers in mainstream schools have to give extra support to a child with autism in regular classrooms in order to help them progress and learn in the least restrictive environment (Jordan and Jones, 1999). Children with autism have the right to free and appropriate education where barriers for their learning are removed (Simpson, 2003). Making the necessary adjustment and accommodation is the role of teachers in mainstream schools, especially when working with students with high functioning autism or Asperger Syndrome who are more likely to be able to cope academically and not emotionally and socially (Simon, 2010).

Being a sibling of a child with autism can be difficult without appropriate support. Sisters and brothers may experience feelings of embarrassment, anger, shame or confusion (Walsh, 2010). In addition, they are more likely to take on the role of supervising their brother or sister with autism. This caring



role may start from an early age to adulthood. Unfortunately, sibling issues are rarely discussed or recognised by service providers. They need emotional support, practical advice and consoling from services providers (Tyler, 2011). As the siblings get older, their fear of the future is likely to increase, especially as their parents age and the responsibilities are transferred to the siblings in addition to their concerns about the genetic risk if they want to have children. It is the role of service providers to provide siblings the information to help them overcome the concerns that they might have about their autistic brother or sister's future by ensuring that they receive continued support and assistance (Tozer, Wenham and Atkin, 2011).

With regard to public places, such places can be stressful and challenging for parents and individuals with autism without appropriate support and public understanding and awareness of their particular needs. Parents of autistic children want to be allowed to go first and avoid queuing, as it is known that waiting is difficult for children with autism. Therefore, they have to be given the appropriate support by services in public places, for instance by providing a special pass and special hand stamp that allows them to go first in accessing any public services. This kind of assistance can be totally absent in developing countries. Thus, parents are more likely to be excluded from many social events and activities because of people being intolerant and judgmental about their children's behaviour (Nice, 2010). The deep meaning of awareness about autism is not only about understanding its characteristics but also understanding its special needs and accommodating them accordingly in the environment.

It cannot be over-emphasised that awareness and understanding among service providers are crucial in influencing the quality of life of individuals with autism and their families. For instance, patients with autism need special care and understanding for their needs among doctors, nurses, paramedics,



dentists and opticians. Going to a hospital can be stressful for a child or adult with autism due to their sensitivity to the environmental stimulations such as lights and sounds, in addition to their difficulties in communication and social interaction. Waiting around in a crowded hospital for an appointment can cause challenging behaviours. Thus, a visit to a hospital has to be accommodated to meet the patient with autism's needs and the needs of his or her family. Without such an understanding of their special needs by healthcare providers, their health can also being affected negatively (Deudney, 2006; Jones, 2006; Wilkes, 2006; Arranga, 2008, Wilkes, 2006).

Finally, individuals with autism have the right to access appropriate services that can meet their special needs in adulthood. For instance, in employment, finding and holding a job for adults with autism can be difficult due to their difficulties in social interaction, communication and due to the sensory issues that they may experience in the workplace. Adults with autism have the same rights to equal opportunities in employment and to financial stability as other people. With the appropriate training and support, they can hold a job and participate equally in society (Simone, 2010; Mawhood and Howlin, 1999, Thomas, Morrissey and McLaurin, 2007, Aylott, 2008, Alston, 2010 and Jones, 2008).

Project design and methods

A web page survey was created and posted on a special page on Facebook for the purpose of this research and the following information was given:

"Enhancing public services for individuals with autism in Saudi Arabia"

The aim of this survey is to enhance the public services provided for children and adults with autism. By monitoring the satisfaction of parents, we



believe that the necessary changes can be made to meet your needs and enhance the quality and quantity of public services that are provided for you.

We encourage all parents to take part in this survey so that their voices can reach policy makers. A report will be written and delivered to the responsible institutions.

This survey should take approximately 5-6 minutes.

Google analytics was used to analyse the quantitative data. The qualitative data was analysed by hand. The number of participants was 36 parents of children and adults with autism in all regions of Saudi Arabia (The Middle, the East, the West, the North and the South). Of these, 83% were male and 17% female. The data was collected between 7/4/2011 and 14/4/2011 (the number of participants increased to 48 by 17/4/2011; see page 16).

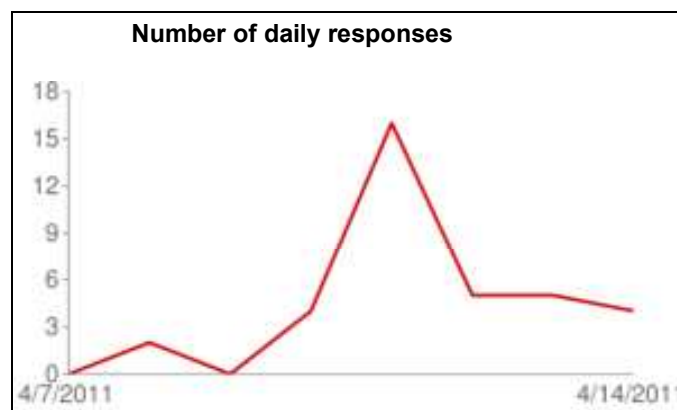


Figure1: The number of daily responses (7-14/4/2011)

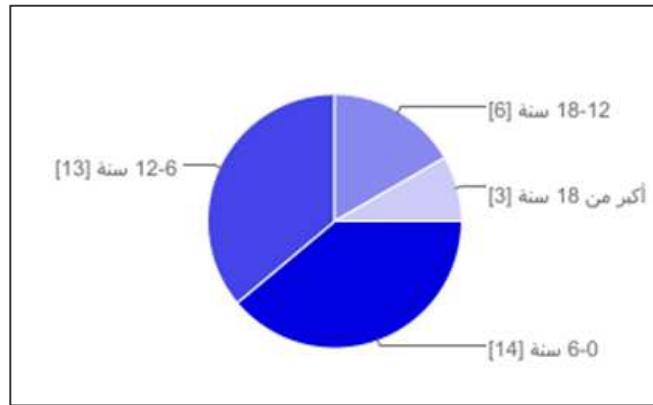


Figure 2: Ages (0-18)



Figure 3: Gender

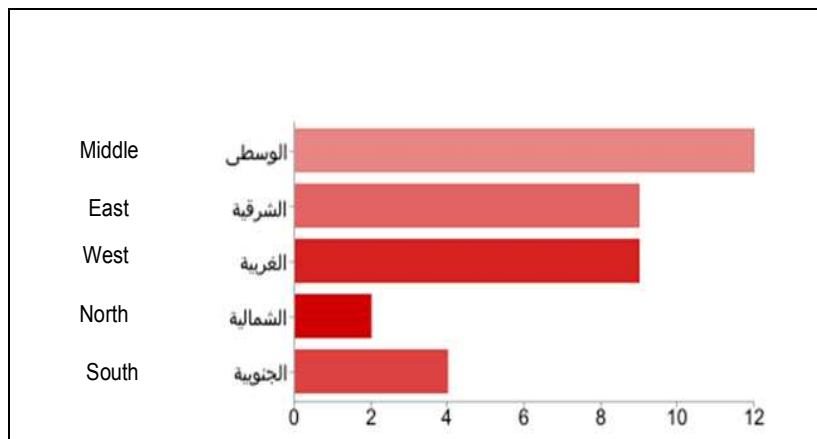




Figure 4: Regions

The study sought answers to 17 questions under the following themes:

Diagnosis services (3 Questions),

- 1. Age of Diagnosis:**
- 2. Diagnosis obtained from:**
- 3. Have you received support after the diagnosis?**

Awareness (3 Questions)

- 4. Do you think that public awareness is good?**
- 5. Do you think that knowledge and understanding among teachers in public schools are good?**
- 6. Do you think that knowledge and understanding among people who provide basic health care are good?**

Public education (3 Questions)

- 7. Do you think that public early intervention services are:**
- 8. Do you think that public schools are satisfactorily including students with autism?**
- 9. Do you think that there are equal opportunities for individuals with autism in public universities and colleges?**

Research and information (2 Questions)

- 10. Do you think that there are enough Arabic sources about autism?**
- 11. What is your opinion about the quality and quantity of research conducted on autism in Arabic?**

Employment (3 Questions)

- 12. Do you think there are equal opportunities in employment for individuals with autism?**
- 13. How do you find the quality of employment training programmes for individuals with autism?**



14. How do you find the awareness about autism among employers?

The role of autism charities and funding (3 Questions)

15. How do you find the role provided by Saudi autism charities in enhancing the services that are provided?

16. How do you find the support provided for his/her siblings?

17. How do you find government financial assistance?

In addition there were two qualitative questions,

- In your opinion, what are the factors that affect the quality of public services?

- If you could make one change to the support your family has received, what would it be?

Results and discussion

With regard to diagnosis services, the majority of the sample (89%) were diagnosed at an early age of 0-6 years old which indicated that early diagnosis is good. However, some parents mentioned that they have some concerns about the accuracy of the diagnosis that they were given. 25% of parents received the diagnosis from people who are not specialists in autism and 39% were given the diagnosis from private clinics, and only 36% obtained the diagnosis from public clinics. In addition, families reported that the process of diagnosis is still confusing for them and it is not clear, even for professionals, in terms of the tests and the process of the diagnosis. In terms of supporting parents after the diagnosis, none of the parents were given enough support after the diagnosis.



With regard to public awareness of the needs of individuals with autism, 97% indicated that the level of public awareness is still poor and 3% indicated that it is at an average level. With regard to the knowledge and understanding among teachers in public schools, 99% think that teachers in mainstream schools do not understand the needs of their children.

In terms of the knowledge and understanding of people in the health sector, 8% think it is at an average level and the rest think it is very poor. With regard to early intervention services, 94% are dissatisfied about them and only 6 % think they are average. In terms of the inclusion in public schools, only 3% think that public schools do include their children in mainstream schools. What is surprising is that the Ministry of Education is not currently willing to include students with autism in regular classrooms as parents indicated, but they stated that the Education Ministry has given permission for the private sector to build special schools for children with autism and children who have been on the waiting list for a long time can be institutionalised inside or outside the country.

With regard to services for adults, 6% think that there are equal opportunities for them in jobs and 88% think that the employment training programmes are unsatisfactory, as is awareness among employers. 75% of families reported that they do not trust Saudi autism associations and charities and they refer to international societies for advice and help. Parents think that the public facilities and services are poor because of corruption, dishonesty and lack of supervision. They also complain about not including them in decisions or involving them in designing programmes, although they do feel they know more than do the professionals in charities and autism societies.



In addition, they reported that the Ministry of Education do not want to include their children in public schools and they refer them to the autism associations who tell parent to institutionalise their children in an Arab country. Some parents are very frustrated and without hope because the government is raising funding for autism associations but they are wasting the funding and not using it to develop services and support for them. A mother of a 6 years old boy wrote "The autism society told me that my son will not be able to receive educational benefits so since he was diagnosed I have been taking him from hospital to hospital seeking treatment and knowing he is in oxygen therapy". Some parents said that they want free, appropriate education for their children. They also want special centres to increase their capacity and stop asking them to institutionalise their children. A mother of a 10 year old girl said, "I want people to treat me and my daughter as human and stop judging her for her behaviour". "All men are created equal", or is it except if they have autism? Edleson,(2008)

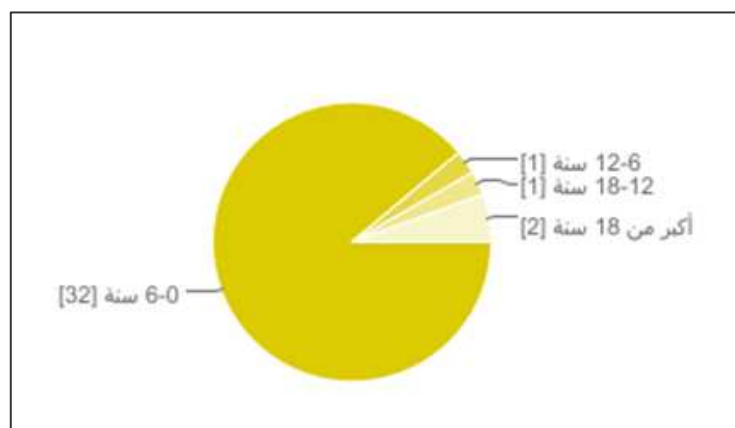


Figure 5: Age of Diagnosis

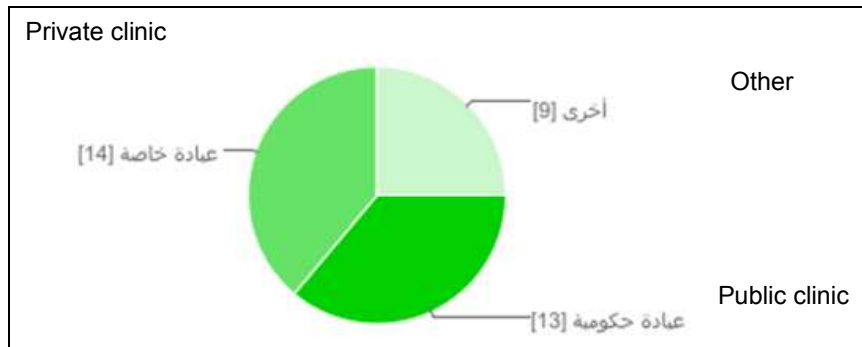


Figure 6: Where the diagnosis was obtained from

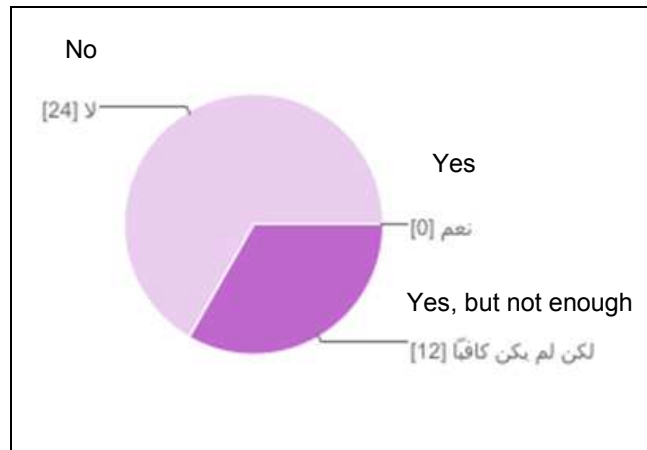


Figure 7: The support after the diagnosis

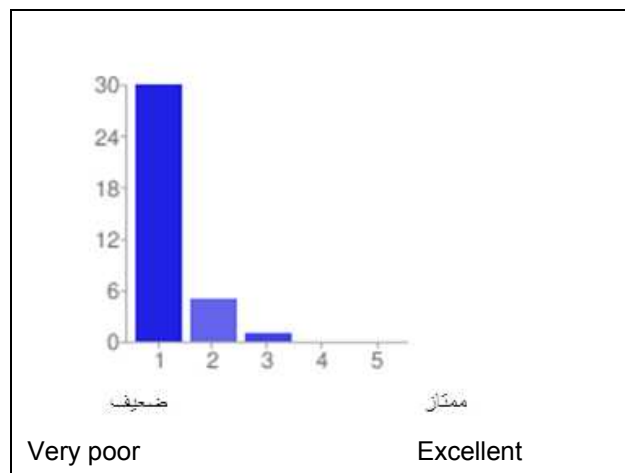


Figure 8: Public awareness

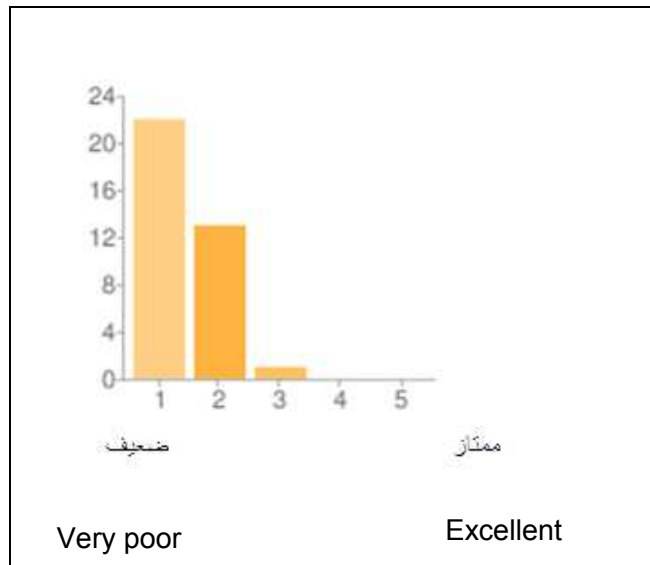


Figure 9: Knowledge and understanding among teachers in public schools

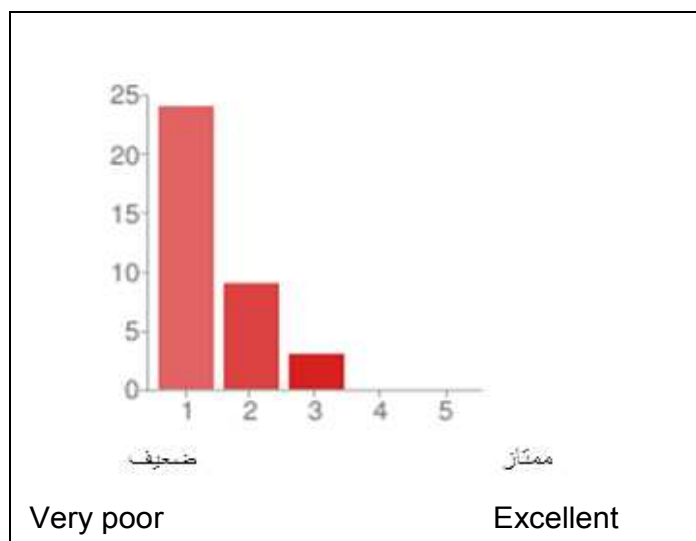




Figure 10: Knowledge and understanding among people who provide basic healthcare

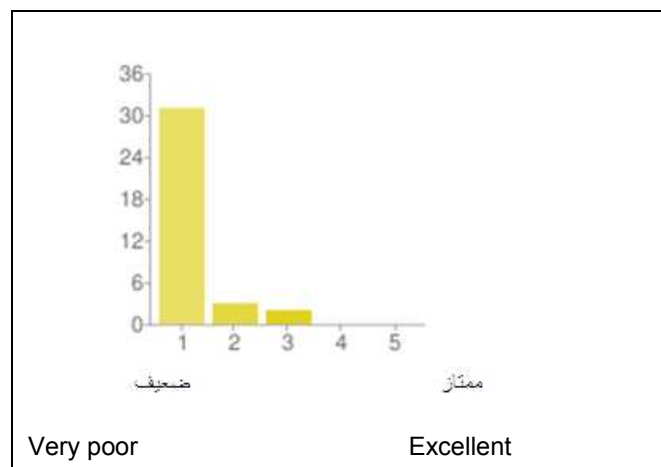


Figure 11: Public early intervention services

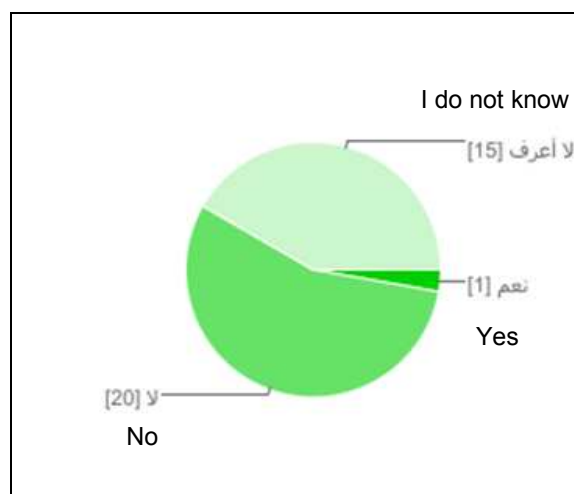




Figure 12: Public schools are satisfactorily including students with autism?

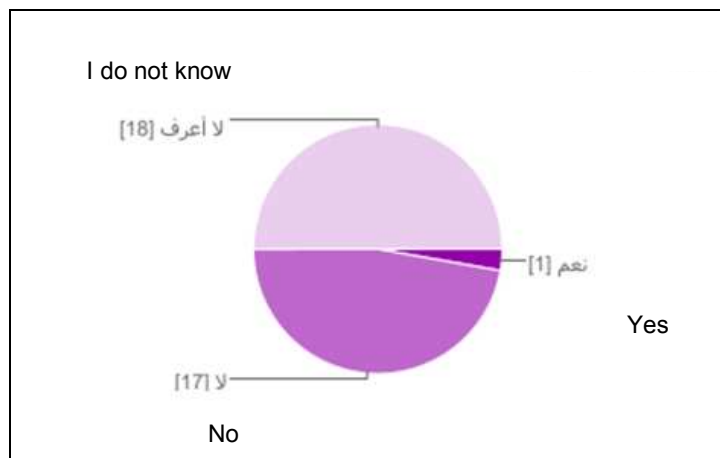


Figure 13: Do you think that there are equal opportunities for individuals with autism in public universities and colleges?

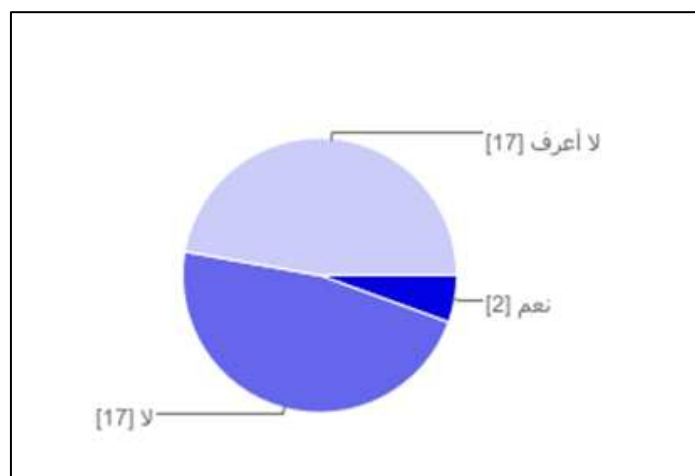


Figure 14: Do you think there are equal opportunities in employment for individuals with autism?

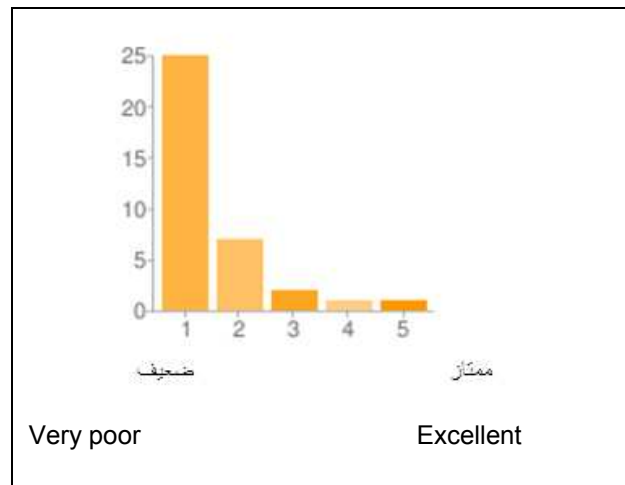


Figure 15: How do you find the quality of employment training programmes for individuals with autism?

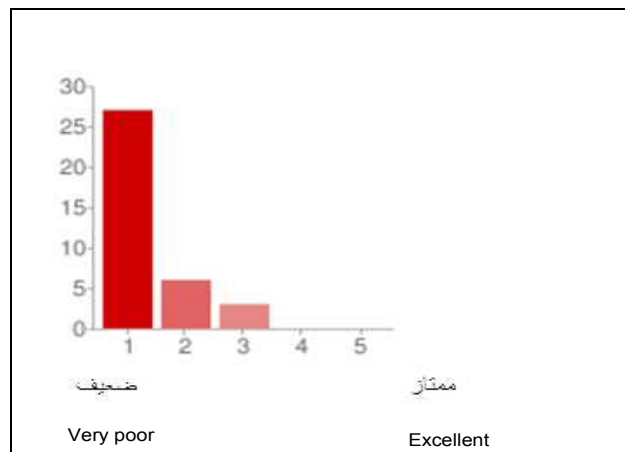


Figure 16: How do you find awareness about autism among employers?

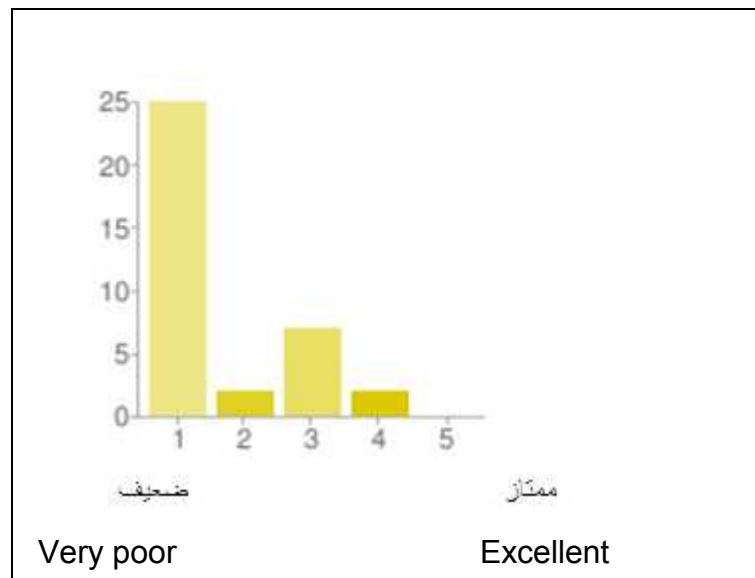


Figure 17: How do you find the role provided by Saudi autism charities in enhancing the services that are provided?

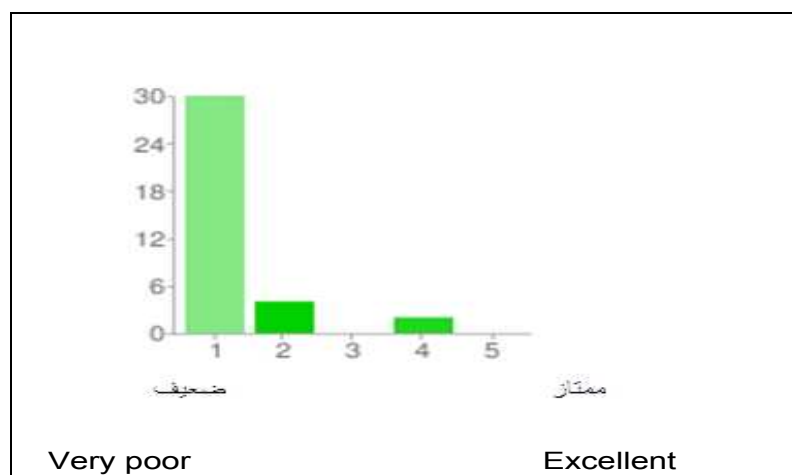


Figure 18: How do you find the support provided for his/her siblings?

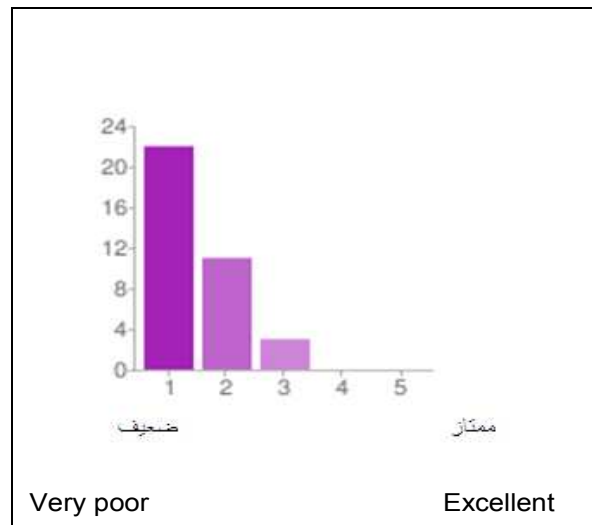


Figure 19: How do you find government financial assistance?

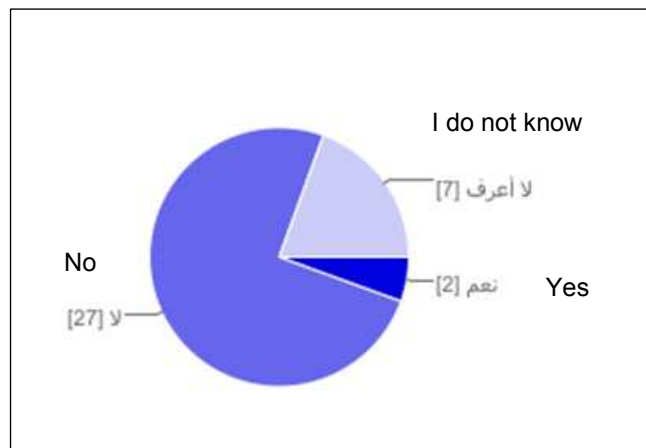




Figure 20: Do you think that there are enough Arabic sources about autism?

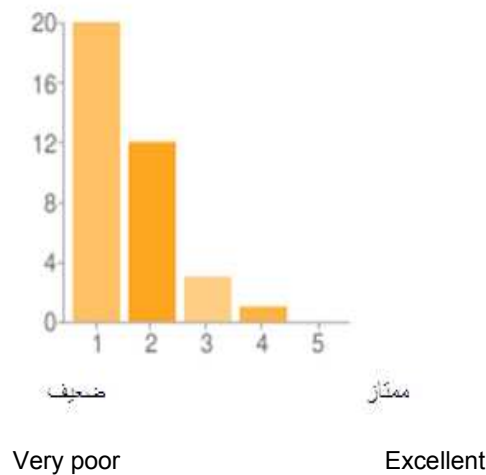


Figure 21: The quality and quantity of research conducted on autism in Arabic?

Some parent indicated that they want autism societies in Saudi Arabia to borrow successful practice and to have joint programmes with international organisations. In addition, they want public bodies to work collaboratively and to develop national training for them and for service providers across the country.

Conclusions and implications

It seems to be a difficult situation for parents and an issue of inequality for people with autism. They are struggling to receive support from charities and Saudi autism societies. Their children are being excluded from mainstream schools because they have special needs which the schools are not capable of dealing with. The debate about inclusion has been going on for years. The Ministry of Social Affairs and the education Minister are closing their doors to families and rejecting their children because of their special needs. In regards to the Saudi government, it has signed international conventions related to protecting the rights of children with special needs. These conventions are accessible to anyone through the National Society for



Human Rights (NSHR) office in Riyadh or on their website. It is not an issue of lack of funding as the Saudi government allocates huge budgets for autism and this has been announced in the media. The government has provided all the resources needed to enhance the quality of life for people with autism and their families but nothing is seen in reality. This issue has been in the media for a long time. People with autism should not suffer in silence anymore and the government must take serious steps to ensure that they and their families are treated equally as citizens and be involved in projects that improve their lives. International conventions are for implementing not for signing



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Appendix



Enhancing public services for individuals with autism in Saudi Arabia

The aim of this survey is to enhance the public services provided for children and adults with autism. By monitoring the satisfaction of parents of children and adults with autism, we believe that the necessary changes can be made to meet your needs and enhance the quality and quantity of public services that are provided.

We encourage all parents to take part in this survey so that their voices can reach policy makers. A report will be written and delivered to the responsible institutions.

This survey should take approximately 5-6 minutes.

Hanan Almasoud

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General information:

18. His/Her age:

(0-6) (6-12) (12-18) (18+)

19. Gender:

Male () Female ()

20. Where do you live?

Middle ()



West ()

East ()

South ()

North ()

Diagnosis services

21. Age of Diagnosis:

(0-6) (6-12) (12-18) (18+)

22. Diagnosis obtained from:

Public clinic () Private clinic () Other ()

23. Have you received support after the diagnosis?

Yes () Yes, but not enough () No ()

Awareness

24. Do you think that public awareness is:

Excellent () Good () Fair () Poor () Very poor ()

25. Do you think that knowledge and understanding among teachers in public schools are:

Excellent () Good () Fair () Poor () Very poor ()

26. Do you think that knowledge and understanding among people who provide basic health care are:

Excellent () Good () Fair () Poor () Very poor ()

Public Education

27. Do you think that public early intervention services are:

Excellent () Good () Fair () Poor () Very poor ()

28. Do you think that public schools are satisfactorily including students with autism?



Yes () No () I do not know ()

29. Do you think that there are equal opportunities for individuals with autism in public universities and colleges?

Yes () No () I do not know ()

Employment

30. Do you think there are equal opportunities in employment for individuals with autism?

Yes () No () I do not know ()

31. How do you find the quality of employment training programmes for individuals with autism?

Excellent () Good () Fair () Poor () Very poor ()

32. How do you find the awareness about autism among employers

Excellent () Good () Fair () Poor () Very poor ()

The role of autism charities and funding

33. How do you find the role provided by Saudi autism charities in enhancing the services that are provided?

Excellent () Good () Fair () Poor () Very poor ()

34. How do you find the support provided for his/her siblings?

Excellent () Good () Fair () Poor () Very poor ()

35. How do you find government financial assistance?

Excellent () Good () Fair () Poor () Very poor ()

Information and research

36. Do you think that there are enough Arabic sources about autism?

Yes () No () I do not know ()

37. What is your opinion about the quality and quantity of research conducted on autism in Arabic?



Excellent () Good () Fair () Poor () Very poor ()

- In your opinion, what are the factors that affect the quality and quantity of public services for individuals with autism?

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- If you could make one change to the support your family has received, what would it be?

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Thank you very much for your time.