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Indicators of Autism in Iranian Children

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1. Introduction

Autism occurs in every country of the world. However its prevalence varies greatly across nations with higher rates being reported in more affluent, English speaking countries. The lower rates in less developed countries have been attributed to a lack of knowledgeable personnel in child assessment and diagnostic services and their slow response to parental concerns [1]. While this is certainly a major impediment to early identification, other social and cultural factors may play a part. In particular, expectations of children's development and behaviours may mean that parents attach less significance to certain early indicators of Autism across different cultures [2]. If this were so, then screening and other assessment tools developed in Western countries may not be sufficiently sensitive to detect early signs of Autism in other societies [3].

This chapter summarises the findings from two studies in Iran that identified the items that best discriminated children who had a diagnosis of autism. In the first study, the Gilliam Autism Rating Scale - Second edition GARS ll [4] was used. Comparisons are drawn between three groups of children aged 3 to 16 years: those with a compared diagnosis of Autism; children with intellectual disabilities and those whose development was considered to be normal.

The second study focussed on the Autism Diagnostic Interview- Revised (ADI-R) [5]. This tool was developed for use by clinicians to assist in making a diagnosis of autism usually after referral that follows from the use of a screening tool such as GARS. In all the performance of 333 children (84%) with a confirmed diagnosis of Autism could be confirmed with those of 64 (16%) who were not given this diagnosis although they had screened positive.

The findings from these two major studies together identify those indicators of autism that appear to be more culturally specific to Iranian or similar cultures. However comparisons are drawn with similar data from other countries to underline the universality of certain au-

tistic traits [6]. Nevertheless the implementation of tools for the identification of children with autism has to be located within wider considerations; notably the education of parents and professionals around indicators of atypical child development and the possible environmental influences on children's behaviours.

2. Identifying children with autism in different cultures

Children with autism have deficits in three developmental domains: communication, socialisation and restricted interests along with repetitive behaviours [7]. These criteria are presumed to hold across all cultures although there is growing evidence of cultural variations in the way children may present with Autism. Indeed there are good theoretical grounds for expecting this to be so. Theories on human development propose that children develop through adapting to the multidimensional, intersecting environments within which they live and grow, the most proximate of which are their parents and families [8]. Parental influences on their child's development may therefore vary in different cultures depending on their beliefs about normative development, the relative value their culture places on different behaviors and the meaning attributed to them[9;10]. For example, in Western societies the absence of direct eye contact is an early indicator of ASD yet in Chinese and Japanese societies, such eye contact is uncommon as looking directly into someone's eyes is considered shameful in these parts of East Asia [11].

Studies done in the Western societies around early signs of autism, [12] found that the most common parental concerns were for delay in speech and language development, followed by abnormal signs of socio-emotional behaviour and medical problems or delay in reaching milestones. By contrast, Daley [13] found that with Indian parents, social difficulties - such as lack of interest in people, poor eye contact and showing no interest in playing with other children - were rated as the first parental concern with delay in speech as a secondary concern. These variations in cultural expectations are likely to exist among indigenous professionals as well as parents.

The diagnosis of autism varies across different ethnic groups within countries. Mandell et al. [14] in a study of over 2,500 eight year-olds in the USA, reported that children from Black, Hispanic and other ethnic or racial groups were less likely than white children to have a documented autism spectrum disorder. Valicenti-McDermott et al. [15] found that children of Hispanic and African American origin, foreign-born children, and children born to foreign mothers were more likely to be diagnosed at an older age than those from white American parentage. Likewise in Holland, fewer children from Moroccan or Turkish immigrants than native born Dutch children were referred for assessments for ASD [16]. Moreover paediatricians (n = 81) more often referred to autism when judging clinical vignettes of European majority cases (Dutch) than vignettes of minority cases.

Cultural influences may also explain to some extent the variation in prevalence rate of ASD reported across different countries. A systematic review of 40 studies [17], reported rates varying from 3.8 per 10,000 in Norway, 5.4 in France and 5.6 in Finland through to a high of

60 per 10,000 in Sweden. However in London, a more thorough study reported a prevalence rate of 38 9 per 10,000 for autistic disorders and for other ASDs at 77 2 per 10,000; giving a total prevalence for all ASDs of 116 1 per 10,000 [18]. A regression analyses of the prevalence studies found that the most significant influence on ASD rates was the diagnostic criteria used, followed by the age of child when identified, the country of origin and urban/rural location of the sample [17].

These same factors may also account for the variation in prevalence rates that have been reported within countries even when ascertainment method, age group and reporting period are similar. In the USA, the prevalence of all ASDs in eight year old children varied across eleven sites from 42 per 10,000 in Florida to 121 per 10,000 in Arizona and Missouri [19]. Using special education data on students with ASD, Coo at al., [20] reported a prevalence of 43.1 per 10,000 among 4–9 years school children in the British Colombia Province of Canada whereas in Quebec it is reported at less than half this, at 21.6 per 10,000 [21].

One explanation for differences in the prevalence and identification of ASD across cultures and regions is varying awareness of the criteria associated with a diagnosis of ASD [6]. More specifically, it appears that differences may be more likely to arise cross culturally due to various factors such as ''when a symptom is perceived, by whom, and what behaviour is noticed first, as well as whether it is perceived as problematic'' ([2], p. 538). Moreover cultural attitudes regarding typical behaviours and what is perceived to be normal or abnormal development for that culture would also have an impact on diagnosis of an ASD. Hence children may be more or less susceptible to a diagnosis of an ASD dependent on the cultural expectations of parents and indigenous professionals. Thus screening and other assessment tools for autism developed in Western countries may not be sufficiently sensitive to detect early signs of autism in other societies and could possibly underestimate the prevalence of the condition [3].

3. Screening and assessing children for autism

A two-stage process for identifying children with autism is operational in many countries [22]. The first stage involves a universal screening of all children and various tools have been developed for use with children at different ages. They consist of a series of items indicative of autism and use parents as the primary informants. For example the CHAT (Checklist for Autism in Toddlers) is a screening tool developed for use with infants aged 18 months developed in the UK [23] that has also been adapted for use in the USA (M-CHAT: [24]) and which has shown promise for use in Arab countries [25]. More recently, ten item screening tools have been developed for use with children, adolescents and adults based on the Autism Quotient developed in the UK [26]. Those individuals who screen positive – their scores exceed a designated cut-off point - are then referred for more detailed diagnostic assessment.

A range of diagnostic tools for autism also have been developed [27]. These are based on DSM-IV/ICD-10 criteria for autism and information about the child is usually obtained

through a detailed, structured interview with parents. However a multi-disciplinary assessment by experienced clinicians is also recommended including a physical examination along with developmental and/or psychometric evaluations. These will enable a differential diagnosis to be made for autism from other conditions in which there is overlap of symptomology [28].

Such assessments can be time-consuming and costly. Their efficiency is determined by the referrals from the screening tests. If individuals are screened as positive for autism but are not subsequently diagnosed as having autism (false positives) this can mean wasted efforts by the diagnostic team. The converse is also concerning. Children may screen as negative for autism but had they been assessed, they might have been given a diagnosis of autism (false negatives). Thus the effectiveness of the screening test needs to be assessed in terms of its sensitivity (true positives are identified) and its specificity (false negatives are avoided). Thus the choice of items that are included in the screening test is crucial. To date, the screening tools have been developed within Western societies and given the earlier comments about cultural influences, it is conceivable that at least some of these items may not be suited for use in other cultures. The risk then is that the efficiency of the screening tool is diminished within that society [11]. Indeed the same argument may apply when screening individuals from immigrant communities in Western countries.

4. Autism in Iran

The Islamic Republic of Iran, formerly known as Persia, is located in the Middle East. The capital city is Tehran. Iranian society is distinct from other Islamic societies of the Middle-East and Central Eurasia in terms of its long history of civilisation, its geographical location, separate language (Persian) and religious denomination (Shia Muslim).

It is a vast country of 1.65 million sq km, extending in the north from the Caspian Sea to the Persian Gulf, Strait of Hormuz, and Oman Sea in the south, and from Afghanistan and Pakistan in the east to Iraq and Turkey in the west. Persians (51% population) are the largest ethnic group in the Republic within the total population of 74.8 million. The main minorities are Azeri (24%), Gilaki and Mazandarani (8%), and Kurds (7%). People are mainly Muslims (89% Shi'a Muslims and 9% Sunni Muslims). Iran became an Islamic Republic in 1979 and is divided into 31 provinces, each of which is headed by a governor-general appointed by the Minister of the Interior.

Children with ASD will usually be diagnosed by medical doctors either privately or through child and family clinics provided by voluntary organisations. State-funded special schools are provided through the Iranian Special Education Organisation although many parents may opt for private schooling. In addition, parents will arrange private therapy for their children. For children more severely affected or with other conditions such as intellectual disability, day centre placements are available through the Iranian State Welfare Organisation. However, these services are only available in larger cities and probably only for more

affluent families. Provision for adult services is mostly through private or voluntary organisations that also rely heavily on parental fees.

Iran is one of the few countries that has a national screening programme for autism prior to children's entry to compulsory education at age 6. An analysis of data obtained on over 1.32 million children aged 5 years of age screened over a three-year period, yielded an overall Iranian prevalence of 6.26 per 10,000 [1]. Although this rate is similar to that previously reported for certain European countries and for Hong Kong, it is much lower than those reported for Sweden, USA and England [29].

4.1. Indicators of autism in Iran

The main aim of the two studies reported in this chapter was to identify the most common indicators of autism for Iranian parents whose children had been given a diagnosis of autism. As argued above, this investigation would identify items for use in screening tests that would be culturally sensitive for an Iranian culture. However the initial pool of items would be drawn from those behaviours that define autism internationally according to DSM-IV [7] and ICHD-10 [30]. These were taken from two commonly used scales for autism – the Gilliam Rating Scale for Autism (GARS) and the Autism Diagnostic Interview – revised (ADI-R). Although developed in the USA and the UK respectively, they have been translated for use in other countries.

The most common indicators of autism would be chosen as those that best discriminated children with a diagnosis of autism from age peers who were normally developing; from those who were considered to have an intellectual disability and from those who were initially suspected of having autism but were not diagnosed as such following assessment.

The resulting set of indicators would have particular relevance for the development of further screening tools in Iran but these findings might have wider applicability to other Muslim cultures and non-Western societies.

4.2. Study 1: Screening for autism

The Gilliam Autism Rating Scale - Second edition GARS ll [4] was developed in the United States of America and is based on DSM-IV diagnostic criteria for autism. It is widely used in hospitals, school and clinics across the USA with good psychometric properties which subsequent evaluation studies have confirmed [40]. The main reservations concerning its use, centre on the cut-off points that are taken to be indicative of autism. The consensus is that these should be set at a lower level than recommended in the test manual [41].

This tool takes the form of a behaviour checklist developed for use with children and youth aged 3 to 22 years. It consists of 42 items grouped into three subscales: Stereotyped Behaviours, Communication, and Social Interaction which are combined into a standard score called the "Autism Index" with higher scores indicative of ASD. A further 14 items contribute data about the child's development during the first three years of life which are used to supplement information about the child's current level of functioning. Reliability and validi-

ty data for the English version of the test is available based on a normative sample of 1,107 individuals with ASD and 328 non-ASD persons and those with other developmental disabilities. Coefficients of reliability (internal consistency and test-retest) for the subscales and Autism Index range from 0.80 to 0.90.

For the purpose of this study the first author translated the GARS II assessment tool from English to Persian. The Iranian version was back-translated and reviewed for language clarity and appropriateness for use in Iranian culture. The tool was then pilot tested with 15 Iranian families with a child who had screened positive for ASD and included parents from different socio-economic backgrounds. Five of the 42 questions were unclear to parents and these items were reworded for greater clarity.

4.2.1. Recruiting samples

Three groups of children aged between 3 and 16 years were recruited: those who had been given a diagnosis of autism; those diagnosed as having an intellectual disability and those whose development was considered to be normal. Recruitment took place in four Provinces of Iran in order to achieve a geographical spread.

Children with ASD in the age range 5 to 10 years generally received a confirmed diagnosis from trained diagnosticians from the Iranian Special Education Organisation (see Samadi et al [1] for further details) or were admitted to the ASD special schools based on being at high risk of ASD which meant that they would be re-evaluated one year after their registration. Other children with ASD above or below this age range, had received a confirmed diagnosis from the paediatrician or neurologists based on DSM IV criteria.

All the children with an Intellectual Disability aged 5 to 16 had received an approved diagnosis from ISEO and children under 5 received a confirmation of diagnosis from the paediatrician based on their developmental assessments and clinical presentation (i.e. Down Syndrome or other conditions associated with an intellectual disability).

Parents of children with ASD and ID were recruited from special schools (both public and private) whereas parents of preschool children were recruited from mother and child clinics. The normally developing sample were chosen from mother and child clinics, schools and from membership of the Parents and Teachers Association which has branches in all the cities in Iran.

4.2.2. Procedure

All parents were informed about the aims of the study initially through a written notification sent from the clinic or schools but these were repeated verbally when the first author met the parents when their consent to participate was obtained. Parents of children with ASD and children with ID were met individually, the written instructions for completing the scales were explained to them and they were assisted to complete the ratings scales as necessary. Also 30 parents of normally developing children in Alborz province were met personally during eight days in two schools. The remainder of parents whose children were

developing normally were given the ratings scales at a group meeting and asked to return them within two weeks and 97% did so.

4.2.3. Study participants

In all data was obtained on 532 children: 390 with autism; 55 intellectually disabled and 87 normally developing. Their mean age was 10.5 years (SD 3.1). However those with autism were significantly older (mean age 10.9 yrs) than those in the other two groups (9.4 years). As commonly found with autism; many more boys than girls were identified (81% v 19%); The gender ratio for the children with ID was (49% male v 51% female) and normally developing (64% male v 36% female).

The children were recruited from four provinces in Iran: Tehran (35%) Alborz (21%) Razavi Khorasan (25%) and Western Azerbaijan (19%). Proportionately more children with ID came from Tehran Province but children with autism and those developing normally came from all four Provinces.

4.2.4. Item analysis

In seeking to identify the items that best discriminated the three groups from the 42 items included in the GARS scale the items were arranged into those that the highest percentage of children with autism displayed but with the least percentage of children with intellectual disability and those who were developing normally. The top 16 items were then selected using the following criteria:

- Over one-third of children with ASD showed the behaviour AND

- Normally developing children did not show the behaviour or it was shown by fewer than 12% of these children AND

- The proportion of children with intellectual disability who showed the behaviour was fewer than half of the proportion of children with a diagnosis of autism.

Our aim was to reflect the range of behaviours that can be indicative of the variation among children with autism and yet maximised their distinctiveness.

Table 1 summarises the percentage of children within each group who were sometimes or frequently observed to show these behaviours. These are ordered by those most commonly seen in children with autism. The subscale from which the item came is also noted.

These 16 items were then tested for their scaling properties. The Chronbach alpha of internal reliability was acceptably high at 0.89 (N=422).

A total score could be calculated for each child on these 16 items with a minimum score of 0 (all items scored as never or rarely seen) and a maximum of 16 (all items scored as sometimes or frequently observed). Table 2 presents the summary statistics for the three groups of children on this computed measure as well as for the total group. With this sample no ceiling effects were present on the scale.

Subscale	Item	ASD	Intellectual Disability	Non-disabled
Communication	Uses gestures instead of speech or uses signs to obtain objects	67.0%	0%	2.3%
Social Interaction	Withdraws, remains aloof or acts stand-offish in group situations	66.2%	21.8%	0%
Stereotyped behaviour	Makes high-pitched sounds (e.g. eee-eee-eee) or other vocalizations for self-stimulation	65.4%	12.7%	6.9%
Social Interaction	Does not imitate other people when imitation is required or desirable such as in games or learning activities	65.0%	3.6%	0%
Social Interaction	Stares or looks unhappy or unexcited when praised humoured or entertained	60.5%	0%	4.6%
Social Interaction	Laughs, giggles, cries inappropriately	56.5%	21.8%	0%
Social Interaction	Behaves in a unreasonably fearful or frightened manner	55.6%	12.2%	0%
Communication	Does not initiate conversations with peers or adults	55.4%	9.8%	11.5%
Social Interaction	Shows no recognition that a person is present (i.e. looks through people)	50.0%	3.6%	0%
Stereotyped behaviour	Stares at hands, objects or items in the environment for at least 5 secs	48.5%	16.4%	11.5%
Social Interaction	Avoids eye contact, looks away when someone looks at him or her	46.7%	12.7%	4.2%
Communication	Uses the word I inappropriately e.g. does not say I to refer to self)	45.7%	14.5%	0%
Stereotyped behaviour	Flicks fingers rapidly in front of eyes for periods of 5 secs or more	43.6%	12.7%	0%
Stereotyped behaviour	Flaps hands or fingers in front of face or at sides	42.4%	9.1%	0%
Stereotyped behaviour	Smells or sniffs objects (e.g. toys, person's hand, hair)	34.4%	3.6%	0%
Stereotyped behaviour	Whirls, turns in circles	34.1%	14.5%	4.6%

*Communication items are scored on N=422 for whom these items were rated; otherwise n=532.

Table 1. The percentage of Iranian children in each sample who were sometimes or frequently observed to show the selected behaviours.

Type of development	N	Mean	Std. Deviation	Median	Minimum	Maximum
Autism Spectrum Disorder	294	8.31	3.71	8.00	1.00	15.00
Intellectual Disability	41	1.41	1.67	1.00	.00	6.00
Normally developing	87	.51	.76	.00	.00	2.00

Table 2. Mean, SDs, Median and range scores on 16 items for the three groups (N=422)

The between group differences were statistically significant (F=252.6; p<0.001) as was the variation within each group as indicated by the Standard Deviations with normally developing children showing the least variation and those with autism the most

Using the summary scores it was also possible to check if these indicators varied by age of the child. The Pearson Product Moment correlation was small although significant r=0.138 (p<0.005) with older children having higher scores. As regards child's gender, boys had significantly higher scores than girls (Mean 6.46 v 4.72: F=11.06: p<0.005). Scores were also higher when fathers were the sole informants (mean 7.69) compared to mothers (mean 5.56) (F=4.98:p<0.01). Also those children residing in the Provinces of Tehran and Mashahd (means 6.92 and 6.71) had higher scores than children in two other provinces Alborz (Mean 5.04) and Western Azarbayjan mean 4.61).

A regression analysis was then used to control for the inter-relationships among these variables and with the children's grouping of autism, ID and normal development. Indeed it was children with autism who had the highest Beta scores (β=7.89: 95% Confidence Interval [CI] 7.25-8.49: t=24.91 p<0.001) and the effect of child's age and gender were not significant. However children living in Tehran (β =1.53: CI 0.75-2.30: t=3.86 p<0.001) and Mashahd Provinces (β=1.45: CI 0.60-2.30: t=3.34 p<0.001) tended to score higher than in the other two provinces.

Finally correlations were computed between the scores on the 16 items with the total scores on the GARS ratings for the three subscales and the total score. All correlations were statistically significant (p<0.001) but highest with the total score and social interaction subscale and lowest with the communication subscale.

Correlations 16 items score with ...	Pearson Product Moment Correlations
Stereotyped behaviours subscale	r=0.861**
Communication	r=0.445**
Social Interactions	r=0.902**
Total score on GARS 42 items	r=0.903**

Table 3. Correlations between 16 item scale and GARS scores

4.2.5. Conclusions

Based on the 42 items included in the GARS Scale, it was possible to identify 16 items based on parental ratings that efficiently discriminated between children with autism and those who were normally developing and those with intellectual disabilities. These items were drawn in the main from the social interaction (N=7) and stereotyped behaviour subscales (N=6) with fewer coming from the Communication domain (N=3). A further paper provides further data on the utility of GARS with an Iranian population and on the sensitivity and specificity of the 16 item as a screening tool [31].

4.3. Study 2: Diagnosing autism

In the second study the focus was in identifying the indictors that would distinguish children who were ultimately diagnosed with autism from those who were suspected of having the condition but on further examination were thought not to have autism. To do this, we accessed children's assessments on the Autism Diagnostic Interview-revised (ADI-R). Although widely used by clinicians internationally, this tool has been criticised on the length of time taken to administer and its focus on more severe forms of the condition [42]. However it was the tool chosen by the Iranian Special Education Organisation to assess children who screened positive for autism in the national screening program.

ADI-R takes the form of a structured interview with parents and consists of 93 items arranged in three functional domains: Language/Communication; Reciprocal Social Interactions and Restricted, Repetitive, and Stereotyped Behaviours and Interests. Items are scored for the behaviour that the child has ever showed as well as those showed at present. It is the latter items that were included in this study.

The Persian version ADI-R [32] had been standardised on a sample of 100 children with ASD, 9 children with intellectual disability and 100 normally developing children. The sample age range was from 4 to 14 and they were drawn from different provinces. A Chronbach alpha of 0.85 (for present behaviours) was reported. The test retest reliability on a sample of 33 children (24 with autism and 9 ID) with a 4-6 week interval was 0.99 for items relating to unusual social interaction, 0.99 for Language and Communication and 0.96 for Repetitive and Stereotyped behaviours.

4.3.1. Procedure

The ADI-R assessments were obtained for 397 children who had screened positive for autism in the national screening programme for all six-years prior to school entry (see Samadi et al.[1]). The ADI-R Persian version was administered by specialists from the Iranian Special Education Organisation in the form of structured interview with one or both parents supplemented by observations of the child. Also included in this sample were older children who had been admitted to schools for children with ASD, but who needed to be assessed to reconfirm the diagnosis which may have been given by a professional other than those employed by the Iranian Special Education Organisation or by means of other diagnostic tools.

Following the diagnostic interview, 333 children (84%) were confirmed in having autism; for 20 (5%) the diagnosis was uncertain and 44 (11%) were thought not to have autism. For the purposes of this study the latter two groups were combined.

4.3.2. Study participants

Of the 397 children 80% were male and 20% female. Their mean age was 7.3 years (range 5 to 14 years). In all, 32% were only children and a further 43% had one sibling with 25% having two to six siblings. In 23 families (5.8%), there was another child with a developmental disability although 30% of families reported having a person with mental or developmental disabilities in the wider family circle.

The mean age of mothers was 35.4 years (range 24 to 53 yrs) and of fathers 40.8 years (range 25 to 77). Of the mothers, 120 (30.2%) had completed university education as had 147 fathers (37%). A further 139 mothers (35%) and 123 fathers (31%) had completed high school. The remaining 138 mothers (27.8%) and 127 fathers (32%) had been to middle or elementary school. In 124 families (31%) the parents were related.

4.3.3. Item analysis

As in Study 1, the items relating the children's present behaviours were arranged into those that the highest percentage of children with autism displayed but with the least percentage of children who were thought not to have autism. The top 13 items were then selected so as to reflect the variation among children with autism but also discriminating those with the condition from those unlikely to have it. The following criteria were applied to do this.

- Over 50% of children with a diagnosis of ASD showed the behaviour AND

- Fewer than 50% of those children not diagnosed as autism showed the behaviour AND

- The percentage of autism children showing the behaviour was at least double the percentage of those without autism.

The 13 items met these criteria are listed in Table 4. They are ordered by those most commonly seen in children with autism. The sub-grouping is also noted.

One previous study in Iran had identified the indicators most commonly found in a sample of 61 children (mean age 7 years) assessed clinically assessed as having autism [33]. They were: stereotyped and repetitive behaviours; lack of make-believe play, failure to initiate conversations, use of rituals, motor mannerisms, no spoken language, poor social reciprocity and impaired peer relations. Most of these behaviours are reflected in this study.

The 13 items were tested for their scaling properties and the Chronbach alpha of internal reliability was acceptably high at 0.866 (N=397).

A total score could be calculated for each child on these 14 items with a minimum score of 0 (all items scored as never or rarely seen) and a maximum of 14 (all items scored as observed). Table 5 presents the summary statistics for the two groups of children on this com-

puted measure as well as for the total group. The differences on scores between the two groups was significant (F=238.0 p<0.001).

Ref num	Item	Autism N=333)	Non-Autism (N=64)
Communication 42	Does not attempt or limited attempt to express interest by pointing	80.2%	31.7%
Communication 37	Mis-uses pronoun 'I' and refers to self by name rather than with pronoun.	80.2%	38.3%
Social Interaction 50	Uncertain, odd or occasional use of gaze in social interactions	78.0%	28.1%
Repetitive Behaviours 69	Play is linked to highly stereotypic use of objects or attention; interested in infant toys such as music boxes and rattles,.	73.4%	21.9%
Social Interaction 53-2	No spontaneous sharing or no sharing.	72.7%	21.9%
Social Interaction 59-2	Stereotyped, inappropriate, very limited or no responses to people except parents.	71.6%	19.0%
Social Interaction 51-2	Little or no smiling at people though may smile at things; no reciprocal smiling.	68.7%	17.2%
Social Interaction 56	Little or no coordination of eye gaze and vocalisations or weakly integrated.	67.0%	25.4%
Repetitive Behaviours 68	Special or circumscribed interests that can interfere with social activities	63.6%	15.6%
Repetitive Behaviours 77	Marked mannerisms of hands and fingers that may or may not interfere with social activities	62.8%	3.1%
Social Interaction 62-2	Lack of interest in other children; may watch them but almost never tries to approach them.	61.9%	20.0%
Repetitive Behaviours 71	Has one to two unusual sensory interests that may take major amount of time.	58.3%	14.1%
Repetitive Behaviours 78	Complex and stereotyped bodily movements	50.8%	6.3%

Table 4. The percentage of Iranian children in the two groups who were observed to show the selected behaviours from the ADI-R.

Group	N	Mean	Std. Deviation	Median	Minimum	Maximum
ASD	333	8.65	2.63	10.00	.00	13.00
Not ASD and uncertain	64	2.97	2.89	2.00	.00	12.00
Total	397	8.37	3.81	9.00	.00	13.00

Table 5. Mean, SDs, Median and range scores on 13 ADI-R items for the two groups

Using the summary scores it was also possible to check if these indicators varied by age of the child. The Pearson Product Moment correlation was small although significant r=-0.162 indicating that younger children scored more highly on these 13 items (p<0.001).

However there were no statistically significant differences by child's gender, mother's age, level of education, if the child had siblings, or if there was a another child with developmental problems in the family. This was further confirmed in a regression analysis to control for inter-relationships among the possible predictor variables and with the children's diagnosis. It was children diagnosed with autism who had the highest Beta scores (β=5.59: 95% Confidence Interval [CI] 4.57-6.40: t=15.57 p<0.001) but the child's age was also a significant additional variable (β =-0.20: CI 0.03-0.37: t=2.37, p<0.05) with younger children scoring more highly irrespective of their diagnosis.

4.3.4. Conclusions

It was possible to identify 14 items on the ADI-R that could reasonably well discriminate between those children who would receive a confirmed diagnosis of autism and those who did not. However these items are also more likely to be found in younger children irrespective of the diagnosis.

5. Comparison of indicators from study and study 2

Finally a common set of 'best' indicators could be identified across the two studies although there was some variation in wording and overlap across the two chosen rating scales – see Table 6. Nonetheless these items reflect the three domains that typify autism although with more emphasis on social interaction and repetitive behaviours than on communication.

However on both scales there were additional items that served to distinguish children with autism (see Table 7) and depending on the intended purpose, these items could be used to supplement those listed in Table 6 for the purposes of screening children for autism (GARS items) or clarifying the diagnosis of autism from other developmental disabilities (ADI-R items).

Items common to GARS and ADI-R

GARS Items	ADI-R items
Withdraws, remains aloof or acts stand-offish in group situations	Lack of interest in other children; may watch them but almost never tries to approach them.
	No spontaneous sharing or no sharing.
Avoids eye contact, looks away when someone looks at him or her	Uncertain, odd or occasional use of gaze in social interactions
	Little or no coordination of eye gaze and vocalisations or weakly integrated.
Uses the word I inappropriately e.g. does not say I to refer to self)	Mis-uses pronoun 'I' and refers to self by name rather than with pronoun.
Flaps hands or fingers in front of face or at sides	Marked mannerisms of hands and fingers that may or may not interfere with social activities
Flicks fingers rapidly in front of eyes for periods of 5 secs or more	
Stares at hands, objects or items in the environment for at least 5 secs	
Smells or sniffs objects (e.g. toys, person's hand, hair)	Has one to two unusual sensory interests that may take major amount of time.
Whirls, turns in circles	Complex and stereotyped bodily movements
Stares or looks unhappy or unexcited when praised humoured or entertained	Little or no smiling at people though may smile at things; no reciprocal smiling.

Table 6. Items common to GARS and ADI-R that best discriminated Iranian children with autism

Items on GARS only	Items ADI-R only
Uses gestures instead of speech or uses signs to obtain objects	Does not attempt or limited attempt to express interest by pointing
Does not initiate conversations with peers or adults	
Shows no recognition that a person is present (i.e. looks through people)	Special or circumscribed interests that can interfere with social activities
Does not imitate other people when imitation is required or desirable such as in games or learning activities	Stereotyped, inappropriate, very limited or no responses to people except parents.
Makes high-pitched sounds (e.g. eee-eee-eee) or other vocalizations for self-stimulation	Play is linked to highly stereotypic use of objects or attention; interested in infant toys such as music boxes and rattles.
Laughs, giggles, cries inappropriately	
Behaves in a unreasonably fearful or frightened manner	

Table 7. Items particular to GARS and ADI-R that best discriminated Iranian children with autism

6. Discussion

These two studies had a number of strengths. Sizeable samples of children with autism were recruited alongside those who were normally developing and those who had intellectual disability or another form of developmental disorder. In both studies, the selected items discriminated effectively the children with autism. Also the studies were located in Iran; a country on which relatively little published research exists. Equally there are some limitations that need to be acknowledged. No independent verification of the child's diagnosis of autism was possible and reliance was placed on either parental reports or data held by the ISEO. This issue may be of relevance also to children with ID in that some of them may have undiagnosed autism. However even within developed countries, it would have been a costly, not to say difficult undertaking, to obtain independent verification of diagnoses and even more improbable in a country such as Iran.

A further limitation is that the first study was retrospective for parents in that their child had already been diagnosed and hence their ratings on GARS may have been influenced by the increased awareness they had about the indicators of autism which they may not have had prior to the diagnosis. Hence it would be important to replicate the study on a prospective basis especially with parents who had limited contact with professionals or with parents who had lower levels of education. The latter recommendation arises from the finding in Study 1 that parents from two provinces had significantly lower scores on the 16 items. In these two provinces professional services are more limited with fewer parents availing of higher education. These factors were also proposed as reasons for the variations in prevalence rates of autism across Iran that has been previously reported [1].

Nevertheless it would be a major undertaking to repeat the study with an unselected population of children although the existence of the Iranian national screening programme for autism on school entry makes this a possibility for five year olds. An alternative approach is to consider the items identified in these studies as the basis for a referral tool [26]. For example, when concern is expressed about a child by parents or preschool educators, or if a child is already experiencing problems, then these items might serve as a guide for primary health or social care personnel to help them decide as to whether a referral should be made for more specialist assessment for autism.

However the issue of identifying children with autism in other cultures has to be set within a broader context than screening. First increased opportunities need to be provided to parents - and to mothers especially – for them to become more knowledgeable about child development and indicators of potential problems particularly those of relevance to their culture. The desire for increased information about autism is a common request of parents in different cultures [34]. Modern technology provides a cost-effective means for doing this.

Second, the beliefs, knowledge and skills of professions involved in diagnosing developmental problems will need to be expanded in relation to autism so that they can undertake appropriate and thorough assessments of the children and devise relevant intervention programme for them and their families [35]. The development of an indigenous knowledge

base in relation to autism is especially pertinent as reliance on assessment and intervention tools from other cultures may prove inadequate. Equally there is an onus on professionals in Western countries to become better attuned to the cultural issues they may face with immigrant communities [9] as part of the endeavour to find more effective and efficient tools for the diagnosis of autism spectrum disorders [42].

A third aspect arises from the previous two; namely the relationships between parents and professionals. Recent guidance in relation to autism in the UK, emphases the need for professionals to take seriously parental concerns [36]. Also diagnostic information often has to be obtained through sensitive and careful questioning about the child's typical behaviours in natural settings as well as observations of the child in clinic or school contexts. This is best done through a trusted relationship between parents and professionals. Moreover parents may experience elevated levels of stress and poorer health because of their child's behaviour and will personally benefit from support offered by professional advisers [37]. Thus professionals may need to acquire wider communication and inter-personal skills in order to effectively support families.

These broader issues relating to the identification and diagnosis of autism are not peculiar to Iran and future cross-cultural research would help to identify practical means of addressing them, especially when health, social care and educational resources are limited [38].

The findings also have international application in another sense. They confirm the universality of certain indicators of autism in children; most notably in Iranian culture of repetitive and stereotyped behaviours and atypical social interactions. Items relating to communication and language were apparently less indicative of autism. As yet there is no directly comparable data with that obtained from other cultures although future research might provide this. However studies that have directly compared children in the UK and USA with those from South Korea and Israel [6] found significant differences in the extent to which items relating to socialisation, verbal communication and restricted interests were reported although all were present across the four countries. It is likely that this cultural variation in parental perceptions of autistic traits reflects the behaviours in children that parents value or perceive as being unusual within their particular culture. Future research could usefully explore this proposition further as it may also account for differences between the perceptions of parents from different socio-economic backgrounds.

It is possible though that some of the inter-cultural differences and perhaps the intra-country variation may arise from other environmental factors. Walker et al [39] have identified from international epidemiological studies the key risks that prevent children from attaining their developmental potential, such as lack of cognitive stimulation, intrauterine growth restriction, maternal stress and exposure to societal violence. It is possible that some of these environmental factors could trigger particular behaviour patterns within children that fall within the broad category of autism. To date much energy has been expended on identifying the genetic bases for autism and even if these were to be found, there may well be environmental factors that mediate the genetic disposition for autistic traits.

Finally cross-cultural research in autism has much to contribute to our wider understanding of this condition and of the factors that may ameliorate its impact on children and families. An essential starting point is to have a common tool for use across countries that not only defines the similarities in children who have the condition but is also sensitive to the cultural variations that may be inherent in its manifestation in varying cultures. These studies in Iran are a contribution to that endeavour and provide a model as to how it could be realised.

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