

Modified checklist for autism in toddlers, revised, with follow-up application in Central Kazakhstan

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Abstract

Objectives: One of the commonly used screening tools (Modified Checklist for Autism in Toddlers, Revised, with Follow-Up, M-CHAT-R/F, 2014) is designed for diagnosis of ASD in children aged 16-30 months. Given the known effectiveness of the M-CHAT-R/F and the need to adjust the tool to the cultural differences of the caregivers, the purpose of this research to test the M-CHAT-R/F test effectiveness and to adapt its Kazakh and Russian versions for the caregivers of Kazakhstan.

Study design: Cross-sectional study

Material and methods: This study was conducted among caregivers of children aged 24-48 months in the period October-November 2020 in Central Kazakhstan. Internal consistency of the Russian and Kazakh versions of the questionnaire was assessed by Cronbach's Alpha. To assess the reliability of the Russian version of M-CHAT-R/F, Guttman's lambda-6 indicator was calculated to consider the variance in each element of the scale explained by linear regression of other elements.

Results: The final size of the analyzed sample was 171 children, among whom the mean age was 30.75 months and 92 (53.8%) were female. The results of the M-CHAT-R/F survey were distributed as follows: the low-risk group included 141 (82.5%) children, the medium-risk group included 23 (13.5%) children, and the high-risk group also included 7 (4.1%) children. The average score for M-CHAT-R and Follow-Up is 1.6 (SD=2.16) and 1.5 (SD=2.3) points, respectively. Both the Russian and Kazakh versions of M-CHAT-R/F demonstrated high internal consistency, with Cronbach's alpha (CI=0.95) calculated as 0.87 and 0.93, respectively. Guttman's lambda-6 also showed an excellent result in the Russian version of the checklist (0.94).

Conclusion: The study findings support the appropriateness of using M-CHAT-R/F in Kazakhstan as an ASD screening tool. The effectiveness of this tool is emphasized by its ease of use and can reduce the average age of diagnosis of ASD in Kazakhstan to two years.

Key words: autism, cross-cultural adaptation, Kazakhstan, M-CHAT-R/F, screening

Introduction

Autism spectrum disorder (ASD) is a developmental disability, associated with significant challenges throughout a person's life and often characterized by repetitive sensorimotor behavior and social communication disorders [1]. The diagnosis of ASD includes several conditions, such as autistic disorder, developmental disorders, and Asperger's syndrome. The Centers for Disease Control and Prevention (CDC) report that in the United States 1 in every 54 children is diagnosed with ASD (<https://www.cdc.gov/ncbddd/autism/facts.html>). The diagnosis is complicated by the absence of medical tests and the reliance on provider

expertise in recognizing the ASD signs and symptoms, which begin in childhood, accompany a person throughout life, and are never cured [2]. While ASD can be detected by experienced professionals in the very early childhood, the final diagnosis is often delayed, subsequently delaying the help a young ASD patient needs (CDC). Early diagnosis and the start of therapeutic interventions are important, because early start of the long-term work on social adaptation and correction with such children may increase their chances of successful adaptation to education requirements, job opportunities, and social life [3].

The risk factors of ASD are commonly listed as environmental and genetic [4]. The epidemiological summary of ASD risk factors includes gender, pregnancy complications, and parental age. For every boy with ASD, there are four girls [5]; low birth weight due to deep prematurity, multiple pregnancies, and short interval between pregnancies are associated with higher risk of ASD [6], the age of both parents over 35 years also significantly increases the risk of child's ASD [7].

According to the Focus on Health portal, the highest prevalence of ASD is observed in Hong Kong, the United States, South Korea, and Japan (1 in 27; 1 in 38; 1 in 45; 1 in 55 children, respectively) [8]. Another source summarized multiple epidemiological studies on the prevalence of ASD worldwide and estimated ASD prevalence as one in every 160 children [9]. However, this is not a generalizable or inferential indicator, because the data is primarily based on studies from high-income countries, while in low-and middle-income countries information on prevalence is limited. In addition, the ASD diagnosis is often grouped with other mental disorders, making accurate estimates impossible.

In Kazakhstan, medical statistics combine ASD with other mental disorders. While the rate of newly diagnosed mental disorders reported in Kazakhstan in 2018 was 54.9 per 100,000 people, with the highest incidence rate reported in Central Kazakhstan (85.1 per 100,000 population [10]), actual incidence rate of the ASD is not known.

Currently, the ASD diagnosis can be assigned to children aged four years and older, preventing early start of correction of existing developmental disorders in younger children. The Kazakhstan Ministry of Health identified three stages for childhood psychophysical development screening (MoH, September 9, 2010 №704), with the third stage of screening called "early childhood screening assessment". The assessment is aimed at children aged 0-6 years with a risk of lagging in the physical, mental and social development. Based on the assessment results, a medical provider prescribes a psychological, medical and pedagogical consultation by a multidisciplinary team, which may refer the child to medical specialists or may recommend the use of special educational settings.

A qualitative study of families with ASD-diagnosed children in Kazakhstan reported on the struggles of caregivers. Many caregivers noticed worrying symptoms in their child at an early age, however, they did not seek medical help immediately and delayed contact with medical specialists. The study also found that many caregivers believed that psychiatric institutions were "unfriendly", "not suitable for their children", and "do not understand the specific needs of children with ASD" [11]. The reluctance to record the diagnosis and general dissatisfaction with available care emphasizes the need for timely detection of ASD in Kazakhstan, both in primary health care and in community settings. A recent study found that only four out of 21 cases of ASD were detected in primary health care settings [12], indicating the need for further use of appropriate screening methods [13]. An early ASD screening approach usually requires minimal training for health professionals, and some screening tools can be used by caregivers themselves.

One of the commonly used screening tools is the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F), developed and tested in 2014 for early detection of ASD in children aged 16-30 months. The tool uses a two-step approach with the questionnaire (M-CHAT-R) completed by the caregivers or healthcare providers followed by a set of clarifying questions or demonstration of skills (Follow-Up) to confirm

the accuracy of the responses. Using this tool may reduce the age at the diagnosis to two years, thereby increasing the time available for early interventions [14]. In addition, M-CHAT-R/F has also been shown to be effective when used by primary care providers to screen low-risk young children in a large, geographically distributed population [15] with minimal costs. The effectiveness of the tool is partly due to its ability to focus on the caregivers' concerns about their child's development in a timely and independent manner. At the same time, this focus on caregivers relies on their opinion about the typical actions of their children, and the effectiveness of this screening method may vary, which indicates the need for appropriate cultural adaptation of the questionnaire [16]. Given the known effectiveness of the M-CHAT-R/F and the need to adjust the tool to the cultural differences of the caregivers, the purpose of this research to test the M-CHAT-R/F test effectiveness and to adapt its Kazakh and Russian versions for the ASD caregivers of Kazakhstan.

In this study, the authors will try for the first time to assess the effectiveness of the M-CHAT-R / F screening tool in a Kazakhstani sample. Currently, there are very few epidemiological studies of autism spectrum disorders in Kazakhstan. More research on autism spectrum disorders in all countries will improve understanding of the epidemiology of these disorders.

Material and methods

This cross-sectional study was conducted in the period October-November 2020 in an area of high mental and behavioral disorders prevalence (Central Kazakhstan). Today, in Kazakhstan, there are no official statistics from the Ministry of Health of the Republic of Kazakhstan on the number of children with autism. Due to the lack of medical reporting such a column reflecting a given diagnosis. Autism is included in the summary statistics of mental retardation, so the prevalence and morbidity rates are not specifically taken into account. At the moment, Central Kazakhstan is leading in the number of cases of mental and behavioral disorders among children under 14 years of age (107.8 per 100,000 population), in Kazakhstan in general, this number is 66.2 per 100,000 population.

Study was conducted in an online format due to the conditions of the pandemic. The study Modified Checklist for Autism in Toddlers, Revised, with Follow-Up 14 was employed as a screening tool. After receiving permission from the developers, a Russian/English bilingual team performed a critical analysis of the Russian version of M-CHAT-R/F, obtained from the official website (www.mchatscreen.com). Subsequently, a Kazakh/English bilingual team translated the questionnaire into the Kazakh language. Both teams were based in Karaganda Medical University and included a psychiatrist to represent the specialty responsible for assigning the ASD diagnosis. The translation was limited to question text and did not include changes in scoring responses or using quantitative score to evaluate the risk of ASD, as 0-2 – low risk, 3-7 points - medium risk, and 8-20 points – high risk group. The questionnaire was translated to Russian and Kazakh languages, then back-translated to English, and reconciled by a bilingual Russian-English and Kazakh-English psychiatrist and researcher.

After completion of the translation process by the research team in October, participants were recruited through use of social media. The study focused on the most popular social medial outlet in Kazakhstan (Instagram) where information about the study was offered on a number of thematic forums about child raising. The forums explained the study goals and

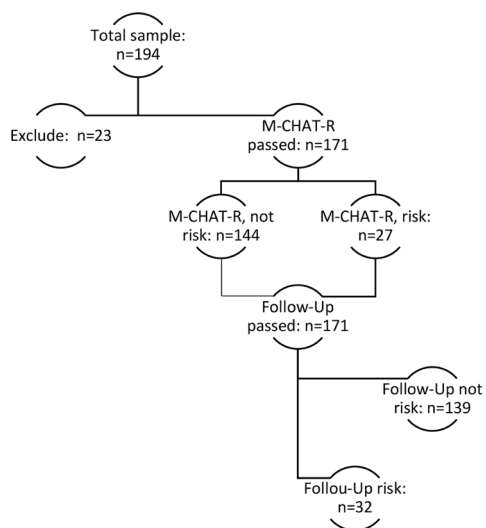
provided a link to be followed for those who were interested in participation. Interested participants who followed the link were screened for the inclusion criterion and were provided details of the study. Informed consent was obtained in an online format. The single inclusion criterion of participants was the child's age in the range of 16-48 months. Eligible participants were forwarded the link to the anonymous M-CHAT-R/F questionnaire. In addition to questionnaire, the study collected data on the child's and parents age and gender, city of residence, ethnic background, and presence of diagnosed developmental delays. Parental ages were grouped into categories: 21-25 years, 26-30, 31-45 years for the mother, and 21-30 years, 31-40 years, 41-48 years for the father. Due to the multiethnic composition of Kazakhstan, additional information was collected on the participant's ethnic background. The participants were given the choice to respond to either a Kazakh or a Russian language questionnaire. To control for the previous diagnosis of ASD, the survey collected responses to question "Has your child been diagnosed with developmental delays?". No reimbursement, reward, or any incentive was offered to participants.

This study protocol was approved by the Ethical committee of the Karaganda Medical University to ensure the protection of participants. The number of Ethical Approval is №26 dated October 10, 2020. Based on the study protocol, the participants signed an online Informed consent. R-studio software was used for statistical analysis. Internal consistency of the Russian and Kazakh versions of the questionnaire was assessed by Cronbach's Alpha. To assess the reliability of the Russian version of M-CHAT-R/F, Guttman's lambda-6 indicator was calculated to consider the variance in each element of the scale explained by linear regression of other elements. Chi-square test of association was used to analyze categorical variables.

Results

The study received 194 completed surveys; after removal of 23 surveys that did not meet the inclusion criterion, the final size of the analyzed sample was 171 children (n=171). One caregiver completed the questionnaire for each of the 171 children. The number of participants at each stage of the M-CHAT-R/F study is shown in Figure 1. Based on the results of the M-CHAT-R screening stage, the low-risk group included 144 (84.2%) children, the medium-risk group included 20 (11.7%) children, and the high-risk group included 7 (4.1%) children.

Figure 1 - The number of participants at each stage of the M-CHAT-R/F screening, as well as the number of children at risk



The results of the Follow-Up survey were distributed as follows: the low-risk group included 141 (82.5%) children, the medium-risk group included 23 (13.5%) children, and the high-risk group also included 7 (4.1%) children. The average score for M-CHAT-R and Follow-Up is 1.6 (SD=2.16) and 1.5 (SD=2.3) points, respectively. After scoring the responses, the scores of 3-7 points (medium risk) and 8-20 points (high risk) were recoded as a binary variable of a single risk group.

Demographic characteristics of the total sample and the risk group are presented in Table 1. The average age of the assessed children was 2.5 years (30 months); the majority of participants were identified as ethnic Kazakhs (n=102, 59.6%), followed by ethnic Russians (n=23, 13.5%). Due to the small number of participants identified as other ethnic groups, they were combined as "Other" (n=46, 26.9%) for the purpose of analysis. Despite the sample having a higher proportion of ethnic Kazakhs, the majority of participants selected Russian language version of the questionnaire (n=149, 87.1%).

Based on the results of M-CHAT-R, 15.8% of participants were at risk of ASD; the percentage increased to 18.7% in the Follow-Up scoring. Although the ratio of boys and girls in the sample was similar (46.2% and 53.8%, respectively), proportion of boys was significantly higher in the risk group for ASD according to the results of M-CHAT-R/F ($\chi^2(1, N=171)=12.7, p<0.05$). Also, a significant relationship ($p<0.05$) was observed between the father's age category and the ASD risk group on the results of the M-CHAT-R/F. A similar relationship between maternal age and child's risk group ($p>0.05$) was not observed. No significant difference in risk level was detected among ethnic groups or based on the survey language preference ($p>0.05$). Overall, 8 participants disclosed an early ASD diagnosis (Childhood autism, Atypical autism, Asperger's Syndrome, and pervasive disorder unspecified) which represents 6.6% of the sample. Statistical analysis revealed a significant difference in the distribution of ASD diagnosis based on both the M-CHAT-R and M-CHAT-R/F results ($p<0.05$). Both the Russian and Kazakh versions of M-CHAT-R/F demonstrated high internal consistency, with Cronbach's alpha (CI=0.95) calculated as 0.87 and 0.93, respectively. Guttman's lambda-6 also showed an excellent result in the Russian version of the checklist (0.94).

Table 2 compares the responses that matched the risk ("Failed" questions) based on M-CHAT-R/F and the risk ("Failed" questions) based on Follow-Up results between the children from the medium/high-risk and low-risk groups. The highest number of "Failed" responses was observed for the M-CHAT-R questions 7 (*Using one finger to point at objects of interest*) and 16 (*Follows the eyes parents*), both at 17 responses (9.94%). Same questions were identified as most common for M-CHAT-R/F, with 18 and 20 "Failed" responses respectively, with additional high-frequency "Failed" response to question 18 (*Follows verbal directions, n=19, 11.1%*). Questions 3 (*Plays pretend or make-believe games, n=13, 7.6%*), 9 (*Shows objects to share, not for help, n=12, 7.02%*), 17 (*Attempts to attract the attention of parent, n=12, 7.02%*), and 18 (*Follows verbal directions, n=12, 7.02%*) represented second group of high frequency of "Failed" responses.

Table 2 also shows some discrepancy in the results between M-CHAT-R and Follow-up in identifying children at risk. For example, in the M-CHAT-R questionnaire among children in the risk group, 13 (7.6%) "failed" the question 3 (*Plays pretend or make-believe games*), and 9 (5.26%) "failed" the question in the low-risk group; however, the Follow-Up did not confirm any "failed" responses. In other cases, such as in question 10 (*Responds to their name*), M-CHAT-R identified a lower number

Table 1

M-CHAT-R and Follow-Up (FU) results and demographic characteristics of the sample

Variables	Total Sample (n=171)	M-CHAT-R risk group	M-CHAT-R, not at-risk group	p-value	FU risk	FU, not at-risk	p-value
Gender							
Male, N (%)	79 (46.2)	23 (13.5)	69 (40.4)	<0.001	23 (13.5)	69 (40.4)	<0.05
Female, N (%)	92 (53.8)	4 (2.3)	75 (43.9)		9 (5.3)	70 (40.9)	
Age							
Mean age in months (SD)	30.75 (7.2)	31.5	30.75	0.54	30.77	30.75	0.57
Mean mother's age (SD)	28.68 (4.2)						
21-25 years	32 (18.7)	3 (1.8)	29 (17.0)		5 (2.9)	27 (15.8)	
26-30 years	98 (57.3)	17 (9.9)	81 (47.4)		21 (12.3)	77 (45.0)	
31-45 years	41 (24.0)	7 (4.1)	34 (19.9)		6 (3.5)	35 (20.5)	
Mean father's age (SD)	31.39 (5.7)			<0.05			<0.05
21-30 years	88 (51.5)	7 (4.1)	81 (47.4)		11 (6.4)	51 (29.8)	
31-40 years	71 (41.5)	18 (10.5)	53 (31.0)		20 (11.7)	77 (45.0)	
41-48 years	12 (7.0)	2 (1.2)	11 (6.4)		1 (0.6)	11 (6.4)	
Ethnicity (%)							
Kazakh	102 (59.6)	13 (7.6)	89 (52.0)	0.11	18 (10.5)	84 (49.1)	0.62
Russian	23 (13.5)	7 (4.1)	16 (9.4)		6 (3.5)	17 (9.9)	
Other	46 (26.9)	7 (4.1)	39 (22.8)		8 (4.7)	38 (22.2)	
Screening language							
Russian	149 (87.1)	24 (14.0)	125 (73.1)	1	27 (15.8)	122 (71.3)	0.82
Kazakh	22 (12.9)	3 (1.8)	19 (11.1)		5 (2.9)	17 (9.9)	
Diagnosis							
Previous diagnosis	8 (4.7)	6 (3.5)	2 (1.2)	<0.05	5 (2.9)	3 (1.8)	<0.05
No previous diagnosis	163 (95.3)	21 (12.3)	142 (83.0)		27 (1.2)	136 (79.5)	

Table 2

Prevalence of the «failed» items across risk groups

№ Child's behavior, questions were shortened for clarity	M-CHAT-R "failed" items frequency (%)		Follow-Up "failed" items frequency (%)	
	Risk	Not Risk	Risk	Not risk
1 Looks at the pointed objects	9 (5.26)	1 (0.58)	11 (6.43)	0
2 Doubts about hearing	7 (4.09)	8 (4.68)	7 (4.09)	3 (1.75)
3 Plays pretend or make-believe games	13 (7.6)	9 (5.26)	0	0
4 Climbs various structures and objects	2 (1.17)	2 (1.17)	0	2
5 Unusual finger movements in front of the eyes	8 (4.68)	22 (12.87)	14 (8.19)	24 (14.04)
6 Using one finger to point at objects for help	5 (2.92)	2 (1.17)	11 (6.43)	1 (0.58)
7 Using one finger to point at objects of interest	17 (9.94)	10 (5.85)	18 (10.53)	16 (9.36)
8 Interests in other children	6 (3.51)	4 (2.34)	10 (5.85)	4 (2.34)
9 Shows objects to share, not for help	12 (7.02)	1 (0.58)	10 (5.85)	2 (1.17)
10 Responds to their name	4 (2.34)	3 (1.75)	11 (6.43)	6 (3.51)
11 Smiles in response to a smile	1 (0.58)	1 (0.58)	5 (2.92)	6 (3.51)
12 Upset by household sounds	7 (4.09)	31 (18.13)	10 (5.85)	7 (4.09)
13 Able to walk	0	0	0	1 (0.58)
14 Direct eye contact in communication	3 (1.75)	3 (1.75)	0	1 (0.58)
15 Copies the actions of adults	5 (2.92)	0	0	3 (1.75)
16 Follows the eyes parents	17 (9.94)	16 (9.36)	20 (11.7)	15 (8.77)
17 Attempts to attract the attention of parent	12 (7.02)	5 (2.92)	3 (1.75)	0
18 Follows verbal directions	12 (7.02)	1 (0.58)	19 (11.11)	1 (0.58)
19 Seeks reaction of parents to an unusual situation	9 (5.26)	9 (5.26)	8 (4.68)	3 (1.75)
20 Likes movement activities or games	0	0	0	0

of fails in both high-risk and low-risk children (n=4 and 3), but the frequency increased in the Follow-Up (n=11 and 6 children). In some cases, such as in question 3 (*Plays pretend or make-believe games*), M-CHAT-R identified 22 "failed" responses, while Follow-up did not confirm any as "failed". A similar tendency was observed for question 17 (*Attempts to attract the attention of parent*) with a decline in "failed" responses from 17 to 3. Overall, this difference may suggest that caregivers may have not fully understood the meaning of the wording in questions despite the accurate translation.

Discussion

This study is the first epidemiological study of ASD in Kazakhstan, introducing the M-CHAT-R/F screening tool for early detection of ASD. The M-CHAT-R/F showed an acceptable internal consistency index and lambda Guttman-6, indirectly confirming correct translation of the questionnaire into Kazakh and Russian. At the same time, the study found a difference in the identification of at-risk children with the first (M-CHAT-R) and second (Follow-Up) stages of the screening. Special attention should be requested to question with high

discrepancy between the stages, such as a child's ability to play pretend games (question 3) or attempts to attract parent's attention (question 17), where the first stage questionnaire detects more failures than the follow up. Utilization of the Follow-up may reduce the frequency of false-positive responses. Similarly, a child's behavior that was not detected as "failed" at the first stage, but failed the follow-up, such as smiling in response to a smile (question 11), may need special attention from the providers. In some cases, additional research is needed to explore the high frequency of failure for some questions (e.g., unusual finger movements in front of the eyes, question 5) to exclude the possibility of caregiver misunderstanding or cultural expectations and to take into account the possibility of ethnically traditional childhood games that may induce similar behavior.

In previous studies on cross-cultural adaptation of the non-English version, M-CHAT-R/F shows high accuracy and efficiency [18, 19–24], and this study also supported its ability to successfully screen for ASD with high specificity and sensitivity levels. The appropriateness of the M-CHAT-R/F for use in Kazakhstan was indirectly supported by the study findings. Higher ASD prevalence among boys was also established in previous studies, and was supported by the [24] findings of this study. Similarly, the study confirmed previously reported [25] influence of the child's father's age on the risk of developing ASD, while there was no such relationship found in this study between the mother's age and the risk of ASD.

Being the first M-CHAT-R/F tool validation study in Kazakhstan, aimed at an increase in early ASD diagnosis, the research is also relevant to Kazakhstan's healthcare policy guidelines. According to the Rules of Emergency Medical Care in the Republic of Kazakhstan, approved by order of the Minister of Health of the Republic of Kazakhstan dated July 3, 2017, No. 450, a primary care provider must identify a patient with possible mental and behavioral disorders. Utilization of the Kazakh and Russian versions of the M-CHAT-R/F by primary care providers can be beneficial for early diagnostic and referral to specialists. Offering the tool for caregivers through primary care settings allows parents to monitor a child's development and seek advice and care at the earlier stages of the child's growth.

The study, however, has a number of limitations. The main limitation of the study is the absence of confirmed ASD diagnosis by medical specialists; therefore, the study findings are limited to the data from the self-screening tool. However, the goal of introducing the screening tool is to attract caregiver's attention and request an early specialist assessment to allow for early diagnosis if appropriate.

Another major limitation is a small sample size of 171 volunteers within a relatively small geographical region of Kazakhstan. The study deliberately did not offer any incentives for participation to avoid false responses. An even smaller proportion of caregivers selected the Kazakh-language version of the questionnaire. Participants' preference for the Russian version can be explained by the high prevalence of ethnic Kazakhs who identify themselves as primarily Russian-

speaking; this limitation is also related to the study region having been predominantly Russian-speaking. Follow-up studies in Kazakhstan should select a geographically broader sample, both in household and in primary health care settings. The same small sample issue led to the grouping of medium and high-risk children into a single "at-risk" category; however, this regrouping does not bias the overall proportion of children at risk.

Conclusion

The Kazakh and Russian versions of the M-CHAT-R/F show acceptable validity and are recommended for use in Kazakhstan. The effectiveness of this screening tool is emphasized by its ease of use, both for caregivers and medical professionals and can reduce the average age of diagnosis of ASD in Kazakhstan to two years. Easy availability of the M-CHAT-R/F will lead to early diagnosis and start of timely intervention, which is commonly associated with the most favorable forecasts for the development of children with ASD.

M-CHAT / R-F screening procedure should be used in daily practice, as it is already a standard procedure in many countries. In the United States, this tool has proven to be an effective tool for screening low-risk toddlers, and the American Academy of Child and Adolescent Psychiatry (AACAP) supports screening ASD in young children. Screening information should be carefully communicated to parents, and in addition to training on how to use the M-CHAT-R / F, the health workers should gain knowledge of caregivers motivational tactic for follow-up diagnosis and treatment.

The implementation of the M-CHAT / R-F should begin with a pediatrician and / or a member of a development team at a primary health care center. They should educate parents about the characteristics of this screening tool.

The introduction of a standardized screening procedure can significantly reduce the time it takes for children and their parents to be referred to centers where they can receive appropriate diagnosis and suggested treatment. In addition, when designing early development policies, it is important to have standardized screening tools in order to be able to identify children at risk and to facilitate the further development of early intervention centers.

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