Department of Psychology

Early Detection of Autism in Primary Healthcare in Iceland: Parental Experience of the Procedure and Services Provided for Toddlers, Following a Positive Screening

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Foreword and acknowledgement

This study is a part of my master's degree in clinical psychology from Reykjavik University in collaboration with Counselling and Diagnostic Centre (Ráðgjafar- og greiningarstöð; RGR). This study aims to examine characteristics of children referred to the RGR through a newly implemented approach of autism screening during the 18-month healthcare check-up in a high-likelihood group in Iceland, as well as their parents' experience with the process. This new approach applies the screening instrument Modified Checklist for Autism in Toddlers, Received with Follow-Up (M-CHAT-R/F) when children show early signs of autism, in order to improve services for the children and their parents if autism is suspected. Common first signs of autism can be developmental delays, difficulties with communication and emotions, and repetitive behavior, and early detection of autism signs is critical for early intervention to improve developmental skills and well-being.

This new approach was established in 2020 and this is the first study conducted on this group of children and their parents' experience with the process. This study consists of both existing data obtained from RGR and parents' responses in a questionnaire and spanned three semesters. During the first semester, the main focus was on obtaining knowledge based on the early detection of autism, the screening tool M-CHAT-R, and the follow-up interview (M-CHAT-R/F) and writing a systematic review based on that knowledge. During the second semester, special emphasis was given to design the questionnaire and obtaining research permission from the National Bioethics Committee of Iceland, together with writing an introduction and method chapter of the thesis. Finally in the third semester data was collected, pre-existing data as well as data from the parent survey was processed, and the study was written. A big part of this survey was the data collecting, both by combining the pre-existing data on the RGR along with designing and sending out the questionnaires.

Many thanks to my supervisors, Emilía Guðmundsdóttir and Sigríður Lóa Jónsdóttir, PhD, from the RGR, and Þórhildur Halldórsdóttir, PhD, from Reykjavik University for their guidance and assistance.

I also would like to thank the parents who participated in the survey, their answers were very important for the evaluation of this new approach.

Finally, I would like to thank my family, friends, and classmates for their support and encouragement throughout this process.

Abstract

This exploratory study examined the characteristics of children, referred to the Counselling and Diagnostic Centre (Ráðgjafar og greiningarstöð; RGR) following an 18-month healthcare check-up if autism is suspected. A high-likelihood group of children who underwent this recently implemented approach was examined along with parents' experience of the process. We examined the percentage of 18-month-old children, who screened positive on the screening tool *Modified Checklist for Autism in Toddlers, Revised with Follow-Up* (M-CHAT-R/F), met diagnostic criteria for autism before age 5 years old, and explored the characteristics (e.g. age at first signs of autism, who first had concerns about development…) of the children and their families who underwent this early screening process and the services they have received subsequently. Participants comprised 69 children referred to RGR following the screening in the 18-month check-up, as well as an assessment of parents' (N = 42) experience of the screening process. RGR's existing data and a parent survey designed by the researchers were used to conduct the study. Most of the children (65%) had completed the diagnostic process, with 86% of them diagnosed with autism. The average diagnosis age was 2.5 years, and the average waiting period was 1.2 years. Parents were generally satisfied with the service provided after the screening in an 18-month check-up, but satisfaction with that service did not significantly affect their attitudes towards the early screening process: ($\chi^2(4) = 6.05$, $p = .196$). Most (84%) of the parents had positive attitudes toward the process, but diagnostic status did not significantly affect their attitudes toward the process: ($\chi^2(2) = 1.88$, $p = .391$). Taken together, the M-CHAT-R/F proved effective in detecting early autism signs among 18-month-olds in healthcare check-up, and parents were generally satisfied with the early screening process during this standard healthcare visit.

Keywords: autism, 18-month-old check-up, screening, M-CHAT-R/F, early intervention, parental satisfaction.

Early Detection of Autism in Primary Healthcare in Iceland: Parental Experience of the Procedure and Services Provided for Toddlers Following a Positive Screening

Autism spectrum disorder (ASD; hereafter autism) is a neurodevelopmental disorder characterized by impairments in social interactions, verbal and nonverbal communication, and a pattern of repetitive and stereotypical behaviors and interests (American Psychiatric Association, 2013). A recent systematic review of studies, using different methodologies during the last decade, showed a 1% median prevalence of autism diagnosis (Zeidan et al., 2022). In Iceland, the prevalence of 7-9 years old has been estimated to be 2.68% (Delobel-Ayoub et al., 2020). The prevalence of autism has been on the rise in the past decades, which may partly be explained by advancements in screening tools (Centers for Disease Control and Prevention, 2023; Hansen et al., 2015; Lundström et al. 2015).

One diagnostic criterion for autism is that the signs must be present during early development, although they may not fully appear until social demands become more complex (American Psychiatric Association, 2013). The timing of the detection of the first signs varies. In more severe cases, the signs may be identified even before the age of 12 months, while in less severe cases, they may not become obvious until after 24 months (French & Kennedy, 2018). The common early signs at first can be developmental delays, difficulties with communication and emotions, and repetitive behavior (Zwaigenbaum et al., 2013). However, in practice, autism most often goes undiagnosed for years, with the average diagnosis age of 60.48 months or around 5.7 years (van't Hof et al., 2021). This is provided that early detection of autism signs is critical for early intervention to improve developmental skills and well-being (Landa, 2018; Reichow et al., 2012).

The American Academy of Paediatrics (AAP) has recommended standardized screening of autism in primary healthcare for all children of 18 and 24 months. They provide an evidence-based intervention that can improve functioning (Johnson et al., 2007). One of

the most researched early screening tools for autism signs in toddlers is the *Modified Checklist for Autism in Toddlers, Revised with Follow-Up* (M-CHAT-R/F). The M-CHAT-R/F is a two-stage parent-report screening tool used to determine the likelihood of autism (Robins et al., 2014). Robins and colleagues found that children in the general population who screened positive, on M-CHAT-R/F in 18- and 24-month-old healthcare check-ups, were 114 times more likely to be diagnosed with autism compared to children who screened negative. Additionally, 94.6% of the children in the same study, who screened positive for autism on the M-CHAT-R/F, showed delay in development or concerns indicated need for early intervention (Robins et al., 2014). The M-CHAT-R/F has also validated children with an increased likelihood (e.g. with a family history of autism or any developmental concerns) of autism and has demonstrated that it can be a valuable screening tool for identifying autism in this population as well as detecting developmental delay (Bradbury et al., 2020; Yuen et al., 2018; Weitlauf et al., 2015).

As of 2020, it has also been used in primary healthcare in Iceland to screen for autism signs among 18-month-old toddlers with an increased likelihood of autism (Development Center for Primary Healthcare in Iceland, 2022). The first objective of this study was to examine this new approach in an 18-month healthcare check-up in Iceland based on the M-CHAT-R and the follow-up interview. We hypothesized that the majority of the 18-month-old children, who screened positive on the M-CHAT-R and follow-up interview, would receive a diagnosis of autism before the age of five years and receive some type of service following the screening (e.g., speech service, occupational therapy). The second objective was to determine the characteristics of the children who were offered the screening and how parents perceived the early screening process. Due to a gap in the literature and with no prior research on this topic, this analysis was more descriptive and exploratory with the aim of informing clinical practice.

Method

Setting

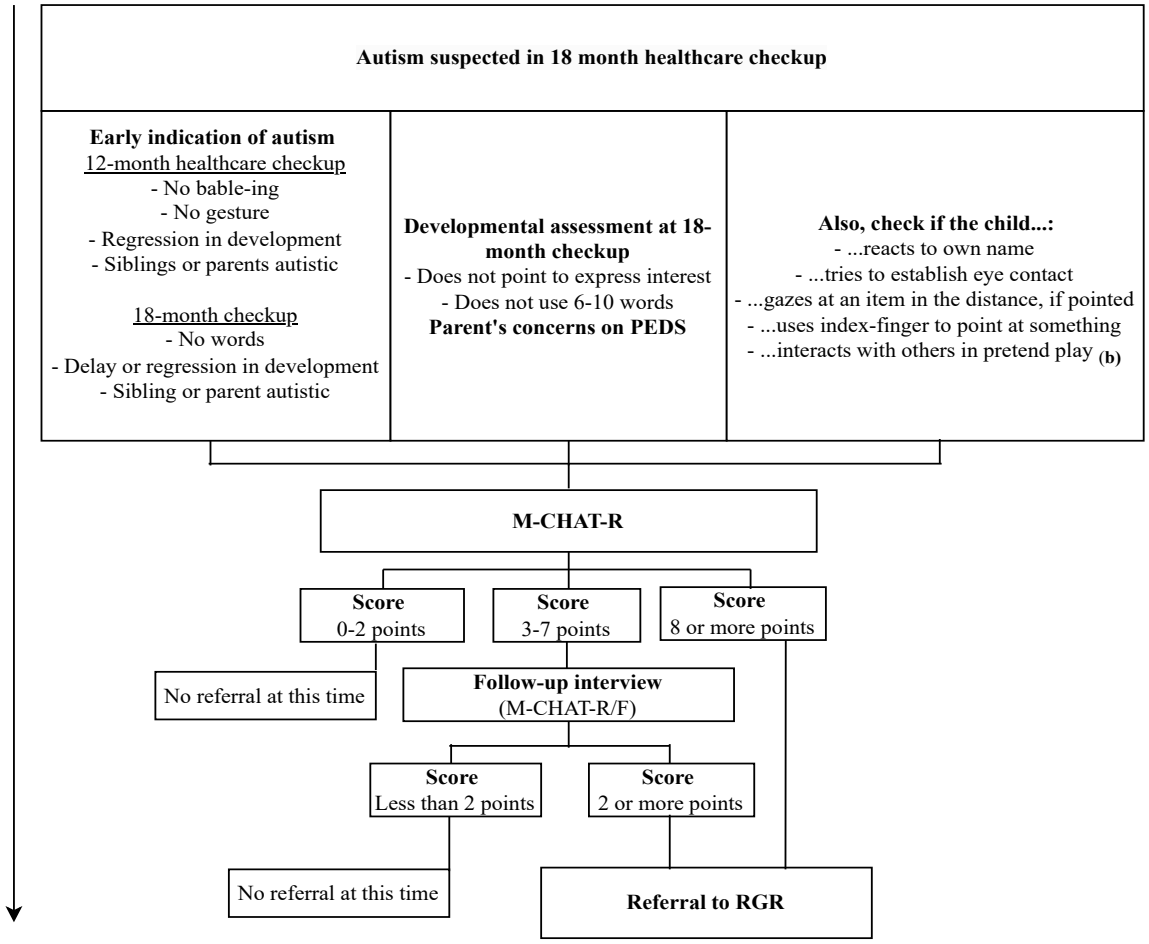
Primary healthcare: Primary healthcare in Iceland is a government-provided service accessible to all individuals. From the time of a child's birth, parents are granted unrestricted access to complimentary primary healthcare services for their children. New parents receive home visits to begin with and subsequently, they bring their infants to the clinic for check-ups (Development Center for Primary Healthcare in Iceland, 2022).

During the 18-month-old check-up, healthcare professionals assess the child's development and well-being and provide information and support to parents. This developmental assessment is performed by direct observation, indirect observation, and information from parents. Gross and fine motor skills are examined, as well as the child's communication, play, and cognitive development (Development Center for Primary Healthcare in Iceland, 2022). To prompt parents' concerns, they are asked to fill out a checklist called Parents' Evaluation of Development Status, PEDS (Glascoe, 1999). If only one concern arises on an item from the aforementioned development assessment list, the role of the healthcare professional is to provide advice to parents and conduct a follow-up during the next primary healthcare visit. If the child struggles with two or more items additional consideration is needed, and parents get a referral to a pediatrician or child psychologist for further examination. Any history of stagnation or regression in the child's development always warrants additional examination (Development Center for Primary Healthcare in Iceland, 2022). Essential components of the autism screening program, when concerns of autism arise in an 18-month-old healthcare check-up, can be seen in Figure 1.

This new approach in 18-month-old healthcare check-up is designed to detect early developmental concerns and shorten the process for children all over the country and refer them directly to the RGR, for further assessment (HH, 2021).

Figure 1

Flowchart of the screening process at the 18-month-old healthcare check-up when autism is suspected[a]



Note. [a] Development Center for Primary Healthcare in Iceland (2022). [b] This part is adapted from JA-OBS: Nygren et al., (2012).
M-CHAT-R = Modified Checklist for Autism in Toddlers, Revised.
M-CHAT-R/F = Modified Checklist for Autism in Toddlers, Revised with Follow-Up.

In Iceland, early intervention is provided in kindergarten. In this study, early intervention in kindergarten refers to support of children, due to disabilities, or social or emotional difficulties, who receive special education and support. Some preschools offer individual support while others provide assistance for the entire department. In 2022, almost

20,000 children attended kindergarten in Iceland, an increase of 635 children from the previous year (3.3%). In the same year, 2,320 (11.7%) children, 1.491 (64%) boys, and 829 (36%) girls benefitted from special support, but that is the largest number that has been observed (Statistics Iceland, 2023).

Participants

Information on participants was gathered in two ways: 1) from a pre-existing database containing diagnostic status obtained from the RGR, and 2) a parent-completed online survey designed by the researchers and sent to parents (see Measures for more information on the survey).

Participants were children referred to the RGR by the Primary Health Care of Iceland, between January 2021 and September 2023, following a screening on M-CHAT-R/F at the child's 18-month-old healthcare check-up. The total number of children examined in this study was 68, of which 53 (77.9%) were boys and 15 (22.1%) were girls.

A total of 103 parents of 63 children referred to RGR, following the early screening approach, were contacted via email to complete a survey regarding the screening process. The parents of two children had inactive email addresses and three children were excluded as the screening was not performed at a typical 18-month-old healthcare check-up due to family circumstances. Out of those 103 parents, 42 completed the survey, 29 (69%) were mothers and 13 (31%) were fathers. The majority, or 33 (79%), had a son referred to the RGR and 9 (21%) had a girl referred. The survey was translated into three languages, Icelandic, English, and Polish; therefore, parents who did not speak those three languages were excluded. Most parents, or 31 (74%), answered in Icelandic, and 11 (26%) answered in English or Polish. Of those who responded to the survey, 22 (52.4%) had completed the RGR diagnostic process, while 19 (45.2%) were in the diagnostic process or were waiting for it to begin.

Permission to conduct this study was obtained from the National Bioethics Committee of Iceland (#23-127).

Measures

Screening for autism signs among 18-month-old

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) was used to assess signs related to autism among children during the 18-month-old healthcare check-up. The M-CHAT-R/F is a two-stage, parent-report screening tool used to identify toddlers between 16 and 30 months of age with an increased likelihood of autism (Robins et al., 2014). In the first stage, caregivers answer 20 “yes” or “no” questions about their children’s behavior. The answers are tallied and the child’s likelihood for autism is reflected in a total score: low-likelihood (total score 0-2), moderate-likelihood (total score 3-7), and high-likelihood (total score 8 or higher). If the total score is moderate (3-7) it is recommended to add the second stage a follow-up interview (M-CHAT-R/F) where parents are asked for more information and examples of the behavior related to the items that indicate autism. If the score is a total of 2 or more after the follow-up interview, the child is referred to a specialist for further diagnostic assessment and determination of the need for early intervention. The follow-up interview can be bypassed, and immediate referrals can be made if the initial total score indicates a high-likelihood (Robins et al., 2014). The M-CHAT-R and M-CHAT-R/F were already validated in an Icelandic population sample of 30-month-old children in Iceland (Jonsdottir et al., 2022).

Following the referral to RGR, diagnostic assessment at the RGR is conducted by interdisciplinary teams, involving physical examination, developmental, medical, and family history, developmental assessment if not performed by the local municipality psychologist beforehand, and further assessment of autism symptoms, sometimes with the use of the Autism Diagnostic Observation Schedule-second edition (Lord et al., 1989).

Demographic and clinical information

Information regarding the children's age, gender, place of residence, national origin, ICD-10 diagnosis, and age when diagnosed was obtained from medical records at RGR. The ICD-10 diagnoses used in this study were: Unspecified Neurodevelopmental Disorders (F89), Emotional Disorders with Onset Specific to Childhood (F93), Intellectual Disabilities (F70-F79), Communication Disorders (F80) and Motor Disorders (F80). Autism refers to all sub-diagnosis under F84.

Parental experience and satisfaction with the screening process

The researchers designed a survey to examine parents' experience of the screening process, including first concerns, referral to RGR, early intervention, and diagnostic results. Questions ranged from parents' background (e.g. age, residence, level of education, and attachment to the child…), first concern about their child's development, early intervention for the child following the screening results (services within kindergartens and other services e.g. speech pathologists, physiotherapists, and occupational therapists), current status in the screening process, referral to RGR and the diagnostic results. Finally, the survey concluded with an open-ended question where parents could provide feedback. The survey was set up in *QuestionPro*, it only took around 10-15 minutes to complete, and each participant only had to answer once. The survey was sent out first on March 6, 2024, and a follow-up reminder was sent to all parents twice.

Statistical analysis

To determine the ability of the M-CHAT-R and the follow-up interview, administered at the 18-month-old healthcare visit to predict a later diagnosis of autism, descriptive statistics were used to describe the percentage of referrals that met diagnostic criteria for autism, autism combined with other diagnostic or other diagnosis than autism (Unspecified

Neurodevelopmental Disorder, Emotional Disorders with Onset Specific to Childhood, Intellectual Disabilities, Speech and Language Disorders and Motor Disorders) at a later stage.

To determine the parents' first concern about development and behavior, descriptive statistics were used to examine how old the child was then the first concerns appeared, the prevalence of who was the first to have these concerns, and the prevalence of the first signs that parents noticed.

Service following the screening was also examined with descriptive statistics, first by looking at parents' attitudes towards the early intervention their child got following the screening and then by investigating what kind of support their children received. To examine whether parents' satisfaction with the service affects the screening process. Satisfaction was divided into three variables: those who were satisfied (quite or rather satisfied), those who were neutral (neither satisfied nor dissatisfied), and those who were unsatisfied (rather or quite unsatisfied). The parents' attitude towards the screening process was examined the same way, three variables were divided, those who were positive (quite or rather positive), those who were neutral (neither positive nor negative), and those who were negative (rather or quite negative). A chi-square was used to examine whether there were significant differences between the groups. The percentage of those who received intervention in kindergarten following the screening was determined as well as the percentage of children who got support outside of kindergarten to find out which service was the most common.

Finally, parents' attitude towards screening was examined to see if it differed depending on whether the diagnostic process had been completed or not. Descriptive statistics were used to describe parents' attitudes toward the screening process, chi-square was used to examine whether there were significant differences between the groups. If a parent didn't answer individual questions, it was marked as missing data.

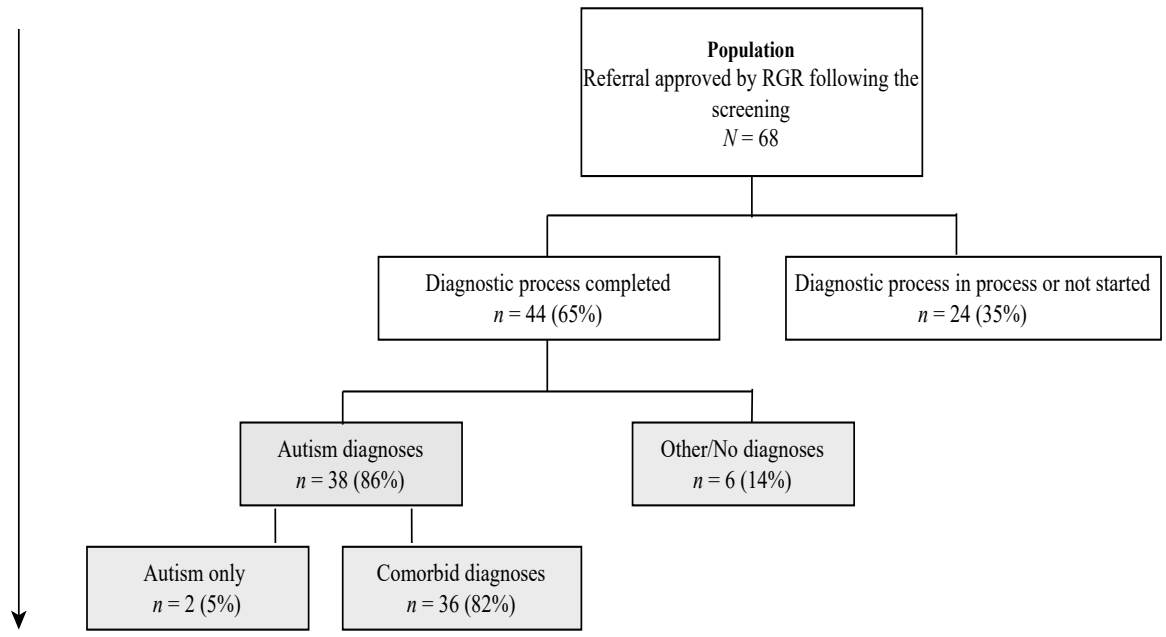
The researcher got the data in two separate *Microsoft Excel sheets,* one for pre-existing data and the other for the parents' survey. Both sheets were transferred to *Jamovi* in two separate sheets for further processing.

Results

Figure 2 provides an overview of the children referred to RGR and the diagnoses after the assessment. Two of the children had scores on the older version of the M-CHAT-R, they were included in the study, not marked separately. Out of the 68 children referred to RGR, 44 (65%) had undergone diagnostic assessment at RGR at the time of the study. Of those, 38 (86%), were diagnosed with autism, and 6 (14%) with other or no diagnoses or no clinical diagnosis.

Figure 2

Number of children referred for diagnostic assessment after screening for autism in the 18-month-old healthcare check-up



Note. **Other diagnoses:** Unspecified Neurodevelopmental Disorder (F89), Emotional Disorders with Onset Specific to Childhood (F93), Intellectual Disabilities (F70-F79), Speech and Language Disorders (F80) and Motor Disorders (F80).

White boxes: Percentage based on the number of references (68).

Gray boxes: Percentage based on the number of Diagnostic Processes completed (44).

The average age of children referred to RGR following the screening was 22 months and 16 days with the standard division of five months and three days. However, in the database, there were some outliers, because their screening was delayed for unspecified reasons. When the average age was calculated without these outliers and based on one standard deviation from the average, the average age of reference was 18 months and five days with the standard division of two months and 22 days. The average age of diagnosis was 42 months and 14 days, corresponding to 3.5 years with a standard deviation of six months and 14 days. When the average age was calculated without the aforementioned outliers, the average diagnostic age was 30 months and 18 days, corresponding to 2.6 years with a standard division of four months and 12 days. Thus, the average waiting period from a referral received at RGR until a determined diagnosis was 14 months and six days, corresponding to 1.2 years with a standard deviation of three months. Without the outliers, the average waiting time was 1 year and 1 month, corresponding to 1.1 years with the standard division of three months.

Table 1 shows the scores on M-CHAT-R and the follow-up interview. Of the 44 children who had completed the diagnostic process, two of them were missing scores on M-CHAT-R and are therefore not in the table. The majority, or 26 (72%) children, who met diagnostic criteria for autism scored in the range of 8-17 on the M-CHAT-R, and approximately one-third of the children, or 10 (24%) scored in the range of 3-7. Scores on the M-CHAT-R and follow-up interviews were missing from two children who later got an autism diagnosis.

All the children (n = 6) who did not receive an autism diagnostic at RGR had scores in the range of 4-7. However, only 3 (50%) of them received the M-CHAT-R/F during the screening process. Of note, 9 (56%) of children with scores in the range of 3-7 received the

M-CHAT-R only, although protocol states that the follow-up interview should also be administered in such cases.

Table 1

Scores on the M-CHAT-R and follow-up interviews by diagnostic groups.

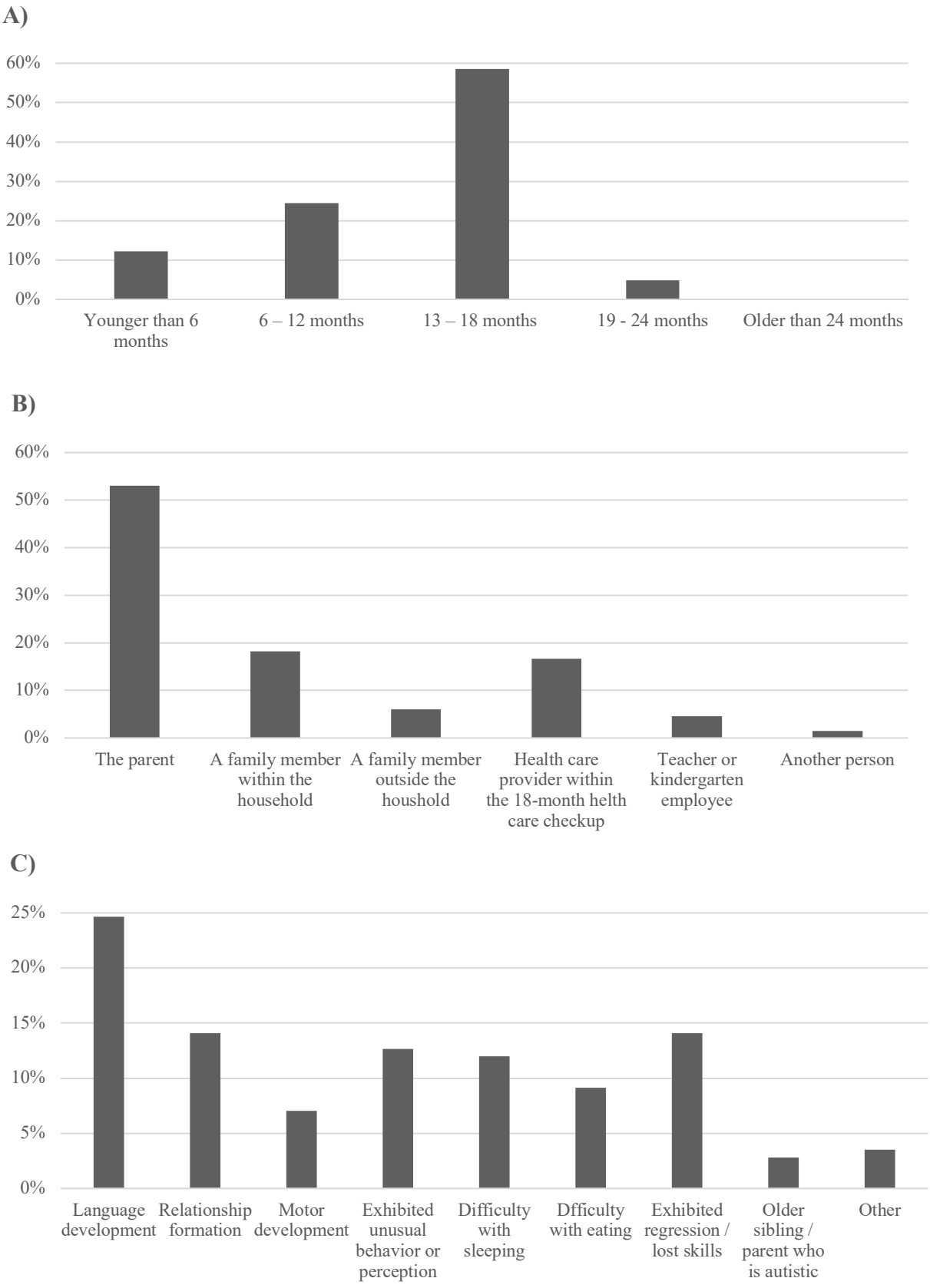
Diagnoses	M-CHAT-R *N* = 42			M-CHAT-R/F *N* = 16		
	Score 3-7 *n* (%)	Score 8-20 *n* (%)	Total *N* (%)	Yes *n* (%)	No *n* (%)	Total *n* (%)
Autism	10 (24)	26 (62)	36 (86)	6 (37.5)	4 (25)	10 (62.5)
Other/No diagnoses	6 (14)	0 (0)	6 (14)	3 (18.8)	3 (18.8)	6 (37.5)
Total	16 (38)	26 (61)	42 (100)	9 (60)	7 (40)	16 (100)

Note. **M-CHAT-R** = Modified Checklist for Autism in Toddlers, Revised.
M-CHAT-R/F = Modified Checklist for Autism in Toddlers, Revised with Follow-Up.

Figure 3A displays the child's age when parents first became concerned about their development. Figure 3B shows the first person who became concerned. Figure 3C takes note of the first behaviors causing concern.

Figure 3

Shows parent's report about first concerns about the child's development or behavior



Note. A) Bar chart showing the age of first concerns. B) A bar chart showing parents' reports on who first had concerns about the child's development or behavior. C) A bar chart showing what were the first signs that concerned the parents.

Parents reported most frequently (95%) that the onset of the first concerns about the child's development and behavior was before the child turned 18 months old. All of them reported that the onset of the first concerns was before the age of 24 months.

Half of the parental group reported that they were among the first to have concerns about their child's development and behavior. The second most common answer was that a family member within the household (18%) or healthcare provider at the 18-month-old healthcare check-up (17%) was among the first people to have concerns. According to 4 parents (9.5%), a healthcare professional was the first to raise concern about the child's development or behavior.

Concern about language development was the most common (n = 35; 25%) parent' answer regarding the first signs of autism. The second most common concern was relationship formation (14%), regression (14%), and unusual behavior or perception (13%).

Of the 42 parents who completed the survey, 40 parents did answer the question about satisfaction. Parental satisfaction with the service they received following the screening was high, with 62% rating it as *good* or *very good* (see Figure 4), 38% of parents did not take a stand on their satisfaction with the service or felt that it was *rather bad* or *quite bad*. When parents were asked if their child had received additional services in kindergarten, 86% reported that their child received support in kindergarten following the screening. When asked about service outside the kindergarten, 34% reported that they had received some service following the screening, while 66% reported that they had not received any services outside kindergarten.

Figure 4

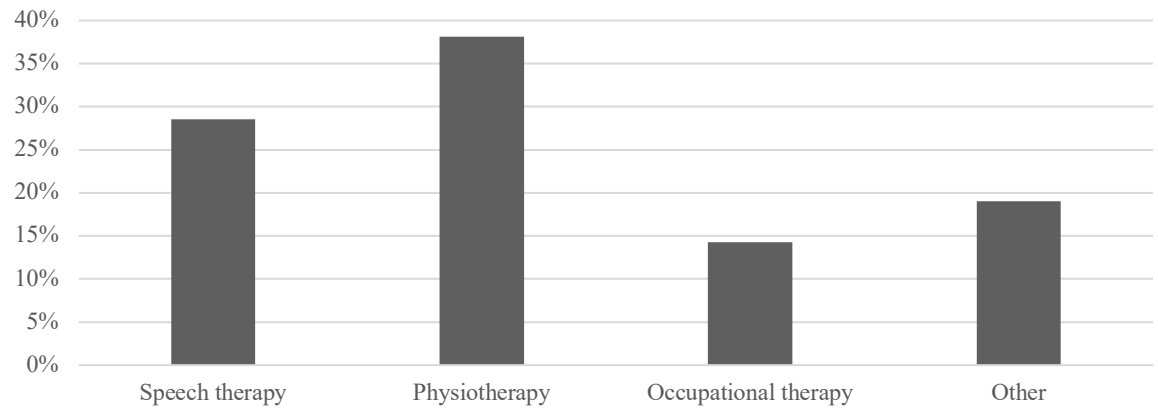
Parents' satisfaction with services received following the screening.

Note. **Question:** How good did you think the service was that you were offered following the screening?

Figure 5 shows which services the children got outside kindergarten following the screening. Physiotherapy was the most common service outside kindergarten or 38%. The second most common service was speech therapy or 29%, only 14% received occupational therapy and 19% reported having some other services not specified further in the questionnaire.

Figure 5

Services the children got outside kindergarten.



Note. **Other:** Services other than speech therapy, physiotherapy, and occupational therapy, are not defined in this study.

Table 2 shows whether the satisfaction towards the services following the screening influenced parents' attitude towards screening for autism signs, during 18-month-old healthcare check-up. Of the 42 parents who completed the survey, 41 answered the question about the attitude. Parents' attitudes towards the screening process were highest among those who were satisfied with services following the screening (68%). None of the parents satisfied

or neutral with the service reported negative attitudes towards the screening process. Among the parents unsatisfied with the service following the screening, the majority (66.7%) had positive attitudes towards the screening process. However, the difference between those two groups was insignificant ($\chi^2(4) = 6.05$, $p = .196$; Table 2).

Table 2

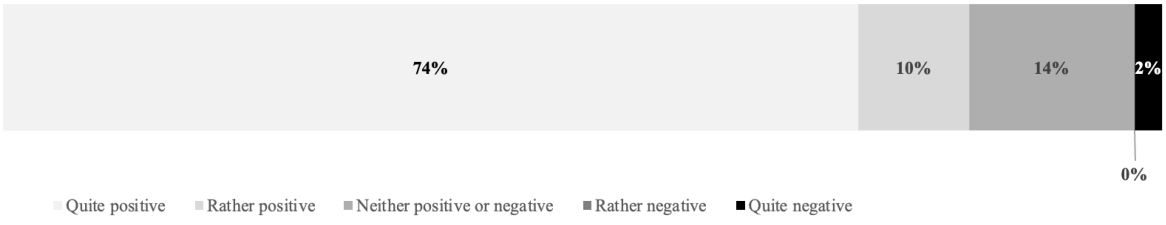
Chi-square test results for Satisfaction with Service and Parents' Attitude towards screening

Satisfaction with the service	Attitude towards screening			
	Negative *n* (%)	Neutral *n* (%)	Positive *n* (%)	Total *N* (%)
Satisfied with the service	0 (0.0)	3 (11.5)	23 (88.5)	26 (100)
Neutral towards the service	0 (0.0)	1 (12.5)	7 (87.5)	8 (100)
Unsatisfied with the service	1 (16.7)	1 (16.7)	4 (66.7)	6 (100)
Total	1 (2.5)	5 (12.5)	34 (85.0)	40 (100)

Figure 6 shows parents' attitudes towards their child being screened at the 18-month-old healthcare visit. The majority (84%) of parents had quite or rather positive attitudes towards the screening process.

Figure 6

Parents' attitude towards screening for signs of autism in the 18-month-old check-up.



Note. **Question:** How do you feel about screening for signs of autism during the 18-month-old check-up?

Of the 42 parents who had completed the survey, 41 answered the question about current diagnostic status, of them 22 (56%) had completed the diagnostic status but 19 (46%)

was in the process or on the waiting list. Table 3 shows that the percentage of parents positive with screening for autism signs, in the 18-month-old healthcare check-up, was higher (59%) within the group that completed the diagnostic process, than the group who did not (41%). None of the parents whose children completed the screening process were negative with the screening. However, there was no significant difference in attitude towards the diagnostic process depending on whether people had completed the diagnostic process or not ($\chi^2(2) = 1.88$, $p = .391$; Table 3).

Table 3

Chi-square test results for Diagnostic Status and Attitude Towards Screening

Diagnostic status	Parents attitude			
	Negative *n* (%)	Neutral *n* (%)	Positive *n* (%)	Total *N* (%)
Diagnostic process not completed	1 (5.6)	3 (16.7)	14 (77.8)	18 (100)
Diagnostic status completed	0 (0)	2 (9.1)	20 (90.9)	22 (100)
Total	1 (2.5)	5 (12.5)	34 (85.0)	40 (100)

Discussion

The aim of this study was to examine the screening process in an 18-month-old healthcare check-up for autism, using the M-CHAT-R and the follow-up interview. The results indicate that the M-CHAT-R/F is an effective screening tool for autism among 18-month-olds. The majority of children screened positive were referred for diagnosis and received autism diagnosis which is in accordance with previous studies (Bradbury et al., 2020; Jonsdottir et al., 2022; Robins et al., 2014; Yuen et al., 2018; Weitlauf et al., 2015).

Most of the children who completed the diagnostic process received an autism diagnosis. Six children were not diagnosed with autism, but only half of them (50%) underwent the follow-up interview. According to the protocol for an 18-month-old healthcare check-up (Development Center for Primary Healthcare in Iceland, 2022), children who score

between 3-7 in the M-CHAT-R should be administered the follow-up interview (M-CHAT-R/F). It indicates that the follow-up interview is an important addition when a child has lower scores on M-CHAT-R.

It is important to note that the children who did not receive an autism diagnosis at RGR may be in need of intervention. As stated by Robins and colleagues (2014), there was a percentage of children who did not receive an autism diagnosis despite the need for intervention. It would also be interesting to see if milder signs that did not receive autism diagnoses, will be detected later as van't Hof et al. (2021) have indicated. The group in this study was small so it was difficult to make further analyses in that group. It is also important to keep in mind that autism is sometimes reassessed because the signs can change, especially among young children (Elias & Lord, 2022).

One of the goals of the early detection program in 18-month-old healthcare check-up is to shorten the process from first concerns to diagnostic assessment by referring children with suspected autism directly to RGR (HH, 2021). The result of this study indicates that autism screening in a high-likelihood group of children during the 18-month-old check-up, results in referrals for diagnostic assessment at a young age, and most of the referred children start an early intervention before diagnostic confirmation.

There were some children who, for some reason, were considerably older when they were referred following the approach. If they were not included in the analysis, the average referral age of the children was 18 months, which is in line with the approach (Development Center for Primary Healthcare in Iceland, 2022). The waiting period was 1.1 years, and the average age of diagnosis was 2.6 years. These results support the aim of the approach, to shorten and facilitate the process when concerns about autism arise (HH, 2021). It is also interesting to see that it did not affect the waiting time when older children were referred.

Consistent with the timing of the approach, most parents reported that their first concerns appeared before the child's age of 18 months, and all of them reported that they had concerns at or before the child's age of 24 months. These findings are in line with a previous study from French & Kennedy (2018). Furthermore, it is interesting to find that parents are observing signs before the age of 12 months and some even before 6 months.

It was most common for the parent, family member, or healthcare professional to be the first to have concerns. However, some of the parents reported that the healthcare professional in the 18-month-old healthcare check-up was the first to raise concern.

One of the goals of early screening for autism is early intervention (Robins et al., 2014). Most children received additional support in kindergarten although there was a minority who received therapy outside the kindergarten. Parents reported that the most common service their children received outside of kindergarten was physiotherapy, but parents also reported other services. Parents differed when asked about their satisfaction with the service following the screening, the majority were satisfied (62%). There was a close adherence to parents who were satisfied with the service and positive with the screening process. This could be a factor in parental dissatisfaction, where parents may feel the child needs additional services (e.g., speech therapy, physiotherapy, or occupational therapy) outside kindergarten. However, the difference was not significant. Further studies are needed to shed light on this issue.

The majority (62%) of parents reported a positive attitude towards autism screening being offered in the 18-month-old healthcare check-up. Although there was a trend of more parents who regarded screening positively after the diagnostic process had been completed, in comparison to when it was still pending, the difference was insignificant. This issue needs further studies.

At the end of the questionnaire, there was an open question where parents had the opportunity to give a written answer about their experience of the screening process. The results indicate that parents were generally satisfied with the screening process in 18-month-old healthcare check-up and note that it is important to listen to parents' concerns. However, parents reported that a long period of waiting, and lack of information and support following the screening was something that could be improved.

This is the first study on the screening process in 18-month-old healthcare check-up in Iceland when autism is suspected. The aim of early detection is always to find these children early in order to provide them with services that can help them in the future (Landa, 2018; Reichow et al., 2012). A longitudinal study with a bigger group of children could give useful information that can improve the process. It would also be interesting to further examine the group of children that did not receive a diagnosis at RGR following the screening, to see if they received an autism diagnosis later or other diagnoses. Since healthcare workers play a significant role in the screening process, their experiences could also add important information.

Strengths and Limitations

There are several strengths in the current study. All children in Iceland referred from the healthcare were directed to the same institution, RGR, for further diagnostic assessment. This provided the opportunity for follow-up on all referrals and contact with most of their parents. This nationwide database includes detailed records about referrals and diagnoses.

Despite these strengths, this study had some limitations. The number of children falling under this category is quite few. The survey was only provided in Icelandic, English, and Polish, possibly excluding the participation of some parents. The only available information was on those who were referred to RGR, so it is possible that some other parents had concerns but for some reason, they were not offered screening.

Conclusion

M-CHAT-R/F is an effective screening tool in 18-month-old healthcare check-up. Parents were generally satisfied with the service provided following the screening, and the majority of them got some kind of service for their children in kindergarten. Parents reported a lack of service outside of kindergarten, indicating the potential for improvement. Parents generally had positive attitudes towards the screening process, which emphasized the importance of listening to their concerns.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)* (5th ed.). Washington, DC: American Psychiatric Publishing.

Bradbury, K., Robins, D. L., Barton, M., Ibañez, L. V., Stone, W. L., Warren, Z. E., & Fein, D. (2020). Screening for Autism Spectrum Disorder in High-Risk Younger Siblings. *Journal of Developmental and Behavioral Pediatrics: JDBP*, *41*(8), 596–604. https://doi.org/10.1097/DBP.0000000000000827

Centers for Disease Control and Prevention. (2024, January). *Data and Statistics on Autism Spectrum Disorder | CDC*. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/autism/data.html

Delobel-Ayoub, M., Saemundsen, E., Gissler, M., Ego, A., Moilanen, I., Ebeling, H., Rafnsson, V., Klapouszczak, D., Thorsteinsson, E., Arnaldsdóttir, K. M., Roge, B., Arnaud, C., & Schendel, D. (2020). Prevalence of Autism Spectrum Disorder in 7–9-Year-Old Children in Denmark, Finland, France and Iceland: A Population-Based Registries Approach Within the ASDEU Project. *Journal of Autism and Developmental Disorders*, *50*(3), 949–959. https://doi.org/10.1007/s10803-019-04328-y

Development Center for Primary Healthcare in Iceland [Þróunarmiðstöð íslenskrar heilsugæslu]. (2022). Vinnulag í ung- og smábarnavernd þegar áhyggjur vakna af einhverfu í 18 mánaða skoðun – notkun M-CHAT-R/F [The work procedure in child healthcare checkup when signs of autism arise during 18-month checkup – utilization of M-CHAT-R/F]. Retrieved April 30, 2024, from https://throunarmidstod.is/library/Ung-og-smabarnavernd/Vinnulag_einhverfuskimun%20%c3%ad%20ung-%20og%20sm%c3%a1barnavernd%202022

Elias, R., & Lord, C. (2022). Diagnostic stability in individuals with autism spectrum disorder: Insights from a Longitudinal Follow-Up Study. *Journal of Child Psychology and Psychiatry*, *63*(9), 973–983. https://doi.org/10.1111/jcpp.13551

French, L., & Kennedy, E. M. M. (2018). Annual Research Review: Early intervention for Infants and Young Children with, or At-Risk of, Autism Spectrum Disorder: A Systematic Review. *Journal of Child Psychology and Psychiatry*, *59*(4), 444–456. https://doi.org/10.1111/jcpp.12828

Glascoe, F. P. (1999). Using Parents' Concerns to Detect and Address Developmental and Behavioural problems. *Journal of the Society of Paediatric Nurses: JSPN*, *4*(1), 24–35. https://doi.org/10.1111/j.1744-6155.1999.tb00077.x

Hansen, S. N., Schendel, D. E., & Parner, E. T. (2015). Explaining the Increase in the Prevalence of Autism Spectrum Disorders: The Proportion Attributable to Changes in Reporting Practices. *JAMA Pediatrics*, *169*(1), 56–62. https://doi.org/10.1001/jamapediatrics.2014.189

HH [Heilsugæslan]. (2021). Nýtt vinnulag þegar áhyggjur vakna af einhverfu í 18 mánaða skoðun. [New approach when concerns of autism arise in 18-month checkup]. Retrieved April 30, 2024, from https://throunarmidstod.is/library/Ung-og-smabarnavernd/Vinnulag_einhverfuskimun%20%C3%AD%20ung-%20og%20sm%C3%A1barnavernd%202022

Johnson, C. P., Myers, S. M., & and the Council on Children with Disabilities. (2007). Identification and Evaluation of Children with Autism Spectrum Disorders. *Pediatrics*, *120*(5), 1183–1215. https://doi.org/10.1542/peds.2007-2361

Jonsdottir, S. L., Saemundsen, E., Jonsson, B. G., & Rafnsson, V. (2022). Validation of the Modified Checklist for Autism in Toddlers, Revised with Follow-up in a Population Sample of 30-Month-Old Children in Iceland: A Prospective Approach. *Journal of*

Autism and Developmental Disorders, *52*(4), 1507–1522. https://doi.org/10.1007/s10803-021-05053-1

Landa, R. J. (2018). Efficacy of Early Interventions for Infants and Young Children with, and at Risk for, Autism Spectrum Disorders. *International Review of Psychiatry*, *30*(1), 25–39. https://doi.org/10.1080/09540261.2018.1432574

Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). *Autism Diagnostic Observation Schedule*. https://doi.org/10.1037/t54175-000

Lundström, S., Reichenberg, A., Anckarsäter, H., Lichtenstein, P., & Gillberg, C. (2015). Autism Phenotype Versus Registered Diagnosis in Swedish Children: Prevalence Trends over 10 Years in General Population Samples. *BMJ*, *350*, h1961. https://doi.org/10.1136/bmj.h1961

Nygren, G., Sandberg, E., Gillstedt, F., Ekeroth, G., Arvidsson, T., & Gillberg, C. (2012). A New Screening Programme for Autism in a General Population of Swedish Toddlers. *Research in Developmental Disabilities*, *33*(4), 1200–1210. https://doi.org/10.1016/j.ridd.2012.02.018

Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early Intensive Behavioural Intervention (EIBI) for Young Children with Autism Spectrum Disorders (ASD). *Cochrane Database of Systematic Reviews*, *10*. https://doi.org/10.1002/14651858.CD009260.pub2

Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F). *Pediatrics*, *133*(1), 37–45. https://doi.org/10.1542/peds.2013-1813

Statistics Iceland. (2023). *Hagstofan: Fjórða hvert leikskólabarn með erlendan bakgrunn*. Resaved April 30, 2024, from https://hagstofa.is

van ’t Hof, M., Tisseur, C., van Berckelear-Onnes, I., van Nieuwenhuyzen, A., Daniels, A. M., Deen, M., Hoek, H. W., & Ester, W. A. (2021). Age at Autism Spectrum Disorder diagnosis: A Systematic Review and Meta-Analysis from 2012 to 2019. *Autism*, *25*(4), 862–873. https://doi.org/10.1177/1362361320971107

Weitlauf, A. S., Vehorn, A. C., Stone, W. L., Fein, D., & Warren, Z. E. (2015). Using the M-CHAT-R/F to Identify Developmental Concerns in a High-Risk 18-Month-Old Sibling Sample. *Journal of Developmental and Behavioral Pediatrics : JDBP*, *36*(7), 497–502. https://doi.org/10.1097/DBP.0000000000000194

Yuen, T., Penner, M., Carter, M. T., Szatmari, P., & Ungar, W. J. (2018). Assessing the accuracy of the Modified Checklist for Autism in Toddlers: A Systematic Review and Meta-Analysis. *Developmental Medicine & Child Neurology*, *60*(11), 1093–1100. https://doi.org/10.1111/dmcn.13964

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global Prevalence of Autism: A systematic review update. *Autism Research*, *15*(5), 778–790. https://doi.org/10.1002/aur.2696

Zwaigenbaum, L., Bryson, S., & Garon, N. (2013). Early Identification of Autism Spectrum Disorders. *Behavioural Brain Research*, *251*, 133–146. https://doi.org/10.1016/j.bbr.2013.04.004