UK National Screening Committee
Evidence summary on screening for autism spectrum disorder in pre-school children under the age of 5 years

Date: 9 November 2022

Contents

Aim

To ask the UK National Screening Committee (UK NSC) to make a recommendation, based on the evidence presented in this document, on whether screening for autism spectrum disorders (ASD) in pre-school under the age of 5 years should be recommended.

Current Recommendation

The UK NSC does not currently recommend screening for autism spectrum disorder (ASD) in pre-school children under 5 years. The previous recommendation was made in 2012 following a review carried out by Solutions for Public Health in 2011.

The 2011 review found that prevalence estimates for the UK were variable and that about one third of children screen detected with autism, and one quarter of those screen detected with ASD at around the age of 2 years, were likely to have lost their diagnosis by the age of 4. Although the reason for this was unknown.

Although a number of screening tools had been developed and assessed there was insufficient evidence on acceptable screening approaches in children in the general population under the age of 5 years. In addition, none of these tools had a sufficiently high sensitivity and positive predictive value (PPV) in a general population with none reporting on both sensitivity and PPV, and very few reporting on sensitivity at all.

In addition, a number of small randomised controlled trials (RCTs) on various interventions reported some improvements in varying, but inconsistent, domains, and only provided short-term follow-up so it was not possible to say whether interventions provided any long-term improvement.

Evidence Summary

The 2022 evidence summary on screening for ASD was performed by Exeter Test Group in accordance with the UK NSC's evidence review process.

The aim of this evidence summary was to address the following questions:

1. What is the diagnostic stability of ASD, in children diagnosed aged under 5 years?
2. What is the accuracy of screening questionnaires in children under the age of 5 to identify ASD at various ages?
3. Has the benefit of early intervention in children aged 5 years and younger, detected through screening been demonstrated?

Summary of findings

Question 1; 5 studies were included. Although one study based in the UK reported 100% diagnostic stability for ASD in a screened population, there were concerns with risk of bias in particular due to the lack of blinding of diagnoses. The other 4 studies reporting on diagnostic stability (ranging from 72%-100%) all raised concerns of bias meaning all were likely to overestimate diagnostic stability. In addition, there was little evidence that diagnoses were stable beyond the age 4 or 5.

Question 2; 21 articles reporting on 20 studies were included. The majority (15 studies) reported on versions of the Modified Checklist for Autism in Toddlers (M-CHAT, the most promising tool identified in the 2011 review). Nine of these were translations into languages other than English. Estimates for sensitivity ranged from 0.67-1, with many reporting a sensitivity of around 0.8 depending on age and cut-off. These studies were also generally at high risk of bias, mainly due to the approaches used to follow-up screen negative children and lack of blinding to screening results in diagnostic evaluations. Some evidence suggested that 2 screening tools where children were observed (Three-item Direct Observation Screen (TIDOS) and Joint Attention Observation schedule (JA-OBS)) tended to perform better when compared to M-CHAT. However, these tools were comparatively resource intensive.

Question 3; 4 studies (3 RCTs and 1 cohort) reported on interventions in children with ASD identified through screening. However, these were small studies, affected by attrition, reported mixed findings and included only short-term follow-up.

Consultation

A three-month consultation was hosted on the UK NSC website. Direct emails were sent to 12 stakeholders. (Annex A)

10 comments were received from the following stakeholders (see Annex B for comments):

- Royal College of General Practitioners
- xxxx xxxx
- Traolach Brugha
- xxxx xxxx
- xxxx xxxx
- NHS England, Learning Disability and Autism Programme
- xxxx xxxx
- Autistica
- Swadlincote Asperger's Society
- Royal College of Paediatrics and Child Health (RCPCH)

Two charities, 4 members of the public, and 4 professionals/organisations representing healthcare professionals provided comments.

Stakeholders were mostly either supportive of the evidence summary's conclusions, or, although supportive of screening recognised that there was not currently enough evidence to recommend it at this time. The lack of a tool that correctly identifies those children who do not have ASD resulting in too many children being incorrectly identified as having ASD and the potential overload this might have on an already struggling service was highlighted.

3 of the 4 professionals/professional organisations agreed with the conclusions of the review. Although the RCPCH were in favour of screening (with a tool designed to identify ASD only at age 18-24 months followed by developmental surveillance) they agreed that the available evidence does not currently satisfy the criteria for screening, recognising that current screening tools were not good enough at correctly identifying those children who do not have ASD and significant benefit of early intervention had not been demonstrated.

One charity commented that screening had the potential for significant benefit but recognised the evidence was not yet available to support this and even when a diagnosis was early there was a need for a clear support pathway. Both charities commented on the potential benefits of early diagnosis and interventions and the harms and traumas (before and after diagnosis) of not receiving an early diagnosis.

3 members of the public agreed that screening at age 5 was not supported. One suggested parental education as an alternative. The other two (who had both received a late diagnosis) suggested screening at an older age and highlighted the harms and trauma they had experienced (and continued to experience) without an earlier diagnosis.

Two members of the public were supportive of screening with one suggesting a standardised self-referral pathway.

Stakeholders suggested support or education programmes for parents and/or families would be beneficial. Some also suggested better education for healthcare professionals in general and those who might come into contact with children presenting with mental health issues, such as schools, community/charity mental health groups and GPs.

Several stakeholders highlighted that ASD and mental health conditions are often present together, as was the wide range within the spectrum of ASD and possible differences between girls and boys.

Most stakeholders commented on the importance of early identification and providing children with the appropriate, tailored support and education they need. Details of trauma and harms that could occur without a diagnosis were commented on extensively.

No changes to the document were requested.

Response: the UK NSC is grateful to the stakeholders for their contribution to the consultation process, and especially notes their feedback on the importance of early identification, and subsequent appropriate, tailored interventions for affected children. However, the current evidence does not support a universal population screening programme in pre-school children under the age of 5 years. Existing screening tools are not accurate enough in this general population of children and the benefit of interventions in the screened population was not shown.

Education and training for families, including education in good parenting skills at school was suggested as an alternative to screening.

Response: The Committee agrees that it would be good if parenting skills were available as part of education in school. This could usefully be taught in secondary school. However, it is not within the remit of the UK NSC to make recommendations on education.

A screening programme for a general neurodiversity was proposed, given the wide-ranging spectrum and overlap between conditions was another suggestion.

Response: Development varies from child to child, even in those considered to be within normal limits. This means that getting a balance between different measures of test accuracy is very difficult. This is particularly the case as we now refer to ‘autism spectrum disorders’. Broadening the target of the screening programme to include neurodiversity, in general, might be more specific, i.e., those who do not have a disorder would be more likely to be correctly assigned and those who are screen positive would be more likely to have a disorder. Good examples of this are those screening tests for ASD which often pick up other developmental conditions. However, the test accuracy measures for neurodiversity as a group, may not be very good unless the cut-offs are adjusted, in which case different measures of accuracy may suffer. We also do not know if this would be acceptable to children, parents and healthcare and educational professionals. For pre-school age children this would involve health visitors or GPs and in school-age children, it would be teachers, school nurses or GPs. Having said that, the possibility of screening for neurodiversity might be a discussion that is needed, and the Committee would suggest submitting a proposal for this to the annual call for topics so it could be properly considered and discussed.

In England and Northern Ireland children are assessed at age 2-2.5 years through the "Healthy Child Programme" and "Healthy Child, Healthy Future" respectively. The "Scottish Child Health Programme" assesses development at 27-30 months, and the "Healthy Child Wales Programme" at 27 months. These assessments are not part of a formal UK N S C recommended screening programme and although they are not designed to identify children with ASD specifically, it is possible that the behaviours and signs of undiagnosed ASD might be identified through these programmes.

A screening programme for older children and/or young people.

Response: The supporters of screening argue for pre-school screening in order to identify children early, i.e., preschool, so as to provide individual support and improve outcomes for the child. The later screening takes place, the less potential impact this may have. However, it could be argued that this is better than not screening at all and at an older age, measures of test accuracy are likely to be much better. If screening were to take place, it would likely fall to education staff to identify since school-age children spend a lot of time at school. It could be argued that it would be better to concentrate on increasing awareness of ASD rather than screening since even if screening were introduced, it is unlikely to be 100% accurate.

It was proposed that education and training in schools, community/charity mental health groups and healthcare professionals, and any professionals encountering children be introduced. This should highlight that ASD and other neurodivergent conditions and mental health issues overlap and often occur together.

Response: The Committee acknowledges that this is important and would be surprised if this was not recognised, in principle, in these groups. The issue would be whether it was recognised in individuals and practitioners were aware of what to do.

A self-referral pathway through standardised hubs using the same criteria and tools and post-diagnostic support including allocated key workers, data sharing and appropriate care plans was another suggestion.

Response: Parents can raise their concerns with health visitors, who should be able to recognise those children whose development is not following the usual pattern. If the health visitor confirms this, they should be able to refer children to local pathways for further assessment. Health visitors are also the professionals who carry out the

Healthy Child Programme (or equivalent) assessments. This would ensure that those who need it are referred appropriately to an already overstretched service.

Guidelines from the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) are also in place for the recognition and management of ASD:

Autism spectrum disorder in under 19s: recognition, referral and diagnosis (NICE)

Autism spectrum disorder in under 19s: support and management (NICE)

Assessment, diagnosis and interventions for autism spectrum disorders (SIGN)

Action

The UK NSC is asked to discuss the consultation comments and responses

Recommendation

The UK NSC is asked to approve the following recommendation:

> Screening for autism spectrum disorders in pre-school children under the age of 5 years is not recommended.

Annex A: List of Organisations Contacted

1. British Association for Community Child Health (BACCH)
2. Faculty of Public Health
3. Institute of Child Health
4. Institute of Health Visiting (IHV)
5. Royal College of General Practitioners
6. Royal College of Paediatrics and Child Health
7. Royal College of Physicians
8. Royal College of Physicians and Surgeons of Glasgow
9. Royal College of Physicians of Edinburgh
10. Royal College of Psychiatrists
11. The British Psychological Society
12. The National Autistic Society

Annex B: Consultation Responses

Note: Personally identifiable information has been redacted from certain comments, where individuals have chosen not to have personal details made public.

1.

Organisation: Royal College of General Practitoners

Role: Senior Clinical Policy Officer

The Royal College of General Practitioners is supportive of the decision not to screen for autism in the general population.

2.

Name: xxxx xxxx,

Member of the public

Notify: True

Affected Comment:

I know a number of people whose children are autistic, both of my daughters had autistic (Asperger's) partners for a number of years and one of my daughters and I are outside the neurotypical range though remain undiagnosed in any official way. It is not easy living with these conditions, and as women we hide it reasonably well and internalise these struggles which in many ways makes it worse, in any case more painful.

Discussion comment:

It is very black and white and clinical, and I don't think that it covers the many greys of neurodiversity. It also does not allow sufficiently for children hiding symptoms, even when very young. This is not a clear-cut black and white case (eg do you have cancer or not) it is a scale and will change over time. It can be influenced by surroundings and people who are caring for a child – some are more understanding and aware and the child's difficulties become less obvious, others make them worse.

Recommendation comment:

I agree that it should not be recommended, it is not a binary sort of situation and high IQ can sometimes mask it (as it does many other challenges such as trauma). It is just too subtle for screening, in my view.

Alternatives comment:

I think it would be more helpful to focus on good parenting skills, by providing education as part of 'life skills' teaching in secondary schools and for parents-to-be and hands-on real-life support (not just assessments, practical actual help) for new parents / carers. This would have 2 benefits: Firstly parents / carers would know how to support their young children so they develop to their full potential (eg by speaking to them and interacting with them actively from day 1, ensuring they have quality food, etc) and secondly it would help to see any issues very early (by parents / carers or those helping them) and be able to request and provide support and diagnosis and treatment as soon as the need is identified.

Other comments:

Parenting is the most important job we ever have and yet one we receive no training for and no help with – no 3-yr apprenticeships or similar. Is this the best we can do?

3.

Name: Traolach Brugha

Organisation: xxxx xxxx

Role: Epidemiologist and adult psychiatrist.

I agree with the results and recommendations of the review.

My current view, given the definition of screening used by the NSC, is that within the foreseeable future it is unlikely that early screening for autism will be supportable.

There is growing evidence that autism traits at least in childhood fluctuate over time. Recent evidence from the ALSPAC birth cohort shows this.

My view is health (and educational) policy should continue to support early identification and monitoring and where indicated offer additional support to individuals at increased risk of autism and to carers (families) while the need can be demonstrated.

4.

Name: xxxx xxxx

Member of the public

Affected Comment:

Yes, I am a late diagnosed (aged 37 at time of diagnosis) female adult with autism.

I have several friends which children who need a diagnosis of Autism

Evidence Comment:

Sorry can’t read well enough today to process that much info – so have to trust relevant people have done the right work

Discussion comment:

what about screening at 6/7yrs old?

Recommendation comment:

Agree there is no one suitable tool for screening.

I don’t agree it is not known if screening would improve long term outcomes for children with autism – early identification of autism would seriously improve life outcomes... have you seen our death rate!

“It is an undeniable and sad fact that individuals with autism suffer much poorer health and shorter lifespan than their peers without autism. One of the most important investigations of recent years revealed that average life expectancy of a person with severe autism is 39.5 years, rising to only 58 years for those with high-functioning autism, or Asperger syndrome.”

(https://www.thinkingautism.org.uk/addressing-poor-health-high-death-rates-in-autism/)

- have you seen the mental health crisis affecting the autistic community – and that young people are sectioned who are then only later found to probably be autistic. there must be some ages we can screen from – maybe not 5 but at some point before the teenage crisis kicks in?

Early identification and early intervention are key to stopping the crisis building in all services when it comes to autistic people not knowing what they are truly living with and thus unable to manage traits/triggers correctly.

I work in social care and education and can spot it a mile off – we need some kind of better early alert system – but yes i see the science doesn't stack up for under 5s... but surly at some age in childhood?

Alternatives comment:

I think you need to use us more – those of us autistics who have succeed into adulthood with skill and determination – those of us who work in the sector and so have professional expertise as well as personal insight.

I spend my day job doing 'bespoke' autism awareness just cos i can and it fits into my job role – there should be some better formal routes of employment for people like me who have the professional skills to come alongside children and help them learn themselves and their autistic self to manage it better and thus stop the demand on services... too many people see autism as a difficulty – this is the culture we need to change and by using people with autism/autistic people who have succeeded at life – not the ones who hold a bitter grudge of being a failed victim of the system

Other comments:

you have my email if you want to chat more :)

I could comment as a professional but I've not asked permission so I won't on this occasion. I work for a local authority in Children's Services department, I have loads of post grad qualifications to name: BSc, EYPS, QTS, NPQICL. I've been a teacher, a Private day care manager, a local authority advisory teacher, a trainer and assessor, a family support worker for social care, an Early Help advisor and more... but cos I am autistic I struggle with the executive function it takes to move up the career ladder, I also have my own 'ACES' that mean manage trauma triggers too (i am not a victim, I am a survivor and there are a lot of us in the autistic world) – so hear I sit quite happily helping people.

But there are many of us like me who would be a great source of advice givers to the generations of ignorant people who can't see autism for the gift it is or the poor kids that are coming through and want to die...

Help us to help you :)

5.

Name: xxxx xxxx

Member of the public

Affected Comment:

I was diagnosed with autism in September 2021 at the age of 21, despite signs and symptoms since I was very young. These symptoms manifested and, due to the lack of therapy directed to the autism, this then manifested into anger and violence at a young age which required long-term counselling for anger and self harm.

Evidence Comment:

I believe that evidence and the wider review should have explored an upper age limit as the symptoms of autism in 5 year olds or younger may not have developed to a point which allows the condition to be distinguished from other conditions or that of a typical toddler behaviour

Discussion comment:

Read previous answer – I agree with the report that evidence, and even my own experience, suggests it would not be practical to screen those 5 years old or under.

Recommendation comment:

Yes, but with older children. Many people, including myself, are often diagnosed at a late stage often in adulthood or the senior stage of childhood (16-18). This often means we grow up with comorbid mental health conditions as well as creating unconscious schemas/models of behaviour that can have negative impacts.

Alternatives comment:

Encourage schools, community/charity mental health groups and GPs who all face children with mental health troubles to include the possibility of autism and other neurodivergent conditions in models of screening and diagnosis.

Other comments:

No

6.

UK National Screening Committee (UK NSC)

Screening for Autism spectrum disorder

Consultation comments pro-forma

Name:	Claire Dowling and Dr Roger Banks
Email address:	xxxx xxxx and xxxx xxxx
Organisation (if appropriate):	NHS England, Learning disability and autism programme
Role:	**Dr Roger Banks, National clinical director and Claire Dowling, Head of Autism programme**

Do you consent to your name being published on the UK NSC website alongside your response?

Yes

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
General	NHS England and NHS Improvement agree with the conclusions reached by the National Steering Committee (NSC) that population screening for autism in children aged under 5 years is not supported by the available evidence. Primarily we wish to stress, in agreement with the NSC, that currently available screening instruments lack the required specificity to produce acceptable positive	

	predictive values given the population prevalence of autism. There is currently not sufficient evidence demonstrating substantial benefit from the potentially earlier initiation of investigation in a few children that could arise from universal screening as opposed to the current responsive referral process. With currently available screening instruments, a high proportion of the children identified by a universal screening programme would prove to have false-positive screening results, not autism. This would generate a large additional volume of assessment work, likely to be unfruitful. Given the limited number of staff available in child development assessment teams, this would inevitably have a significant detrimental impact on access to assessments for those identified as showing clear evidence early autistic features by parents, nursery staff and infant teachers.	

7.

Name: xxxx xxxx

Member of the public

Affected Comment:

My son has displayed autistic traits from age 2 and his father and I suspect he would meet the criteria if he were assessed thoroughly, with his developmental history included in the data.

Evidence Comment:

There needs to be a survey of the referral pathway, which are also a potential drop-out point, before screening has even started. All too often the information shared between primary care staff is not accurate or weighed up according to the same baseline criteria for dysfunction.

Discussion comment:

While a diagnostic tool that can be universally applied and has a high sensitivity rate with minimal false diagnosis risk, it is vital that policies for clinicians are consistently applied and robustly monitored to avoid families being referred and the pathway to diagnosis be disrupted by differing opinions. Second-line services like the GOSH high-functioning autism service are oversubscribed and do not have access to the same historical data on patients and families which local primary care should be joining up in assesment.

Recommendation comment:

Screening should be recommended to accompany the legal requirement for mandatory training for staff. Screening will promote the uptake of training for healthcare staff and also promote peer training for families, making LD and A awareness a community issue and potentially avoiding the high-cost, long term effects of late or misdiagnosis on young people.

Alternatives comment:

A self-referral pathway that links families up with standardised hubs where all assessment methodologies use the same criteria/tools. No waiting list and allocated key workers for anyone self-referring would promote adequate data sharing and a better picture of the individual being assessed, as well as the formulation of suitable care plans.

Other comments:

Pediatricians training in ASD by lived experience partners as a matter of urgency, to avoid cases being missed or discharged through lack of skills and knowledge in this key field.

8.

Name: Georgia Harper

Organisation: Autistica

Role: Policy Manager

Understanding how and why someone might be different from their peers can be hugely beneficial, both for their own self-understanding and for providing the right support and adjustments. Currently, too many children grow up without this understanding, with knock-on effects later in life. Screening for autism therefore has the potential to bring significant benefits if it is accurate, holistic, and proportionately accounted for in terms of support after diagnosis. However, we do not believe these conditions are met at present.

The evidence around current commonly used screening tools is mixed. In particular, specificity may be low in the presence of other neurodevelopmental conditions or mental health conditions, both of which frequently co-occur in autistic people. Many people struggle for years to receive an accurate neurodevelopmental diagnosis due to diagnostic overshadowing from a range of other neurodevelopmental and mental health conditions. Just as autistic people may be misdiagnosed with mental health difficulties before autism is recognised, those with lesser-known neurodevelopmental conditions may be misdiagnosed with autism, and sending all children on the more well-known autism pathway may exacerbate this problem.

In this context, mass screening can also lead to other avoidable harms, such as unnecessary anxiety for families whose children do not ultimately meet the criteria. There would also be a knock-on effect on diagnostic services which are already overstretched, with autistic people and their families frequently waiting years for a diagnosis. Further research is also needed on the accuracy of autism screening tools in those historically overlooked by autism research, such as girls and young women; autistic people who are not identified by screening tools may consequently be deterred from seeking a diagnosis later in life.

Development is lifelong, and the trajectory of a person's development can change over time. Instead, we would encourage the Committee to consider the potential for a more general neurodiversity screening programme which could highlight a range of neurodevelopmental conditions, and possibly transdiagnostic difficulties related to neurodivergent traits that do not meet specific diagnostic criteria but may nonetheless benefit from certain supports. It may also be beneficial to consider a longer-term development surveillance programme over multiple time points, to develop a more holistic view of a child's overall development and transitions between developmental stages.

At present, there is no clear post-diagnostic support pathway for autistic people. Much of the basis for screening is to ensure timely access to support; many autistic people do not receive this even with a timely diagnosis, with families often telling us they were sent away with no more than a simple leaflet. Last year, we published the

Autistica Support Plan to set the foundations for a lifelong support system for autistic people by 2030, and we are continuing to support NHS England and the Department for Health and Social Care in implementing these recommendations.

Autistic children often still receive more informal support, usually through their school. We believe this support can and should pre-date a formal diagnosis. Given the lengthy waiting lists, the diversity of the autistic spectrum and high levels of overlap across neurodevelopmental conditions, informal support and adjustments should be made available when the need becomes apparent, without the need to wait for the formal diagnostic pathway first.

9.

Name: Graham Rodgers

Organisation: Swadlincote Aspergers Society

Role: Treasurer and resident expert by experience.

Currently screening for Autism is not recommended because of a belief that there is no test good enough for screening the general population.

But as research into Autism had improved in the last few years, so has the understanding of Autism as a spectrum. No two people with an autism spectrum disorder have the exact same set of symptoms. ASD is referred to as a spectrum because of the variety of its signs and symptoms, and their differences in severity. Some people with ASD experience symptoms that make daily life difficult. Others who are considered “high-functioning” may simply feel like something is “different” about them. They might have felt that way since childhood but haven’t been able to pinpoint exactly why. Similarly, they may not notice that they feel or behave differently, but others around them may notice that they behave or act differently. There are no medical tests for ASD. This means that ASD can’t be detected using methods like blood tests or imaging tests. Instead, doctors review behaviours to make an ASD diagnosis. For adults, this usually means an in-person visit where the doctor asks questions and evaluates how you respond. They will also consider self-reported symptoms.

Self-administered ASD questionnaires for adults are available online. These tests include the Autism Spectrum Quotient (AQ) and derivatives like the AQ-10, AQ-20, and AQ-S, among others. However, these tests are not as reliable as a professional evaluation and should not be viewed as definitive.

There is increasing awareness among the general public about autism. Parents actively ask paediatricians to screen their kids if they suspect their kids are not following the normal developmental pattern.

The older version of the Diagnostic and Statistical Manual of Mental Disorders (DSM) did not allow children to be diagnosed with both autism and attention-deficit hyperactivity disorder (ADHD). The DSM-5 version, which is a more recent one, allows multiple diagnoses and we now use the term autism spectrum disorders

(ASDs). The listing of conditions like Asperger's syndrome as separate conditions has also added to misunderstandings about what to look for in the screening process.

Other problems include "diagnostic overshadowing"; when a child has clear characteristics of another disorder like ADHD, problems are attributed to that. If developmental milestones are met, such as timekeeping or the child walked and talked on command, people may say "they will grow out of it." But the individual has likely learned to "mask" certain symptoms or to avoid problematic situations. There is a negative belief that autistic children are anti-social, so when a child has a clear desire to interact socially then autism is not considered, even though social skills are still poor. If a child is self-contained and not particularly disruptive this can be interpreted as disciplined in a school setting. This often happens with girls. There may be a lack of clinical expertise available in the area itself where the child lives. High intellectual ability allows the child to work around challenges up to a certain point, particularly in verbal domains, after which demands become too great. Symptoms are less troublesome until the child's ability to adapt is exceeded. If a child begins to act out and develop symptoms of mental illness as they mature, they may be dismissed as "typical teen drama" without considering there may be something more underlying, as autism has long been associated with childhood and thus seen as a childhood condition. As awareness of ASD continues to grow and more detailed diagnostic criteria for adults are put into place, new resources and support will also continue to become available.

Thousands of people in Derbyshire alone are waiting way in excess of a year for vital autism assessments. Official reports show that the average waiting time for an autistic spectrum disorder assessment in Derbyshire is now 66 weeks – a year and three months. The latest figures show more than 14,000 local people are waiting for an assessment. In March there were around 14,320 people with an open "suspected autism" referral. That compares to 11,080 people in April 2021 – an increase of 29%. In the area, around 3,315 referrals had been open for at least 13 weeks, and of those, only 30 patients (1%) had received their first appointment within that time, which may have been for an initial assessment or triage. It comes as NHS figures show there has been a huge increase in the number of people waiting for an autism assessment across England.

Nationally, there were 100,250 patients with an open referral for suspected Autism in March of this year, a 39% increase from 71,954 in April 2021, which may be due to the pandemic. Of those, 82,076 had been open for at least 13 weeks. The number of people receiving their first appointment within 13 weeks has steadily increased, from 5,640 in April 2021, to 7,536 in March 2022, a rise of 34%. The proportion of people receiving an appointment within 13 weeks has also increased slightly, from 9.2% in April 2021, to 9.5% – but that still means that fewer than one in 10 patients were seen within three months in March.

If screening for Autism where to take place at key moments of a child's developmental life, regardless of the question of a child's underdevelopment, the screening for ASD would be more successful.

Also, currently the screening of Autism is not recommended as at the time of the last review, it wasn't known if screening would improve the long-term outcomes for children with autism.

If Autism is screened early in child development, then early intervention would be highly beneficial for the child. Although the idea that Autism in itself may not be a severe disability, because of the way an ASD presents itself in an increasingly socially conscious world, this can create friction within the relationships with the parents, the schools, the authorities, and with the child's own sense of self. An early diagnosis of Autism can prevent the following issues coming up in later life, as the following paragraphs are based on collective lived experiences of adults diagnosed later in life.

An unscreened child may be the subject to out-of-date and possibly neglectful parenting methods which can stump personal development from a young age.

With the right education and training, parents can learn how to communicate with their child and raise them constructively, without resorting to harsh punishments.

Even if an unscreened child proves high functioning enough for mainstream education, they are still subject to other school traumas. Although they may appear to be coping at school, autistic pupils can experience high levels of stress and anxiety. Often, their emotions remain bottled up until the end of the school day and released when they are at home. Families can see different behaviour at home to that at school and this can be distressing and even endanger families. If the triggers for this behaviour are not identified and addressed at school, it can lead to regular school refusal and mental health difficulties. The wrong teaching methods would also traumatise or trigger an undiagnosed child and create misunderstandings with the teachers and the school board, and could lead to the trauma of expulsion.

Children with autism are bullied three to four times as often as those without disabilities, including their own siblings: 40 to 90 percent of children with autism are bullied, compared with 10 to 40 percent of typical children, according to various studies. Many parents make the mistake of not screening their children because they believe labelling a child would make them a target for bullies. But even without a diagnosis, a child would still be subject to bullying due to lack of developed social skills and esoteric intelligence. An unscreened child may even come to mimic their aggressive environment and become the aggressor themselves, leading to incidents of violence on the school grounds, and more “correctional” styles of teaching which would confuse the unscreened child further.

Even the stress of school work can become enough to trigger aggressive meltdowns. Many teachers are not trained in working with Autism and thus wouldn't be able to tell the child has autistic traits, and may dismiss their behaviour as aggressive, rude, and disruptive.

With the right education for the school and the other children, a diagnosed child would be protected and supervised in a developmentally positive way.

If childhood intervention is not met, the unscreened child will develop into young adulthood where the expectations of a social life would become more stressful. Such early traumas would begin the development of mental illnesses such as anxiety and depression that can last a lifetime if the unscreened child is not given a channel to communicate with and have their feelings validated by a trained professional. Even if a child has learnt to unconsciously “mask” their unscreened autistic traits, the pressure to be social can still lead to a mental breakdown later on.

They will continue to experience new versions of bullying such as grooming. If they do become involved in group activity, they can still become victims of peer pressure and manipulation into early illegal activities.

This of course means more likely encounters with the police force. In a recent study of adolescents and adults with autism, researchers found that 16% of people with autism had an interaction with police during an 18-month period. The study found that while in almost half of the interactions the police response had a calming effect, in almost one-third of the cases the police response had the opposite effect. In 19% of police interactions, physical restraints were used, which would have made the meltdown of the unscreened person worse. In 30% of the cases, the person was escorted to an emergency department. Only two of the interactions resulted in criminal charges. But the study has found that people with less severe autism symptoms were as likely to interact with police as those with more severe symptoms.

If an unscreened person does enter into a relationship, they can still be subject to relationship abuse or even sexual abuse. A study has found that 9 out of 10 autistic women are victims of sexual assault, and that 56.28% of the victims were 15 years old or younger when they experienced the first instance of assault, with 67.8% of people aged 18 or younger. The overwhelming majority of autistic women, 75%, reported several experiences of aggression. In contrast to the frequency of abuse, a small minority of these people were able to file a complaint or receive care. If an undiagnosed teen has no healthy support network, or hasn’t been taught how to speak up against abuse, they would most likely never report such abuse.

Also, relationships with teachers and the school board would continue to diminish which would affect their final exams. Many autistic people struggle with major moments of transition such as the final days of school, which can lead to greater stress about post-school opportunities.

With a diagnosis, the school would be able to educate them further in safety and healthy sexual relationships and accommodate exam methods benefitable for them, and the authorities would have greater power to protect the underage child from further harm.

Moving into a more adult setting would continue to pose challenges to an unscreened person, such as finding ways to self-mediate feelings of stress and anxiety. Another study found that although autistic adults were less likely than non-autistic individuals to use substances like alcohol or drugs overall, autistic adults are 9 times more likely than non-autistic peers to report recreational drug use to manage symptoms of mental illness.

Obtaining employment can also be an issue. A recent report says that autistic people are the least likely to be in work of any other disabled group. Just 21.7% of autistic people are in employment. Yet through character development many autistic people have a strong drive and want to work. One mayor throwback is the interview screening process, which can be challenging when neither the employer nor the interviewee knows of an autism spectrum condition, leading to many misunderstandings. Even if an unscreened person does obtain employment, they can still be subject to harassments by colleagues and employers, or stationed in environments which can elevate unscreened stress and anxiety, which can lead to demotion or even a dismissal.

A diagnosis later in life although helpful would also create more issues as they would struggle to come to terms with a lifelong diagnosis, and need help accepting that their emotional, educational, and social needs have not been met. Research indicates that autistic people are more likely to report symptoms of PTSD. Although research has yet to establish clear prevalence rates, the rates of probable PTSD in autistic people (32-45%) are higher than those in the general population (4-4.5%). The risk of PTSD is higher for groups who are more likely to be exposed to traumatic events. Research indicates that autistic people may be more likely to experience traumatic life events, particularly interpersonal traumas such as bullying and physical and sexual abuse. In the general population exposure to interpersonal traumas and a lack of social support increases the risk of PTSD. If not addressed correctly with the right psychotherapy or medication, this can fuel further episodes of depression and anxiety. Such unresolved trauma could potentially make them reach crisis point with an admission to A&E or other crisis services. There is also the risk of being sanctioned, and being sent miles away from home into an unsuitable and unfamiliar environment for treatment which would only serve to traumatise them further.

Such extreme trauma would make them experience intrusive thoughts and even suicidal thoughts, thus increasing the risk of suicide. Researchers have found that 10% of people who die by suicide had evidence of elevated autistic traits, indicating likely undiagnosed autism. This is 11 times higher than the rate of autism in the UK. Autistic people are at an increased risk of suicidal thoughts and attempts, compared to non-autistic people. The exact numbers, however, remain unknown.

All in all, the above facts and figures presented mainly refer to people WITH an autism diagnosis, but an unscreened child will still be subjected to such maltreatment which can be more traumatising and create more problems without the benefit of a diagnosis to create a full picture of the situation. A diagnosis of autism at a tender age would help improve services for everyone in accordance with the Autism Act of 2009 and the UK government’s adult autism strategy, and shift accountability away from an otherwise vulnerable individual.

Another reason screening is not recommended is at the time of the last review it was believed that there is not an established approach to screening that is acceptable to the parents of the child.

Many parents avoid screening their children for an ASD partly due to outdated notions about autism and disability in general. They may believe that autism is caused by “bad parenting,” even though research has found that this is not the case, but certain generations of people may still be living with this belief. A parent’s circle may not even discuss this subject if not needed.

Until the 1980s, many people with autism were institutionalized, rendering them effectively invisible. Studies show that parents who are aware of autism's presentation by living near someone with the condition for example, are more likely to seek a diagnosis for their children than parents with no knowledge of the condition.

Parents may dismiss their unscreened child's behaviour as typical behaviour for their age, such as interpreting lack of eye contact as shyness. At meetings with professionals, they may also downplay the child's behaviour such as dismissing meltdowns as childhood tantrums.

Many parents under peer pressure themselves by parent circles and may focus on their child's strengths rather than perceived weaknesses.

A diagnosis of an Autism Spectrum Condition would help ease these pressures, and open the parents up for support and education about what Autism is actually about.

UK National Screening Committee

10.

UK National Screening Committee (UK NSC)

Screening for Autism spectrum disorder

Consultation comments pro-forma

Name:	Comments received on behalf of Neel Kamal, Ramla Mohammed and Janice Allister
Email address:	xxxx xxxx
Organisation (if appropriate):	Royal College of Paediatrics and Child Health
Role:	

Do you consent to your name being published on the UK NSC website alongside your response?

Yes

Section and / or page number	**Text or issue to which comments relate**	**Comment** *Please use a new row for each comment and add extra rows as required.*
Page 70	Case attrition, lack of long-term developmental follow up	Issues relating to currently available evidence do not satisfy the required criteria to include screening for early ASD. Lack of evidence if early intervention has significant benefit.
General		Young people with mental health conditions appearing in early adolescence or beyond seem increasingly to have autism being diagnosed as one aspect of their condition. We are grateful for the flexibility and support being offered by some schools and educational settings in respect of this.

General		The increasing prevalence of ASD and the emerging evidence of the efficacy of early intervention has focused attention for the need for early identification of young children of having ASD. Mounting research has shed light on limitations (concerns for risk bias, lack of blinding limited number of studies) gaps and uncertainties (Carbone et al 2020, Guthrie et al 2019, Yuen et al 2018). Large scale studies have also shown limitations in widely used screening tests such as M-CHAT, M-CHAT/R (Stenberg et al 2021, Stewart et al 2017). The questions to be addressed are: • How accurate are the screening tests for ASD? • What is the effect of interventions targeting young children identified with ASD, in short- and long-term outcomes? • Does screening for ASD in young children improve short- and long-term outcomes? • What are the potential harms of early screening? The rationale for screening and the conclusions derived from the above queries are that by screening and identifying ASD in early life especially before the critical age for language development enables the child to thrive better and have a good quality of life through EIBI (Early Intensive Behavioural Interventions) and other interventions. Given the importance of early detection, it is critical to understand the non-linearity in the manifestations of ASD before age 24 months, when ASD symptoms are beginning to consolidate through the age of 36 months, when stability of ASD diagnosis is reportedly high into school age when increased demands may challenge previously successful compensatory processes thus permitting first ASD detection. Studies suggest that ASD symptoms may emerge or attenuate over time with some children meeting diagnosis at follow up and others not meeting the diagnostic criteria.

General		Studies have concluded that the harms of screening for ASD and subsequent interventions are likely to be small based on the evidence about the prevalence, accuracy of screening and likelihood of minimal harms from behavioural interventions. The potential harms of early screening are misdiagnosis and the time, effort and anxiety associated with further testing. This is of particular concern when there is a delay in confirmatory testing because of resource limitations. Thus, all children should be screened with an ASD specific instrument during well child visits at ages 18 to 24 months in conjunction with developmental surveillance and broad band developmental screening.
General		We believe there is a critical need for validated and accurate screening tools for ASD in very young children (as challenging it may be), so that families can access tailored interventions as early as possible. Simple, safe, precise, and validated tests together with tools based on observation of the child by the parents could lead to improved estimates of sensitivity. More ongoing research is needed to better understand diagnostic stability and developmental trajectories associated with different patterns of ASD vs non-ASD and children with ASD vs their typically developing counterparts.