**Expression of Interest Children & Young People’s Autism Diagnostic Pathway Funding:**

**Expression of Interest Process**

**Purpose of the document**

This document is for NHS England & Improvement (NHSE/I) regional teams, Integrated Care Systems (ICSs) and clinical leaders who commission and provide local children and young peoples (CYP) autism diagnostic services. Its purpose is to:

1. Explain the new funding available to enable local innovations to autism diagnostic and post-diagnostic pathways for children and young people.
2. To help regions prepare Expression of Interests (EOI) for investing part of that funding.

**Within this document**

The following three sections are included in this document.

1. **An introduction** to the funding available and process for submitting an Expression of Interest for it.
2. **Innovation guidance** document outlining the issues and suggested solutions to making improvements across the key stages in the pathway process.
3. **Expression of interest submission form**.

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**Section 1**

**Context for the new funding**

**Service Development Funding (SDF)** – A small number of national programmes have been given the go-ahead to include SDF in allocations from Q1 as delivery of their Long Term Plan (LTP) work is entirely aligned with recovery from the pandemic. The Learning Disability & Autism Programme is in this category.

**Improving autism CYP diagnostic pathways are an NHS policy priority** –The NHS Long Term Plan is committed to improving the assessment and support of children and young people who may be autistic (page 53, paragraph 3.33). To help achieve this, NHSE has secured three years of front-loaded funding to enable regions to invest in changes to local assessment, diagnostic and post-diagnostic autism pathways.

In the first year, 2021/2022, regions will receive a combination of Long-Term Plan and Spending Review (SR) funding. This takes the allocated amount to 7 million in total across the 7 regions, which will be allocated on a targeted fair share basis. Funding for years two and three is 2.5 million per year which will also be allocated on a fair share basis.

NHSE’s new Autism Team have formed a workstream bringing together lived, clinical and scientific experts to scope out how these pathways differ, where they appear to fall short, and what may work in order to make them more accessible, effective and efficient. The *Innovation Guidance* within this document presents some of those learnings to support regions to decide how to invest the money available.

**Funding available**

|  |  |  |  |
| --- | --- | --- | --- |
| **1. Autism Diagnostic Pathways – Children and Young People** | | | |
| **Priority:** to improve the response for autistic children, young people and adults. | | | |
| Source of funding | SDF with extra Spending Review funding in Year 1 | Format of distribution | Targeted Fair Share at Regional level |
| Length of funding | 3 years, starting 2021-22 | Budget Group | Transformation |
| SRO | Claire Dowling | Lead Team | NHSEI Autism Team |
| Funding breakdown | Year 1 – £2.5m (plus £4.5 million SR funding)  Year 2 – £2.5 Million, Year 3 £2.5 Million | | |
| **What is this funding for?** | | | |
| To help local services attempt innovations to their pathways for providing autism diagnostic assessments and post-diagnostic support to children and young people. | | | |

Information about the EOI process is available in the next sections.

**Expression of Interest (EOI) Process**

This funding stream will be allocated through an expressions of interest (EOI) process.

1. NHSEI will share and agree EOI documentation with regions.
2. Regions will work with Systems to develop and submit EOI plans.
3. NHSEI will work with regional leads to agree and award fair share funding to systems based on the EOI returns.
4. Allocations will be made directly to lead CCGs for TCPs as appropriate.
5. The EOI documentation will suggest opportunities to improve diagnostic/post-diagnostic pathways, based on the scoping work the national autism team have been completing with lived, clinical and scientific experts over the last 6 months. It will also include an EOI template, to help systems consider what to include in their plans.
6. Systems will submit their EOI plans to Regional Teams in Q1 21/22 (June 2021).
7. Funding will be released by the end of July 2021. 7. Quarter two and quarter three 2021/2022: Implementation of investment projects and formal evaluation supported by national autism team.
8. There will be ongoing support and guidance from the national autism team with regions/local areas to discuss projects and to enable connectivity between systems and professionals.

Planning should be aligned across children and young people with a learning disability and/or autism, CYP mental health, special educational needs and disability (SEND), children and young people’s services, and health and justice.

**How this funding should be invested**

**This funding is intended for innovation**, to try out new ways of organising services/ pathways and see if that appears to improve outcomes and/or create efficiencies. This funding is not meant to bolster business as usual in autism diagnostic pathways. A COVID-inspired service innovation may be eligible, as long as the changes remain relevant and sustainable beyond the pandemic. Innovations will need to be underpinned by a strong clinical rationale, as it is acknowledged that not all of these will have already been widely empirically tested.

**Projects must be evaluated**. The Autism Team will help each region consider how best to evaluate the feasibility, acceptability and effectiveness of the changes made. Innovations are not guaranteed to work – the intention is to determine what changes are acceptable, effective and impactful, and potentially worth replicating in other areas.

**Projects can focus on any part of the diagnostic pathway** for people aged 0-25 (or a smaller age range); from initial identification of possible autism, referral for autism assessment, to the support children and families receive during and/or after assessment or diagnosis. Sustainable waiting list initiatives will also be considered.

**We strongly encourage you to be strategic**. You may choose to fund a series of innovations throughout the pathway or focus on a more substantial change to one end of the pathway. Similarly, you may focus investment on a single pilot location or this across many ICSs. We will not be critical of EOI proposals that decide to focus regional investment in testing out a major change to a limited part of the pathway. The accompanying *Innovation Guidance* suggests issues and topics to consider.

**Areas for Innovation**

**Assessment, pre-assessment support, diagnosis & post-diagnostic support are important** –If we get these pathways right, we can prepare the NHS and other public services to support young autistic people and their families before difficulties escalate; ensuring more people go on to live happier, healthier, longer lives.

NHS England & Improvement’s Autism Team are working with lived, clinical and scientific experts to identify potential ways of improving diagnostic and post-diagnostic autism pathways. The ***Innovation Guidance*** aims to help regions and services consider and plan where improvements are most needed and will benefit from this funding. The guidance focused on the following five stages of the pathway.

***Post-diagnostic support***

***Pre-assessment support***

***Surveillance   
& referral***

***Screening & triage***

***Diagnostic assessment***

**Training and workforce**

Training and upskilling the autism workforce is an important aspect of delivering a sustainable diagnostic service. Specialist autism professionals are few and we need to think innovatively about the wider workforce and ensure they have the competencies required to support the specialist teams, allowing them to focus on those individuals with the greatest complexity. The differentiated model of assessment identifies standard versus complex needs and allocates the skills of the autism and community workforce accordingly. Collaboration with other organisations such as Health Education England, the Department for Education, Third Sector and Research may be required to ensure a wide skill mix that supports cross boundary working.

**Section 2**

**Innovation Guidance**

**Purpose of this section**

NHSE & Improvement’s Autism Team have formed a workstream bringing together lived, clinical and scientific experts to scope out how these pathways differ, where they appear to fall short, and what may work in order to make them more accessible, effective and efficient. This guidance presents some of those learnings.

**Guidance on areas for innovation**

Based on discussions with autistic people, families, clinicians and researchers, we recommend focusing on innovating in one or more of these five components of the diagnostic pathway.

***Post-diagnostic support***

***Pre-assessment support***

***Surveillance   
& referral***

***Screening & triage***

***Diagnostic assessment***

**The processes through which children can enter autism diagnostic pathways differ across the country.** Local areas may use different criteria to determine those who should be referred for triage or assessment; local health and education professionals may be more or less confident and/or capable in making appropriate referrals; and local services may be more or less coordinated in monitoring for signs that a child is developing differently.

**1. Surveillance & referral**

**1.1 Areas for innovation**

**Introducing developmental surveillance** – As autism is a neurodevelopmental condition, the signs that someone may be autistic are likely to become more apparent as a young child develops. While there is evidence that some autistic traits can be identified at early ages, this can vary person-to-person.[[1]](#endnote-1) Regardless, there is often a significant delay between a parent first spotting differences in the way their child is developing and their child receiving a diagnostic assessment.[[2]](#endnote-2)

There is emerging evidence that universal developmental surveillance could potentially improve outcomes for children who are more likely to be autistic.[[3]](#endnote-3) Unlike population screening, this would involve systematically checking in with a child throughout the early years of their life to identify signs that they are developing differently to most children their age. Clinical tools,3 data sharing processes,[[4]](#endnote-4) and pathway models such as the, early identification of n*eurodevelopmental needs* study, commissioned by the Department for Education, exist or are being tested to help local health and education services introduce a more comprehensive surveillance of children’s development. EOIs could use these and other resources to develop an integrated local system of developmental surveillance.

**Standardising referral processes** – The information within referral letters to autism diagnostic services can vary widely between settings and health professionals. This can lead to referrals being rejected or accepted inappropriately; and can delay the diagnostic process while services gather additional information or ask families to retell their stories. ICSs could explore introducing standardised referral forms and information sharing processes to help relevant parties provide the information that diagnostic services will need to triage a child for a neurodevelopmental assessment.

NHS England & Improvement’s recent Deep Dives with autism diagnostic services suggest variation in the volumes of autism diagnostic referrals across the country; while research with GPs suggests key groups of clinical professionals may lack confidence in their ability and responsibility for identifying and referring people to autism diagnostic services.[[5]](#endnote-5) EOIs could include proposals to educate specific staff groups in what to look for, how to discuss observations with parents and how to make a useful referral (including what information to gather and include).

**Screening and triage are used to determine what diagnostic assessment(s) are most appropriate for an individual.** Referrals for an autism assessment may vary in quality, certainty and completeness of information. Screening tools are used by triaging professionals to streamline children into different pathways, dependent of the urgency of their needs or the apparent complexity of their presentation. Similarly, triage could be used to determine when it may be more appropriate to assess a child for other neurodevelopmental conditions, as well as, or instead of, autism.

**2. Screening & triage**

**2.1 Areas for innovation**

**Improving information sharing processes** – While strong surveillance and referral processes should enable swifter triage, there may still be occasions where diagnostic services need to gather additional information about a child or young person. In these instances, the timely sharing of comprehensive information between health, social care and education will be vital for reducing waits and improving family’s experience.[[6]](#endnote-6) EOIs could outline plans for how information sharing between services could be better managed, including integrated (electronic) record systems.

**Quality of triage** – As a key decision point in the diagnostic pathway, it’s important that triaging is robust. Decision making about what assessment a person does (or does not) receive, should be informed by considerations such as the range of neurodevelopmental, mental and physical health factors which could influence an individual presentation. ICSs, therefore may wish to consider what seniority of staff they would want conducting triaging appointments as well as what screening tools are used to support decision making. EOIs could also explore triage models involving two or more health professionals from different disciplines to enhance the expertise involved in formulation. In this case EOIs should consider what enablers (staffing, shared IT infrastructure, etc.) would help streamline the additional steps created within the triage process.

**Efficient triage planning** – It is important to ensure that triaging assessments do not become a congestion point in the pathway. ICSs could explore allocating new referrals to named professionals (similar to a key worker), to clarify responsibilities, and consider ways to organise triage waiting lists to deliver efficiencies. Similarly, EOIs could consider how to optimise the sequencing of standardised screening tools – which could be undertaken by various professionals – with triage appointments, whose timing may be limited by the availability of senior clinicians.

**Referral for an autism assessment should not preclude access to support** from other sources. Young people referred for an assessment may already have accessed support at school or via clinical services for difficulties or co-occurring conditions. Once on a waiting list, specific support may be offered by the diagnostic team.

**3. Pre-assessment support**

**Pre-assessment support could improve children and young people’s outcomes**. Waiting times can mean that the needs of children and young people remain unmet for long periods of time. Offering effective interventions, while a child is waiting for assessment, could improve their outcomes during and beyond the diagnostic process.

**Pre-assessment support could improve caregiver well-being**. Families often put their lives on hold while awaiting a diagnostic assessment and feel ‘stuck in limbo’ about their ability to access support. This can place further burden on parents’ ability to cope with challenges. Interventions that meet urgent support needs or improve families’ resilience while awaiting diagnostic assessments could be impactful.

**3.1 Key considerations**

**Pre-assessment support cannot be the same as post-diagnostic support**. Services do not have clear information about a child or young person’s neurotype when offering pre-assessment support. It’s therefore important that the interventions offered are those which would be delivered in the same way, regardless of whether the young person is autistic or not.

**Pre-assessment support could increase diagnostic waiting times.** If pre-assessment support is burdensome, it will draw staff time and other resources away from the diagnostic process. ICSs will need to consider how they balance the breadth and depth of pre-assessment support, with the speed and quality of the diagnostic assessment process, by considering the potential role of other agencies in supporting the child and family at this stage.

**3.2 Areas for innovation**

**Pre-assessment support could provide a set of low intensity individual or group interventions.** These could involve formal or informal peer support models with other young people or parents; access to diagnosis-neutral guided self-help interventions for common co-occurring difficulties; or regular check-in with a named professional in the diagnostic service to manage queries and concerns. EOIs taking this approach may want to consider what evidenced interventions would be considered *in scope* in the absence of information about a person’s neurotype and a more comprehensive assessment of their individual strengths and needs.

**Pre-assessment support could provide more holistic, personalised support.** In practice, ICSs could bring forward the needs and strengths assessment and tailored support packages described later in the post-diagnostic support section of this guidance. Resulting interventions could include supports for practical needs, such as eating and sleeping difficulties, or therapies for co-occurring conditions. EOIs taking this approach should consider what resources will be needed to deliver more intensive pre-assessment support; how it might impact on capacity in diagnostic services; how therapeutic decisions could be affected by the uncertainty of someone’s diagnosis; and how support packages would respond to changes is someone’s diagnosis.

**4. Diagnostic assessment**

**Autism assessment waiting times continue to be long**, while the nature and quality of assessment varies significantly. Key factors include the variability in commissioning arrangements, the availability of qualified and experienced staff, and year-on-year increases in referrals. NHS England has commissioned research into the optimal service delivery models of autism diagnostic pathways for children and young people.[[7]](#endnote-7)

**Currently, two types of services commonly assess for autism:** Child Development Centres (CDCs) or the Child and Adolescent Mental Health Service (CAMHS). Typically, CDCs are more likely to see children aged 0<5 with more general developmental delays, while CAMHS will receive referrals for children or young people aged 5> after issues are identified at home or school. For various reasons, CDCs and CAMHS have different skills mix and staff experience. Evidence suggests a child referred to CAMHS is unlikely to have access to paediatric or physical health checks as part of their assessment. Equally, a young child referred for developmental difficulties may not have access to a child psychiatric assessment in the CDC.

**4.1 Areas for innovation**

**Differentiated diagnostic pathways** –Autism diagnosticpathways are currently inflexible.Feedback from clinicians and researchers suggests that full autism assessment protocols may not be essential for every presentation at a diagnostic clinic.[[8]](#endnote-8),[[9]](#endnote-9) Instead it may be useful to implement a differentiated diagnostic pathway, to take account of varying levels of complexity of diagnostic referral (i.e., straightforward versus complex versus highly complex). This ensures pathways are as efficient as possible, that families are not over-burdened with excessive assessment, and that resources are not diverted from those with complex or highly complex needs.

EOI proposals should seek to identify key criteria for people having abbreviated, standard or complex assessments; and outline how to measure the acceptability and effectiveness of them (for example against measures of parental satisfaction and an expected balance of false negative and false positive diagnosis). They would also need to consider the content and protocols for the differentiated assessments, including the minimum level of Multi-Disciplinary Team (MDT) involvement.

**Integrated neurodevelopmental pathways** –There is emerging consensus that neurodevelopmental conditions among children should be diagnosed through an integrated pathway; particularly conditions like autism and ADHD which often co-occur and overlap in presentation.

Interested ICSs could consider what pathway designs would allow children, young people and families to move easily and quickly between specialists, to minimise unnecessary delays and the repetition of families’ stories. EOI proposals may also want to consider the integration of diagnostic pathways across CDCs and CAMHS.

**Quality of assessment** – For a differentiated pathway, EOIs should consider developing a standardised/manualised protocol of core components for the abbreviated assessment. Beyond a differentiated pathway, ICSs may benefit by identifying exactly what a good quality diagnostic assessment should include, such as every child seen by multiple professionals, decisions based on a combination of direct observation, screening for obvious differential diagnosis such as Obsessive Compulsive Disorder or social anxiety, clinical interview and collateral information from informants, MDT consensus diagnosis, etc.

**Commissioning and staffing** – Practically, EOI proposals should consider how new models of autism diagnostic assessments could be commissioned and who would deliver them. Depending on the nature of the assessment protocols, various professionals may participate at different stages, with appropriate training and supervision. To build capacity for sustainable practice, ICSs could also consider alternative ways to boost diagnostic capacity, for example by offering special interest sessions or placements to clinical trainees.

**5. Post-diagnostic support**

**Post-diagnostic support is our chance to make a diagnosis mean something.** The NHS and social care systems are traditionally set up to be reactive and treat problems. This can mean waiting until things go wrong before we start helping an autistic person and their family. This approach does not live up to the NHS’s ideals and is unsustainable. Autistic children now account for 95% of under 18s and 70% of 18-24 year olds in the Transforming Care cohort.

**We don’t need to wait for bad things to happen**. We already know many of the things that young autistic people are more likely to find difficult. Once we know that a child or young person is autistic, we can plan for the difficulties that person and their family are more likely to experience. Where we have safe and effective interventions that have been tested to prevent problems, we can offer them before those issues emerge or escalate.

**Improving post-diagnostic support may be the most impactful way to improve local autism pathways right now**. The regular lack of meaningful post-diagnostic support is an increasingly prominent source of dissatisfaction (and poorer outcomes) among parents, autistic people and professionals regarding diagnostic pathways. [[10]](#endnote-10),[[11]](#endnote-11),[[12]](#endnote-12),[[13]](#endnote-13),[[14]](#endnote-14),[[15]](#endnote-15) Compared to more developed parts of the diagnostic pathway, introducing changes to post-diagnostic support is likely to represent a more significant change to the status quo and so a greater chance to significantly improve outcomes.

**5.1 What an innovative model of post-diagnostic support could look like**

Post diagnostic support should be designed around an autistic person’s needs. The challenge is that autistic people have a wide variety of support needs that can vary greatly person to person. Designing a practical pathway model that can account for that diversity is difficult. We recommend a two-part approach:

* A “**core support package”** of well-evidenced interventions could be routinely provided to meet the most common/universal support needs.
* A “**tailored support package**” could then be created to meet the individual needs an autistic person may have, based on the results of an agreed strengths/needs assessment.

**5.2 What core support packages would involve**

**Core support packages would need to be standardised and narrow in scope** to ensure they are relevant to all (or almost all) autistic people. In practice this means providing interventions which are intrinsic to an autism diagnosis.

**Core packages would focus on Psychoeducation Plus programmes**; interventions which provide information about autism as a diagnosis, help people come to terms with their diagnosis, identify additional coping strategies for everyday challenges (such as managing difficult sensory environments or stigma) and provide opportunities to meet other autistic people who may have had similar experiences.

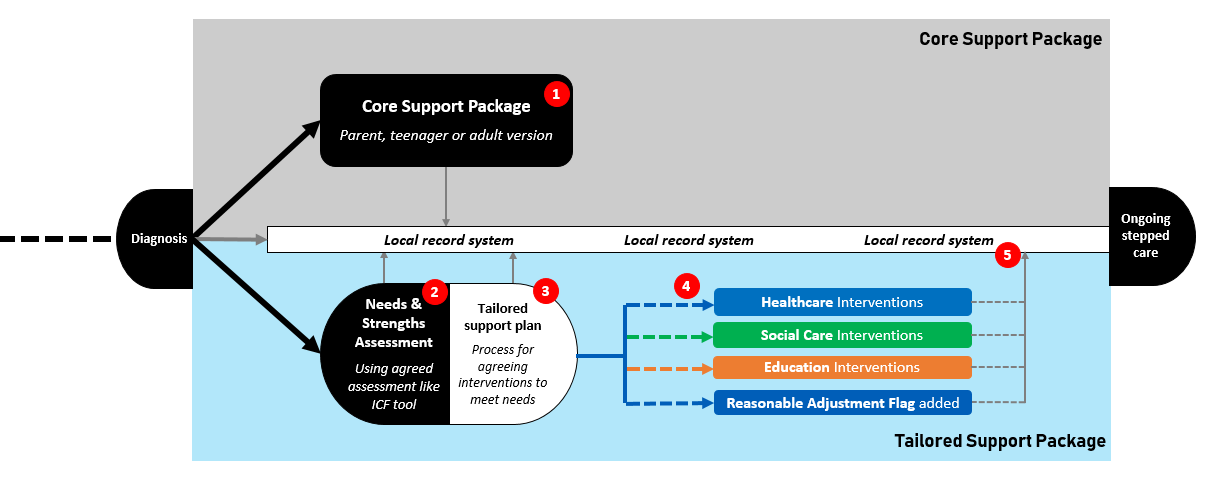
If there are well-evidenced interventions for difficulties that are core to autism as a diagnosis these could feature in core support packages. We are aware of only one therapy that meets the criteria set out in NICE CG170[[16]](#endnote-16) and has high quality evidence of being effectively improving social communication skills: PACT (the Paediatric Autism Communication Therapy).

* **Standards of evidence should be high** for interventions in core support packages, as they will be the most widely available support.
* **Different core packages should be available for individuals of different age groups, with options for individuals with and without a learning disability.** The most appropriate means of delivering psychoeducation to autistic teenagers and young children will differ greatly.

**5.3 What tailored support packages would involve**

**In contrast, tailored support packages will need to be personalised and broad in scope** to account for the diversity of needs an autistic person may have. In practice, this means providing a high-quality needs and strengths assessment which is recognised by local services and used to plan the interventions an individual is offered.

* **Needs assessments should be standardised locally**, so their outputs have a consistent format and can form a basis of a shared care planning system.
* **Standards of evidence may need to be pragmatic**. We lack well-evidenced interventions for many of the support needs autistic people are more likely to have. While national bodies and research funders work on closing those gaps, services may need to provide the *best available* interventions for acute support needs.

**5.4 Example post-diagnostic pathway**

For a pathway model like this, NHSE regions and ICSs may way want to consider:

**How core support packages are commissioned.** These may best be delivered by the clinical teams commissioned to provide the local autism diagnostic service (such as a Specialist Autism Team).

**Who delivers needs and strengths assessments.** Again, as an activity that should following naturally from receiving a diagnosis (and may utilise information from the diagnostic process), ICSs may want to consider increasing capacity in diagnostic teams to deliver this. Depending on the assessment used it may be possible for health professionals with different levels of seniority to lead on conducting them

**How interventions are agreed on in the tailored packages**. ICSs should consider what expertise will be needed to determine the best interventions to support strengths or difficulties that are identified. It may be possible to agree standing referral rules for some standard outputs of the needs assessment or it may require input from a multidisciplinary team, as is recommended for the diagnosis of autism.

**How support will be coordinated across different services.** It is likely that different services (across the NHS, social care and education) will be needed to meet identified needs. ICSs may want to consider whether dedicated staff (such as a keyworker) would help coordinate and track the delivery of an agreed *tailored support plan* across different services. These roles could also be responsible for adding a reasonable adjustment flag to a person’s record following the needs and strength assessment.

**How information will be shared across services.** ICSs could consider the optimal ways to ensure information about a person’s diagnosis, support needs, intervention plan, intervention history and outcomes is shared between relevant local services. Shared digital records infrastructure could address this issue or ICSs could focus on agreeing more manual processes to ensure information is passed between services.

**5.5 Resources available to help with innovations**

* ***Psychoeducation for parents of autistic children (0-10 years)*** – A [randomised control trial](https://fundingawards.nihr.ac.uk/award/17/80/09) testing a psychoeducation plus programme called EMPOWER-ASD will complete in 2023. In the meantime, some interventions with psychoeducation elements have evidence of acceptability and feasibility, although lack reliable evidence of effectiveness, including: [ACT](https://www.tandfonline.com/doi/abs/10.1300/J019v28n01_01), [ASCEND](https://journals.sagepub.com/doi/abs/10.1177/1359104509340945), [EarlyBird](https://journals.sagepub.com/doi/10.1177/1362361318760295), [Cygnet](https://daneshyari.com/article/preview/369975.pdf), [Stepping Stones Triple P](https://pubmed.ncbi.nlm.nih.gov/19023654/) and [Incredible Years](https://onlinelibrary.wiley.com/doi/10.1002/aur.2265).
* ***PACT for parents of autistic children (0-10 years)***– [PACT (the Paediatric Autism Communication Therapy)](https://www.pacttraining.co.uk/) is a non-invasive therapy that helps parents adapt to the distinctive ways an autistic child may play. It is currently the only social communication therapy that is demonstrated to be efficacious through high quality Randomised Control Trials.[[17]](#endnote-17),[[18]](#endnote-18) This could be a component of a core support package for autistic children aged 0-10, alongside psychoeducation for parents.
* ***Psychoeducation for young autistic people (10-16 or 10-18 years)*** – NHS England has commissioned Autistica and King’s College London to run a small scoping project to deliver evidence-led recommendations about psychoeducation for young autistic people. The results of this project are due in Spring and can be made available to ICSs innovating in this area.
* ***Incorporating strategies for coping with stigma*** *–* NHS England has commissioned a scoping project from University of Bedfordshire to make recommendations for incorporating evidenced strategies to manage stigma into core post-diagnostic support packages. The results of this project are due this Spring and can be made available to ICSs innovating in this area.
* ***ICF strengths & needs assessment tool*** – In 2019, an international research programme synthesised previous studies and the views of autistic people, parents, caregivers, clinicians and researchers, into lists of factors most likely to be enabling or disabling for autistic people.[[19]](#endnote-19) The *ICF Core Sets for autism* and *ADHD* are now being developed into a practical needs and strengths assessment tool. An initial English version of the tool ready by the end of Spring and the researchers are open to piloting the tools with NHS services. NHS England can help facilitate discussions between interested ICSs and the Karolinska Institute in Sweden.
* ***Other formats of needs and strengths assessment*** *–* NHS England has commissioned a small project from the University of Bath, to scope existing approaches to assessing autistic people’s support needs. The results of this project are due this Spring and can be made available to ICSs innovating in this area.
* ***Models of enduring support*** – NHS England has commissioned the University of Manchester to scope the components of care systems that could effectively meet autistic people’s developing and enduring support needs**.** The results of this project are due this Spring and can be made available to ICSs innovating in this area.

**6**. **Innovations to support sustainable waiting list management (including short-term and longer-term solutions)**

* ***Pilot a non-autism-specific early needs-led triage*** to identify needs; decide whether full autism assessment is needed and to ensure diversion where appropriate
* **Staffing & resources:** Identify and evaluate impact on waiting times through increased staffing and innovative use of resources, such as: (i) expand current wte roles within service where possible; (ii) utilise skills within partner/local/independent organisations (e.g., PHD students experienced in ADOS-2); (iii) develop hub and spoke model with local mental health provider services to prepare referrals for full assessment by conducting standardised developmental history/ADOS-2. In return the providers receive autism training and CPD for their mental health staff.
* **Benefit from use of standardised collection of developmental history** at an early stage to inform pathway and likely level of autism assessment, e.g., abbreviated vs complex assessment.
* **Paper-based review of clinical cohort (those who did and did not receive a diagnosis of autism)** to establish key indicators of likely autism diagnosis and to inform a triage protocol that reduces inappropriate referrals
* **Pilot innovative pathway processes** such as reducing time-intensive diagnostic reports through digitalising processes and providing families with online portal from point of referral to post-diagnosis (e.g., Silvercloud)
* **Pilot use of autism champions in** mental health settings to help triage referrals from secondary care to an autism service.

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    Autism statement of support

    NICE is aware of on-going work to develop new ways of working within autism services to support partnership working across health, social care and education to strengthen multi agency approaches.

    NICE’s new five-year strategy highlights the need to develop timely recommendations on innovations that have a real impact on people’s lives and on the delivery of health and care services, while representing good value for the system.

    This includes setting clear expectations in conjunction with system partners on the use of NICE guidance.

    Clinicians are asked to use NICE’s recommendations alongside their own clinical judgement and shared decision making with their patient. Following our guidelines should not be a barrier to service innovation.

    **Section 3 – Submission Form**

    **Purpose of the document**

    This template form is intended to help NHSE/I regions, or an ICS on behalf of an NHSE/I region, prepare a draft EOI proposal to be shared with NHS England & Improvement’s Autism Team.

    We recommend using the ***Innovation Guidance*** and***Expression of Interest Process*** documents to help complete this form.

    If you have questions about the EOI form, process or guidance, or would like to discuss initial ideas for an EOI proposal with NHS England & Improvement’s Autism Team please do not hesitate to can contact:

    *Sheriden McKiniry – Programme Manager, NHS England Autism Team*[*Sheriden.mckiniry@nhs.net*](mailto:Sheriden.mckiniry@nhs.net) *| 0782 524 4772*

    *Edward Smith – Policy Development, NHS England Autism Team*[*edward.smith13@nhs.net*](mailto:edward.smith13@nhs.net) *| 0777 192 1017*

    |  |  |  |  |
    | --- | --- | --- | --- |
    | **About** | | | |
    | NHSE/I Region: |  | | |
    | ICS(s) in proposed project: |  | | |
    | Project Title: |  | | |
    | Lead contact name: |  | Telephone:  Email: |  |
    | Lead CCG:  *\*Required for transferring funds* |  | | |

    |  |  |
    | --- | --- |
    | 1. **Scope of your proposed project** | |
    | 1. What stage (or stages) of the autism diagnostic process will your proposed service changes focus on | |
    | Surveillance & referral | Screening & triage |
    | Pre-assessment support | Diagnostic assessment |
    | Post-diagnostic support | Other (please specify): |
    | 1. What age groups of children and young people will your proposals cover? *(up to 200 words)* | |
    |  | |
    | 1. What geographies will your services in your proposed project cover? *Please list the ICS, CCG, local authority or other significant commissioning boundaries.* | |
    |  | |
    | 1. What organisations would be partners in the proposed project? *Please list the organisations (CCGs, NHS providers, schools, third sector bodies, etc.) and very briefly describe their role/involvement in the project*. | |
    |  | |

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    | --- |
    | **2.Description of proposed project** |
    | 1. Please give a brief summary of what your proposed project is *(up to 300 words)* |
    |  |
    | 1. Please describe the reason for the project. *(up to 600 words)* *What is the ‘problem’ this proposal is intended to address?*  *Does the ICS/geography know of specific local challenges that the proposed changes are intended to help address. For example: long waiting times, poor parent satisfaction, inappropriate referrals, unusual or inconsistent rates of diagnosis, poor outcomes following diagnosis, a lack of post-diagnostic support, etc.* |
    |  |
    | * 1. . Please describe your proposed changes. *(up to 2000 words)* *What will the new pathway/service structure look like? How will that differ from the previous pathway (if applicable)? What service models, interventions or tools will be key to the new approach?* |
    |  |
    | *2.4.* What are the major ways in which your proposed pathway will differ from existing service offer? *(up to 500 words)* |
    |  |
    | 2.5 How will the proposed changes integrate with other parts of the diagnostic pathway? *(up to 500 words)*  *Are different organisations involved in delivering proceeding or succeeding sections of the pathway? How will information about the autistic person or family be shared with the next part(s) of the pathway?* |
    |  |

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    | --- |
    | **3. Evaluation of the proposed innovations**  *Evaluation is required as innovations are not guaranteed to work and we need to determine what changes are impactful and worth replicating in other parts of the NHS.*  *This section is intended to help regions, ICSs and NHSE/I consider how best to measure that. These questions are intended as an initial planning aid, so you will not be held to what you write in response to these questions but to the contents of your final plan agreed with NHSE/I.* |
    | What would “success” look like for this project? *(up to 500 words)*  *Would success mean:*  * *Improvements in autistic children or parents’ mental wellbeing following diagnosis?* * *Improvements in other specific outcomes following diagnosis.* * *Improvement in parents/young peoples’ satisfaction with the diagnostic process?* * *An increase in the number of young autistic people with education, health and care plans?* * *A reduction in waiting list or times for diagnosis?* * *A change in the number or source of referrals to an autism diagnosis?* * *A change in the proportion or number of children diagnosed as autistic?* * *A reduction in the average age of diagnosis?* * *Something else…* |
    |  |
    | 1. Do local services routinely collect data at key points e.g. that could help track the desired outcomes or outputs of your proposed changes? *(up to 500 words)* |
    |  |
    | 1. Do any other areas have a similar pathway to your existing (pre-innovation) service offer, that could act as an informal control for your changes? *(up to 500 words)* |
    |  |
    | 1. How could you measure whether the new service arrangements are acceptable to those (e.g. health professionals) who will deliver them? *(up to 500 words)* |
    |  |
    | 1. How could you measure whether the new service arrangements are acceptable to those (e.g. autistic people or parents) who will receive them? *(up to 500 words)* |
    |  |
    | 1. What practical issues are most likely to make it unfeasible to deliver (or continue delivering) the proposed service arrangements? *(up to 500 words)* |
    |  |
    | 1. Do you have access to a Research & Development Team or Quality Improvement Team who could help with developing methods of evaluation? *If so, have you contacted that Team and what did they recommend?*  *(up to 500 words)* |
    |  |

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    | --- |
    | **4. Initial financial breakdown**  *At this stage we do not expect a detailed financial plan.* |
    | 1. Overall, how much do you anticipate will be needed to deliver these proposals? *If possible, please present a rough estimate for individual financial years (2021-22, 2022-23, 2023-23). Individual projects do not necessarily have to run for all three years.* |
    |  |
    | 1. Please provide any additional detail you can on the major costs involved in delivering the change in pathway/service model? *What would the major items of expenditure be?*  *Who would be funded to do what (if known)?*  *Do your proposals include costs for an independent scientific evaluation?* |
    |  |

    |  |
    | --- |
    | **5. Co-production of the proposed project** |
    | 1. How have/will autistic people and families be involved in the development of your proposed pathway changes? *(up to 300 words)* *Have you consulted on proposed changes? Would these changes be part of a wider locally agreed plan? Have you considered forming an advisory group for the project that includes autistic people and families with relevant experience of local pathways?* |
    |  |
    | 1. How have/will clinicians and other professionals be involved in the development of your proposed pathway changes? *(up to 300 words)* |
    |  |
    | 1. How have/will scientific or other experts be involved in the development of your proposed pathway changes? *(up to 300 words)* |
    |  |

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    | --- |
    | **6. Pandemic planning**  *We do not expect regions or ICSs to be able to provide plans for all the eventualities that COVID-19 and resulting restrictions could bring. This section is intended to help prompt thinking about how any particularly high risks might be mitigated for.* |
    | 1. What are the most likely ways (if any) that the pandemic could affect the delivery of your proposed changes? *(up to 300 words)* *E.g. If you must delay changes, would you lose money covering the salaries of staff allocated to this project?* |
    |  |
    | 1. What could be done to prevent or mitigate the impact of those risks on the overall feasibility or impact of your project? *(up to 300 words)* |
    |  |

    [↑](#endnote-ref-19)