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Five-year NHS autism research strategy for England

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Contents

Introduction

Autism is not a rare condition (about 1–2% of England’s population is autistic).[1,2] Autism should not bar anyone from a happy, healthy and long life; yet relative to their non-autistic peers, autistic people frequently experience the following:

- **More mental ill-health.** Autistic people have higher rates of almost all mental health conditions when compared with non-autistic people; for example, attention deficit hyperactivity disorder, oppositional defiant disorder, anxiety disorder, disordered eating, mood disorders or personality disorders.[3,4]

- **Greater likelihood of poor physical health and/or disabilities.** Autistic people are more likely to have cardiovascular conditions,[5] epilepsy,[6] a physical disability or a learning disability.[7,8]

- **More and/or broader determinants of poor health.** Autistic people are more likely to be underemployed[9], live in inadequate housing[10], experience stigma and discrimination[11], be obese,[12] be physically inactive,[13] or to have restricted and undernutritious diets.[14]

- **Greater difficulties accessing care.** Accessing an autism diagnosis takes too long and the system is adversarial.[15,16] Access to, and quality of, both diagnostic assessment and post-diagnostic support is also regionally inconsistent.[17,18] Autistic people often struggle to access general health services because of providers failing to accommodate their sensory sensitivities, communication difficulties, anxiety, or poor planning and organisational skills, further compounding their already poor outcomes.[19]

- **Shorter life.** Sadly, we now know that autistic people, on average, die younger than their non-autistic counterparts. For autistic people without a learning disability, a leading cause of early death is suicide with the highest rates among those not diagnosed until later life. For autistic people with a learning disability, the leading cause of early death is epilepsy. [20,21]

Most autistic people have multiple co-occurring long-term conditions which underscores the importance of not only improving autism-specific services but of improving care for autistic people across all health and care services.

The typically poor outcomes experienced by autistic people, described in brief here, are not acceptable. These poor outcomes remain despite the total estimated societal lifetime economic cost of supporting autistic people being higher than for cancer, stroke and heart disease combined.[22] These poor outcomes remain despite an increasing number of public policies committing to improving autistic people's lives throughout the last decade. These outcomes can be improved if more policies are backed by reliable evidence.

We must build an evidence-based healthcare system that systematically and incrementally reduces the health inequalities to realise autistic people's equal rights to happy, healthy, and long lives.

Policy context

The Autism Act (2009) prompted the publication of successive adult autism strategies in 2010 [23] and 2014.[24] In 2018, following alarming evidence that autistic people were at greater risk of dying early,[25] the Department of Health and Social Care (DHSC) refreshed the then current strategy to make improving autistic people's life expectancy an overarching health policy objective.[26] In 2021, the adult autism strategy was replaced by the national strategy for autistic children, young people and adults.[27]

In 2015, NHS England, the Local Government Association and Association of Directors of Adult Social Services published a national plan called Building the Right Support[28] to address instances of poor and abusive care of people with a learning disability and autistic people in mental health hospitals. It directs efforts to improve the quality of community care and to reduce the reliance on mental health inpatient care for autistic people and people with a learning disability.

In 2019, NHS England and NHS Improvement took on a more focused role in autism policy following the inclusion of autism as a clinical priority in the NHS Long Term Plan, and in 2020, formed a national autism team to drive improvements in autistic people's health.

The policy documents listed above and associated funding may or may not be effecting positive change, but for us to be confident in the outcomes of these policies, they need to be underpinned by research evidence and evaluated with health information systems. Policy changes and clinical guidelines should always be rooted in evidence and routinely evaluated to ensure real-world impact on improving health care for autistic people.

This document sets out a five-year strategic plan for anyone with a personal or professional stake in improving health services for autistic people in England. This is a plan to improve the generation and use of high-quality evidence to improve autistic people's physical and mental health.

Information systems

One challenge when trying to improve health care for autistic people has been the availability and use of health information systems. For the commitments articulated in these successive autism policy documents to be effective they must be turned into practical steps and implemented in a wide variety of health settings in every area of the country. For professionals and policy makers to determine if investments made by the NHS are effective at achieving their intended purpose, information about the health of autistic people and their use and experience of health services needs to be routinely collected and reported.

To support this and in parallel to this strategy, NHS England and NHS Improvement will publish an autistic people's health information strategy which seeks to ensure that we routinely use nationally collected data to document changes in autistic people's health and their use and experience of services.[29]

The use of health data as described will improve our ability to identify when a service, policy initiative or intervention is working, represents value for money and may warrant further investment. Increased data analysis will also allow us to determine whether services are underperforming, if policy initiatives fail to yield positive results and when interventions are not (cost) effective.

Research evidence

A related but separable challenge to improving healthcare for autistic people is the extent to which improvement efforts are backed by science. This is a two-part issue, first, relevant, high-quality evidence must exist, second, this evidence must be applied judiciously when healthcare decisions are taken.

The NHS Long Term Plan emphasised "the critical importance of research and innovation [...] to drive future outcomes improvements". It also set out the ambitious goal of ensuring all autistic people can live “happier, healthier, longer lives”; a vision shared with Autistica, the UK's leading charitable autism research funder, who supported the development of this strategic plan.

Why a research strategy is needed

Change is needed to ensure health policy and clinical decisions about the care provided to autistic people is consistently based on the best available scientific evidence.

Subjective belief, of professionals, commissioners, clinicians, patients or advocates, irrespective of its provenance and no matter how principled, provides an insufficient justification for policy or clinical decision making.

Moreover, changes to the healthcare system are often driven by political urgency which can result in decisions that preclude the possibility of meaningfully evaluating the effect of those changes (eg assigning all patients to a treatment, not allowing random assignment, commissioning inappropriate evaluation method, etc.).

The need for urgency should not be used as a justification to act without adequate evidence, especially when those actions may hamper the ability to generate evidence in future.

Co-ordinated and strategic action is needed to improve our ability to act with urgency without undermining our ability to measure the effectiveness of healthcare changes made. This research strategy sets out the first steps that need to be taken to build better evidence-based healthcare for autistic people in England.

The aims of this strategy

1. Determine which areas of NHS autism service provision in England are based on reliable evidence and which areas require further research.
2. Ensure there is a better fit between the evidence produced and the evidence gaps in the NHS in England.
3. Facilitate the use of the best current evidence when making decisions about autism services provided by or paid for by the NHS in England.

4. Improve the mechanisms to robustly evaluate the effectiveness of policy and funding decisions about NHS-provided healthcare for autistic people in England.

Evidence-based healthcare

The NHS, through the NHS Constitution, is committed to providing every member of the population with health and care that is safe, effective and, where possible, tailored to individual needs. This includes a commitment from the NHS to provide the best value for taxpayers' money. Finally, the NHS Constitution represents a binding commitment to the promotion, conduct and use of research to improve the current and future health and care of the population.

To fulfil its duties outlined in the NHS Constitution and its responsibilities to meet autistic people's right to a happy, healthy, long life the NHS and the organisations with a remit in public healthcare must ensure services for autistic people are run based on the principles of **evidence-based practice, evidence-informed practice,** and **evidence-based health policy.**

Each concept is explained below followed by a plan for the actions that need to be taken over the next 5 years to successfully build an evidence-based healthcare system for autistic people in England.

Evidence-based practice

"Evidence-based practice requires that decisions about health care are based on the best available, current, valid and relevant evidence. These decisions should be made by those receiving care, informed by the tacit and explicit knowledge of those providing care, within the context of available resources".[30]

Critically, evidence-based practice relies on the availability of scientific evidence that is rigorously obtained in a manner that controls for the biases intrinsic to anecdotal experience.[31]

Research methods are not all equal in the extent to which they control for bias or in their usefulness in evidence-based practice. Science is a process that involves first making observations, then formulating a theory or hypothesis, followed by making testable predictions based on that hypothesis and then testing those predictions. This is an iterative cycle, when predictions are not supported hypotheses and predictions may need to be reformulated and re-tested.

When predictions are supported, we need to test if the findings can be reproduced or extended to incrementally increase our knowledge and confidence. “Best current available evidence” in evidence-based practice therefore refers to the accumulated scientific literature on a given subject and not a single paper or finding. Several systems have been created to place levels of evidence into linear hierarchies from most to least robust for use in evidence-based practice, for example, the Oxford Centre for Evidence-Based Medicine created Levels of Evidence.

Accordingly, the most compelling evidence, on the basis it provides the most robust protection from bias, is a high-quality systematic review of well-conducted randomised controlled trials (RCTs). Formal structures exist for converting systematic reviews of evidence into clinical practice guidelines, such as Cochrane Reviews and National Institute for Health and Care Excellence (NICE) guidelines. The least robust level of evidence, on the basis it can never be free from bias, is the opinion of clinical or lived experts.

Some limitations of evidence-based practice are worth considered attention as they apply specifically to the care of autistic people:

1. Despite enormous growth in the volume of academic papers published about autism over the past 20 years, there remains too little research generating or testing hypotheses about what services work for whom, when, in which contexts and in what doses.[32,33] Yet, a majority of research funding has focused on generating and testing hypotheses about the fundamental biology and genetics of autistic people.[34]

2. Presently most autism research studies produce a level of evidence that does not reach the quality threshold required to influence clinical guidelines, either because of methodological weakness[35] or because researchers involved have (often undeclared) conflicting interests.[36,37]

3. Most autistic people are diagnosed with more than one condition and clinical guidelines do not always provide guidance for care decisions in such cases.

4. Autism is a relatively prevalent and lifelong condition which can attract attention from vested interests.[38]

5. While autism is a clinical diagnosis it is also an intrinsic identity trait which intersects with other aspects of a person's social, cultural, and economic situation. That means being autistic is not something that requires a cure; nor do autistic people necessarily seek a reduction in the core traits of the condition.

Consequently, we lack succinct evidence-based guidelines for certain clinical indications common for autistic people and existing autism guidelines may lack detail about recommended interventions and supports. Individual busy clinicians do not have the skills or the time to supplement incomplete clinical guidelines with their own reading of the literature, not least because of the quantity of low-quality autism evidence described in the literature.

Care may not be provided by the health service for many common clinical needs which creates space for untested and potentially unsafe alternative and complementary autism therapies to proliferate.[39]

For autism care to be both comprehensive and evidence-based, we need more RCTs with enough statistical power to determine if a given intervention is safe and effective.

Some assumptions of evidence-based practice do not always hold in relation to autism, for example, that there is always a true effect, that it can always be reliably measured, and the methodological rigour of a study dictates its usefulness. Instead, complex adaptive systems theory may sometimes be a more appropriate framework to make decisions about autistic people's health using diverse sources of evidence available to inform practice decisions about whether a certain course of action will likely produce positive outcomes.[40]

Evidence-informed practice

As outlined above, one shortcoming of evidence-based practice is that it is not well suited for determining cause and effect in a complex system where dynamic processes and static factors interact, adapt, and co-evolve in an interdependent relationship.[35] Complex systems are hard to define, the boundaries between individual components are unclear and they behave in ways that are unpredictable and their properties are not always neatly measurable.

One source of complexity is the make-up of the intervention itself. Interventions can be simple (ie they have one active ingredient that does not change) or complex (they may have multiple active ingredients that can interact and change).[41,42]

The target that an intervention seeks to change can also differ with respect to complexity, some interventions aims to change an outcome for an individual patient and others may seek to change the behaviour of an entire professional discipline or the structure of a healthcare service, for worked examples see Table 1.

Table 1: Examples of simple and complex interventions

Intervention target	Description	Example intention of intervention
Simple interventions		
Individual patient care	An action where one component causes a change in one outcome	Medication reducing anxiety significantly more than a placebo
Complex interventions		
Individual patient care	Several interacting actions taken between a professional(s) and an individual or group that causes a change in one or several outcomes	Cognitive behavioural therapy significantly reduces panic more than a placebo or control condition for autistic people
Organisational or service modification	An action or actions taken to change something about an organisation of people involving several interacting components between the people changing the organisation, the people running the organisation and the patients ultimately receiving care from the organisation	A new appointment scheduling system saves clinician time and in turn reduces the waiting time for a diagnosis
Health or care professional	An action undertaken with a specified group of professionals to cause a change in the way that group of professionals provide care to patients. This type of intervention relies on several interacting components from the person undertaking the action, the individual professionals receiving the intervention and the wider context in which they practice	A one-day autism training course for all healthcare professionals to improve staff knowledge and confidence in caring for autistic people to increase provision of reasonable adjustments for autistic patients across the NHS
Population	Intervening with a whole population to cause a specific change	A national communications campaign to improve public knowledge about autistic people to reduce stigma

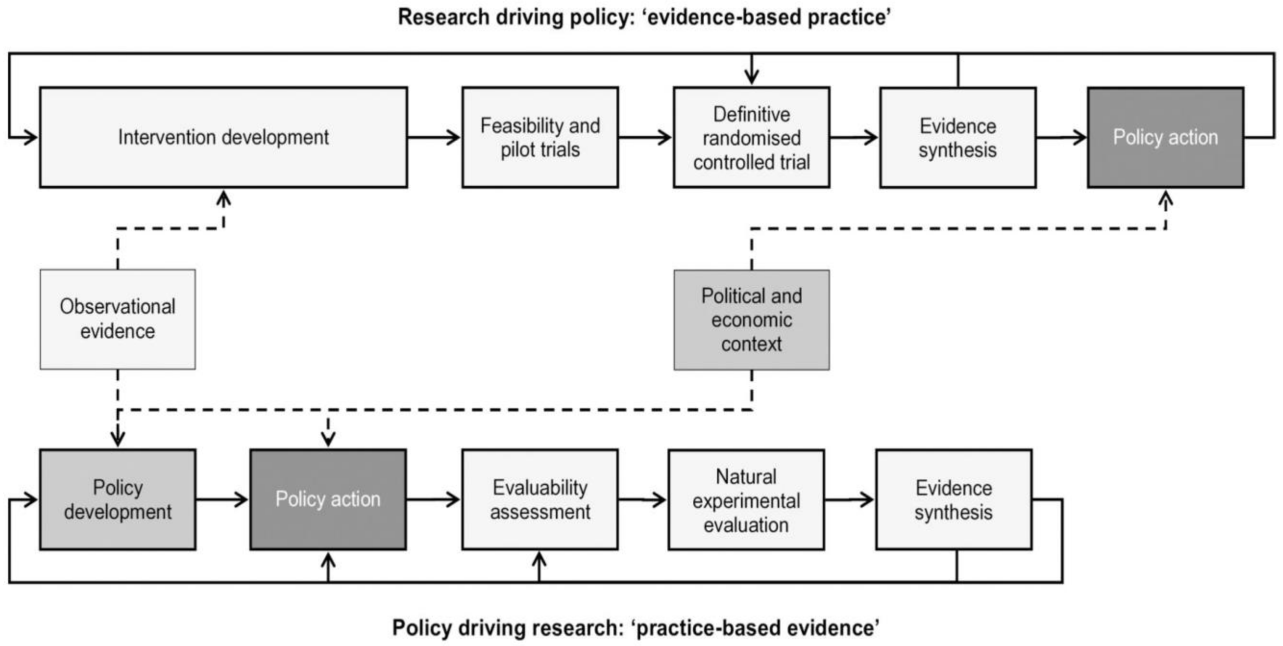
In addition to complexity as a feature of an intervention, complexity is also a feature of the system in which interventions are delivered. This means that the system in which an intervention (eg providing training to all staff in a hospital) is made will interact with its context (eg pre-existing beliefs about the usefulness of training, staff baseline knowledge about the topic and the openness to change culture within the hospital). These interactions should not necessarily always be controlled for in RCTs, they need consideration to determine the overarching effect of an intervention as it happens in the real world.

A challenge deciding when practice should be based on or informed by evidence remains for autism policymakers. Better integration of research and practice is needed to develop skills in both communities to ask better clinical research questions that increasingly clarify the appropriateness of evidence-based practice or evidence informed practice to a given context.

Evidence-based health policy

Just as clinical decisions ought to be backed by robust evidence, we must also ensure policy decisions are too. Evidence-based health policy refers to efforts to ensure policy is based on evidence (evidence-based practice) or policy actions are robustly evaluated (practice-based evidence), see Figure 1 for a schematic of both pathways.

Figure 1: Ogilvie et al.[43] models of evidence-based practice and practice-based evidence. Reproduced under CC-BY-4.0 licence from authors' original.



An example of the evidence-based practice pathway described here would be where an intervention is developed for a specific population (eg a language skill intervention for pre-school children) with the intention of improving a specific outcome (functional communication skill), it is found to be feasible to deliver and to trial. A trial, large enough to be definitive, is then conducted and shows it improves the target outcome, this finding is independently reproduced and then a policy is written to make the intervention nationally available to everyone in the target population.

An example of the practice-based evidence pathway described here would be an instance where action is taken that is driven first and foremost by a policy decision (eg nationally commission the roll out of a service) before the effects of that action on the intended goals (eg to increase patient discharge) have been empirically and definitively demonstrated so an evaluation is also funded. For this to reach the criteria of evidence-based policy, both the policy itself and its evaluation must be executed in such a way so as to be able to determine if the changes made result in the progress sought.

To determine if a health policy is evidence-based the policy itself must meet three essential characteristics, detailed below.[44]

1. **Policy must be well specified.** Policy documents must be specific enough to determine if they are producing the precise and specific changes they were intended to produce. This includes providing enough information to meaningfully situate what targets a policy is designed to achieve, which may be complex and nuanced. Brief slogans and coarse numerical targets are rarely specific enough to achieve this.

2. **Policy goals must be clearly articulated.** Distinguishing between policies and their goals is required because a single policy may have many effects, it could make some outcomes worse and others better, it may have a large effect on one outcome but a small effect on another. Articulating the specific goals and the relative merits of differing goals intended by a policy are both critical steps when appraising the effectiveness of a policy.

3. **The magnitude of effects of the policy on these goals must be measured.** Collecting anecdotes or self-reflecting on a policy cannot be used to measure its effect. Measuring the effectiveness of a policy is an empirical exercise and it must involve quantifying the size of the observable changes resulting from the policy to inform appraisals of whether and how far the policy achieved its goals.

General principles

The principles below should guide work undertaken in service of this strategy.

1. Make a future together

All stakeholders in autism research (ie autistic people, parents/carers and other family members, researchers, professionals, commissioners) must be meaningfully involved and engaged in the research process.[45]

There are many forms of engagement (eg a researcher informing or consulting a person or group on a topic) and involvement (eg when a researcher, autistic person, parent/carers and clinicians collaborate or jointly decide what actions to take) in research. Different formats should be used to suit situations and contexts.

It is important to note that co-production and public involvement/engagement are not alternatives to research evidence. Instead they are an ethos with specific methodologies that should be employed to design inclusive studies[46] and interventions, and to select outcome measures that respect the need to balance the views of experts by experience on what good outcomes are and the scientific evidence about what works.

2. Embrace complexity

The autism evidence base needs to reflect the diversity of the autistic community.[47]

Autistic people often have co-occurring conditions: for example many have a general learning disability or specific learning disabilities (eg dyslexia or developmental co-ordination disorder), mental health conditions (eg depression or anxiety), physical health conditions (eg epilepsy) or any combination of these. We must move beyond excluding people with multiple conditions from research. To ensure everyone is represented in our research evidence, we will sometimes need to include people with multiple co-occurring conditions in studies and we will sometimes need to conduct studies that focus on specific subgroups of the autistic population.

Similarly, we must consider how generalisable evidence is to all subgroups in the community: socioeconomic, ethnic, faith, sex, gender or cultural group

Autism is a developmental condition so we must build a developmentally phased evidence base to understand people’s needs and to test the effect of interventions at different ages.

Strategic action to be taken

The following section focuses on the actions to be taken to increase the extent to which evidence-based healthcare is provided for autistic people in England.

1. Build an evidence culture in NHS autism services

a. **Appoint a national autism research team at NHS England and NHS Improvement.** This team will be responsible for implementing the actions outlined in this strategy.

b. **Ensure plans to achieve the autism-specific NHS Long-Term Plan commitments are informed by evidence.** The national autism research team will support the use of evidence in efforts to achieve progress against the NHS Long-Term Plan autism commitments.

c. **Establish a research advice clinic.** The national autism research team will run regular drop-in clinics for people involved in national autism policy making or local commissioning of services for autistic people or people with a learning disability. The clinics will be an opportunity to seek advice about:

    - Commissioning a review of existing evidence.
    - Using evidence syntheses to inform policy decisions or service design.
    - Building the evidence base for a specific intervention.
    - Supporting the apportioning of resource to evaluation when policy decisions are taken without appropriate supporting evidence.
    - Finding appropriate research experts to advise.

d. **Run research and evidence workshops.** The national autism research team will increase research and evidence literacy among everyone employed within NHS England and NHS Improvement's learning disability and autism programme. The workshops will aim to increase understanding about the importance of and practicalities of building evidence-based autism healthcare.

e. **Support autistic people and their advocates to ask for the evidence supporting their clinical care decisions.** The national autism team will work to encourage autistic people and their advocates to ask for the evidence being used by the clinicians providing their care. Clinicians will be supported to be transparent when evidence is currently limited to increase awareness for the need for new experimental supports.

f. **Appraise the evidence supporting existing national autism initiatives.** The national autism research team will act as research ambassadors and will foster an evidence-oriented culture within the Learning Disability and Autism Programme at NHS England and NHS Improvement.

2. Appropriate funding for autism research in England

a. **Host a quarterly national autism research funding co-ordination forum.** NHS England and NHS Improvement will organise a forum between organisations funding or using research to build an evidence-based healthcare system for autistic people in England (eg Department of Health and Social Care, National Institute for Health Research, National Institute for Health and Care Excellence, UK Research and Innovation, and national charitable research funders). The purpose will be to encourage funders to be more co-ordinated, to strategically distribute funds across different types of research, to reduce duplication and to seek greater overall investment.

b. **Report on the national autism research funding trends conducted on a five-yearly basis.** NHS England and NHS Improvement will conduct or commission a report of the trends in the total annual national autism health research investment and track the proportions invested by type of research (eg granted to applied or basic research, childhood or adulthood research, descriptive or experimental research, etc.).

c. **Encourage private and charitable investment in building evidence-based autism healthcare.** The provision of products or services for the promotion of autistic people’s health is a growing industry. For example, technology companies building health management apps or charities funding and developing new models of care. NHS England and NHS Improvement will seek to work with private and charitable sector organisations to increase public-private partnerships that seek to fund research, knowledge translation or implementation.

3. Answering relevant research questions

a. **Communicate NHS autism evidence gaps to the research community.** The autism research team at NHS England and NHS Improvement will conduct an exercise on an annual basis to identify some pressing gaps in evidence for designing and delivering healthcare services for autistic people. The gaps identified will be communicated directly to research funding organisations and researchers.

b. **Support longitudinal cohort studies.** Autism is a developmental condition and yet, few longitudinal studies are conducted to improve our ability to offer reliable prognostic information in clinical settings. NHS England and NHS Improvement will convene stakeholders from relevant organisations to support efforts to conduct a longitudinal cohort study about autistic people's health and health needs.

c. **Launch an adaptive platform trial to test multiple autism-related interventions.** Evidence-based practice requires lots of well powered RCTs to test if interventions improve outcomes known to commonly be poor. Platform trials offer an efficient mechanism to simultaneously evaluate the effectiveness of multiple interventions and lead to a rapid step change in the availability of evidence about interventions. NHS England and NHS Improvement will support work to scope the possibility of establishing an autism platform trial, similar to the Randomised Evaluation of COVID-19 Therapy (RECOVERY) trial and the STAMPEDE prostate cancer trial.

d. **Support for evaluations of complex interventions.** Interventions for autistic people are not always well suited to RCTs because there may be multiple interacting factors involved in the intervention, population, context or outcomes. The NHS must therefore improve its ability to assess the effectiveness and safety of complex interventions for improving autistic people's outcomes.

4. Raising the quality of research

a. **Support the establishment of a national registry of research participants.** Support the development of a system to routinely offer autistic people in receipt of NHS care the opportunity to join a participant registry that regularly invites them to take part in clinical research, inspired by the success of similar initiatives for other conditions (eg Join Dementia Research and the NHS coronavirus participant registry).

b. **Improve research participation in inpatient care settings.** Establish closer collaboration between researchers, people in receipt of inpatient care and the professionals working in these settings; for example, by collaborating with the ENRICH network to include autism-specific information.

c. **Foster the development and maintenance of a research-active workforce.** NHS England and NHS Improvement will seek to collaborate with DHSC, UK Research and Innovation (UKRI), National Institute for Health Research (NIHR) and charitable funders to develop the autism-focused clinical academic workforce.

d. **Improve the inclusion of autistic people in clinical trials that are not autism specific.** Most healthcare accessed by autistic people is not in autism-specific services. NHS England and Improvement will work to increase the number of autistic people included in trials testing interventions for other health conditions, for example, by providing autism-specific guidance to the NIHR INCLUDE initiative.

5. Using evidence in national autism health policy

a. **Increase the use of professional evidence synthesis to support national policy and local commissioning decisions.** NHS England and NHS Improvement will improve its ability to commission expert researchers to conduct rapid systematic reviews of existing evidence that can be used to inform decisions about autism health services.

b. **Establish a framework the NHS will use to determine whether evidence supports use of interventions with autistic people.** NHS England and NHS Improvement will support the development of a framework, periodically updated, that will systematically appraise and publicly document the extent to which a given intervention is evidence-based. This may involve collaborating with NICE or building on other existing frameworks.[48]

c. **Conduct regular horizon scanning of international evidence.** The national autism team will regularly engage with evidence emerging from other countries; for example, through closer working with the NIHR Innovation Observatory.

d. **Support autism evidence implementation science.** Implementation scientists specialise in increasing the uptake and use of evidence in practice. When an intervention is found to be evidence-based, NHS England and NHS

Improvement will work will specialist implementation scientists to ensure it is universally available in clinical practice.

e. **Require evidence appraisal in applications for national NHS project funding.** The national autism team will introduce a strengthened requirement for Integrated Care Systems autism leads to appraise the current available evidence in support of their planned initiatives and will offer support to them to do so.

f. **Improve evaluation of policies lacking in supporting evidence.** NHS England and NHS Improvement's Learning Disability and Autism Programme will improve the use of robust and definitive evaluation when autism policy decisions are taken without appropriate supporting evidence.

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