

Evidence Brief: Autism

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Produced by the HEE Knowledge Management team, Evidence Briefs offer a quick overview of the published reports, research and evidence on a workforce-related topic. A starter for 10 on the evidence if you will.

Key publications – the big picture

[Interim NHS People Plan](#) NHS, June 2019

Our Interim NHS People Plan, developed collaboratively with national leaders and partners, sets a vision for how people working in the NHS will be supported to deliver that care and identifies the actions we will take to help them. See p. 30: “We will promote nursing roles working with people with mental health needs, learning disability and/or autism”.

[NHS Long Term Plan](#) NHS, January 2019

As medicine advances, health needs change, and society develops, the NHS has to continually move forward so that in 10 years’ time we have a service fit for the future. The NHS Long Term Plan is drawn up by frontline staff, patient groups, and national experts to be ambitious but realistic. See Chapter 3: “Further progress on care quality and outcomes”. [Section 3.2 covers what the Long Term Plan says about Learning Disabilities and Autism.](#)

[‘Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff](#) Department of Health and Social Care, November 2019

The majority of respondents agreed that the training should reflect the [Core Capabilities Framework for Supporting People with a Learning Disability](#) and the new

[Core Capabilities Framework for Supporting Autistic People](#). These frameworks identify the different levels of skills and knowledge staff need to support people with a learning disability and autism. Most respondents also agreed that employers should assess the level of training their staff need and ensure that their staff received this training. Frequently cited concerns included the need for employer support and time and cost pressures potentially leading employers to opt for the most basic level of training.

[Briefing paper: Learning disability – policy and services](#) House of Commons Library, February 2020

The [Government’s Mandate to NHS England](#) directs the NHS to reduce the health gap between people with mental health problems, learning disabilities and autism and the population as a whole, and support them to live full, healthy and independent lives.

[Building the right support](#) LGA, ADASS, and NHS England, October 2015

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

See also the [“Transforming Care” programme](#) and [Transforming Care Partnership Workforce Planning Guidance](#).

[Recruiting and retaining staff to support people with Learning Disabilities or Autism](#) Skills for Health, Skills for Care, HEE and Northumbria University

This resource aims to suggest a range of strategies, based on research evidence and stakeholder opinion, which may help improve the recruitment and retention of high-quality staff to support people with a learning disability and/or autism.

[The learning disability improvement standards for NHS trusts](#) NHS Improvement, June 2018

NHSI has developed four standards that trusts need to meet; doing so identifies them as delivering high quality services for people with learning disabilities, autism or both. These standards are supplemented by improvement measures or actions that trusts are expected to take to make sure they meet the standards and deliver the outcomes that people with learning disabilities, autism or both and their families expect and deserve.

[Workforce development and people whose behaviour challenges: a review of the evidence](#) Skills for Care/Institute of Public Care,

November 2012

This review was commissioned by Skills for Care’s Workforce Innovation Programme which explores how people’s care and support needs change and how the workforce has to adapt to meet, the challenges that change can present. The key questions that the evidence review aimed to address with reference to people whose behaviour challenges and the social care workforce were:

- What are current reported practices to support workforce intelligence, planning and development?
- What works, and what does not work, in current practice to support workforce intelligence, planning and development?
- What are the key characteristics of effective practice in workforce intelligence, planning and development?
- Is there any relevant international evidence?

[Learning disabilities: making a difference toolkit](#) HEE, 2014

[This toolkit](#) brings together a range of resources to promote understanding about what it’s like to live with a learning disability, allowing healthcare professionals to adjust the care they deliver and helping people with a learning disability access the services they need.

[The adult social care workforce supporting people with learning disabilities and/or autism](#) Skills for Care, December 2018

This report provides an overview of the adult social care workforce supporting people with learning disabilities and/or autism. This report shows that there were an estimated 665,000 jobs in the adult social care learning disabilities and/or autism workforce in 2017/18. 57,600 were in the local authority sector and 575,000 were in the independent sector.

[Learning disability and autism training for health and care staff: a consultation](#) February 2019, Department of Health & Social Care

This consultation considers how we can ensure staff working in health and social care have the right training to understand the needs of people with a learning disability and/or autism and the skills to provide the most effective care and support. The 2nd annual report of the Learning Disabilities Mortality Review Programme (LeDeR) recognised this in its sixth recommendation: that mandatory learning disability training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.

[People with a learning disability, autism or both: Liaison and Diversion Managers and Practitioner resources](#) NHS England and NHS Improvement, 2019

This practitioner guidance covers working with people with a known or suspected learning disability, autism or

both. It includes useful information about working with this group of people, along with case studies, recommended actions and signposting to other resources and services.

[Autism skills and knowledge list, for workers in generic social care and health services](#) Skills for Health, 2011

The *Autism skills and knowledge list* has been developed to help improve awareness of autism and skills among workers in generic health and social care services. The list is intended to enable individual workers, or services and teams, to work out whether they have the knowledge and skills needed to provide a good service to people who have autism.

Professionals in the training field may also find an accompanying document, [Implementing the Autism skills and knowledge list through staff training and development](#), useful in helping them to co-ordinate future activity in this area.

[Think Autism - Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update](#) Department of Health, 2014

[Think Autism strategy governance refresh](#) Department of Health, 2018

The adult autism strategy sets out a programme of action the Department of Health and other government

departments will take to improve the lives of autistic people. A revised governance model to oversee implementation of the strategy has also been established. To ensure the future sustainability of the workforce caring for and supporting people of all ages with autism, the revised model laid out two overarching strategy objectives:

- Reducing the gap in life expectancy for autistic people
- Autistic people are able to play a full role in society

The two objectives were broken down across five domains – including “workforce development”, which became the responsibility of the Department of Health and Health Education England.

See also: [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#), Department of Health, 2015

[Enabling positive lives for autistic adults](#) NICE, December 2019

This quick guide, which is based on research evidence, supports social workers to work with each person to develop a personalised plan, based on an accurate picture of their strengths, wishes and needs, including any sensory differences.

Case Studies

[Youngsters in Ealing benefitting from an intensive therapeutic and short break service](#)

NHS Long Term Plan, January 2019

A service for young people with a learning disability, autism or both is helping keep them at home with their families and communities.

[Beyond the high fence: From the unheard voices of people with a learning disability, autism or both](#)

NHS England, February 2019

This report is for NHS England, specialist commissioners, clinical commissioning groups (CCGs), local authorities and anyone working in the criminal justice system. It was co-produced with people with a learning disability and autistic people with the help of Pathways Associates and NHS England.

[Learning disability and autism support in an acute setting](#) NHS England, February 2019

The Clinical and Nursing Lead for Learning Disabilities/Autism Spectrum Disorder (LDASD) at South West London and St George’s Mental Health NHS Trust led on the implementation of the Green Light Tool Kit (2017) across the Trust. This programme has improved outcomes, experience and ensured resources are used

effectively ensuring services remain focused on individuals' needs and provision of high-quality care.

[Supporting planned admission and discharge](#)

Health Education England, December 2019

This case study focuses on Ayisha, and highlights the skills, competences and knowledge needed to make a positive change.

HEE Star

More resources and tools are available if you search for “autism” in the HEE Star:

<https://www.hee.nhs.uk/our-work/hee-star>

Statistics

You can find relevant statistics if you search for “autism” on the Health and Care Statistics Landscape

<https://gss.civilservice.gov.uk/hc-statistics-landscape/>

HEE National Data Programme

HEE staff can look at the [National Data Warehouse \(NDL\)](#) SharePoint site to find out more about datasets and Tableau products.

HEE Knowledge Management Team, March 2020

Published Peer-Reviewed Research

Workforce planning

[Systematic Review: United States Workforce for Autism-Related Child Healthcare Services](#) Journal of the American Academy of Child & Adolescent Psychiatry, January 2020 *OpenAthens account required**

Across provider categories, we found that workforce availability for autism-related services was limited in terms of overall numbers, time available, and knowledgeability. The greatest unmet need was observed among minorities and in rural settings. Most studies were short term, were limited in scope, and used convenience samples.

[Developing a sustainable and secure workforce supply, for people that have intellectual disabilities and/or autism, who require support from and/or access to services](#) Journal of Intellectual Disability Research, July 2019 *OpenAthens account required**

There is little to no evidence-based workforce development tools or resources readily available to support either the generic or specialist ID workforce to develop. Using a programme managed iterative approach which has been co-produced and led by the workforce, we are identifying and sharing existing good practice, and

developing evidence of what good can look like where there are research gaps.

[*Inconsistent staffing and its impact on service delivery in ASD early-intervention*](#) Research in Developmental Disabilities, April 2017 *OpenAthens account required**

Findings suggest that lacking a consistent staffing structure is problematic when attempting to provide high quality early intervention services to children with ASD and suggest that future research should investigate the extent of inconsistent staffing, impacts of inconsistent staffing on providing intervention, and develop a range of tools to help measure these effects.

[*Report of a mixed methods systematic review of literature to inform the development of 'sustainable safe staffing' improvement resource in learning disability \(LD\) services for NHS Improvement*](#) NHS Improvement, August 2016 *OpenAthens account required**

This mixed-methods systematic literature review seeks to uncover and synthesise any evidence on sustainable safe staffing levels in learning disability services. It identifies themes of relevance to learning disability teams, and the delivery of sustainable, safe, and effective care for people with learning disabilities, and assesses if any of the emerging evidence affirms or negates the context of care tool as an MDT model of care.

Demographics and trends

[*"We were on our own": Mothers' experiences navigating the fragmented system of professional care for autism*](#) Social Science & Medicine, October 2018 *OpenAthens account required**

This article draws on data from a survey of 620 parents of autistic children, including 385 written narratives, to examine the experiences of mothers as they engage with this fragmented system of professional care for children with autism. Findings suggest that engagement with treatments sent families into a complex and confusing universe of diagnosis and treatment.

Support workforce

[*Delivering allied health services to regional and remote participants on the autism spectrum via video-conferencing technology: lessons learned*](#) Rural & Remote Health, July 2019 *OpenAthens account required**

Given that overall staff attraction and retention issues are reported to be exacerbated in regional and remote areas of Australia, it is important to seek innovative ways of supporting individuals on the autism spectrum in their local communities. Technology has the potential to provide a timely and low-cost alternative that extends

access to specialist services for people in remote locations.

Education and training

[*An Interprofessional Education Initiative for Allied Health Students Preparing to Serve Individuals with Autism Spectrum Disorders*](#) *Journal of Allied Health, June 2018* OpenAthens account required*

The need for effective services for persons with autism spectrum disorders (ASD) is driving efforts to better prepare teams of allied health professionals. To address this need, an interprofessional graduate course was piloted with students from three allied health professions: physical therapy, occupational therapy, and speech-language pathology. The course aims were to address knowledge and competency in the field of ASD and to promote interprofessional abilities during entry-level preparation.

[*Creating a person-centred culture within the North East Autism Society: Preliminary findings*](#) *British Journal of Learning Disabilities, December 2013* OpenAthens account required*

This paper provides preliminary findings of the impact of a workforce coaching intervention that used video feedback in a service for children and adults with autism. The results suggest that the participants found the intervention a positive experience that raised their confidence in their

work role. They reported heightened awareness of the individual needs of the people they worked with and a new appreciation of the potential for relationship between themselves and the services' users.

[*Examining unconscious bias embedded in provider language regarding children with autism*](#) *Nursing & Health Sciences, June 2019* OpenAthens account required*

In healthcare settings, language used by healthcare providers can influence provider-patient encounters with individuals with autism spectrum disorder, impacting feelings of stigma and marginalization. This study highlights the unconscious biases healthcare providers might have regarding their patients with autism spectrum disorder and how those beliefs are articulated.

[*A Framework for Developing a Curriculum Regarding Autism Spectrum Disorders for Primary Care Providers*](#) *Journal of Clinical and Diagnostic Research, October 2015* OpenAthens account required*

GP supervisors and medical and nursing educators can use findings from this paper for developing structured learning activities for training primary health care workforce regarding ASD.

Models of care

[Models of community based integrated care for people with a learning disability and/or autism: evaluation findings from a national implementation programme](#)

International Journal of Integrated Care, August 2019 *OpenAthens account required**

The evaluation has directly engaged people with lived experience and their families through workshops and focus groups and has also sought perspectives from local and national representative groups and forums. We found that despite common endorsement of the integrated service model, there are continued gaps in care and support: receiving integrated care was not a common experience of most people and their families.

Nursing

[Self-perceived autism competency of primary care nurse practitioners](#)

Journal for Nurse Practitioners, June 2013 *OpenAthens account required**

This study examined the self-perceived autism competency and barriers of 126 nurse practitioners (NPs) who provide primary care to patients under the age of 18. NPs reported a lack of self-perceived competency ($P < .05$) and identified significant barriers to providing care to children with ASD compared to children with neurodevelopmental or medical conditions. Based on

study results, education is needed to expand NPs' knowledge that may improve the delivery of care to patients with ASD.

Burnout

[Burnout in providers serving individuals with ASD: The impact of the workplace](#)

Research in Developmental Disabilities, February 2020 *OpenAthens account required**

The present study examines the relation between the six areas of work-life and burnout in staff providing direct care services to individuals with ASD. The areas of workload, reward, fairness, and values emerged as the best predictors of burnout. While workload, fairness, and values predicted emotional exhaustion, values and reward predicted personal accomplishment, and values alone predicted depersonalization. Lower levels of training satisfaction and frequency of supervision were related to burnout. Findings provide direction regarding which aspects of the workplace may be most relevant for this workforce and how these areas may be targeted for change.

Competency Frameworks

[Core Capabilities Framework for Supporting Autistic People](#)

Health Education England, 2019

Use of this framework can support all aspects of workforce development including recruitment and selection, practice leadership, establishing culture and dealing with poor performance. The framework will enable individuals and organisations to:

- Identify key capabilities required for job roles
- Identify the capabilities needed within a team or service
- Plan the content of education and training
- Commission education and training
- Conduct training needs analysis
- Support the assessment of capabilities and the sharing of learning and outcomes across the whole workforce.

[Advanced Clinical Practice: Capabilities framework when working with people who have a learning disability and/or autism](#) Health Education England, due early 2020

The 'advanced clinical practice framework' is relevant to Allied Health Professionals (AHPs) and Nursing staff in learning disability and autism services.

***Help accessing articles or papers**

Where a report/journal article or resource is freely available the link has been provided. If an NHS

OpenAthens account is required this has been indicated. It has also been highlighted if only the abstract is available. If you do not have an OpenAthens account you can [self-register here](#).

If you need help accessing an article, or have any other questions, contact the Knowledge Management team for support KnowledgeManagement@hee.nhs.uk