

Evidence Brief: Autism

Contents

Key publications – the big picture	2
Case Studies.....	3
The Star for workforce redesign.....	4
Statistics.....	4
National Data Programme.....	4
Published Peer Reviewed Research.....	4
Workforce planning	4
Education and training.....	6
Lived experience	8
Models of care.....	10
Burnout.....	11
Ways of working	12
Competency Frameworks	14
*Help accessing articles or papers.....	15

Produced by the Knowledge Management team Evidence Briefs offer an overview of the published reports, research, and evidence on a workforce-related topic.

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Key publications – the big picture

[The Oliver McGowan Mandatory Training on Learning Disability and Autism](#) September 2023, Health Education England
The [Health and Care Act 2022](#) introduced a requirement that regulated service providers must ensure their staff receive learning disability and autism training appropriate to their role. The Oliver McGowan Mandatory Training on Learning Disability and Autism is the standardised training that was developed for this purpose and is the government's preferred and recommended training for health and social care staff. (See also: [Oliver McGowan draft code of practice on statutory learning disability and autism training](#).)

[The government's 2023 mandate to NHS England](#) June 2023, Department of Health and Social Care
Alongside the above objectives, we expect NHS England to continue their wider work to deliver the key NHS Long Term Plan ambitions to transform the NHS for the future, in line with NHS England's operational planning guidance and its wider duty to promote a comprehensive health service. As part of this, they should continue to work with the NHS and other partners on improving patient safety, quality of care and health outcomes, including through specific NHS programmes. This includes [...] improving access to and quality of services for people with a learning disability and autistic people.

[2023/24 priorities and operational planning guidance](#) January 2023, NHS England
This document sets out the most critical, evidence-based actions that will support delivery - based on what systems and providers have already demonstrated makes the most difference to patient outcomes, experience, access, and safety. See p. 16: "Develop integrated, workforce plans for the learning disability and autism workforce to support delivery of the objectives set out in this

guidance", and "Test and implement improvement in autism diagnostic assessment pathways including actions to reduce waiting times".

[Supporting disabled staff in the workplace](#) NHS Employers, May 2022

Our [understanding disability infographic](#) provides an explanation of what a disability is, some of the associated health conditions and key statistics. It also includes a list of actions for organisations and managers which can help address some of the barriers that disabled staff may experience in the workplace.

Not all disabilities are visible: some are not obvious and can make everyday life demanding for so many people. Hidden disabilities are a wide range of physical and mental conditions that range from a speech impediment, reduced sight, bipolar, chronic fatigue syndrome, colitis, autism, depression, and many others.

[The NHS Learning Disability Employment Programme](#) March 2022, NHS Employers
NHS Employers launched the Learning Disability Employment Programme (LDEP) in partnership with NHS England in 2015 to support the development of local and national solutions to remove barriers and increase employment opportunities for people with a learning disability and/or autism in the NHS. The programme is key to delivering a specific commitment to employ more people with a learning disability and/or autism set out in the NHS Long Term Plan. It forms part of our work to support NHS trusts to design services which serve and reflect their diverse patients, people and communities.

[Enabling positive lives for autistic adults: A quick guide for social workers](#) December 2019, Social Care Institute for Excellence

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.

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

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.

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

[The adult social care workforce supporting people with learning disabilities and/or autism](#) Skills for Care, December 2018
Evidence Brief: Autism HEE Knowledge Management Team, March 2020 5 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 disabilities: making a difference toolkit](#) 2014, Health Education England

[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.

Case Studies

[‘Real life’ scenarios](#) (no date), Health Education England
We believe that by providing accessible ‘real life’ scenarios that many people encounter with applied understanding of the potential impact for someone on the autistic spectrum that it will raise awareness, reduce the stigma and promote greater equality for people on the autistic spectrum to live fulfilling and rewarding lives. These scenarios are not intended to be an education resource on autism rather a tool to support greater awareness when thinking about how to support someone with autism and /or their families in practical ways.

[Supporting people with a learning disability or autism to have positive personal relationships](#) April 2023, Skills for Care
The training covers topics including why relationships are important, what it means to have capacity to consent, gender and sexual identity, and how to support people to have healthy and safe relationships. The training is mandatory training for all staff and part of the induction for new-starters.

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

January 2019,

NHS Long Term Plan

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](#)

February

2019, NHS England

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](#)

February 2019, NHS England

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.

The Star for workforce redesign

More resources and tools are available if you search for “autism” in [the Star](#)

Statistics

You can find relevant statistics on the [Health and Care Statistics Landscape](#) under “**Health and Care**” (search for “**autism**”)

National Data Programme

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

Published Peer Reviewed Research

Workforce planning

[Autistic nurses: do they exist?](#) *British Journal of Nursing*, February 2023 (*OpenAthens log-in required**)

Autism spectrum disorder is an increasing diagnosis on a global scale. Despite limitations related to the diagnosis, many people with autism are active in the workforce, often within the health care sector. It is reasonable to assume that some of those are nurses. There are very few examples of nurses with autism in the literature, mostly in non-scientific contexts, and that these mention both autism-related strengths and limitations at work. A conclusion is that research about nurses with autism is almost non-existent, and it is high time to conduct explorative research in this area. If employers are given the knowledge and the ability to support the needs of nurses with autism, it is likely to benefit the health of the individual nurse, the psychosocial working climate and patient safety.

[Effects of the COVID-19 pandemic on mental healthcare and services: results of a UK survey of front-line staff working with people with intellectual disability and/or autism](#) BJPsych Bulletin, May 2021 (*OpenAthens log-in required**)

Staff who worked with people with intellectual disability and/or autism during the first wave of the COVID-19 pandemic identified challenges related to infection control and to adapting to new, mostly remote, ways of working. As the pandemic continues, staff need to be supported by their employers to feel safe and to minimise the risk of acquiring or transmitting COVID-19, and with interventions and initiatives that maintain their well-being and reduce the risk of burnout. Staff believe that remote service provision to people with intellectual disability and/or autism is both possible and desirable; the challenge to our specialty is the development of accessible and effective models of remote care.

[The experiences, views, and needs of health professionals who provide care to adults on the autism spectrum](#) Research and Practice in Intellectual and Developmental Disabilities, April 2020 (*Abstract only**)

The aim of this research was to describe the experiences, views, and needs of health professionals providing care to adults on the spectrum. 78 health professionals, 42 from disability-specific or autism-specific settings, across Australia completed an online survey about providing health care to adults on the autism spectrum. About two-thirds of the health professionals strongly agreed or agreed that they felt knowledgeable (63%) and strongly agreed or agreed that they felt competent (62%) in providing care to this population. Fifty-nine percent strongly agreed or agreed that they felt confident in providing care to adults on the autism spectrum. A higher proportion of health professionals working in disability-specific or autism-specific settings strongly agreed or agreed to feeling competent, knowledgeable, or confident, or any combination of these three variables, providing care to adults on the autism spectrum in

comparison to professionals not working in these settings. Over 80% wanted further training, particularly in behaviour and mental health management and communication. Training delivered in a preferred format that addresses the topics identified could improve the quality of care provided to adults on the autism spectrum and their healthcare experiences.

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

[Barriers to Healthcare for Persons with Autism: A Systematic Review of the Literature and Development of A Taxonomy](#) Developmental Neurorehabilitation, January 2020 (*Abstract only**)

Barriers to healthcare access for persons with autism are prevalent and occur at the patient, provider, and system levels. The taxonomy developed may facilitate measurement of barriers within health-care facilities and prompt identification of areas where interventions are warranted to improve care.

[Care Coordination of Autism Spectrum Disorder: A Solution-Focused Approach](#) Issues in Mental Health Nursing, July 2019 (*Abstract only**)

The expanding practice of multi-disciplinary care to address the complex nature of Autism Spectrum Disorder (ASD) suggests that there is a need for a means of coordinating care that transcends the disciplinary distinctions of relevant ASD treatment

providers. As ASD services become more specialized, there is a growing need for effective care coordination with providers across the systems of care. Nursing professionals are ideally qualified to support families affected by ASD, as they provide a necessary holistic lens of health and wellbeing to obtain the appropriate treatments. Solution-focused brief therapy has been applied to a growing number of clinical settings, indicating solution-focused techniques are applicable to the various contexts associated with ASD treatments. We provide a case presentation to demonstrate a solution-focused approach to address ASD-related concerns within the family that are generalizable to coordination of care.

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

Education and training

[Development, delivery, and evaluation of a training program for the early identification of autism: Monitoring of Social Attention, Interaction, and Communication](#) *Frontiers in Neurology, July 2023 (OpenAthens log-in required*)*

The early identification and support of Autistic infants and children is critical as it can result in improved outcomes for children and families (10, 20, 39, 40). This paper describes how the study team designed the MoSAIC program to train the entire Victorian MCH workforce to: improve competency in the early

identification of autism; use an autism specific early identification tool – the SACS-R; initiate conversations about autism screening and a child's 'likelihood' for autism; and refer infants and children with a high likelihood of autism for supports, services, and further assessment. To our knowledge this is the first study to demonstrate the feasibility of designing and implementing a very large-scale, state-wide, training program for a MCH nurse population serving a state with 6.66 million residents (41), or indeed any primary care population. The method included four key stages: (1) a training needs analysis, (2) training design, (3) training implementation, and (4) training evaluation. The results and findings of each stage have contributed to the existing literature on early autism training, identification, and referral for further assessment and access to services.

[Knowledge of autism gained by learning from people through a local UK Autism Champion Network: A health and social care professional perspective](#) *Autism, May 2023 (OpenAthens log-in required*)*

This study has highlighted the value professionals who work with autistic people and their families place on developing different kinds of knowledge to improve their practice. In particular, the benefits of learning from people, colleagues and autistic individuals, were emphasised. In order to develop a real understanding of the impact of day-to-day living with autism, interacting with autistic individuals outside the therapeutic relationship was the most powerful. Therefore, developing knowledge of autistic people above developing knowledge of autism is what appeared useful. To accommodate this, engagement in an Autism Champion Network such as this could be considered as an adjunct to traditional training and e-learning on autism for Tier 2 and above.

[Medical student perceptions of autism education: A qualitative study](#) *Frontiers in Rehabilitation Sciences*, February 2023

(OpenAthens log-in required)*

At present, autism education is not always included in undergraduate medical curricula. In England, the Department of Health and Social Care has mandated that autism education should be included in all undergraduate medical curricula but current evidence relating to the delivery and receipt of autism education is poor. A greater understanding of medical student perceptions of autism education is required to inform curriculum development. This qualitative study sought to explore the perceptions of autism education in final year medical students at a medical school in South-East England by 1) assessing their perceived preparedness to care for autistic people once they have graduated from medical school and 2) determining their perceived acceptability of a new undergraduate education programme, Time for Autism (TfA).

[Developing an e-learning curriculum to educate healthcare staff in the acute hospital setting about autism](#) *British Journal of Nursing*, September 2023 *(Abstract only*)*

When attending acute hospital settings, autistic children and adults rely on health professionals and ancillary staff to interact with them appropriately to facilitate accurate diagnoses and management of health concerns. Health outcomes for autistic people are adversely affected by comorbidities as well as difficulties in accessing and navigating acute healthcare environments. These factors demonstrate a need to develop targeted education for healthcare staff working in the acute hospital setting. This article discusses the background to the project, including the results of a literature review that highlighted some of the difficulties this patient group experiences in accessing health care. It discusses the development and evaluation of an e-learning education programme for healthcare staff working in an acute hospital setting using Kern et al's (1998)

six-step approach to curriculum development. Staff reported a desire to learn more about autism and how to make patient consultations and experiences more accessible and productive. It was acknowledged that there are many undiagnosed autistic adults navigating the acute health system and it is anticipated that the e-learning programme will assist staff in identifying and meeting their needs. During research with an autism advocacy group, there was a clear recommendation for the use of the term 'autistic person' rather than 'person with autism', which is reflected in the resulting education programme and this article.

[Developing undergraduate autism education for medical students: a qualitative study](#) *BMJ Paediatrics Open*, August 2022

(OpenAthens log-in required)*

Despite calls for improved autism knowledge and awareness in the medical profession, this study found that parents/carers of autistic children perceived a generalised lack of understanding of autism in medical settings.

While there is a lack of evidence demonstrating new and innovative ways to enhance autism awareness, education that incorporates lived experience can enhance positive attitudes and values towards chronic conditions. Findings from this study can be used in the design of new initiatives to improve autism awareness in healthcare education. Participants in this study were willing to take part in new programmes, such as Time for Autism (TfA) to improve understanding of autism in future doctors. A full evaluation of the experience of medical students and parents/carers in TfA will be undertaken on the new programme.

[Assessing Interdisciplinary Trainees' Objective and Self-Reported Knowledge of Autism Spectrum Disorder and Confidence in Providing Services](#) *Journal of Autism and Developmental Disorders*, March 2021 (Abstract only*)

The importance of accurate identification and high-quality intervention for individuals with autism spectrum disorder (ASD) is indisputable. Clinicians from multiple professions need adequate knowledge of ASD to make appropriate referrals to specialists, conduct thorough evaluations, and provide effective interventions. ASD knowledge development for many professionals may start at the pre-service training level.

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

[Healthcare Providers' Experiences with Autism: A Scoping Review](#) *Journal of Autism and Developmental Disorders*, February 2019 (Abstract only*)

Gaps in research knowledge exist regarding patient-provider interactions with individuals with autism in healthcare settings. To address this, a scoping review was conducted focusing on the experiences of healthcare professionals working with individuals with autism. A systematic search and screen of the literature resulted in 27 relevant studies. Six key themes were found across these 27 studies including (1) complexity beyond usual role, (2) limited knowledge and resources, (3) training/prior experience, (4) communication and collaboration, (5) need for information and training, and (6) need for care coordination and

systemic changes. The results of this review have implications for future research and practice and should be considered when reflecting on opportunities to enhance research and service provision with individuals with autism.

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

Lived experience

[Experiences of Sensory Overload and Communication Barriers by Autistic Adults in Health Care Settings](#) *Autism in Adulthood*, March 2022 (OpenAthens log-in required*)

The study contributes with information on specific sensory challenges and suggests that auditory noise is particularly problematic for autistic people. On the topic of communication, the findings point to a “double empathy” problem, whereby the provider's own limitations contribute significantly to communication barriers. This was apparent in accounts of nonverbal communication, where the provider's expectations of neurotypical body language caused misunderstandings that were difficult to overcome.

The consequences of sensory and communicative barriers may go entirely unnoticed when autistic differences are not visible.

Unsuccessful interactions with the health care system may have enormous effects on the health and quality of life of autistic people. Therefore, educators and providers may use the insightful information provided by autistic participants in this study to inform decisions on staff training or design of sensory environments.

[Barriers and Benefits Experienced by Caregivers Seeking Medical Care for Their Children with Autism Spectrum Disorders: a Qualitative Meta-synthesis Review](#) *Journal of Autism and Developmental Disorders*, February 2022 (Abstract only*)

Themes were generated related to caregiver challenges, positive experiences, and suggestions to improve medical care. We suggest additional training of medical professionals, an interdisciplinary approach to care, more support for caregivers, and increased adaptability of the medical environment. Implications for practice, limitations, and future research directions are discussed to ensure the highest quality care to support the needs of children with ASD and their caregivers.

[Barriers to Accessing Healthcare: Perspectives from Autistic Adults and Carers](#) *Qualitative Health Research*, December 2021 (Abstract only*)

Autistic adults have higher health needs compared to most, yet they continue to experience barriers to accessing appropriate healthcare. Elements such as support, responsibilities and protective factors exhibited by caregivers, may impact healthcare access for autistic adults. Results indicate the need for further research exploring interdependent factors that impact healthcare access by caregivers, so evidence-based interventions can be developed to support caregivers in the future.

[Healthcare service use patterns among autistic adults: A systematic review with narrative synthesis](#) *Autism*, December 2021 (Abstract only*)

Autistic adults often have complex healthcare needs due to factors like having other health conditions, sensory sensitivities, and limited access to healthcare providers who are trained to provide care for them. All these factors may influence the healthcare services that autistic adults use. In this review, we searched six electronic research databases to gather the most recent evidence about how often autistic adults use five important healthcare services (the emergency department, hospitalization, outpatient mental health, preventive services, and primary care) compared to populations of non-autistic adults. A total of 16 articles were ultimately included in this review. Most articles found that autistic adults had equal or higher use of healthcare services than non-autistic adults. Autistic adults frequently used the emergency department and hospital. This may indicate that routine outpatient care in the community is not meeting their needs. Our findings show the importance of improving care at this level for autistic adults to reduce overuse of the emergency department (in this article referred to as ED) and hospital.

[“We were on our own”: Mothers’ experiences navigating the fragmented system of professional care for autism](#) *Social Science & Medicine*, October 2018 (OpenAthens log-in 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.

Models of care

[‘It seems like a luxury to be able to offer that’: Factors influencing the implementation of annual health checks for autistic people in England](#) *Autism*, July 2023 (*OpenAthens log-in required**)

This study identified a series of potential barriers and facilitators to the implementation of autism-specific annual health checks (AHCs), as well as possible interventions that could encourage implementation. The barriers and facilitators outlined in phase 1 were categorised within five theoretical domains: environmental context and resources; knowledge; memory, attention and decision processes; skills and social and professional role and identity. Findings from phase 2 confirmed the perceived salience of these domains, and the potential utility of interventions targeting these issues. Indeed, while participants in phase 2 were generally enthusiastic about autism-specific AHCs, concerns were shared about the practical aspects of implementation, including a perceived limited capacity, and a lack of knowledge about autism. Based on these findings, we make recommendations for policy elements that cut across the identified TDF domains to either circumvent barriers or unlock facilitators to providing autism-specific AHCs.

[Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings](#) *British Journal of Hospital Medicine*, April 2023 (*OpenAthens log-in required**)

Autistic people experience significant health disparities and reduced life expectancy. Barriers to accessing healthcare are associated with adverse health outcomes. Autism training and healthcare professionals' knowledge about autism is variable, and heterogeneity among autistic people leads to additional educational and clinical complexities. Autism remains nebulous for many practitioners, who are unclear about communication differences, access needs or life experiences common to autistic people. Healthcare environments can be challenging for all

patients but autistic people may require specific accommodations to allow equitable access. The authors have developed a simple framework which may facilitate equitable clinical services at all points of access and care, using the acronym 'SPACE'. This encompasses five core autistic needs: Sensory needs, Predictability, Acceptance, Communication and Empathy. Three additional domains are represented by physical space, processing space and emotional space. This simple yet memorable framework encompasses commonalities shared by autistic people.

[Identifying Components of Autism Friendly Health Care: An Exploratory Study Using a Modified Delphi Method](#) *Journal of Developmental & Behavioral Pediatrics*, January 2023 (*OpenAthens log-in required**)

Autistic individuals report lower health care satisfaction. However, there is currently no set of "best practice" standards about caring for autistic individuals. In this exploratory study, we aim to identify features of Autism Friendly practice according to a sample consisting of mainly professionals whose interests include autism using a modified 3-round Delphi-a method that identifies a consensus view across subject participants.

[Views about primary care health checks for autistic adults: UK survey findings](#) *BJGP Open*, December 2022 (*OpenAthens log-in required**)

The findings suggest strong support from autistic people for a health check and provide useful information for its design and delivery in primary care. The majority thought a health check should be available for all autistic people, irrespective of intellectual ability, and include consideration of personalised reasonable adjustments to improve access to health care, with flexible delivery methods to maximise acceptability.

[For autistic persons by autistic persons: Acceptability of a structured peer support service according to key stakeholders Health Expectations, November 2022 \(OpenAthens log-in required*\)](#)

A structured peer support service for and by autistic persons could be an innovative way to answer the unmet support needs of autistic people. It seems essential to anticipate potential barriers and facilitators and to communicate among health professionals to promote this approach and reduce possible prejudice about the ability of autistic people to offer support to their peers. More studies are necessary.

[Co-design of an NHS primary care health check for autistic adults Autism, November 2022 \(OpenAthens log-in required*\)](#)

Autistic people are on average more likely to experience poor health than people who are not autistic. Health checks have been shown to improve access to effective healthcare. This study investigated people's views about a primary care health check for autistic adults. We held discussion groups and interviewed autistic adults, adults with intellectual disabilities, supporters and health professionals. People wanted the health check to look at a person's physical and mental health, and how they were doing socially. They thought people should be able to share information about their needs and the reasonable adjustments they would like before the health check. They wanted healthcare services to change the way they communicate with autistic people, such as being able to book appointments online rather than by telephone. They wanted a choice in how the health check was completed, with video call or email offered as well as face-to-face appointments. People thought further training of primary care staff on autism was needed, to increase awareness of the diversity of experiences of autistic people and ways in which difficulties, such as pain, may present differently to non-autistic people. Clinicians raised questions about whether mental health and social care services

could meet the additional needs that might be identified through the health check. We used this information to design an NHS primary care health check for autistic people in collaboration with autistic people, supporters and health professionals.

[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 \(OpenAthens log-in required*\)](#)

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.

Burnout

[Burnout in providers serving individuals with ASD: The impact of the workplace Research in Developmental Disabilities, February 2020 \(OpenAthens log-in required*\)](#)

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.

[Predictors of Burnout, Job Satisfaction, and Turnover in Behavior Technicians Working with Individuals with Autism Spectrum Disorder](#) *Review Journal of Autism and Developmental Disorders*, May 2019

Identifying predictors of turnover may be beneficial to service providers as it gives providers areas to address proactively to reduce turnover. Pertinent information may be gleaned from research on predictors of turnover and burnout in other demanding professions, like child welfare workers (DePanfilis and Zlotnik 2008; Kim and Kao 2014), direct-care staff in services for individuals with intellectual disability (ID) and DD (Gray and Muramatsu 2013; Hatton et al. 2001), and special education teachers (Billingsley 2004; Brunsting et al. 2014); however, working specifically with individuals with ASD poses unique challenges. For instance, teachers working with children with ASD have been found to experience greater levels of burnout in comparison to teachers working with children with ID and children who are deaf (Zarafshan et al. 2013).

Ways of working

[A survey of assessment practices among health professionals diagnosing females with autism](#) *Research in Developmental Disabilities*, April 2023 (*OpenAthens log-in required**)

This study has identified a number of potential issues with the assessment process which may be contributing to the challenges of diagnosing females with autism. The most commonly used measures to assess females with autism by health practitioners have been informed by an understanding of the male autism phenotype (Kreiser & White, 2014), and training in the assessment of autism in females is limited or non-existent during University studies which undermines confidence in early career health professionals. This combination of factors has helped sustain the phenomena of misdiagnosis and under-identification of autism in females. Further development of screening tools

such as the CAT-Q (Hull et al., 2019) or the Q-ASC (Ormond et al., 2018) may help assist in the assessment process if their ability to identify female-specific autistic traits can be established. Given the small number of health professionals who currently use measures that may be more sensitive to the presentation of autism in females, it is important to increase awareness of any new or existing measures that may assist in the assessment process in order to increase their use in practice. There is also a pressing need for development of training that will enhance health professional competency in the identification and assessment of autism in females, particularly those who are early in their career, to reduce the likelihood that autistic females will continue to be under-identified (Evans et al., 2019, Lai et al., 2015).

[Expectations and Concerns about the Use of Telemedicine for Autism Spectrum Disorder: A Cross-Sectional Survey of Parents and Healthcare Professionals](#) *Journal of Clinical Medicine*, June 2022

To develop an optimal and promising model of health service for ASD, it is necessary that the telemedicine service tries to meet the preferences of health professionals and families, taking into account the resources and needs of both of them. There is little doubt that telemedicine is not suited for all patients with ASD and that it cannot be used in all scenarios. However, there is sufficient evidence that telemedicine provides several advantages. For example, it could be used to provide adequate training for families, which has been shown to be one of the most relevant needs of parents of children with ASD. Giving parents practical and concrete counsel on how to manage everyday life, also using digital devices that we have become accustomed to, especially during the pandemic, could considerably improve their quality of life and reduce the burden on caregivers in these families. Undoubtedly, the use of telemedicine takes great efforts from professionals and family members. Modeling health

interventions based on their needs and expectations would allow us to lay the foundation for a new doctor–caregiver alliance that would be a real strength in the complex process of caring for a child with ASD.

[Recognising autism in healthcare](#) *British Journal of Hospital Medicine*, December 2021 (*OpenAthens log-in required**)

Recognition of autism and the associated co-occurring physical and mental health issues has increased over recent years. However, undergraduate and postgraduate curricula take time to adapt and to impact on what is delivered in training so healthcare professionals, including doctors, report little training on these topics. Doctors need to know when someone might be autistic in order to respond to them appropriately. This article sets out the reasons why recognition of autism is important and the positive impacts of recognising and understanding autism on health outcomes, service delivery and patient experience. The negative consequences of not recognising autism or understanding the impact of autistic traits on the person are also explored. A companion article then covers how practice can be made more appropriate for autistic people to improve outcomes.

[Development and preliminary evaluation of a novel physician-report tool for assessing barriers to providing care to autistic patients](#) *BMC Health Services Research*, August 2021 (*OpenAthens log-in required**)

Best practice denotes that physicians and other HCPs provide accommodations to their autistic patients to ensure healthcare is accessible and equitable. The current paper has presented a preliminary version of a novel physician-report Barriers to Providing Healthcare tool which, after further evaluation and validation work, may be used in practice to help physicians distinguish the barriers that exist for them in specific healthcare contexts. Obtaining this information may help identify the

supports physicians need to overcome these barriers, and to identify and implement the required accommodations. Finally, as information is gathered on barriers to healthcare for the autism community, there is a need, going forward, to translate this information into effective quality improvement initiatives regarding the care of autistic individuals.

[How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians](#) *Autism*, 2021 (*OpenAthens log-in required**)

Research has shown that on average, autistic people are more likely to die earlier than non-autistic people, and barriers can stop autistic people accessing healthcare. We carried out a study where we interviewed healthcare professionals (including doctors and nurses), and held discussion groups of autistic people. Our results highlighted several key points: seeing the same professional is important for autistic people and clinicians; both clinicians and autistic people think making adjustments to healthcare is important (and often possible); autistic people process information in a different way and so may need extra support in appointments; and that clinicians are often constrained by time pressures or targets.

[A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People](#) *Review Journal of Autism and Developmental Disorders*, May 2021

This paper systematically reviewed the quantitative literature exploring healthcare professionals' knowledge, self-efficacy and attitudes to autism and providing care for autistic people. The resulting evidence suggests that many of these professionals report only moderate levels of knowledge and self-efficacy in their practice, and often lack autism-specific training in their professional education. Although there is some variation in results between countries and the periods of diagnostic change

from the early 2000s to the present day, limited knowledge and a lack of comfort and self-efficacy in working with autistic people may continue to be a significant barrier for autistic people accessing healthcare.

[Autism spectrum disorder and complex healthcare needs: The role of healthcare experiences](#) *Research in Autism Spectrum Disorders, May 2020 (Abstract only*)*

Parents of children with an autism diagnosis frequently described the excessive costs and inordinate amount of time associated with coordinating autism – specific treatments. These ongoing sources of stress have adverse effects on parents' personal wellbeing. Findings suggest that the systems of care aimed at improving outcomes for children with autism may, in fact, negatively affect their parents. Further research is necessary to evaluate the degree to which system – level variables affect the relationship between autism severity and parental wellbeing.

[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 log-in 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.

Competency Frameworks

[The Capability Framework for Autism Peer Support Workers](#) July 2022, Health Education England

The development of new autism peer support worker roles is an exciting opportunity for health service providers to harness the skills and lived experiences of autistic people, who, as part of the workforce will offer peer support to help other autistic people to maintain their wellbeing. It is hoped that many commissioners and service providers who are developing new specialist autism teams will embrace these new roles and embed them within the fabric of future services and that this document will support them with their workforce development journey. Universities and training providers may also find this framework important and helpful in planning education and training. (See also: [Autism Peer Support Worker Curriculum](#).)

[Core Capabilities Framework for Supporting People with a Learning Disability](#) 2019, Skills for Health, Health Education England and NHS England

This revised framework builds on its predecessor outlining the capabilities that a whole workforce, across both health and social care, need to have to successfully enable people with a learning disability to reach their fullest potential and live meaningful lives. It covers twenty five capabilities conveniently divided into 5 domains and arranged in tiers of complexity depending on individual roles. It gives the desired learning outcomes for each topic and links to key references and documents that will be valuable to those planning training or curriculum content. Importantly it recognises and encourages transferability of knowledge and skills between sectors, encouraging the necessary integration between health and social care that this group of people particularly will benefit from.

[Core Capabilities Framework for Supporting Autistic People 2019](#), Skills for Health, Health Education England and NHS England

This framework has been coproduced with autistic people of all ages and their families in a spirit of collaboration. The framework covers 19 capabilities arranged in 5 domains in tiers of complexity depending on individual roles. It gives links to key references and documents that will be valuable to those planning training or curriculum content. Importantly it recognises and encourages transferability of knowledge and skills between sectors, encouraging the necessary integration between education, health and social care that this group of people particularly will benefit from.

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