

# **Research Space**

Journal article

A scoping review examining the impact of learning disability and autism training on healthcare professionals' perspectives and practice

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Title: A Scoping Review Examining the Impact of Learning Disability and Autism Training on Healthcare Professional's Perspectives and Practice.

### Abstract

Healthcare professionals (HCP) attitudes and behaviour in practice play a critical role in the health inequalities experienced by adults with learning disabilities and autistic adults. Poor awareness of adjustments required in communication and enabling capacity for autonomous decision-making can lead to substandard treatment outcomes and avoidable deaths. This paper presents a scoping review of HCP education & training, knowledge skills and abilities in the fields of learning disabilities and autism and the impact that education and training linked to national capabilities frameworks could have on attitudes and practice. The limitations and results highlighted from this study will not only supplement current research, but aid future research and support the development of a reliable, contemporary evidence base in the field of learning disabilities and autism, to inform staff training mandated in England and Wales.

# Introduction & Background

Healthcare professional's (HCP) knowledge, attitudes and behaviour have a considerable role to play in the health inequalities experienced by people with learning disabilities or autistic people in NHS services (Nancarrow et al., 2019; Corden, Brewer and Cage, 2022). Poor awareness around core concepts and differences in treatment needs have led to avoidable deaths, identification and poor treatment outcomes, highlighted by the Kings College 'Learning from Lives and Deaths (LeDeR)' report (Kings College London, 2021).

A growing appeal for neurodiversity-affirming practices in academic discourse advocates a moral imperative and implores all healthcare staff to embrace neurodiverse-affirming care (Dallman, Williams and Villa, 2022); in this context, neurodiversity-affirming practices can be described by the social model (Dwyer et al., 2023). While acknowledging the insinuation that not all people with a learning disability see themselves as neurodiverse (Dwyer, 2022), it was felt to be an important implication for supporting people with learning disabilities (and autistic people) within NHS mental health services (O'Dell et al., 2016; Anderson-Chavarria, 2020).

While not every person with a learning disability or autistic person will see themselves as disabled, there is provision under the Equality Act 2010 for 'reasonable adjustments' to be made. However, it is often beholden on the HCP to both identify the individual as having a learning disability or being autistic and understand their responsibilities under the act. Clinical frameworks such as the 4C

Framework (Marsden, 2023) offer some guidance to the HCP, however, education and training are essential to reinforce practice developments.

While three of the four devolved UK governments are at different stages of mandating learning disability and autism training (Health and Care Act 2022, Improvement Cymru, 2021, Scottish Government, 2023), in England the requirement has been added to the Care Quality Commission Statutory Guidance (2023) and care providers are required to provide evidence of training aligned with the Health and Care Act requirements.

The development of training based on the Core Capabilities Framework in England and Educational Framework for Healthcare staff in Wales (DHSC, 2019, Health Education England, 2019, Improvement Cymru, 2021) is a contemporary issue in healthcare practice, alike national projects such as 'STOMP' - Stopping the over medication of people with learning disabilities, autism or both (Nancarrow et al., 2019).

This paper aims to broach these concerns by critically evaluating the current research on HCP education and training relating to learning disabilities and autism, through a scoping review of the literature. This will frame the impact of learning disability and autism training on HCP's perspectives and practice.

The lead author has chosen to explore this topic as they are a neurodivergent mental health nurse.

Literature review:

Methodology

A scoping review of the literature was undertaken, and data was analysed using thematic analysis (Clarke and Braun, 2013).

Sources of Information

For the scoping review, 5 databases were searched—CINAHL, PubMed, BNI, Google Scholar, ScienceDirect — using search terms such as 'autism', 'learning disability', 'education', 'staff' and 'outcome'; please see table 1. Boolean operator "OR" was used in the search, the "AND" was not used, due to evidence suggesting it would affect the validity of the results produced (Wilczynski et al., 2007). Creating a search strategy that was tailored to "health problem/life process response diagnoses of nursing", was useful, (Lavin et al., 2005; Lavin et al., 2008), however it was recognised that valuable research could be found across disciplines, and therefore, the approach was tailored to capture the diverse data for this area of study (Snyder, 2019).

Table 1 Search Strategy and terminology used for the semi-systematic literature review.

Search Strategy	Search terms used	
Terminology variation	Autism, ASC, ASD, autism spectrum	
	Condition, autism spectrum disorder	
	Learning disability, Learning difficulty	
	neurodiversity, neurodiverse,	
	neurodivergent	
	mental health nurse, staff	
	Psychosis, schizophrenia, psychotic disorder	
Synonyms for training	Training, education, development, learning	
Synonyms for impact	Impact, effect, influence, outcome, result,	
	consequence, evaluation	
Synonyms for comorbidity	Comorbidity, comorbidities, comorbid, co-	
	occurring	
Specific training content	Training on autism and/or learning	
	disabilities	

Table 2 Inclusion and exclusion criteria for the scoping review.

<u>Include</u>	<u>Exclude</u>	
Research articles containing one or more of	Duplicated articles.	
the key search terms.	Research exploring training provided to	
Publishing date <10 years.	staff within older adult services (patients	
Research articles from a reputable source.	>65).	
Research articles evaluating/exploring the	Research exploring training provided to	
impact of training for healthcare staff [only]	staff within children and young people	
on autism and/or learning disabilities.	services (patients <18) *bar Early	
Healthcare settings only.	Intervention for Psychosis (EIP) services, due	
Research exploring training provided to [all]	to their age criteria being 14-65.	
staff within healthcare services.	Repetitive data.	
English language only.	Studies not relevant to exploring the impact	
	of autism and/or learning disability training	
	for healthcare professionals or	

organisational development concerning
autism and/or learning disability education
• Research articles exploring predominantly
public perception of autism and/or learning
disability.

#### Selection Criteria

Over 4000 research articles were initially found, therefore, an inclusion and exclusion criteria -see Table 2- were created and implemented. The resulting returned articles amounted to 201.

The screening process involved appraisal of these articles for eligibility, excluding research articles including repetitive or irrelevant data, which included articles that predominantly focused on the public perception of people with learning disabilities and autistic people or focused on providing training *to* people with learning disabilities and / or autism. Due to the high quantity and repetitive nature of the data retrieved, articles that focused on the impact of training within forensic services, older adult services or children and young people services were excluded, to ensure the suitable data could be extracted comprehensibly. To synthesise this data effectively for clear and concise reading, a themed matrix – see table 3 – was created, influenced by the PRISMA extension for scoping reviews (Tricco et al., 2018). Utilising this checklist, articles which were deemed biased or contained unreliable data were discounted and consequentially, 11 publications were found to meet the final eligibility criteria.

#### Results

Of 11 research articles for review: 6 were found to be evaluating the efficacy of training programmes, 1 article explored the research and training priorities of staff who support people with an intellectual disability, 2 explored staff perspectives and/or attitudes, knowledge and/or self-efficacy and behaviour [surrounding learning disabilities and autism], 1 aimed to identify necessary components of 'autism-friendly healthcare', and 1 evaluated the impact of implementing a new protocol that increased autism screening and diagnostic behaviours in HCPs.

Table 3 Literature Review included articles

Date	Author(s)	Title	Methodology	Findings
2022	NDTi	Evaluation of The Oliver Mcgowan Mandatory Training Trial in Learning Disability and Autism	Kirkpatrick (1998) Four- Level Training Evaluation Model. Mixed method study.	Recommended that the blended learning package developed by Trial Partner B should be used. 'Tier-2 Training C' was found to have better outcomes, however, barriers recognised were the length of time it took to deliver
2022	Kyle, G. and Connolly, A.	Developing An E-learning Curriculum to Educate Healthcare Staff in the Acute Hospital Setting About Autism	Systematic literature review using the six-step approach to curriculum development.	Almost 80% had undertaken no formal education on autism. Almost 90% believed it to be important to understand the characteristics of autism. 94% want to know about issues to consider when an autistic person accesses the healthcare system.
2019	Nancarrow, T., Rencher, J., Wilcock, M., Bonell, S., Wolke, T., and Shankar, R.	Bespoke STOMP Training for Learning Disability Teams—does It Work?	Quantitative study	Training was associated with better knowledge.  Nursing and psychology are essential to STOMP delivery but scored lower than AHPs, despite both reporting STOMP to be considered a priority.
2016	Clark, A., Browne, S., Boardman, L., Hewitt, L., and Light, S.	Implementing UK Autism Policy & National Institute for Health and Care Excellence Guidance- Assessing the Impact of Autism Training for Frontline Staff in Community Learning Disabilities Teams.	Mixed method study	Compared with clinical staff, administrative staff had a reduced understanding of autism, with less training available. Focus group feedback concluded a positive outcome from the training and changes to practice.  Changes to practice included alterations to waiting environments adapted communication and increased communication between staff about the needs of autistic people using the service.
2022	Rudra, S., Dave , R., Eady, N., Smith, J., and McNamara, E.	Evaluating The Impact of a Simulation- based Training Course in Intellectual Disability Psychiatry and Autism Co- delivered By Actors with Intellectual Disability.	Mixed method study.	Eight psychiatrists had a significant increase in confidence for all scores following course participation. Follow-up interviews elucidated themes of the importance of supported and structured training opportunities with people with intellectual disability, and the value of connection with peers and supervisors.

2022	Clarke., L. and Fung, L. K.,	The Impact of Autism-related Training Programs on Physician Knowledge, Self-efficacy, And Practice Behaviour: A Systematic Review	Systematic literature review using the 'Medical Education Research Study Quality Instrument'.	Results indicate specialized autism training programmes are associated with positive changes in physician knowledge and self-efficacy related to the care of autistic patients.
2022	Simpson, K., Adams, D., Manokara, V., and Malone, S.	Research And Training Priorities of Staff Supporting Individuals with Intellectual Disabilities with or Without Autism.	Quantitative study.	Analyses found that staff were more likely to rely on training than research to inform their knowledge. Staff indicated understanding and managing behaviours as a training priority. Staff identified interventions and support for caregivers as a research priority.
2022	Crowley, N., O'Connell, H., and Gervin, N.	Autistic Spectrum Disorder Without Intellectual Impairment in Adult Mental Health Services – Fostering New Perspectives and Enhancing Existing Services.	Systematic literature review.	Findings indicated autistic adults are often vulnerable to mental health problems, and experience higher rates of physical and psychiatric morbidity. Also, autistic adults displayed barriers to engage with effective interventions, with poor recovery outcomes compared with the general population.  Proposing further research into the benefits of having specialist staff within adult mental health teams and a practical model for the application of such.
2022	Corden, K., Brewer, R. & Cage, E.	A Systematic Review of Healthcare Professionals' Knowledge, Self- Efficacy and Attitudes Towards Working with Autistic People.	Systematic literature review.	Narrative synthesis indicated that healthcare professionals report low to moderate levels of autism knowledge and self-efficacy, and often lack training. Health professionals' limited knowledge and self-efficacy in working with autistic people is a challenge to the provision of healthcare for autistic individuals.
	O'Hagan, B., Krauss, S. B., Friedman, A. J., Bartolotti, L., Abubakar, O., Broder- Fingert, S., and Augustyn, M.	Identifying Components of Autism Friendly Health Care: An Exploratory Study Using a Modified Delphi Method.	A modified Delphi method.	Highly ranked statements include topics such as environmental/operational modifications and staff training to support autistic patients.  Findings highlighted previously reported barriers, including the need for inclusive engagement with the autistic community.
2021	Triese, C., Simmons, C.,	Autism Spectrum Disorder in Early	Quality improvement	The implementation of the protocol identified previously

Marshall, N., Painter,	Intervention in Psychosis Services:	project	unidentified autism cases (~1 in 10) and increased
M., and Perez, J.	Implementation and Findings of a 3-		understanding of engagement, treatment, and recovery in
	step Screening and Diagnostic		patients with co-occurring ASD and psychosis.
	Protocol.		
			Findings indicated ASD-P has a specific clinical presentation
			and treatment approaches differed compared to non-autistic
			patients, for instance, increased external referrals were
			required.

#### Themes

The dominant common theme, throughout all 11 research articles, designated,

-Learning Disability and autism training is a priority for all staff within healthcare services -

and such is necessary to create 'autism-friendly environments' and neurodiverse-affirming healthcare practices, which are anticipated to reduce the health inequalities experienced by this demographic. A theme recognised throughout was that HCPs either report feeling or are identified to be, unsure or unprepared to support people with learning disabilities and autistic people, particularly nursing staff – for example, knowledge of core aspects of learning disabilities and autism is required for effective identification and communication skills (Corden, Brewer and Cage, 2022; DHSC, 2019, Health Education England, 2019; O'Hagan et al., 2023).

Research observes that autism is significantly under-identified, misdiagnosed and there remains a nuance regarding the diagnosis of autism without learning disabilities (Crowley, O'Connell and Gervin, 2022; Kyle and Connolly, 2022). Triese et al. (2021) indicated a high comorbidity between autism and psychosis, with percentages reaching up to 34. 8%, and 5 out of 11 research articles identified several significant implications for treatment, prognosis and suitable accommodations required to make healthcare environments more accessible (Triese et al. 2021; Clarke et al., 2016; Nancarrow et al., 2019; Crowley, O'Connell and Gervin, 2022; Kyle and Connolly, 2022).

Comparatively, 6 out of 11 research articles shared a common theme that indicated nursing staff regularly displayed poor knowledge of guidelines, best practices, or ability to effectively identify and appropriately support people with learning disabilities or autistic people (Clarke et al., 2016; Nancarrow et al., 2019; Triese et al., 2021; Corden, Kyle and Connolly, 2022; O'Hagan et al, 2023) with most studies found to be predominantly exploring the impact of learning disability and autism training on medical staff, or favour allied health professionals (AHP) over nursing staff (Clarke et al., 2016; Nancarrow et al., 2019; Clarke and Fung, 2022; Simpson et al., 2022; Rudra et al., 2022).

Another common theme expands on the idea of training being a priority, advocating learning disability and autism training is beneficial in improving HCP knowledge and positively changing behaviours in practice. In conjunction with a prevailing theme also indicating that training is exceptionally successful when co-produced or simulation-based, with research advocating for inclusive engagement of experts by experience (Nancarrow et al., 2019; Kyle and Connolly, 2022; NDTi, 2022; Rudra et al., 2022; O'Hagan et al., 2023).

Nonetheless, it is acknowledged that only short-term screening behaviours are currently researched, with Clarke and Fung (2022) highlighting the need for research to focus on evaluating the

longitudinal impacts [on behaviour] of learning disability education for HCPs and further requests are documented for the continued evaluation of the development and the impacts of training (Kyle and Connolly, 2022; Simpson et al., 2022; Clarke and Fung, 2022; Rudra et al., 2022; O'Hagan et al., 2023).

NDTi, bemix and My Life My Choice (2022) were the independent providers invited to evaluate the trial of the Oliver McGowan Mandatory Training programme for health and social care staff. They evaluated 3 different training packages (A, B, C) between 2020 and 2022. The evidence for training B is that it was fit for purpose, good quality and well received, and NDTi recommended 'Tier 1 Training B' to be suitable in practice and ready for use.

With predominantly positive responses, 100% reported an increase in their knowledge, skills and confidence, 63% had changed their practice when supporting someone with learning disabilities or an autistic person and 27% working in roles where they could implement changes, reported doing so at the time of follow-up (NDTi, 2022).

NDTi (2022) concluded that developing a standardised training package, effective for large groups, will be challenging, however, the data can help inform decisions about the content and mode of training while indicating "Further exploration of the benefits of training being delivered within organisations or staff teams," was crucial. It is important to acknowledge the impact the COVID-19 pandemic had on the integrity of the results, which NDTi paid consideration to in their report, also recognising the impact that a limited understanding of the longitudinal impacts has [on care and treatment outcomes for people with learning disabilities and autistic people], and advocate for further research to be undertaken.

Rudra et al. (2022) advocate for inclusive engagement with autistic individuals and promote the positive benefits of co-produced simulation training, demonstrating greater results compared with training programmes that do not use experts by experience, additional evidence substantiates this (Clarke et al., 2016; Nancarrow et al., 2019; Triese et al., 2021; Kyle and Connolly, 2022).

Rudra et al. (2022) research was conducted on a small participant sample of psychiatric speciality doctors and subsequently advocated for further research to substantiate the claims.

Triese et al. (2021) implemented a screening protocol, that, on evaluation, highlighted a significant number of un-identified autistic patients on their caseload (~10), highlighting a poor understanding of core concepts / presentations of autism held by HCPs within this service. The study identified pivotal differences in treatment profiles, with a dominance of persecutory delusions experienced by the 'ASD-P' patients and identified that all ASD-P patients experienced a comorbid anxiety disorder.

Suggesting further research is desirable, noting the increased external referrals for support of ASD-P patients. Indications from other research suggest a negative impact of increased external referrals and implied it could stem from a lack of core understanding of how to support people with learning disabilities and autistic people in practice (DHSC, 2019; Corden et al., 2022; Crowley et al., 2022).

Simpson et al. (2022) explored the research and training priorities of healthcare (HC) providers who support individuals with intellectual disabilities (with or without autism), and predominantly established that nurses were prone to rely on training programmes to inform their knowledge, rather than perusing research. Their findings indicated that staff felt training for understanding and managing behaviours was a priority and staff suggested interventions and supports for caregivers were a priority for research. While this research is from an international source, it has applications drawing on a diverse sample, and considers the indication above a conceivable motivator for the health inequalities faced by people with learning disabilities and autistic people.

# Implications & limitations

The literature reviewed was limited in patient perspectives and experiences – exploring whether training enhances an individual's experience and treatment outcomes. On reflection this could potentially be attributed to challenges in patients safely participating in research during the COVID-19 pandemic, however, this is not a contemporary issue; a large-scale questionnaire study, published in 2014, highlighted that while researchers perceive themselves to be engaged with the autism community, autistic community members [autistic people and their families] do not share the same view (Pellicano, Dinsmore and Charman, 2014).

The review offered a significantly smaller data pool for training exclusively on learning disabilities, this review recognises that the undertone that learning disability education, has more recently been in conjunction with autism education. Acknowledging these limitations and potential impacts, clarity as to the commonalities and distinctions across the two populations is essential, it is recommended that additional stand-alone education is required with research evaluation of such ventures.

The authors also acknowledge the limitations of this review, due to the exclusion of research regarding training being delivered in children and young people's services, older adult services and forensic settings, and suggests that further research be undertaken to explore the impact of training on learning disabilities and autism in these settings.

Content delivered by experts by experience provided significantly better outcomes, however, the authors are aware of the implications of delivering such training and recognises that the scope of

this review does not analyse in enough depth the cost efficacy and ethical considerations for implementation.

There was insufficient identification of the specific changes to HCP behaviour/practice, as Clarke and Fung (2022) insinuated, increased screening was the only change to behaviour recognised and evaluated in the literature. Although Triese et al. (2021) suggested the protocol provides HCPs the opportunity for "adjustments to engagement and treatment", no further clarification of adjustments was offered.

While debate as to the Learning Disabilities Nurse's future practice contribution to the health and care of autistic people is ongoing (Beebee, 2023), their value in facilitating good quality education and training to health and care professionals in collaboration with autistic experts by experience and those with learning disabilities is without question. However, Chief Nurses across the devolved nations will want to act to stabilise the supply of Learning Disability Nurses to maximise the opportunity that mandatory training could provide.

# Conclusion & Recommendations

To conclude, the literature unswervingly advocates for training to be developed, delivered and evaluated to improve outcomes for people with learning disabilities and autistic people. The evidence establishes that while training is beneficial, particularly in increasing knowledge and screening behaviours, the most advantageous results were produced when training was either simulation-based or co-produced. This review highlights the need for further research to evaluate the longitudinal impacts, particularly on HCP behaviours in practice, and ultimately review the impact mandatory training has on the health inequalities faced by people with a learning disability and autistic people (with or without a learning disability).

This review of the research has uncovered a potential unconscious bias by Nurses and indicates the importance of further research in this area. Therefore, the writer recommends that further research be undertaken to explore the impact mandatory learning disability and autism training will have on Registered Nurses – particularly Mental Health and Learning Disability Nurses – practice when supporting people with learning disabilities and autistic people in England and Wales.

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# A Scoping Review Examining the Impact of Learning Disability and Autism Training on Healthcare Professional's Perspectives and Practice Peer Review Actions

Re	viewers Feedback	Adjustments and updates
1)	there are areas where this lacks supporting evidence	The paper has been reviewed with additional evidence and references added, particularly linked to the legal frameworks associated with learning disability and autism training.
2)	You have excluded older adults and children and young peoples service but you have no provided a rationale for this which is limiting	Explained how this was necessary due to such high quantities of data and it being repetitive.
3)	I would consider the identification of people with learning disabilities as neuro-divergent as contested with in both the Learning Disability community and by neuro-diverse people. Please identify support evidence of inclusion or reframe this discussion	Explained the neuro-diversity affirming practice can be described by the social model and added context that this is not identifying people with a learning disability as neurodiverse, rather a favoured way of working with everyone.
4)	You switch between capitalization and non-capitalization of Autism, please choose one.	Replaced with non capitals.
5)	It should be clearer that the act does not mandate training across all areas of the UK.	Have reviewed details for references of mandatory training across devolved nations added clarifying sentences in introduction.
6)	This article focusses heavily on Autism, if there is more limited evidence for people with learning disabilities, I would expect this to be seen as a limitation and possibly a	Identified the lack of data returned in this review for solely learning disability education and recommended further research, also noting the implication that most training is delivered in conjunction with autism education, and this could have the implication of conflating the two groups for learners.

	recommendation.	
7)	Its unclear until the conclusion that	Edited to clarify that it is focusing on all HCPs but there was a recognised potential bias in nursing staff
	you are focusing on the RNMH	and recommend further research specifically in this area.
	perspective, this should be indicated	
	in the abstract and and the	
	introduction	
8)	the construction could have greater	Edited some sentences to make them flow better and rewritten certain parts.
	definition as there are short	
	sentances and this does not flow	
	well	
9)	i am concerned there appears to be a	Further clarifying statements, such as autistic people (with or without a learning disability) have been
	forgone conclusion that the autistic	included, along with a specific paragraph relating recommendations for learning disability nursing
	people concerned will all have a	contributions to mandatory training.
	learning disability whereas this is not	
	a given and this may not be intent	
	here - this is how I have understood	
	this paper, but please clarify in the	
	text.	
10)	The article offers no further	Identified as a limitation and further research is recommended.
	discussion beyond the known need	
	for increased education for health	
	staff	