

ABSTRACT

Aim: Our aim is to review published literature to explore, identify, and describe the journey for practitioners towards advanced practice in learning disability and autism and the impact on care delivery.

Background: Like other fields of practice in health care, practitioners working in the field of learning disability and/or autism have been expanding their roles over several decades to promote the complex needs of this population group. The nuances and intricacies of working with this group of people may be less clearly defined, but the requirement to advance practice across the four pillars of clinical practice, leadership and management, education, and research are key components of the work of advanced practitioners.

Design: Scoping review

Review Methods: A scoping review approach will be used to address the review question. The PRISMA extension for scoping reviews (PRISMA-ScR) guidelines will be used as a structured format to report the review.

Main Review Question: What is the positionality, identity, and impact of advanced practice for care delivery by advanced practitioners in learning disability and autism?

Discussion: This scoping review is being designed to conceptualise the journey towards advanced practice, with a specific focus on learning disability and autism, exploring the impact on care delivery in this field of practice by advanced practitioners.

Key Words: Advanced and Advancing Practice; Learning Disability and Autism; Identity and positionality; Scoping Review, PRISMA-ScR

Key points

The professional construct of 'Advanced Practice' in England has a multi-professional dimension, which can challenge perception of roles and responsibilities for professionals working to deliver complex care. However, the specific journey to, and positionality of advanced practice in learning disabilities and autism, in comparison to well established areas for advanced practitioners such as emergency care or general practice, is less well understood. The development of the *Multi-professional framework for advanced clinical practice in England* provides guidance to how advanced practice is applied in practice settings as a level of knowledge, skills, and experience informed by its capabilities across the four pillars of advanced practice. This planned scoping review aims to review published literature to explore, identify, and describe the journey for practitioners working towards advanced practice in learning disability and autism and the impact on care delivery.

Reflective questions

1. What is your experience of advanced practice in the care of people with a learning disability and/or autism?

2. How can you relate to the pillars of the Multi-professional framework (clinical practice; leadership and management; education; and research) as a guide to reflecting on advanced practice with people with a learning disability and/or autism?
3. What training have you received which you feel has impacted positively on your ability to provide advanced practice care for people with a learning disability and/or autism?
4. In your journey towards advanced practice for caring for people with a learning disability and/or autism, which elements of your practice do you feel you are advancing?

1 INTRODUCTION

Health systems and those professionals responsible for designing and delivering care packages in those systems are becoming ever more complex. At the same time, health professionals' role, identity, and scope of practice in delivering complex care has become increasingly challenging to identify and articulate (Htay and Whitehead 2021). The professional construct of 'Advanced Practice' in England has a multi-professional dimension inclusive of nurses, allied health professionals (AHPs), and pharmacists working in advanced practitioner roles, with a range of associated role titles, such as (though not exclusively) 'Advanced Nurse Practitioner', 'Nurse Practitioner', 'Advanced Clinical Practitioner', 'Advanced Physiotherapy Practitioner', and 'Advanced Pharmacist Practitioner' (Cooper *et al.* 2019), which can challenge perception of roles and responsibilities for professionals working to deliver complex care, due to a prior lack of standardisation of education and training preparation for functioning in advanced practitioner roles (King *et al.* 2017). Additionally in learning disabilities and autism services, due to the multi-factorial nature of learning disabilities and autism, other professionals such as psychologists and social workers may sometimes also be engaged in advanced practice developments, such as developing innovative advanced practitioner roles.

Health Education England (HEE) (2017, 8) defines advanced practice as "a level of practice characterised by a high degree of autonomy and complex decision making". Four pillars underpin advanced practice; clinical practice; leadership and management; education; and research, which are embedded in advanced practice education programmes (HEE 2017). The move towards framing advanced practice as a specific academic award with associated practice-based learning for role preparation offers a way forward to standardising professional scope and practice for advanced practitioners. However, the specific journey to, and positionality of advanced practice in discrete speciality areas, such as learning disabilities and autism, where advanced practice innovations are in a more development space in comparison to well established areas for advanced practitioners such as emergency care or general practice, is less well understood (King *et al.* 2017).

Therefore, with a focus on developing advanced practice in learning disability and autism, this planned scoping review aims to articulate the journey for health and care professionals working in this area of practice, and the impact on their care delivery for its recipients.

1.1 BACKGROUND

People with learning disability and/or autism have a range of complex health and social care needs. People with learning disabilities are known to experience significant health inequities (Hosking *et al.*, 2016), have high co-morbidity rates (Cooper *et al.* 2018; Heslop *et al.* 2020), such co-morbidity includes obesity (Biswas *et al.*, 2010), epilepsy (Heslop *et al.*, 2020), respiratory disease (O'Leary *et al.* 2018) and cardiovascular disease (Glover *et al.* 2017). This places an emphasis on a health

promotion, surveillance, and an education role. Enhanced roles in this field have also focused on defined areas of practice matched to need, such as forensic, mental health, and epilepsy. Like other areas of practice, working at an advanced practice level with this group of people demands capability, skill, and knowledge enacted across the health system to be able to demonstrate positive outcomes. Despite this complexity of need associated with this group of people, relatively little is known about advanced practice innovations in the field of learning disability and/or autism with minimal published work in this area. Furthermore, locating specific examples of Advanced Practice in an International context is challenging. This is compounded by Learning Disability being a contentious term, a term that has never featured in a diagnostic criterion-based assessment for clinicians (Lovell 2021). The interchangeability of terminology adopted in an international context, Intellectual Disability, Learning Disability, Learning Difficulties and Developmental Disability (Sweeney & Mitchell 2009) not only impacts searching literature for associated practice examples, but also could impede the adoption of advanced practice in learning disability and/or autism on an international level. Whilst there is a Professional Association for Nurses in Developmental Disability in Australia for example, the United Kingdom and Ireland are currently the only twenty-first century jurisdictions to maintain a specialist pre-registration programme for Learning Disability Nursing (Sweeney & Mitchell 2009). However, there are likely to be examples of where workers may be advancing care in different government and non-government organisations in Australia, not employed with the title of Nurse, but may performing specialised tasks and using advanced skills (Hayden *et al.* 2018).

Work has been undertaken, in Ireland for example, related specifically to Clinical Nurse Specialist roles at the enhanced level of practice, centred on “client advocacy, client focus, audit/research, education/ training and consultancy” (Doody *et al.* 2017;2019:388), and stated such collaborative and supportive roles were difficult to document in terms of impact. A high level of assessment skills for advocacy utilising holistic frameworks and the capacity to champion inequitable access to mainstream health provision were also noted (Doody *et al.* 2019).

HEE’s (2017) development of the *Multi-professional framework for advanced clinical practice in England* provides a definition of advanced practice and greater consistency on how the term is applied in practice settings as a level of knowledge, skills, and experience informed by its capabilities across the four pillars of advanced practice. The establishment of the Centre for Advancing practice is progressing this agenda by the introduction of processes such as endorsement of advanced practice capabilities frameworks, advanced practice credentials in speciality areas, accreditation of advanced practice Master’s programmes, and retrospective recognition of existing advanced practitioners, thereby ensuring a consistent approach to advanced level practice education and training across England (HEE 2023). The delivery of a high-quality capabilities framework and a subsequent credential for learning disability and autism for children, young people and adults are key for developing service delivery at an advanced practice level. Developing and retaining the advanced practice workforce is a strategic priority for the NHS. *The NHS Long Term Plan* (NHS 2019) recognises the potential of advanced practice for meeting short-term and long-term workforce demands. Correspondingly the *We are the NHS: People Plan for 2020/2021 – action for us all* (NHS 2020) is supportive of scaling up and delivering new roles and models of advanced practice. HEE’s, and now from April 2023 onward, NHS England’s Workforce, Training and Education Directorate, advancing practice programme supports this agenda by working collaboratively across the health and care system, to develop safe and effective advanced level practitioners who can be relied upon to provide high quality patient care regardless of role or setting. A clinical career pathway and targeted continuing professional development at an advanced practice level have the potential to support the retention of highly valued and skilled staff and facilitate workforce transformation.

A recent national survey reviewing the contribution of advanced practice in England has reported the majority of work was in clinical practice domain and practitioners had varied levels of educational attainment (Forthergill *et al.* 2022). Whilst learning disability and/or autism was not cited as a specific speciality within this survey, it is reasonable to assume clinical practice would also be the dominant pillar of practice.

Two factors interplay with impact of advanced practice care delivery within learning disabilities and autism services. Firstly, socio-professional factors affecting this discipline of practice, the context for the practice employer and service delivery model and the identified need it focuses on, for example Epilepsy, Forensic, Mental Health/Dual Diagnosis. Secondly, contribution and impact on care delivery can also be seen in areas associated with improving quality of life, providing clinical advice and education and review of policy influences. Critically the key contribution to advanced practice relates to health promotion and health related needs assessment, leadership, and reviews of quality in service provision (McCarron *et al.* 2018).

Our review begins from a positional standpoint that mapping the components of advanced practice in learning disability and autism practice is desirable and necessary for today's healthcare climate, both for practice in the UK and to foreground work internationally. This has the potential implication for global collaboration and knowledge sharing once domain areas of care against the four pillars of advanced practice are revealed.

Raising awareness of advanced practice for professionals engaged in this area of care will help those caring in this sector in the UK and internationally benchmark their experiences and promote reflective practice. To gain a comprehensive understanding, we will include a wide range of literature.

2 AIM

Our aim is to review published literature to systematically explore, identify and describe the journey towards advanced practice and impact on care delivery in learning disability and autism.

2.1 Review Objectives

Specific objectives of the planned scoping review are to:

1. Review the context and development of advanced practice in learning disability and autism (evidence-base)
2. Identify the underpinning identity/positionality of advanced practice for learning disability and autism (evidence-base)
3. Explore the impact of advanced practice on health professionals' delivery of care for Learning Disability and Autism

The intention will be to capture the evidence-base of 'advanced practice' and 'advancing practice' in nursing and allied health professional groups working in the field of Learning Disability and Autism. Those professionals allied to health professionals, such as medicine, who take on a complementary role in the management of care in autism and learning disability will be excluded. **Our review**

question is: What is the positionality, identity, and impact of advancing health care practice for care delivery in Learning Disability and Autism?

3 DESIGN AND METHODOLOGY

Methods of Scoping Review (Munn *et al.* 2022; Khalil *et al.* 2016; Arskey and O'Malley 2005) will be used to address the research problem and map the journey and impact of advanced practice in learning disability and autism. There are six broad indications for scoping review (Munn *et al.* 2022). Of the six broad indicators, in this review it has been identified that there is a need to identify two clear areas: firstly, to identify key characteristics or factors related to the concept of advancing practice; and secondly to identify and analyse knowledge gaps in the delivery of advancing practice. Applying these indicators will help to address our research problem and demonstrated a good fit with scoping review methodology.

The purpose of scoping reviews is to access a broad range of literature, and map against a specific topic, field, concept, or issue (Peterson *et al.* 2016; Munn *et al.* 2022). In our review, a range of empirical, descriptive, and policy-based evidence will help to provide a rich contextual basis to address our main research question. As an evidence-based review, similar to integrative review methodology, it also has the potential to potentially help inform policy and practice (Munn *et al.* 2021).

To enhance rigour, the recommended five stage process of scoping review will be used (Khalil *et al.* 2016). Identifying the research question; identifying relevant studies; careful selection of studies, charting the data; and collating the results. Our intention is to be systematic in the application of this process, and to use similar levels of data-processing as a systematic review (Page *et al.* 2020). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extensions for Scoping Reviews (PRISMA-ScR) will be used as a general framework to systematically report the review (Tricco *et al.* 2018). It is acknowledged that the PRISMA-ScR extension (Tricco *et al.* 2018) was developed against the reporting PRISMA 2009 reporting items (Moher *et al.* 2009). The new PRISMA 2020 statement recommends that to enhance the reporting of scoping reviews, additional changes that apply to scoping reviews should be considered (Page *et al.* 2020). Therefore, to enhance transparency of reporting and rigour, noteworthy changes from the PRISMA 2020 statement will be used in this scoping review. These changes will be integrated in to the PRISMA-ScR checklist (Tricco *et al.* 2018) and help our research team enhance review reporting, such as in searching and synthesis. Noted integration of PRISMA 2020 recommendations will include for example, searching and selection of studies (item 7 and 8); using the abstract checklist for more complete reporting as a summary (item 2); qualitative methods of meta-summary will used for synthesis reporting of methods used (item 13). Some PRISMA 2020 recommendations will not be used, such as the methods that relate to handling quantitative data which are not relevant in this scoping review. This review focuses on drawing out a conceptual understanding of advanced practice not defined by numbers. Please see **Table 1 'Accommodating recommended PRISMA 2020 changes'** (see separate file) for the changes we have highlighted and will use for our scoping review.

Our research team of experienced nurse academics has experience in several systematic forms of review and can call on their institutional evidence-based information practice expertise to enhance application of search processes.

3.1 Stage 1: Identifying the main research question

Internationally, there is a growing evidence-base that health care professionals operating at advancing levels improve effectiveness in care, patient safety and person-centred care (Woo *et al.* 2017; CNOD 2017a). However, much of the evidence-base supporting effectiveness is from health professionals in a specific role, such as 'Advanced Nurse Practitioner' (Woo *et al.* 2017; CNOD 2017b). Further randomised controlled evidence demonstrates positive clinical and patient satisfaction outcomes, from Advanced Practitioners working in primary care, outpatients, or specialist centres (Htay and Whitehead 2021).

The *Advanced Clinical Practice: Capabilities framework when working with people who have a learning disability and/or autism* (Skills for Health 2020) builds on the *Multi-professional framework for advanced clinical practice in England* (HEE 2017) providing guidance for those wishing to practice at an advancing level of practice within those respective areas. However, the journey and actual impact of working at an advanced level for this group of health professionals is unclear. Therefore, our focus is on: the context and development of advancing practice in learning disability and/or autism; identifying the underpinning identity/positionality of advancing practice for learning disability and/or autism; and exploring the impact of advanced practice on health professionals' delivery of care for learning disability and/or autism.

Our research question is: **What is the positionality, identity, and impact of advancing health care practice for care delivery in Learning Disability and/or Autism?**

3.2 Stage 2: Identifying relevant studies

3.2.1 Literature Search

We will search for and synthesise the following types of evidence:

1. Peer reviewed academic literature identified through systematic databases searching and search techniques such as a review of reference list, and citation searching.
2. Grey literature, including non-peer reviewed articles and online reports located through a structured online web search.

3.2.2 Systematic search of academic literature

A comprehensive electronic search will be conducted guided by information specialists. Databases and search terms are summarised in Table 2. We will search from 1985 onwards, given that background literature indicates a conceptual and professional interest in advanced practice developments from that timepoint.

Table 2: Summary of search terms (see separate file)

3.2.3 Structured search of grey literature

A structured search of unpublished literature will include searching the following databases: Electronic Theses Online Service (EthOS); King's Fund Library; British Library Catalogue. We will also use Google Scholar using key terms and phrases. Reference list of all included items will be reviewed to identify further potentially relevant sources.

Stage 3: Careful selection of studies

3.3 Inclusion and exclusion criteria

Our evidence-base criteria for inclusion are purposely broad as, following scoping review methodology and given the nature of our question, we are unlikely to identify a significant body of empirical studies. In addition to empirical studies, we will include descriptive papers and policy documents. Opinion papers and editorials (i.e. not relating to an evidence-base for advanced practice) will be excluded.

A list of excluded studies and the reasons for exclusion will be registered. A Flowchart of Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) will be populated to present the results of the search, screening and selection. The extracted data will include: study references; study types; and participants.

Table 3: Inclusion and exclusion criteria (see separate file)

3.3.1 Title Screening

The Inclusion and exclusion will be applied in a three-phase process of title screening, abstract screening, and full text review. Two authors (BA & SK) will review the title of each publication identified in the search. Those that are clearly not relevant, for example those not focusing on advanced practice or an included health professional group will be excluded. Any titles considered ambiguous or where reviewers disagree will progress to abstract screen.

3.3.2 Abstract Screening

Two authors (BA & SK) will independently review the abstracts of articles included from title screening. Any disagreements will be resolved by discussion between the two reviewers and if agreement cannot be reached a third author (MB) will be involved. Discussion will continue until consensus is achieved. Publications will proceed to full text review if it is clearly relevant, or the abstract suggests it may be relevant but contains insufficient detail to make a decision.

3.3.3 Full Text Review

Two authors (BA & SK) will independently review publications to ensure inclusion criteria are met. Disagreements will be discussed and, if not resolved, will be escalated to the third author (MB) with a casting vote. A data extraction form will be developed to represent the components of empirical papers, other resources identified and outcomes of interest to the study. These will include a summary which will be used to inform categorizing papers by type and focus.

3.4 Stage 4: Charting the data

3.4.1 Bibliographic management

Our searching and screening process will be recorded using the bibliographic data management system (RefWorksTM). This will provide an audit trail of decision-making at each stage of screening.

3.4.2 Data Evaluation

The purpose of this scoping review will not be to apply a rigorous inclusion criterion on methodological merit. Rather, the scope of methodological quality of literature will be documented as part of the evaluation. Empirical evaluation of quantitative, qualitative and mixed methods research will be aided by using the Critical Appraisal Skills Programme (CASP) checklist (2016). Similarly, different types of study report, and theoretical papers will be analysed against the logical structure of each papers aims and objectives, and outcomes to consider if the paper holds sufficient rigour for inclusion. Two authors (BA, SK) will apply these criteria to papers that have been included and fit the inclusion criteria. Again, a third author will be involved to discuss further and resolve discrepancy.

3.4.3 Data Analysis and Synthesis

The data set we retrieve is likely to be from a variety of sources. Kaster *et al.* (2016) highlights that process of analysis need to be transparent. In line with well-trodden and reliable processes of integrating literature (Whitmore and Knafelz 2005) this scoping review will aim to identify and categorise the different types of included literature (empirical, policy, report, theoretical) against emerging themes. In this way data can be displayed within and across groupings collectively and provide a clear picture as to the emerging evidence base in each theme.

Meta-summary (Dixon-Woods *et al.* 2004; Finfgeld-Connett 2018; Aveyard 2020) will be used as a method of synthesis. The process involves grouping similar studies to make collective sense of the complex data from different types of included literature (Aveyard, 2018). In classic qualitative content analysis (Miles and Huberman 1994; Graneheim and Lundman 2003) data synthesis will involve three steps: (a) data extraction and interpreting the main focus of each paper: (b) exploring the relationship in and between studies, which will involve grouping similar studies: and (c) assessing the robustness of the synthesis by reflecting on the value of synthesis methods in addressing the main aims of the study. The synthesis of outcomes across all included papers will be organised to address key aims of the study.

Using this step-like process will help to clarify the level of evidence in each developed theme and enhance the rigor of the review (Munn *et al.* 2022). Using this approach should also help identify exemplars of good, advanced practice in the care delivery of Learning Disability and Autism.

4.0 Stage 5: Collating and presenting the results

The report of results will be illustrated in a thematic table, so readers can have confidence that the organisation and interpretation of papers in each theme are grounded in the data. There will also be clear reference to where, what, and how many papers have contributed towards the results in each theme. Dissemination will target the advanced practice professional audience, through conferences and publications.

4.1 Ethical Considerations

There are no specific ethical considerations for this review.

4.2 Validity and reliability

Methods of scoping review (Munn *et al.* 2022) will provide a focus for the scoping review of available evidence. This scoping review will aim to provide new insight into advanced practice. The use of review methods and a clear report of decision-making will ensure a transparent review process. The use of the PRISMA-ScR framework (Tricco *et al.* 2018) will provide a systematic process for reporting

the review of evidence and enhance reliability. Elements of method-specific reporting guidelines for specific streams of evidence will be used as required to enhance rigour.

Discussion

This timely review is designed to offer insight into advanced practice developments for the specific area of learning disability and autism. The aims of the planned scoping review are designed to contextualise not only the journey towards advancing practice but also evidence and perceptions of impact of advancing practice in care delivery. We anticipate this scoping review will be of interest to all health professionals with an interest in advanced practice, including patient groups and policy makers.

Limitations

Scoping review methodology has evolved and embraced rigorous and systematic process of similar reviews, such as integrative review. Applying a step-like process and using PRISMA-ScR to guide reporting should enhance validity and reliability. However, it is possible that not all relevant data will be captured in the search process. Interpretation and evaluation of data intentions are to avoid bias, but there is always an element of subjectivity and multiple perspectives of the review team which could be seen as a limitation.

Conclusions

This review is designed to offer insights not previously explored in this developing area of practice. Given the scope of the review and the international interest in advanced practice we hope to disseminate our work widely. The findings will offer a nuanced insight to advanced practice in learning disability and autism and provide direction for future research.

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