



BMJ Open Barriers to and enablers of the transition from child and adolescent to adult mental health services for autistic young people and/or those with attention deficit hyperactivity disorder: protocol for a scoping review

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ABSTRACT

Introduction Autistic young people and/or those with attention deficit hyperactivity disorder (ADHD) who have co-occurring mental health conditions experience significant challenges when transitioning from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). However, barriers and facilitators to this service transition are poorly understood for this population. This scoping review aims to synthesise the available evidence on barriers and enablers to the transition from CAMHS to AMHS for autistic young people and/or those with ADHD.

Methods and analysis Arksey and O'Malley's six-step framework for scoping reviews will be used. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist will guide the reporting of this review. Electronic databases of Medline, PsycINFO, CINAHL, Scopus, ProQuest Central and Google Scholar will be searched for relevant articles published in English with no date limitations. Title, abstract and full-text screening will be completed by two independent reviewers. Studies will be eligible for inclusion if the article focuses on (1) adolescents and/or young people (aged 18–24) with a primary diagnosis of autism spectrum disorder and/or ADHD (population) and (2) describes factors associated with service or care transitions (concept) (3) from CAMHS to AMHS (context). Study quality will be evaluated using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. Data describing the factors that enable or inhibit the transition from CAMHS to AMHS will be extracted and synthesised using the Bronfenbrenner's social ecological model as a framework for organising and reporting results.

Ethics and dissemination Ethics approval is not required. Findings will be disseminated via peer-reviewed publications and presented at conferences.

Trial registration number <https://doi.org/10.17605/OSF.IO/BZPQF>.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review will synthesise the literature on barriers and enablers to the transition from child and adolescent mental health services to adult mental health services for both autistic young people and/or those with attention deficit hyperactivity disorder (ADHD) with co-occurring mental health conditions.
- ⇒ A methodological strength is the use of a conceptual framework to synthesise the data on barriers and enablers, allowing for the systematic identification of gaps in the evidence base and research.
- ⇒ This scoping review is specific to the target population (autistic young people and/or those with ADHD) and results may not be applicable to young people with other types of neurodivergence.
- ⇒ The review is restricted to studies published in English, which may introduce a bias towards mental health systems in high-income countries.

INTRODUCTION

Globally, one in seven young people between 10 and 19 years of age experience a mental health condition,¹ of which depression and anxiety are the most common. Approximately 70% of adolescents with a mental health condition experience challenges that persist into adulthood² and consequently will require ongoing mental health services and support beyond adolescence.³ Importantly, neurodivergent adolescents are at greater risk for the onset and persistence of these mental health conditions than their neurotypical peers.⁴ Neurodivergence is an umbrella term that refers to lifelong neurological conditions such as autism, attention deficit hyperactivity disorder (ADHD), as well as learning difficulties such as dyslexia, dyspraxia and dyscalculia.^{5 6} Like their neurotypical peers, the

most common mental health condition among neurodivergent young people is anxiety and depression.^{4,7-9} In the US National Survey of Children's Health (2016–2019), the prevalence of anxiety and depression was significantly higher among autistic children with co-occurring ADHD than their neurotypical peers.⁴ Given the high prevalence of these conditions among neurodivergent young people, they are likely to comprise a substantial proportion of young people who require mental health services extending from adolescence to adulthood.⁴

The transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) can be difficult for all young people.^{2,10} However, it has been suggested that this service transition is more challenging for autistic young people and/or those with ADHD.⁵ One possible reason why autistic people and/or those with ADHD experience increased difficulty with this transition is that they tend to experience change as unsettling and anxiety provoking.⁵ This may contribute to the higher rates of care disruption and poorer experiences of the service transition process reported for this patient population.^{5, 10-15} Consequently, autistic people and/or those with ADHD are likely to require neurodiversity-specific support to reduce the impact of the barriers and maximise the factors that enable their transition from CAMHS to AMHS.

A small number of systematic and scoping reviews on barriers and enablers associated with neurodivergent young people's transition from CAMHS to AMHS have been conducted.¹⁶⁻¹⁹ These reviews reported lower than anticipated rates of transition from CAMHS to AMHS and high rates of disengagement from services for neurodivergent young people.^{16, 18} They identified several service and system-level barriers to the transition process including a lack of awareness among young people and carers of AMHS. Furthermore, CAMHS providers appear to have a lack of knowledge of how to facilitate the transition, which may be due to the absence of protocols for supporting this process.^{16, 19} These literature reviews also highlighted other barriers including a complex transition process with stringent eligibility criteria to access adult services, lack of support for neurodivergent young people during this period and inadequate support due to services not being able to accommodate the specific needs of neurodivergent young people.¹⁶⁻¹⁹

Despite these findings, the previous literature reviews are limited in number and scope, highlighting the need for further research on this topic. More specifically, the four previous literature reviews of barriers and enablers associated with the transition from CAMHS to AMHS for neurodivergent young people¹⁶⁻¹⁹ which limited their population focus to ADHD, neglecting to include autistic young people and those with other forms of neurodiversity. Additionally, these reviews focused on treatment continuation for the ADHD diagnosis only, with none of them examining the continuity of care for co-occurring mental health conditions such as anxiety or depression. Finally, three of the literature reviews were limited in

their methodology, including only qualitative studies.¹⁶⁻¹⁸ Consequently, previous reviews have limited utility for informing the strategies to support neurodivergent young people in navigating the transition from CAMHS to AMHS. In addition, no previous literature review has used a conceptual framework to guide evidence synthesis, limiting the critical reflection on the current evidence gaps that require further investigation. An updated and conceptually grounded scoping review that responds to these limitations is warranted. Given the aim of this review was to determine the extent and nature of literature on the transition from CAMHS to AMHS for neurodivergent young people, and identify gaps in knowledge, a scoping review was determined to be the most appropriate approach. Drawing on the socioecological framework,²⁰⁻²² this review aims to identify and synthesise available literature on barriers and enablers to the transition from CAMHS to AMHS. A synthesis of the research evidence on transition barriers may be useful for mental health system planners and policymakers as they develop guidelines for improving equity of access to mental health services for young people with complex needs.^{11, 23}

Conceptual framework

This review will use Bronfenbrenner's social ecological model (SEM)^{20, 21} in conjunction with some constructs used in the Social-ecological Model of Adolescent and young adult Readiness for Transition (SMART) framework²⁴ to inform the process when evaluating the barriers and enablers to the transition from CAMHS to AMHS. The SEM framework²² conceptualises health and health-seeking behaviours as arising from the complex interplay between a person and their environment.²⁰⁻²² According to this framework, barriers and enablers to healthcare can exist at the intrapersonal (individual beliefs, practices, knowledge and behaviours), interpersonal (immediate formal and informal social supports and relationships, eg, family, friends or work colleagues), community (extended formal and informal social support systems that impact the person, eg, workplace or community services), institutional (policies and organisation of services that affect how treatment is provided to the person) and policy (local, state, national or global policies that influence allocation of resources and accessibility to services) levels. Similarly, the SMART framework acknowledges the dynamic interplay between an individual and their environment by reviewing their sociodemographics, access to healthcare, medical history and how these elements contribute to their knowledge, skills, values, goals, relationships and psychosocial functioning between those involved.²⁴ In the context of this proposed study, those involved will be the neurodivergent young person, their caregivers and healthcare providers.²⁴

In both frameworks, factors at one level influence factors at another.²⁰⁻²² The strength of the frameworks is that it allows for a comprehensive understanding of a broad range of factors that influence healthcare utilisation to be developed.²⁰⁻²²

The SEM has been applied widely to examine the barriers and enablers to health services, including public health promotion, geriatric preventative health, colorectal cancer prevention, end-of-life care for older people, access to health services by sex workers, promoting the health of refugee women, breastfeeding, violence prevention and employment for people with disabilities.^{25–32}

METHODS AND ANALYSIS

This proposed study will explore and synthesise the literature on the barriers and enablers to transitioning from CAMHS to AMHS for neurodivergent young people. While recognising that there are a multitude of neurodiversities, this review will focus on the transition from CAMHS to AMHS for autistic young people and/or those with ADHD, as these are the most common forms of neurodivergence reported in the child and adolescent mental health literature.⁵

The proposed study will use Arksey and O'Malley's methodological framework for conducting a scoping review.³³ This framework involves six steps: (1) identifying the research question; (2) identifying relevant literature; (3) selecting appropriate studies; (4) extracting, analysing and charting the data; (5) synthesising and reporting on the data; and (6) consultation with autistic young people and/or those with ADHD and co-occurring mental health conditions advisory group.³³ This review will be

reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.³⁴ This protocol was pre-registered with the Open Science Foundation on 18 September 2023 (<https://doi.org/10.17605/OSF.IO/BZPQF>).

Research question

The planned review aims to describe what *barriers and enablers to the transition from CAMHS to AMHS exist for autistic young people and/or those with ADHD*. This research question has defined the population (young people with mental health conditions, who are autistic and/or have ADHD), the concept (care/service transition) and the context (transition from CAMHS to AMHS).

Identifying relevant studies

The proposed search strategy was developed in consultation with the Faculty of Health Sciences (Curtin University) Librarian and guided by the Peer Review of Electronic Search Strategies checklist.³⁵ The draft search strategy, including a full list of search terms, can be found in [table 1](#). A multistep approach to searching the literature will be adopted. First, electronic databases, including Medline (Ovid), PsycINFO (Ovid), ProQuest Central, Scopus and Google Scholar, will be searched for primary texts published in English, with no date limitations. To include studies that reflect the changes in terminology

Table 1 Initial search strategy optimised for Medline

Search terms	
1	(neurodiverse* or autism* or asperger* or ASD* or 'pervasive developmental disorder*' or PDD* or ADHD* or ADD* or 'attention deficit disorder*' or 'attention deficit hyperactivity disorder*').mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
2	Autism Spectrum Disorder/ or Asperger Syndrome/ or Autistic Disorder/ or Attention Deficit Hyperactivity Disorder/ or Attention Deficit Disorder/ or Pervasive Developmental Disorder/ or Neurodiverse/
3	1 or 2
4	('mental health services*' or 'child and adolescent mental health services*' or CAMHS or 'youth mental health services*').mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
5	Mental Health Services/
6	4 or 5
7	(transition* or transfer* or handoff* or 'hand off*' or handover* or 'hand over*').mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
8	(teen* or youth* or adolescents* or 'young people*' or 'young adult*' or 'young person*').mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
9	3 and 6 and 7 and 8

over the years, search terms such as Asperger's syndrome and pervasive developmental disorder—not otherwise specified have been included even though they have since been subsumed under autism spectrum disorder in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.

Lastly, the reference lists of all included studies will be checked for additional studies that may have been missed in the searches. Spidercite (<https://sr-accelerator.com/#/spidercite>) will be used to conduct forward and backward citation checks of included studies to identify any additional studies missed in the database searches.

Trial searches will be conducted to assess whether relevant literature can be identified using the proposed strategy. The search strategy will use Medical Subject Headings terms, Boolean logic and operators ('and', 'or', 'not'), proximity operators and filters to improve precision. After an initial trial search, the research team will work with the Health Sciences Librarian to review the search strategy, to improve the precision of searches and to tailor it for the selected electronic databases.

Study selection

All articles identified by the database searches will be imported into EndNote and an Excel spreadsheet for screening. After removing duplicates, the article screening will occur in two stages: first, title and abstract screening, and second, full-text review. Two reviewers will independently screen and review the titles and abstracts of the identified publications against the eligibility criteria described in [table 2](#).

All eligible papers and those whose relevance is unclear based on the title and abstract will be included in the next stage of full-text review, which will be screened by two reviewers independently. Where the study team is unable to access full-text articles, they will email the authors to request a copy of the full-text article for screening. Authors will be contacted three times before a non-response is recorded.

Only full-text papers that meet the inclusion criteria and examine the transition from CAMHS to AMHS in adolescents and/or young people with a primary diagnosis of autism and/or ADHD will be included for data extraction. Additionally, the reference lists of the included full-text

articles will be screened against the inclusion criteria and considered for full-text screening.

At both the title/abstract and full-text screening stages, any discrepancies between the decisions made by the two reviewers will be discussed and resolved by a third member of the research team. Reasons for exclusion of full-text articles will be recorded and presented in a PRISMA scoping review flow diagram.³⁴ The intercoder agreement will be calculated and presented in the final manuscript paper.

Data charting and extraction

The following categories of data will be extracted from each article: study characteristics (year of publication, study design, sample size, study setting); study population (demographic characteristics, diagnoses); barriers and enablers influencing the transition process; and concepts and indicators used to assess barriers and enablers. A data extraction form will be developed and piloted on the first five included articles and revised as required. Data extraction will be completed independently by two reviewers. They will meet to discuss and resolve any discrepancies with inputs from a third research team member where required.

After extracting the data, the research team will meet to discuss and categorise each reported barrier and enabler as either an intrapersonal, interpersonal, community, institutional or policy-level barrier or enabler, in keeping with the SEM.²⁰

Collating, summarising and reporting of results

A narrative synthesis approach³⁶ will be used to describe, summarise and interpret the findings of included studies. As quantitative and qualitative studies will be included in this review, we will use a results-based convergent synthesis approach³⁶ in which quantitative and qualitative findings will first be presented separately in tables before being collated into themes related to the SEM.^{20–22} First, a preliminary synthesis will be undertaken, in which we will list and present the results of each included study in tables. Next, the research team will meet to discuss these results and categorise each reported barrier and enabler as either an intrapersonal, interpersonal, community, institutional or policy-level barrier or enabler, in keeping with the SEM.²⁰ The team will discuss these results again

Table 2 Study selection eligibility criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> ▶ Population: adolescents and/or young people (aged 18–24) with a primary diagnosis of autism and/or ADHD. ▶ Concept: service/care transition between CAMHS and AMHS. ▶ Setting: mental health services. ▶ No date limitation. ▶ Qualitative and quantitative studies. 	<ul style="list-style-type: none"> ▶ Forms of neurodivergence other than autism or ADHD. ▶ Studies that do not report on individual study data, that is, systematic reviews, scoping reviews, literature reviews, case reports, congress reports, clinical practice guidelines and editorials. ▶ Non-peer-reviewed studies. ▶ Studies that were not written in English.
ADHD, attention deficit hyperactivity disorder; AMHS, adult mental health services; CAMHS, child and adolescent mental health services.	

and summarise and collate findings into themes related to individual, interpersonal, community, institutional and policy factors that inhibit and enable the transition process from CAMHS to AMHS. Where findings are unclear or do not fit into the SEM framework, the research team may propose additions to the SEM framework to incorporate these factors for this topic.

The quality of the included studies will be examined and recorded by two reviewers independently using Kmet *et al's*³⁷ Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.³⁷ As per the study selection stage, a third member of the research team will discuss and resolve any discrepancies between the decisions made by the two reviewers independently.

Patient and public involvement

An advisory group with lived experience of mental health services and neurodivergence was consulted before the research team embarked on the scoping review to ensure the relevance of the research question. The team will present collated findings from this review to this advisory group to elicit feedback on interpreting study findings in line with their lived experience.

ETHICS AND DISSEMINATION

Ethics approval is not required for this scoping review. Findings will be disseminated via peer-reviewed publications and presented at conferences.

DISCUSSION

This scoping review will explore the barriers and enablers to the transition from CAMHS to AMHS for autistic young people and/or those with ADHD. Unlike previous literature reviews, which focused on a single type of neurodivergence (typically ADHD), the proposed review will examine the transition from CAMHS to AMHS for both autistic young people and/or those with ADHD. Second, unlike previous literature reviews, which were not guided by a conceptual framework, this review will use the SEM with some components of the SMART constructs to organise, synthesise and interpret the literature. Using the SEM will facilitate a systematic approach to identifying the potential gaps in the evidence base. Third, the previous literature reviews have focused on the transition from child to adult services to ensure continued treatment for ADHD and did not focus on continued support for co-occurring mental health conditions like anxiety. This review responds to these gaps by examining continued treatment for co-occurring mental health conditions among young people who are neurodiverse. As a result, this review has the potential to extend the findings of previous reviews by offering insights into the barriers experienced by a broader range of neurodivergent young people and by offering an approach to conceptualising the known barriers and facilitators to the transition.

The proposed scoping review will have some limitations. First, based on previous literature reviews,^{16 19} there may be few studies examining the transition from CAMHS to AMHS for autistic young people and/or those with ADHD, therefore possibly limiting the number of articles to be included in the proposed scoping review. If this is the case, it will indicate the need for further research. The exclusion of articles in languages other than English may introduce a bias towards mental health systems in high-income countries. The exclusion of studies not published in the English language will limit the understanding of barriers and enablers to the transition process in those countries. Consequently, findings from this review may not be relevant to non-English-speaking countries where cultural factors and different ways of organising mental health systems may impact the service transition process. In addition, the planned review will focus on autistic people and/or those with ADHD, as such results may not apply to other forms of neurodiversity, such as intellectual disability or dyslexia, dysgraphia and dyscalculia.

Despite these limitations, this review has the potential to offer a valuable addition to the literature. Notably, it will be the first review to consult with an advisory group with lived experiences of being autistic and/or having ADHD who have transitioned from CAMHS to AMHS to ensure the relevance of the review. The results of this planned scoping review will broaden the understanding of the barriers that need to be overcome and the enablers that can be leveraged to facilitate the transition from CAMHS to AMHS for neurodivergent young people. Additionally, the planned review will identify gaps in the knowledge base that will help guide future research on this topic.

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Contributors KT is responsible for the overall content (as guarantor). KT led the design and conceptualisation of this review protocol and drafted it with support from BM, CT, EH and EP. KT also led the development of the search strategy, and CT, EH and BM supported the refinement of the search strategy and data extraction forms. All authors provided feedback on the manuscript and approved the publication of this protocol manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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