Early mental health intervention and supported self-care for LGBTQ+ young people in the UK: a mixed-methods study

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Scientific summary

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Scientific summary

Background

Lesbian, gay, bisexual, trans, queer/questioning, plus (LGBTQ+) young people report significantly higher rates of depression, self-harm, suicidality, and poor mental health than cisgender and heterosexual youth. Despite this mental health inequality, LGBTQ+ young people have elevated unmet mental health needs compared to their cis-heterosexual peers and underuse mental health services. In addition to the underutilisation of mental health services, studies suggest LGBTQ+ youth have poor overall experience of mental health services and school-based support. Problems highlighted are the limited staff understanding of LGBTQ+ issues and minority stresses, fear of being 'outed' and exclusion from the decisions made about their care.

The UK evidence base examining LGBTQ+ young people's early intervention mental health support needs and services is very limited. Consequently (and despite this manifest inequality and underutilisation of mental health services), there is no UK research on how to develop appropriate mental health early intervention and supported self-care provision to this vulnerable group. This study delivers rigorous evidence to fill this gap, address this inequality and fulfil the requirements of NHS mental health strategic direction.

Objectives

- To produce a synthesis of the evidence on mental health early intervention services and self-care support to LGBTQ+ young people.
- To identify service models for mental health early intervention and supported self-care which are accessible and acceptable to LGBTQ+ young people.
- To develop a programme theory of how, why and in what context mental health early intervention services and self-care support work for LGBTQ+ young people.
- To increase understanding of LGBTQ+ young people's access to and navigation of formal and informal mental health early intervention services and self-care support.
- To generate commissioning guidance (including service costs) on mental health early intervention and supported self-care services for LGBTQ+ young people.

Methods

This research project was a multi-methods theory-led case study evaluation with three distinct stages.

Stage 1: meta-narrative review

This was a systematic review of existing literature concerning early mental health interventions and selfcare support for LGBTQ+ young people. The meta-narrative review on mental health early intervention support for LGBTQ+ youth aimed to develop a theoretical framework to explain effective mental health support. Using the RAMESES standards for meta-narrative reviews, we identified studies from database searches and citation-tracking. Two research team members applied the inclusion/exclusion criteria and quality assessment tool. Data extraction and synthesis were conducted through conceptual coding in Atlas.ti in two stages: (1) conceptual mapping of the meta-narratives and (2) comparing the key concepts across the meta-narratives to produce a theoretical framework.

Stage 2: service mapping

This stage of the study investigated and mapped current LGBTQ+ youth-specific mental health service provision across the UK. An online and offline service mapping exercise was undertaken to locate current mental health early intervention and self-care support for LGBTQ+ young people in the UK. Data collection was desk based and basic details (e.g. target population, mode of delivery, theoretical approach) of potential services obtained from any source were extracted and entered into an Excel spreadsheet. The service mapping data were then organised using these dimensions. A full summary of the mapping data was then used through framework analysis to produce a typology of services. Case study selection criteria were applied to the mapping data set to select 12 case study sites from across the service typology for stage 3.

Stage 3: case study evaluation

The third stage of the research was a theory-led case study evaluation of 12 case study sites to establish the components of appropriate, quality early intervention mental health and self-care support for LGBTQ+ young people. This study received ethical approval from NHS North West – Greater Manchester Central Research Ethics Committee.

The 12 case studies were purposively selected from services identified in Stage 2 (service mapping) to reflect the different dimensions of the Stage 2 service typology. Data were collected from key stakeholders in each of the case study sites (n = 12) to examine factors such as service acceptability, gaps in provision, barriers/facilitators to access, views on service improvement and encouraging access/ engagement. At each case study site, data were collected via (1) online interviews with LGBTQ+ young people, family members and service staff; (2) documentary review; (3) non-participant observation; and (4) service cost. Case study evaluation is a theory-driven evaluation methodology, and therefore, we drew on Yin's (2018) explanation-building data analysis strategy that is designed for case studies with multiple case sites and aims to build a general explanation that fits each individual case. We used a four-stage data analysis strategy that was both deduction/inductive and within-case/cross-case.

Patient and public involvement

The aim of the patient and public involvement (PPI) strategy was to involve LGBTQ+ young people, the public, service providers and commissioners from the outset to help us to ask the right questions, in the right way and gain an in-depth rigorous understanding of the mental health support needs of LGBTQ+ young people. The PPI strategy involved three strands:

- 1. Charlie Tebrook was a member of our research team. Charlie is a LGBTQ+ young person with direct experience and knowledge of mental health services and the issues faced by LGBTQ+ young people.
- LGBTQ+ young people, aged 12–25 years, from Allsorts, Brighton, The Proud Trust, Manchester, ARC Darlington and YPAS (Liverpool) contributed through face-to-face/online meetings with researchers and an online forum.
- 3. A project advisory group of a range of stakeholders with experience in service delivery that involved experts in Child and Adolescent Mental Health Services (CAMHS), mental health commissioning and charity sector LGBTQ+ support services.

Key activities our PPI contributors were involved with included, for example:

- Design of the website and research materials
- Terminology, for example 'LGBTQ+' acronym
- Inclusion criteria such as age range
- Managing risk and taking care of participants
- Identifying ways of describing the project in accessible formats to facilitate informed consent for participants

- Development of fieldwork materials and reorientation of fieldwork approach due to COVID-19 disruptions. Materials included consent forms, demographic forms including options/language, project information (written and audio-described video material) and interview resources (including picture prompts)
- Trialling of WhatsApp chat methodology with Charlie Tebrook and online consultation with LGBTQ+ young people (age 15–18 years) to finalise data collection resources
- Validation of research analysis and interpretations with LGBTQ+ young people through three group visits (SAYiT × 2, Gyro at YPAS) and consultation on outputs that would be useful to young people
- Specific steering group devised for consultation on production of NHS commissioning guidelines

The impact of having a PPI strategy integrated throughout the study design meant that PPI activities were central to the research design and delivery. It shaped resources, methodological approach, validated findings and guided the way we have presented and disseminated outputs.

Results

Stage 1

In total, 2951 titles and abstracts were screened, and 200 full papers reviewed. Eighty-eight studies were included in the final review. Stage 1 synthesis identified three meta-narratives: psychological, psychosocial and social/youth work. Stage 2 synthesis resulted in a non-pathological theoretical framework for mental health support that acknowledged the intersectional aspects of LGBTQ+ youth lives and placed youth at the centre of their own mental health care. The study of LGBTQ+ youth mental health has largely occurred independently across a range of disciplines such as psychology, sociology, public health, social work and youth studies. The interdisciplinary theoretical framework produced indicates that effective early intervention mental health support for LGBTQ+ youth must prioritise addressing normative environments that marginalises youth, LGBTQ+ identities and mental health problems.

Stage 2

One hundred and eleven services were identified across the search strategies, the majority in urban settings in England. There were three significant characteristics of LGBTQ+ adolescent mental health UK provision. First, there was an absence of mainstream NHS support that specifically addressed the needs of LGBTQ+ young people. Second, the majority of LGBTQ+ youth mental health support was provided by voluntary/community organisations. Third, there was an emerging model of service based on collaborative working between NHS trusts and community/voluntary organisations.

The results of this mapping exercise suggest that there is a reliance on the voluntary/community sector to provide mental health provision for LGBTQ+ young people. Furthermore, there was a distinct divergence in the approaches of the support provided by the voluntary/community sector and those from within the NHS. The affirmation of LGBTQ+ identities that is pivotal to the support provided by voluntary/community services contrasted with the 'treating everyone the same' approach prevalent in mainstream service provision.

Stage 3

Our analysis of the data from an evaluation of the case study suggests that an intersectional, youthrights approach to early intervention mental health support for LGBTQ+ young people is the most appropriate way of supporting poor mental health in this population group. Youth rights should underpin the delivery of mental health support for LGBTQ+ young people to address the multiple marginalisation, isolation and stigmatisation that LGBTQ+ young people may experience and to enable them to make informed independent decisions about their own bodies and lives, and for the right to freedom of safe self-expression to be upheld. The model of early intervention mental health support for LGBTQ+ young people that we have produced contains 13 principles (see *Chapter 5*) that are necessary to the provision of mental health support, and to improve access to, engagement with, and navigation of mental health services. To improve mental health support to LGBTQ+ young people, service provision must:

- acknowledge isolation and hopelessness as major factors impacting LGBTQ+ young people's mental health.
- develop connectedness, self-expression and hope for the future on young people's own terms.
- acknowledge that LGBTQ+ young people are more likely to access mental health support when they
 can see clearly that the service is safe, knowledgeable and affirming, and when the support offered
 fits into their lives.
- provide a safer service.
- ensure that young people feel recognised, respected and affirmed.
- acknowledge that LGBTQ+ young people have better experiences of mental health services when they feel ownership of the support space and can build trust with the people providing support.
- ensure mental health provision supports LGBTQ+ young people's informed independent decision-making.
- create spaces that centre LGBTQ+ young people.
- foster trusting relationships.
- develop agency and informed independent decision-making.
- centre asset-based emotional support.

Each principle in the model should be viewed with all component parts *interacting*. These principles of support are designed to guide mental health services in a variety of settings – education, clinical, community – and can be operationalised in a number of ways.

Conclusions

In the UK, a rights-based approach to mental health service provision is not prominent or mainstream. There is very little evidence that young people's rights are of concern in the realm of mental health services. Research suggests that current practice in CAMHS in the UK highlights some disparities in services which result in questions about human rights for young people. Key concerns have been identified around children's rights to access mental health services, information, participation in decision-making and non-discrimination of vulnerable groups suggesting current practice approaches fall short of a rights-based framework.

In addition, at the time of this report being written, LGBTQ+ young people are facing active legislative and policy attacks on their human rights. Legislative attacks have placed young people's access to gender-affirming health care at risk. Within this uncertain landscape, it is more important than ever to centre and uphold children and young people's human rights in mental health services and support.

This study provides the first large-scale theory-led evaluation of early intervention mental health support for LGBTQ+ young people with common mental health problems. The resulting intersectional, youth-rights model directly provides the means to tackle the elevated prevalence of mental health problems in this group of young people. It provides evidence on ways of improving access to, navigation of, and engagement with mental health support, to improve LGBTQ+ young people's mental health.

Further research on the *implementation* of an intersectional, youth-rights approach to early intervention mental health support for LGBTQ+ young people with mental health problems is required.

Study registration

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This article

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