**A referrals audit and qualitative analysis of staff experience of referrals in a specialist community learning disability service**

2980 words (including references, excluding title page and abstract)

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Specialist community teams are set up to support people living with Learning Disability (LD) who are unable to access mainstream mental health (MH) teams with reasonable adjustments. National guidance is available to guide best practice in making reasonable adjustments, to support increased access to mainstream services. This audit of referrals into a specialist Community LD team, aimed to establish referral acceptance rates and reasons for referral rejection. Total referrals and referrals made specifically from mainstream MH teams were investigated. A focus group explored LD clinicians' experiences of the referral process and criteria in the context of working alongside mainstream MH teams. A lower acceptance rate of referrals from mainstream MH teams than overall acceptance rate was found, and differences in the reasons for rejection were highlighted. No LD diagnosis in the referral was the most common rejection reason for mainstream MH team referrals. Thematic analysis highlighted four themes of clinician's experiences which focused on: referral point struggles; service limitations; lack of diagnostic clarity; and attempts to bridge a gap between services. Recommendations include review of the referral process, joint working protocols, clarification of remit and dissemination of shared learning.

*Keywords:* Learning Disability; referrals; mental health; clinician experience

## Introduction

The Department of Health (DOH) define learning disability (LD) as a condition characterised by reduced intellectual ability and functional daily challenges starting before adulthood, with ongoing developmental impact. People living with LD are known to experience inequalities, spanning areas of housing, employment, and health care, in particular experiencing exclusion from services (DOH, 2001, 2009). Whittle et al (2019) conducted a systematic literature review of LD access to mental health (MH) services specifically, concluding several barriers to access, including organisational obstacles, lack of services, and absence of appropriate service model consensus.

Following the revelation of systematic abuse at an inpatient hospital in 2011, a commitment to improving care for people with LD in the community has been pledged (DOH, 2012). The resulting Transforming Care agenda has been supported by a national plan which provides a framework for commissioning community services (NHS England, 2015a). There are now 48 specialised commissioning groups in the UK, providing local, community services for people with LD.

NHS adult community MH teams are commissioned to provide multidisciplinary support to adults with MH needs (Rethink Mental Illness, 2021). Services have a legal duty under the Equality Act to make reasonable adjustments promoting LD accessibility, and should implement these in a proactive manner (Public Health England, 2020). The Green Light Toolkit provides examples of adjustments and includes an audit tool for service self-assessment (Foundation for People with Learning Disabilities et al., 2004). Reasonable adjustments involve the proactive adapting of services to support accessibility for all; examples of reasonable adjustments include having shorter or longer appointment times; providing easy-read information; and using LD specific tools such as Hospital Passports. Sometimes, mainstream services may not be able to sufficiently meet the needs of some people with LD, and in these instances, specialist commissioned services can provide support.

Chaplin et al (2009) highlight several gaps in MH service provision, including for those living with LD. They propose these gaps arise from some groups of people being excluded from both

mainstream and specialist services, with a lack of clarity regarding which service is best suited to meet the person's needs. This may lead to inappropriate service referrals and referrals 'bouncing' between services, with neither mainstream nor specialist services believing they are best suited.

## Rationale and Aims

Despite the national focus on promoting equal access to support for people with LD, a problem remains in which people may be left without MH support; provided support by an inappropriate service; or have lengthy waits due to the time taken to agree the appropriate service. Difficulties in establishing the appropriate support for people with LD can also impact upon the capacity of mainstream and specialist services to provide clinical interventions, as this process can be complex and time consuming.

The current project aimed to explore referrals within one specialist LD team to better understand problems faced with such referrals. Due to the emphasis on the gap between mainstream and specialist services, particular focus was given to referrals made from mainstream MH teams. Questions posed were:

- What are the acceptance rates of referrals into the specialist LD service over a 12 month period (September 2019 – August 2020)from:
    a) All referral sources?
    b) Mainstream MH teams?
- What are the reasons for referrals being rejected?
- How do clinicians experience the referral process and criteria for MH provision for people with LD?

## Methodology

A mixed methods design was adopted, consisting of a quantitative audit and a qualitative clinician focus group.

Audit data included: referral source and date, referral outcome, reason for acceptance/rejection, and demographics. All referrals between September 2019 – August 2020 were included, (n= 502), and mainstream MH referrals were looked at in more detail, n=26. These were extracted from existing data stored on electronic recording systems.

Focus group participants were clinicians working in any clinical role within the specialist LD team; five participants opted into the study, however three attended the focus group. Attendees were qualified clinicians in psychology and psychiatry. The group was facilitated online for 90 minutes, utilising a semi-structured schedule.

A 30-minute consultation took place with a clinician working within a mainstream MH team to support understanding from this perspective; although this was not analysed as part of the data set.

## Ethics

The project was registered with the trust audit and clinical effectiveness team, confirming its remit as a clinical evaluation project.

Informed consent was sought via an information sheet, and debriefing was offered directly after the group. Care was taken in the development of the interview schedule to encourage discussion of strengths and challenges, in order to allow opportunities to hear both positive and difficult experiences in this field.

### Data analysis

**Audit.** Referral data was imported into Microsoft Excel and analysed using descriptive statistics. Referrals were organised in four tabs reflecting the research aims:

- All referrals
- Accepted and rejected referrals from mainstream MH services
- All rejected referrals

- Rejected referrals from mainstream MH services

Acceptance rates were calculated using Excel formulas. Reasons for rejection were explored for all rejected referrals and seven distinct reasons were identified. Rejected referrals were coded 1-7 indicating the rejection reason and percentage rates for each reason were calculated.

**Focus group.** The group recording was transcribed verbatim and analysed using the six-step thematic analysis process outlined by Braun and Clarke (2006). This was done in an inductive fashion as there were no pre-existing codes established prior to analysis. Initial thoughts from the transcript were noted, then data was coded and sorted into themes and sub-themes. The process was recursive in that the researcher moved back between the data, codes, themes, and sub-themes throughout. A thematic map was devised to understand the relationships between themes and subthemes and these were checked for credibility in a supervisor-led research session.

The analysis was situated within a critical realist epistemological stance (Bhaskar, 1989) in that there was an assumption that the data was informative of a 'reality' about the service and referral process. However, with recognition that the data represented participants perspective and researcher interpretation, which are influenced by context and experience.

## Results

Compared to the overall acceptance rate of 68%, the acceptance rate for referrals made by mainstream MH teams was lower (31%) (Table 1). Other sources of referrals included GP surgeries, care providers, and social care. There were differences in the proportion of the seven distinct rejection reasons in MH mental health referrals than in the overall referrals. From these teams, the most common reason for rejection was that there was no LD diagnosis (Table 2). There were no instances of referral process errors in referrals made from mainstream MH teams.

**Table 1**

*Referral numbers and acceptance rates into the specialist LD service*

| | All referrals | Referrals from mainstream MH teams |
|---|---|---|
| Total referrals | 502 | 26 |
| Number of accepted referrals | 342 | 8 |
| Number of rejected referrals | 160 | 18 |
| Acceptance rate | 68% | 31% |

**Table 2**

*Percentages of reasons for rejection from all referrals and referrals from mainstream MH services.*

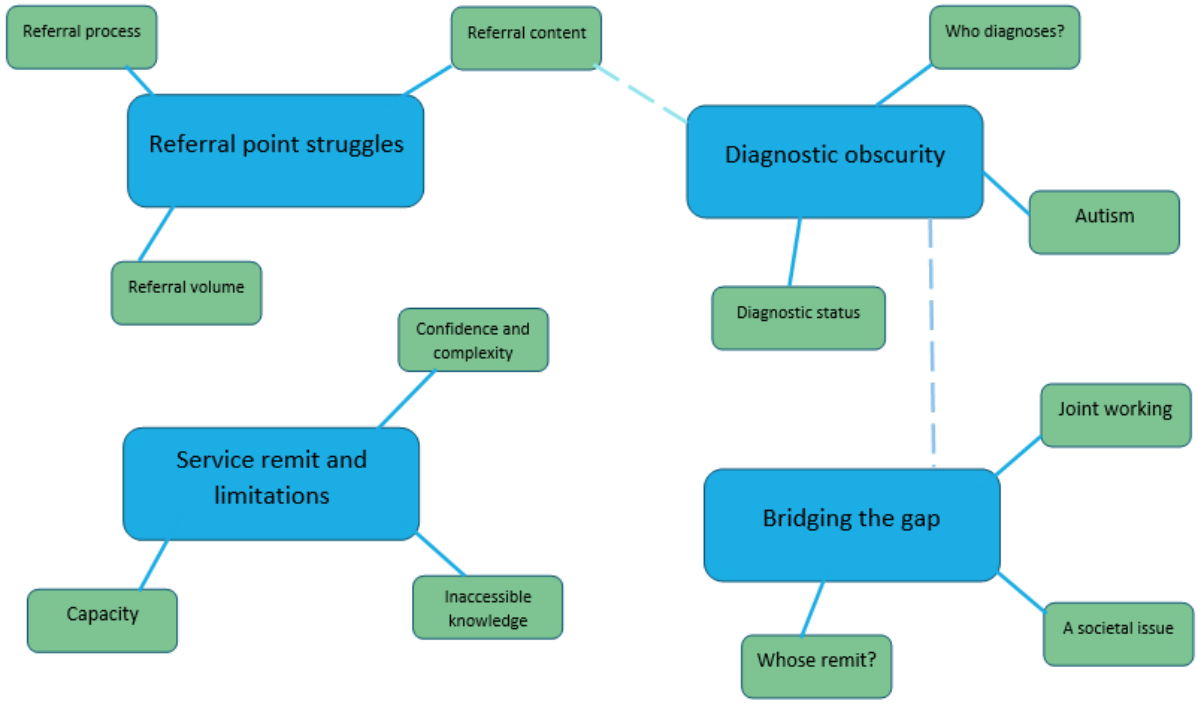
| Reason for rejection | % of all rejected referrals | % of mainstream MH team rejected referrals |
|---|---|---|
| Social care intervention more appropriate | 26 | 17 |
| No specialist health need | 8 | 17 |
| Another specialist service better suited | 24 | 6 |
| Able to access a mainstream service | 11 | 17 |
| Referral process error or issue | 11 | 0 |
| Non-commissioned area | 9 | 17 |
| No learning disability diagnosis | 11 | 28 |

The focus group findings expand on these outcomes; themes and sub-themes are visually represented in Figure 1. Ambiguity and confusion about diagnostic criteria were highlighted as a focal point when considering referrals from mainstream MH teams, which complements the finding of this being the main rejection reason in the audit. Group data highlighted questions about who

should diagnose LD and a lack of understanding of diagnoses such as mild/borderline LD and Autism. Further themes included experiences of service remit limitations, challenges at the point of referral and attempts to bridge a gap that was discussed as being apparent on both a service, and societal, level.

**Figure 1**

*Thematic map of themes and sub-themes*




**Theme: Referral point struggles**

Challenges were identified at the point of referral triage, including struggles with the process, content, and volume of referrals; and the complex nature of obtaining the required information.

*"…services need to have conversation about referrals, you know, people are not always going to fit in the boxes that are so neatly created"*

**Theme: Diagnostic obscurity**

A lack of clarity regarding diagnosis was experienced as a challenge. Participants questioned which service should diagnose LD and suggested differing understandings of diagnoses such as Autism, borderline LD, and learning difficulties.

*"…or used different terms such as learning difficulty, which obviously you know, a very severe learning difficulty can be a very mild LD"*

**Theme: Service remit and limitations**

Service limitations were discussed as problematic in both specialist and mainstream teams and a knock-on impact of this on service provision was identified. It was acknowledged that the complex nature of supporting people with LD can be difficult for mainstream teams to feel equipped for, and the limitations of services meant that any positive joint work became "lost" or inaccessible.

*"…once it is done, then keeping it, making it visible in a systematic way, rather than it being, as many things are in our services, on a shared drive which you have to know to look 5 folders deep, to the special folder, where the special file is for that particular thing"*[referring to written guidance for working with LD within services].

**Theme: Bridging the gap**

A gap of people who did not seem to fit clearly with either mainstream or specialist services was referenced throughout. There was suggestion that the commissioning push for the mainstream agenda may have widened the gap, by making their LD service more specialised, seemingly resulting in a large group of people "falling between this gap".

"*…we moved to a commissioned model of care where services are commissioned to do this, commissioned to that. You know, if you had a big cake and you commissioned a slice out here, and commissioned a slice out here, you're inevitably left with a gooey mess in the middle"*

## Discussion

The findings support the need for continued focus on equal provision of MH support for people with LD, highlighting ongoing difficulty in agreeing and identifying the most appropriate service for this population.

A common rejection reason, especially for referrals from mainstream MH teams, was lack of LD diagnosis; including referrals for people with Autism, mild-borderline LD, and/or learning difficulties. As these diagnoses do not sit within the remit of the specialist LD team, unless also accompanied by a LD diagnosis, these referrals were not able to be accepted. This appears to be a difficulty experienced by MH services more broadly, for example, Maddox et al (2020) found that clients, clinicians, and service leads in the USA identified that there was a disconnect between community MH services and systems supporting neurodevelopmental conditions. They linked this to people being turned away from services at the point of referral, as was seen in this evaluation. Recommendations from these findings were for increased community education and implementation of reasonable adjustments, such as slower pacing and sensory considerations in mainstream services. With their resources, expertise and established inter-service working, the specialist LD service may be well placed to lead on such education.

The 'confidence and complexity' subtheme in the focus group data suggested a lack of confidence of mainstream MH clinicians with the perceived complexity of working with people with LD, potentially perpetuated by low frequency of contact. Indeed, in consultation with a mainstream MH team clinician, they reported never having worked with somebody with LD in their role and they suggested this may be why they were unclear about some of the guidance. The clinician commented that the consultation itself had highlighted the need to check such processes, suggesting that the inclusion criteria for the specialist service may not always be clear to external services. Furthermore, it may be beneficial for this service to audit the documentation of diagnostic status to ensure this is being captured. Hashmi & Davidson (2021) found that in one NHS Trust, only 1/30 cases had a

diagnostic status of Autism updated on their electronic record. If clinicians are not aware of client diagnoses, opportunities for implementing skills in reasonable adjustments will be missed.

Clinicians in the focus group highlighted instances of lost knowledge due to learning not being cascaded, maintained or accessible. Rose et al (2012) highlighted challenges in staff knowledge, attitudes, and skills in MH services for people with LD in both mainstream and specialist services in their literature review. Recommendations prioritised the need for a comprehensive training strategy, incorporating regular supervision. The current focus group suggested some capacity within the service for joint working; this could include a supervisory, consultative role to support follow-through of training. With increased contact and visibility the mainstream teams may feel better equipped in providing support. The Learning Disabilities Public Health Observatory published guidance and actions for commissioners and providers of health care in the UK (Turner & Robinson, 2011). Suggestions outlined the need for clear and accessible links on NHS Trust websites; LD specific working groups; electronic flagging systems for reasonable adjustments; and regular auditing.

The present findings also highlight that an area of disparity was the understanding of which service should assess and diagnose LD, and which diagnoses would warrant acceptance by the specialist team. Consultation with a mainstream MH team clinician substantiated this, as they suggested that IQ assessment to establish LD diagnosis would be something they would refer to the specialist team for. In the group it was suggested that, historically, the agreement was that the querying team should complete the diagnostic assessment. It was not known whether this was still the current agreement. Clarity on this, and visibility of guidance across both services may help reduce inappropriate referrals for diagnostic assessment and improve services for the individuals with LD who may otherwise have a delay in the care that they receive due to these issues.

A sub-theme that provided insight into potential ways forward was ‘joint working’. Participants shared examples of successful joint working between teams and described these as

aligning with the national guidance of good care. NHS England (2015) provide actions for commissioners under their service model, stating that commissioners should ensure inter-agency collaborative working, specifically between mainstream and specialist services.

The evaluation was limited by the data being drawn from the specialist team alone, and the experiences of the mainstream MH teams were not within the remit of the current study. As this topic is so intertwined across these teams, representation from both would have been ideal. Furthermore, the project looked only at one service within one NHS Trust and there are likely local and service specific logistics that are not generalisable to other trusts. However, there do seem to be parallels to issues identified nationally in guidance from the DOH and NHS England. Participants themselves reflected that some issues were likely a product of larger scale practicalities, rather than service specific issues.

Whilst there were 502 referrals into the service during the year, only 26 of these were from mainstream MH teams. It would have been beneficial to audit data over a longer time span, to attain a greater number of referrals. However, this did highlight that only 5% of referrals over the year were made from mainstream MH teams. It may be beneficial for further auditing to explore the rejection reasons from other referral sources. A total of 11% of all referrals were rejected as they were deemed more appropriate for mainstream MH teams. The current audit did not explore whether these referrals were more common from specific referral sources. Identification of sources making these referrals may be beneficial in supporting work to clarify service remits and avoid inappropriate referrals being made from all sources.

It was found that 26% of all referrals were rejected due to being deemed more appropriate for social care and 24% due to being deemed more appropriate for another specialist service, such as epilepsy or LD nursing. This equates to 50% of rejected referrals being redirected to other services, suggesting there may be a broader lack of clarity for referrers about service remit. Review and dissemination of provision remit to their key referrers and local services may therefore be

useful. Some areas of broader development from the evaluation outcomes include reviewing how learning is captured, stored, shared, and maintained within services and how online systems can be used more collaboratively. Further research into the societal and national gap highlighted may also be of benefit and the outcomes support the ongoing need for work to support equal access to MH healthcare for those with LD

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