SPECIALIST COMMUNITY TEAMS FOR ADULTS WITH LEARNING DISABILITIES: IMPLICATIONS OF REFERRALS TO AN ENGLISH COUNTYWIDE SERVICE

INTRODUCTION

In England and other parts of the UK, the closure of the long-stay social care 'hospitals' for people with learning disabilities that began in the 1970s was accompanied by the development of geographically-based community multi-disciplinary teams (hereafter, CTs) to meet the specialist health and social care needs of adults with learning disabilities. The CT model of service provision, comprising practitioners from different disciplines and, often, different agencies, supporting people not just to remain in, or return to, their communities but also to improve the quality of their lives within those communities, remains dominant in the UK (Slevin *et al.*, 2008). It has also been adopted in other 'high income' countries, such as Australia, Canada, and the USA, that share the UK's history of mass institutionalisation of people with learning disabilities.

Within the general framework provided by a CT model, there has always been wide variation. For example, some areas provided services to people with neurodevelopmental conditions other than learning disabilities if it was believed that the approach taken by a CT would best meet their needs. Anecdotally, it appears there has been a reduction in this 'needs based' approach, despite its person-centredness. Elsewhere, CTs have focused on a particular group of people with learning disabilities with specific difficulties such as perceived 'challenging behaviour' (Emerson *et al.*, 1996; Hassiotis *et al.*, 2009) or, more recently, behaviour that may bring them into contact with the criminal justice system (see, for example, Browning *et al.*, 2016). Mixed approaches also exist, with multi-disciplinary 'generic' and more focused 'intensive support', CTs working together as part of the same service. In addition to this variation, there are also differences in the extent to which different kinds of health practitioners are represented within CTs, and in the extent to which healthcare teams run in parallel with, or are integrated with, local authority social workers and/or care managers carrying out care reviews and commissioning and monitoring the contracts of independent service providers.

One of the strengths of the CT model is its flexibility. Potentially, locality-based services can respond to developments in legislation, policy and practice in ways that meet the needs of specific populations (for example, the presence of a substantial ethnic minority group) within

a given local area. However, the flexibility of the model also has potential weaknesses. First, while no national audit of CTs, even within one country in the UK, has ever been carried out, there is anecdotal evidence of very different management arrangements and structures, and even within one geographical area, variation in the composition of different teams (see Walker *et al.*, 2003). This makes it difficult for people with learning disabilities and their families to know what service, for whom, and from whom, they can expect. Recently, in an attempt to clarify long-standing concerns (see, for example, Greig and Peck, 1998) about the role of CTs, the British Psychological Society (2015) reiterated that their task is to (i) complement and support 'mainstream' primary and secondary NHS healthcare provision to reduce health inequalities, and (ii) provide assessment, treatment and support to people with behavioural or complex physical and/or health needs. The extent to which these tasks are carried out by CTs is, however, unknown. This leads to the second weakness of the model. With very few exceptions (for example, Walker *et al.*, 2002) there is limited recent empirical research into any aspect of 'generic' CTs (Slevin *et al.*, 2008).

As part of a larger project using empirical data to investigate the role, functioning, and design of CTs (Farrington *et al.*, 2015; Clare *et al.*, 2017; Clare *et al.*, 2018) we report data on 270 referrals to one integrated (health and local authority) county-wide service for adults with learning disabilities. Using these data, we consider their implications for the development of CTs.

METHODS

Ethics

No people with learning disabilities or their care-givers were directly involved in the project. Advice was sought from the R & D Department of the relevant NHS Trust and County Council. Since only the research team's practitioner researchers, all of whom held clinical contracts, had access to identifiable health and social care information, National Research Ethics Service approval was not judged to be necessary. All data were coded and completely anonymised before being passed to the research team's academic members.

Context

The study formed part of a larger project investigating the work of five CTs for adults (normally aged 18 years or more), as part of a county-wide service. The county has an estimated population of 625,000, with both urban and rural constituencies, each containing wards with serious levels of deprivation. When the data were collected, each team was managed by the

Local Authority and comprised health care practitioners employed by the local NHS Trust, with Local Authority care managers (some of whom were also social workers) commissioning and monitoring specialist social care 'packages'. Data collection took place over a three-month period chosen because it was thought least likely be affected by seasonal fluctuations in the everyday lives of service users.

Data collection

A pro-forma was devised[1] to collect referral data from the weekly or fortnightly (depending on the particular CT) inter-agency (health and care management) meeting held by each of the teams. The data were of two kinds: (i) 'external referrals', including referrals from service users, family carers and other care-givers, such as social care providers, employers, General Practitioners, other CTs, and others; (ii) referrals from health care practitioners in a particular CT to care managers in the same team (or *vice versa*). Referrals from one health care practitioner to another in the same team (e.g. from psychiatry to nursing) were not included since many of these were made orally and/or outside formal meetings; piloting suggested that information on these referrals could not be collected reliably. Where available, anonymised copies of written referrals were also available to the research team.

For three calendar months, the referral meetings of each of the five CTs were attended by one of three practitioner researchers. Pro-formas were collected on 292 referrals, based on the information available at the meeting; where possible, this was supplemented and corroborated using relevant CT records.

Analysis

Operational definitions were developed so that the reasons for referral could be categorised. These definitions were refined iteratively until an acceptable level of independent agreement was reached. The resulting categories and their definitions are reported in Table 1. An attempt was then made by two independent raters to categorise each referral. During this process, twenty two referrals were excluded: ten because the 'reason for referral' section of the pro-forma had not been completed, and a further twelve because they appeared to be general enquiries (e.g. seeking advice about the status of a previous referral). Among the remaining 270 referrals, it sometimes appeared that more than two categories of 'reasons for referral' were relevant. Where this was the case, we tried to make a judgment about the 'primary' reason but for 27 (10%), the information available was fragmentary so they were placed in an 'insufficient information' category. There were two referrals in the 'Other' category; both related to the completion of paperwork for which the referrers (one self-referral and one referral by a parent) felt support from a CT was needed.

Table 1: Operational definitions of categories of reasons for referral

Grounds for referral:	Referral comprises request for:
Access to health/entitlement to, or review of, social care 'package'	Assessment of entitlement to access specialist ID health and/or meet eligibility criteria for specialist social care services; assessment of need for change to health and/or social care package, including amendments to accommodation, funding, CT, support hours, or transition to a personal budget
Mental health and/or behavioural needs	Assessment, treatment and/or support for unusual (for that person) and/or 'challenging behaviours' (including alleged offending or a criminal conviction).
Physical health needs	Information or support regarding co-morbid physical conditions, such as epilepsy or diabetes; health education; continence; attendance at health appointments and/or procedures such as dental check-ups or blood tests.
Skills and independence	Assessment of need for support and/or equipment (including assistive technology) to maintain or increase independence in daily living skills and/or mobility.
Social skills, communication, and personal development	Assessment of need for support and/or equipment (including to support or develop social skills and/or communication and/or support to develop such skills through education or equipment (including assistive technology). Also includes requests for support for a service user engaged in or seeking a romantic relationship, or to build appropriate friendships and/or relationships, including understanding of sexuality. Do not include referrals relating to sexual health, which may better fit in physical health.
Capacity assessments and/or best interests decisions	Support in establishing and/or maximising decision-making capacity or participation in relation to a particular decision, or support in determining 'best interests'.
Safeguarding	Support in safeguarding following abuse or risk of being abused.
Medication	Review of medication or support in medication adherence or management.
Parenting	Support around parenting or a wish to be a parent.
Other	Did not fit into any of the categories, for example, needing support with completing forms or other paperwork.
Referrals containing insufficient information for assign to any category	.

Inter-rater agreement was reached on 195 (72%) of the 270 referrals with usable data

(unweighted Cohen's *k*: 0.67 (95% CI: 0.6, 0.73)). For 69 of the remainder, a consensus was reached following initial disagreement but there remained a small   number (2%, n=6) for which this was initially impossible, either because the information provided was very complex or (more often), so fragmentary.   These six were discussed with the lead author (ICHC), and a consensus was reached.

RESULTS

Over three months, data relating to 292 referrals, ostensibly requests for assessment, treatment and/or support, were collected from the five CTs. Of these, at least some useable data were obtained for 270 referrals. Since the reasons for referral did not differ between the five different CTs, they were pooled.

Characteristics of those referred

The 270 referrals of individuals with diagnosed or putative learning disabilities related to 255 individuals, just over half (54%, n=137) of whom were reported to be men. The age range was broad (17-78 years, median=33; standard deviation=14.5), as was the range of putative learning disability reported. Of the 204 (80%, n=255) for whom data were available, their learning disabilities were described, normally without any supporting evidence, as 'mild' (35%, n=71), 'moderate' (22%, n=44), 'severe' (27%, n=55) or 'profound' (3%, n=7). The remaining 27 individuals (13%) apparently fell within the 'borderline' intellectual functioning range or above. At the time of their first contact with a particular CT during the study period, almost equal numbers of those referred (n=255) were reported to be living in residential accommodation (mostly supported living) managed by a third sector or independent organisation (40%, n=101) or with family members (37%, n=94). Of the remaining 60 individuals, only 34 people were living on their own, and just 10 were living with a partner. The remaining 26 people were accommodated in a range of settings, including acute and psychiatric hospitals, prisons, and homeless shelters. Almost three quarters of referred individuals (74%; n=189) were already known to one or more members of the service prior to their first referral during the data collection period.

Reasons for referral

Figure 1 shows the primary reasons for referral. As can be seen, requests for assessment of entitlement to access specialist health care and/or eligibility for specialist social care and/or a review of an existing 'social care' package (including transition to a personal budget) formed the most frequent category. They were followed by three categories: mental

health/behavioural needs, physical health needs, and requests for support with skills and independence, all with close to 40 referrals each.

Figure 1: Bar chart summarising the 'primary' reasons for referral (n=270)
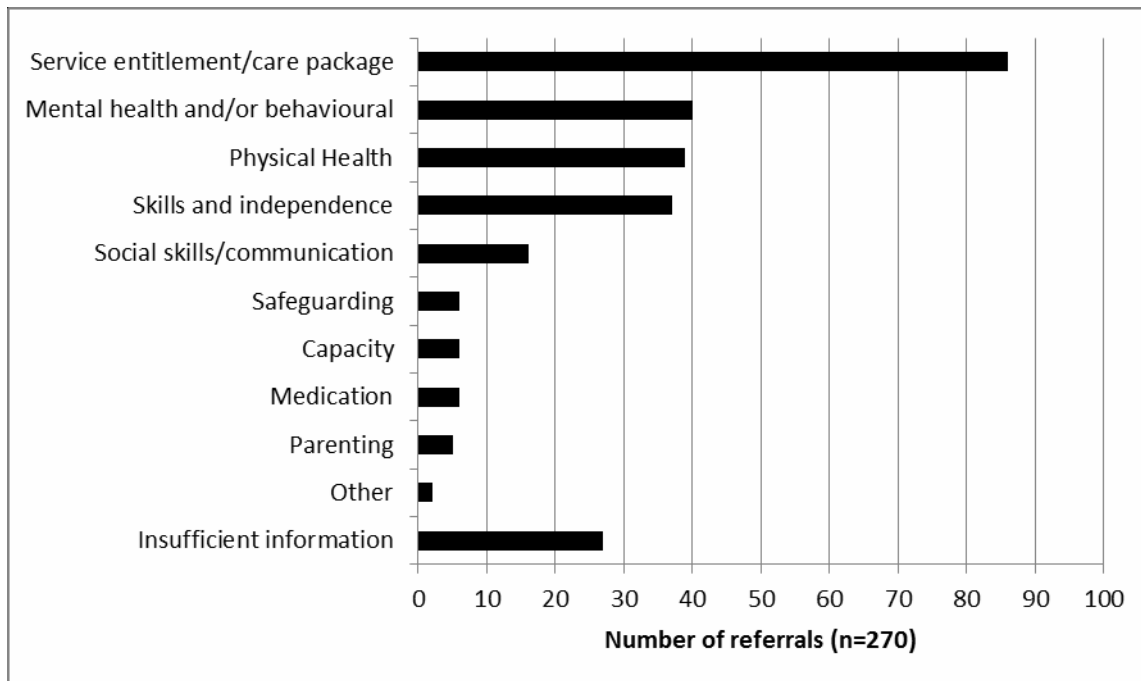
Outcomes

The overwhelming majority of the 270 referrals (87%, n =235) were accepted without any further information being sought by the CT. Most (83%, n=211) of the 255 individuals for whom the referrals were made were judged to meet both 'access' criteria (criteria for 'mental retardation' (*sic*); ICD-10, World Health Organization, 1992) and 'eligibility' criteria for specialist social care support (had 'substantial' or 'critical' needs, using the criteria in place at the time; Fernandez and Snell, 2012). Eight (3%) of those referred were only entitled to specialist health care. A further 16 (6%) people met eligibility criteria and were therefore entitled to specialist care management as 'vulnerable persons', but were judged not to meet access criteria. By far the main reason that 35 referrals were not accepted immediately was that the person did not meet relevant criteria (n=31). One referral was passed to the physical disability service that was believed to be more appropriate; another was withdrawn following the sudden death of the referred person. Decisions about the remaining two referrals were deferred so that further information could be collected.

Referrers

Of the 270 referrals made to the service, more than three-quarters (78%, n=211) were made by 'external' referrers (from outside the service). As Table 2 shows, the range of referrers was

very broad, with the largest groups comprising care-givers such as support workers and their managers in social care provider organisations (19%, n=50), General Practitioners (GPs; 12%, n=32), and carers/partners (11%, n=31). Four service users were self-referrals; all had previous experience of the service.

Table 2: Sources of 'external' referrals to the Community Teams (n=211)

Source of external referral	n	%
Care-giver (support worker/manager from social care provider organisation)	50	23.7
General Practitioner	32	15.2
Carer (family member or partner)	31	14.7
Day-service/employer	21	10.0
Secondary health care (general hospital; in-patient ID service)	16	7.6
Transitions team for individuals moving from children's to adult ID services	7	3.3
Self	4	1.9
Child & family team due to concern about the person's care of others	4	1.9
Care Manager from another Community Team in the ID service	2	0.9
Child & family team for a young person in the care of the local authority	2	0.9
Police or other criminal justice agency	2	0.9
In-patient general psychiatric service	1	0.5
Care Manager from outside the county for person placed within the area covered by one of the CTs	1	0.5
Other (e.g. Independent Mental Capacity Advocate; Neighbourhood Housing Officer/Warden; community Occupational Therapist; Direct payments officers; NHS Direct) or uncertain	38	18.0

DISCUSSION

The purpose of this study was to gain a better understanding of the support sought from five integrated health and care management Community Teams in a single, county-wide, service in order to consider, more broadly, their roles and responsibilities. Given that our data comprised consecutive referrals to five different CTs over a three month period, it is likely that they were reasonably representative of the referrals received by NHS health care practitioners and local authority care managers in a service in which there were very few staff vacancies.

The study has a number of limitations. First, we did not include referrals that were either already being addressed by one of the CTs or were 'internal' referrals between health care practitioners or between care managers within each CT. As a result, the sample is not representative of the entire caseload of the service. Referrals to specific disciplines, such as arts therapies, which arise almost entirely from intra-Team discussions, are under-represented. What this means is that the findings should *not* be used to make a case for resourcing; they can only be used to argue that, if such Teams are to continue, then CTs need to be able to address at least the referral issues identified. We wish also to emphasise that the findings cannot provide guidance about the number of referrals to be expected. There were different practices both across disciplines and in different Teams that could not be explained simply by features of the locality in which the CT was based. At one extreme, there was an 'assess, treat, and discharge' model, akin to that of acute secondary care. Proponents of this view were likely to see continuing contact with services as encouraging people to see themselves primarily as 'service users'. In contrast, other practitioners or teams adopted a model similar to that used by General Practitioners in primary care: they retained referred individuals on their caseloads for many years and tried to adapt the frequency and intensity of contact to the needs of the person, their care-givers and their social networks. Their argument was that such an approach provided security for individuals, and their care-givers, through enabling a preventative approach that acknowledged the fragility of some service-users' well-being. We would argue that both approaches have merit, depending on the service user and their needs. In addition, while we found no differences in the referrals made to the five different CTs, we cannot know the extent to which our findings are generalisable to other parts of England. It is likely that local contextual factors, such as the competence of staff and managers in social care provider organisations, their willingness to collaborate with CTs, and the ability of the CTs to respond to referrals and work proactively to support people with learning disabilities and their care-givers, will all be relevant to both the number and the type of referrals received.

Nevertheless, there are a number of findings that deserve further consideration. First, the data indicate the broad spread of age level and of impairment among the 255 people referred. More importantly, the range of reasons for referrals, even within a single category and focussing only on the 'primary' reason, was very varied. This is not surprising: people with 'learning disabilities' are a heterogeneous population whose range of needs seems to require the broadest interpretation of the tasks of a CT set out by the British Psychological Society (2015). Our data suggest that, to respond to referrals, CTs should have access to a range of expertise and the involvement of more than one agency. Even assessing a person's entitlement to specialist health or social care and/or the review of an existing social care 'package' (the commonest reason for referral) could engage health care practitioners. Similarly, assessing and/or treating mental health and/or behavioural needs may require disciplines familiar with and able to support: the diagnosis of mental and/or physical disorders, the functional assessment of behaviour, the development and improvement of communication environments, sensory integration, support in maintaining and developing skills, support with eating and drinking, training and support for care-givers, and the commissioning by care managers of competent social care provision. Even less common frequent referrals, such as requests to support with decision-making capacity, or safeguarding concerns, often required the involvement of more than a single health care discipline and/or an inter- or multi-agency approach.

Secondly, three-quarters of the individuals referred for the first time in the three months of data collection were already known to the CTs: they were in fact re-referrals. It is possible that the lack of explicit information about the level of impairment of some of the referred individuals reflected the extent to which tacit knowledge about the person was believed to be shared within a particular Team (see Farrington *et al.*, 2015), for more detailed discussion). The limited number of new referrals is perhaps not surprising given that the needs of many of those individuals in contact with CTs will be life-long, and require long-term or repeated input. It is, however, disappointing to find that such a small proportion (1.9%) of people with learning disabilities referred themselves to services. This suggests that CTs have more work to do to encourage participation by potential service users. The delivery of health care to people with learning disabilities should reflect partnerships with people with learning disabilities as well as care-givers or service providers. These considerations lend support to a model of CTs that is not only multi-disciplinary and inter-agency but also has a strong locality-based focus, working with service users directly, care-givers, primary care staff (particularly General Practitioners), employers, and others in their geographical 'patch' to ensure that the strategies used by CTs are ethically and clinically sound, effective, and maintained.

Thirdly, the existence of specialist service such as CTs, occupying a space between primary and secondary health services, creates boundaries that have to be managed. We suggest that these take three forms: first, in a service for adults with learning disabilities, specialist health care is only available to adults who meet the necessary ICD-10 (World Health Organisation, 2002) criteria. For many of the individuals referred to our sample, there was little dispute since the individual was very well-known to the service, was transferring from children's learning disability services, had a severe or profound disability, or was recognised as having a neurodevelopmental syndrome characterised by impairments in intellectual and adaptive functioning. In contrast, there were many more difficulties in making decisions about a person's entitlement to access specialist health services when they had no previous contact with learning disability services, but had, for example, a history of marked psychosocial deprivation, substance misuse, and/or were living in a challenging situation such as a homeless persons' hostel. The second boundary relates to making decisions about whether a person's needs might best be met by a CT or would be more appropriately addressed by mainstream health services or some other service. As part of the vision for the service, clarity is required about the needs that should be met primarily by the CTs, and those for which their role might be that of signposting to, or working in partnership with, another service. For example, in response to referrals about prospective or new parents, CTs contributed a learning disability perspective to decision-making by mainstream child and family services. The final boundary relates to the structure of the CTs described here: they were integrated health and care-management Teams managed by the local authority but also with the responsibility of meeting health needs. In England, health interventions are the responsibility of the NHS and are mainly delivered free at the point of delivery. In contrast, the availability of additional social support depends on meeting specific local authority criteria. As our findings illustrate, a small number of referred individuals were entitled to specialist health care but were not eligible for additional social care even when a lack of adequate or sufficient support may have contributed to, or maintained, the person's health care needs. This emphasises the importance of close inter-agency working within CTs through, for example, joint budgets.

The findings also have implications for service design. A number of issues arise from the requirement for inter-disciplinary and inter-agency working, including confidentiality, record-keeping, cultural differences in working practices, and training and supervision needs. Addressing these issues requires a clear vision of what the CTs are there to do (Clare *et al.*, 2017), sensitive leadership that manages tensions between health services and local authority services, and practices that optimise the sharing of tacit and explicit knowledge between different Team members (Farrington *et al.*, 2015). Finally, there must be an acknowledgement

that boundaries between CTs and other services are inevitable. Flexibility is required to ensure that people with learning disabilities and their care-givers are supported across these boundaries rather than falling between them because of the intransigence of different services.

In this paper, we have focussed on referrals to five CTs and identified the kinds of needs that they are expected to meet. As Slevin *et al.* (2008) pointed out more than a decade ago, the efficacy of CTs' responses   to these needs remains little investigated and this should be a priority in future research.

NOTE

[1] Available from the last author

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