



Delivering Effective Specialist Community Learning Disabilities Health Teams / Services for Adults with Learning Disabilities and their Families and Carers

**Guidance on Service Specifications and Best Practice for Professionals, NHS Commissioners,
Health and Social Care regulators and Providers of Community Learning Disabilities Health
Services**

By the National Learning Disabilities Professional Senate

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Introduction

Community Learning Disability Services provide specialist healthcare to adults with learning disabilities whose needs cannot be met by mainstream services alone. These teams help to ensure that people with learning disabilities receive specialist health services when they need this, enabling effective care and treatment when there is a concern about their physical or mental health. Community Learning Disability Services work in collaboration with other professionals and agencies to ensure that the person's health needs are met.

Historically Community Learning Disability Services for people with learning disabilities have only worked with autistic people who also have a learning disability. New models of service delivery means that some services, with additional investment and resources, now also work with autistic people who do not have a learning disability. Although this is acknowledged, the work of the Learning Disability Professional Senate continues to focus solely on people with learning disabilities. (see LD Senate document 2023).

Locally commissioned effective specialist Community Learning Disabilities Health Teams/Services are critical to providing the essential support needed by people with learning disabilities, their families, support staff and their wider systems. Adults with learning disabilities should be enabled to live full lives as well as experience health outcomes in line with the wider general population. Key policy drivers which underpin the current delivery of services for people with learning disabilities include: Building the Right Support; Learning from Lives and Deaths (LeDeR); Stopping overmedication of people with a learning disability, autism or both with psychotropic medicines (STOMP); Annual health checks; the NHS Long Term plan; CQC Quality of Life Tool and Framework, Bamford Review of Mental Health and Learning Disability – Equal Lives Learning Disability Report (2005); NI Mental Health Strategy 2021-31.

More recently research evidence is emerging about the scope and effectiveness of community learning disability teams. This includes:

- Reduction in inappropriate use of psychotropic medication
 - Acton (2022) describes a successful reduction of psychotropic drugs with the support of the local community learning disability team.
 - Clare et al (2018) report that minimising inappropriate use of psychotropic medication had to be supported by investment in multidisciplinary and interagency working to develop person centred interventions and crisis plans, feasible data collection and integrated formulations.
 - Da Costa et al (2021) found that a significant proportion of patients open to psychiatrists were prescribed psychotropic medication in the absence of psychological and environmental interventions (da Costa et al 2021).
- Diagnoses of co-occurring conditions and health needs, such as dementia
 - Chapman et al (2018) report on a multi-professional and inter-agency approach to the detection and diagnosis of dementia and identification of other health needs associated with better service provision and improved outcomes.
- Support for discharge to community services
 - Chester et al (2017) found that interagency and interdisciplinary working has a positive impact on the assessment and management of risk assessment and management processes while dealing with discharge of patients from secure to community services.

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- MDT Approach
 - Coleman and Sharrock (2022) assert that a multidisciplinary approach and collaboration with the person, family and carers is key to supporting people with learning disabilities with any relationship concerns.
- Wider role of CLDT
 - Mafuba & Gates (2013) demonstrated that community learning disability nurses are involved in health surveillance, health promotion, health facilitation, health prevention and protection, health education, and healthcare delivery.

Intensive Support Teams (IST) have developed over time with different models of service. One is an independent team distinct from the CLDT; a second is an enhanced provision based around the CLDT (Hassiotis et al 2020), and a third model where there is integration between the inpatient assessment & treatment unit and the community based Intensive support team (Dodd et al 2021). Some areas have also developed Community LD Forensic teams.

These models need further evaluation to establish clinical and cost effectiveness. White et al (2019) provide evidence that Intensive Support Teams may consider basing themselves within the CLDT to provide more readily accessible support and improve confidence of community team staff to implement behaviour programmes. Dodd et al (2021) showed that, within the integrated model between the Intensive Support Team and the inpatient assessment and treatment unit, the majority of people referred to the service avoided both admission to an inpatient unit and placement breakdown. This model has proved effective, resulting in consistently low numbers of people in the inpatient unit including a two week period in June 2023 when the unit was empty.

These developments necessitated a review of this document and the role of CLDTs and the development of effective models of working in synergy with intensive support teams to increase community capacity and reduce undue reliance on inpatient services – a key goal of national strategies across the UK.

Relationship Centred Care incorporating Person Centred Principles, Culture and Values

Quality care happens when there are strong reciprocal and interdependent relationships among everyone involved in care, including the person, family members, support staff and others in their circle of support. Relationship Centred Care means recognising that meeting the person's needs and wishes are essential through a partnership approach based on strong and positive relationships.

Person Centred Care	Relationship Centred Care
The focus is on the person rather than the medical diagnosis	The focus is on enhancing the care experience for the person, family, and support staff
Efforts are directed toward nurturing continued strengths and abilities	Efforts are directed toward building and nurturing relationships
Attention is given to meeting the needs of the person	Attention is given to meeting the needs of the person, family, and support staff

(Dupuis, Whyte, & Carson, 2012)

Relationship Centred Care incorporating Person-Centred Practice within a rights-based approach and individual service design should be at the heart of specialist CLDTs practice.

The principles are:

- Empowerment & advocacy
- Prevention and early intervention
- A whole systems life course approach
- Focus on the importance of a relational approach in addition to a person-centred focus
- Family carer and stakeholder partnerships
- Behaviours of concern are reduced by recognising and understanding a person's communication needs in a relational context and therefore being better able to meet a person's needs.
- Recognising, understanding and meeting physical health needs
- Recognising, understanding and meeting mental health needs
- Providing Function based holistic assessment
- Recognising and responding to additional needs
- Positive behavioural support
- Trauma informed Practice
- Safeguarding
- Advocacy
- Ensuring a full range of professionals and therapeutic approaches
- Workforce development for professionals
- Monitoring quality as a core role
- Co- production with the person with learning disabilities and involvement of their families and/or carers

Good quality learning disability services are based on strong community support services, planned around people in the environment that they are in, focussing on relationship centred care incorporating person-centred care, and looking at each person's needs and aspirations. This approach should be applied to all, including people with very complex needs. Services must be committed to achieving the outcomes of 'rights, inclusion, independence and choice', and to ensuring that they 'stick with' people in spite of the difficulties experienced in meeting their needs.

This positive approach towards supporting people with learning disabilities must also be accompanied by equal attention to the needs of families, and to other carers and support services.

Getting Healthcare Right for People with Learning Disabilities

The core purpose of the NHS is to protect life and maintain health within the rubric of 'Adding life to years and years to life'. This applies to people with learning disabilities and their families as much as the wider population and across the lifespan. NHS England have two other critical priorities for action: Reducing Restrictive Practices and Reducing Health Inequalities, which echo policy drivers in other parts of the UK.

The key principles adopted in designing, developing and delivering services have focused on the need to put the person and their surrounding family or carers at the heart of a service, which should be personalised and designed to meet their needs. To enable this to happen, services have been guided to be organised by the person-centred principles, cultures and values outlined above. This has now been extended to recognise the importance of a relational approach which recognises that quality care happens when there are strong reciprocal and interdependent relationships among everyone involved in care, including the person with learning disabilities, family members, and staff.

In addition to this values-based approach, services need to be equipped to deliver timely, comprehensive assessment and effective evidence-based interventions. This includes equality of access to high quality mental and physical health care.

Life is now better for people with learning disabilities than decades ago, and presents more opportunities for people and their families with more valued community options and experiences. However, this is not the case for all people with learning disabilities, and in particular for people with learning disabilities who may display behaviours of concern who are more likely to be subject to unnecessary restrictive options. Further, people with learning disabilities generally experience poorer health than the general population and significant health inequalities, contributed to by high rates of multimorbidity from a young age, that result in often avoidable differences in life chances and avoidable, preventable and premature deaths. This is especially of concern for people with profound and multiple disabilities who are likely to have more co-morbidities (NHS England 2022), and a poorer service offer (HEE 2020).

Specialist Community Learning Disabilities Health Services

This document refers to all the specialist community learning disabilities services that offer support to people with learning disabilities. Services may be configured in a variety of ways but should include, as a minimum access to a core specialist multi-disciplinary Community Team (CLDT), Intensive Support Team functions (IST), and Acute and Primary Care Liaison services. To strengthen the offer, local Community Learning Disabilities Services must have links to all parts of the health and social care system including primary care, secondary physical and mental health services, and local authority services with these services all knowing what the CLDT is commissioned to provide.

Core Specialist Community Learning Disabilities Team (CLDT) Professional Practice

Community Learning Disabilities Health Teams (CLDTs) are at the heart of Community Learning Disabilities Services and should operate as fully multi-disciplinary teams which include specialist health professionals who collectively work to support people with learning disabilities to reduce health inequalities and restrictive practices and provide co-ordinated specialist advice and practical help to live meaningful and quality lives.

Although there are a variety of models for CLDTs, access must be available from a full range of core registered health professionals working to nationally defined standards from HCPC or other regulatory bodies or defined professional standards. Those team members who are not a registered professional (e.g. behaviour analysts delivering positive behaviour support or support workers/ assistants), must be supervised by a registered professional with clear accountability and governance arrangements from their employer.

There will need to be a range of staff skills commissioned and recruited as part of these community health infrastructures. This will depend on local defined need and access to mainstream services. The professions should include (but not necessarily be limited to): clinical psychologists, learning disability nurses, occupational therapists, physiotherapists, psychiatrists, speech and language therapists, dietitians, art, music drama and dance movement therapists, podiatrists, specialist audiologists, family therapists. Local services may include other professions as appropriate e.g. specialist optometrists, audiology, dental services, pharmacy etc.

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At a minimum, this should include sufficient numbers of registered practitioners and assistant practitioners (as appropriate) across all these professions. A CLDT without easy local access to all these core professional staff resources will be unable to meet the agreed functions described above and therefore not meet the health needs of people with learning disabilities.

However, the particular mix, number and form of the local team must be based on the identified local needs and required functions to be served at a point in time, and to deliver on the requirements of Building the Right Support and the Learning from Lives and Deaths programme (LeDeR) to reduce health inequalities and premature mortality. There will need to be particular attention to ensuring access to a critical and adequate mass of staff from newly qualified to senior clinicians with the range of specialist knowledge, skills and capability. This also means valuing the positive contribution and role of learning disability social workers and social care providers to enable health interventions to work in supportive social contexts.

As such, it is expected that senior clinical leaders will be in place as senior members of the CLDT. They should support both the Team Manager and more senior Operational Managers, who should have learning disabilities experience, across both health and social work agencies, in co-ordinating and managing referrals and prevention initiatives to deliver the 5 core functions and ensuring safe governance and compliance with the QNLD community teams standards. Senior Clinical leaders will need to develop and continually evolve effective workforce plans to ensure an appropriately skilled and competent workforce who can deliver high quality care and support.

Integrated Health and Social Work Community Learning Disabilities Teams / Services

Providing health interventions in a social context that fails to match a persons' essential support needs can be ineffective and, in some cases, can be harmful. Similarly, providing social support in a context devoid of effective health support can be ineffective. Both are two sides of the same coin and need attention to avoid support failure.

Historically, services for people with disabilities have been based on departmental or agency systems consisting of separate groups of professionals organised according to discipline. However, separate health and social care service responses are confusing, fragmented and expensive due to the considerable overlap in professional roles. National policies have defined a vision for effective CLDTs supporting integrated professional work across disciplines and agencies with organisational structures in place across agencies which encourage and promote inclusive working.

However, in reality this is often not achieved, and services should, where possible, work together through co-location, integration of referral, assessment and review processes and joint working. A clear care co-ordination framework is integral to making this work, with an underpinning principle being to single points of access to deliver continuity of care for vulnerable people with complex needs requiring intensive intervention and/or long-term support. Whilst commissioning arrangements may vary across various jurisdictions, it is critical that specialist, multidisciplinary healthcare teams operate in the context of effective social services.

Community Learning Disabilities Health Teams / Services Eligibility Criteria

CLDTs / Services must be available to all people with learning disabilities in the agreed local area. This may be defined by either the person's address or by GP Practice, with clear feedback mechanisms in place to inform commissioners of any practice issues and concerns. Local arrangements/agreements should be in place where bordering services work to differing systems of GP/postal address eligibility, to avoid people being left without a service.

CLDTs / services should be open to anyone with a learning disability who needs specialist health support. Eligibility **should not** be informed by the severity of the learning disability, nor by eligibility to social care under the Care Act.

Although CLDTs often include both health and social care workers, specialist health services must not be restricted to only those people with severe learning disabilities or those meeting social care criteria, as this is not in line with the NHS Responsible Commissioner guidance. Services must be provided on the basis of assessed clinical/ specialist health needs.

Community Learning Disabilities Services - Core Purpose

Health teams and services should be organised as a full multidisciplinary team with sufficient critical mass in each locality to enable to deliver the following 5 Essential Community LD Team functions. CLDTs and ISTs should initially offer a MDT core assessment to identify need; current and past risks and protective factors, rather than just responding to the specific referral. CLDTs also have a wider role in public health, education, training, audit and research.

These are:

1. Direct Specialist clinical therapeutic interventions for people who need specialist LD health support with complex behavioural and/or mental and/or physical health support needs.
2. Responding Positively and Effectively to Adults with Learning Disabilities in Crisis and with Urgent Care Needs to keep people and their support systems well and in their own home; and to prevent both out of area placements and avoidable acute and mental health hospital admissions
3. Enabling others to provide effective Relationship Centred Care (including Person-Centred Support) to People with Learning Disabilities and their families/carers
4. Supporting positive access to and enabling reasonable adjustments in mainstream services
5. Quality assurance and strategic service development to meet national and local priorities

1. Direct Specialist Clinical Therapeutic Support for People with Complex Behavioural and Health Support Needs (through specialist assessments and formulations, advice, training, longer-term care coordination within the team and clinical support)

Direct Specialist Clinical therapeutic support is primarily through specialist assessments and formulations, advice, training, coordination of practitioners within the CLDT and clinical support. CLDTs should provide services to people with learning disabilities that cannot access mainstream service even with reasonable adjustments.

Specialist health professionals in CLDTs with the support of assistant practitioners (as appropriate, where available and under the direct clinical supervision of an appropriately qualified professional) should carry individual specialist caseloads of people with complex health needs related to learning disabilities. These

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include people with physical disabilities; with behaviours of distress, complex communication needs, mental health difficulties, dementia, dysphagia, long-term conditions, epilepsy, autism, attachment disorder; trauma or those who are part of the criminal justice system, and/or who have been victims of abuse or are otherwise at risk.

In these cases, the CLDTs specialist health professionals should provide the full range of services including specialist assessments; formulations; unified care plans specifying both the specialist therapeutic interventions to meet the person's identified specialist physical and mental health needs and risk management; specialist information, consultation, advice and support to relatives and carers; training others to meet the specialist health needs; and a focus on outcomes.

CLDTs must be able to support identified people with learning disabilities who because of on-going complex support needs will remain in contact with the CLDTs for on-going interventions as the intensity of their support needs fluctuates over time. This can necessitate specialist coordination and monitoring for periods of several years or even life-long in some cases. In such cases, traditional models of referrals, repeat assessments and care pathways are inappropriate as they do not match the reality of learning disability as a lifelong condition with some people requiring on-going coordination with options to step-up and step-down matching the changing intensity of their specialist health needs.

As a result, some people in contact with learning disability community teams require active interventions from senior health professionals, while for others it may be possible for oversight and care reviews by assistant practitioners, with the option for rapid step-up when problems arise and/or when mainstream solutions are insufficient and specialist care navigation is necessary. This requires consideration of new ways of working and on-going team skill mix reviews matched to planned and presenting needs.

CLDTs are called upon to provide support to people with learning disabilities who have been detained under the Mental Health Act (referred to as Section 117 aftercare in England) and for people with significant additional health needs (referred to as Continuing Health care). This is on behalf of local commissioners (Referred to as Integrated Care Boards in England) who have legal obligations for these groups.

2. Responding Positively and Effectively to Adults with Learning Disabilities in Crisis and with Urgent Care Needs

CLDT /IST specialist health professionals must identify and work with people who present with or are at risk of sudden/unplanned and urgent changes to their physical or mental health presentation and people within their support system, and at risk of admission to any acute services, to plan ahead for when things might be difficult. They should work proactively with mainstream services, service providers and families to stop crises from happening, and there should be well developed contingency plans in place for situations where a crisis might happen. If a crisis does happen, they should make sure that the right sort of help is at hand to support the person and their family / carers to rapidly defuse and stabilise the situation. CLDTs and ISTs need to take a multi-faceted approach to rising to the challenge of supporting people to deal effectively with crisis, enabling a response on at least 3 levels:

- Proactive crisis prevention
- Reactive crisis management and describing what needs to be in a person's crisis plan
- Proactive strategic planning and service development (informed by the first 2 levels)

When people are experiencing a serious problem or crisis, it is essential that services can respond to their needs with appropriate and effective advice and support 7 days a week and outside office working hours.

There needs to be seamless working between services based on the person's presenting needs. Access to primary care, 24-hour emergency on-call and community crisis centre or in-patient outreach resource is essential, including access to psychiatric cover as part of the agreed local crisis response system. This may be from the community learning disabilities team, a specialist learning disabilities intensive support team or an appropriate generic health and/ or social care team. This should include access to short-term crisis access beds and intensive in-reach/out-reach assertive outreach and home support teams. As well as improving service accessibility and responsiveness this joined up service positively impacts on the number of out-of-area placements, high-cost care packages and inappropriate admissions to in-patient units.

3. Enabling Others to Provide Effective Relationship Centred Care (including Person-Centred Support) to People with Learning Disabilities (through targeted specialist assessments and formulations, liaison advice, person-focused training, short-term care coordination and clinical support) and including Transition from Childrens' Services and Liaison Support

An effective CLDT should be able to:

- Provide prompt and expert evidence-based practical focused assessments and formulations which provide an understanding as to why these issues have occurred and offer specialist health interventions enabling others to mitigate these.

Aims should be to:

- Address specific learning disability-related concerns in the context of rights, inclusion, choice and independence
- Reduce and shorten distress and suffering
- Ensure that inappropriate or unnecessary interventions are avoided
- Use the information gathered in assessment and intervention period to protect against future repetition through training, advice, consultation etc
- Work together to achieve good quality of life outcomes
- Provide specialist advice and person-specific training to people with learning disabilities, families, carers and service providers across the statutory, independent and voluntary sectors
- Establish a detailed understanding of all local resources relevant to support people with learning disabilities and their families/carers and promote effective integrated working maximising the health and well-being outcomes for people and the local community.

CLDTs support to wider local multi-agency and multi-professional training programmes should be encouraged as part of an agreed workforce development strategy.

4. Supporting Positive Access to and Responses from Mainstream Services - Health Promotion, Health Facilitation (through Individual Consultations, Supervision, Training and Policy/Practice Development)

Specialist health professionals in CLDTs must engage in strategic development work that supports better universal access to mainstream services and positive outcomes reducing known health inequalities. This includes involvement in planned programmes of multi-agency training, education, mentoring, informing and consultancy to others about responding to the needs and concerns of people with learning disabilities and their families and carers.

CLDTs should have the capacity to provide on-going support, supervision and advice to services (especially primary care, community health, specialist acute/mental health; community forensic and criminal justice services) to support them in:

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- Establishing flagging systems for all known local patients with learning disabilities, thereby using data to promote targeted local health initiatives to address known health inequalities; and ensure the provision of 'reasonable adjustments' and positive support plans that mitigate known health inequalities in accessing the services they need (see NHS Digital – Reasonable Adjustment flag 2023 and the NDTi Greenlight toolkit 2022)
- Ensuring regular opportunities are in place with mainstream health and social care services to discuss issues concerning people with learning disabilities accessing their services effectively
- Developing increasing confidence, skills and experience in supporting people with complex health support needs through training and other service development interventions

This should be seen as a core function of CLDTs, especially in relation to supporting key target groups (Primary Care, Acute Hospitals, Mental Health Services, Social Care agencies, Police, Probation and Job Centre Plus) where their understanding of learning disabilities will be critical to achieving high quality health and social care outcomes.

5. Quality Assurance and Strategic Service Development

CLDTs health professionals should play an active operational or role in strategic planning, care package contract oversight and policy development, in support of local commissioners. By the nature of their work, they are often the people most in contact with service providers, and their knowledge of, and ability to critically evaluate the work of providers should not be underestimated and health professionals should be actively included in commissioning conversations at both an individual and service level.

CLDT professionals should contribute to the design, creation, and monitoring of provider support arrangements for people, particularly for those who need a lot of support from family and community, and a range of agencies.

Work related to this will include professional expert support prioritised to support commissioners ensuring adequate policies, procedures and support structures to ensure that the goals of national learning disabilities agendas (e.g. Building the Right Support, NHS Long Term plan) can be achieved through which people with complex support needs and with behaviour of distress, have their identified needs met through effective local support and care arrangements.

Whilst co-ordination/care management is a primary role for social workers and care managers, all members of other disciplines within CLDTs should be expected to offer care navigation and coordination role for people on their case load as a lead practitioner (in addition to providing professional advice, and where necessary, therapeutic/remedial interventions) if needed.

CLDTs need to continually develop their capacity to respond to local needs and adapt the skills base to match changing demand. Community Learning Disabilities Health Teams are expected to be key agents that support the effective functioning of Local LD Partnerships Boards and Forums, and Integrated Care Boards.

Transition of Children into Adult Services

A learning disability is a lifelong condition, and there needs to be effective services to meet the needs of people with learning disabilities across the life span. Specialist CLDTs should be available for joint working with young people with complex health support needs and behaviours of distress to facilitate effective transition to adult services, in line with locally agreed protocols. There should also be in place specific local Transition plans in line with NICE guidance on Transitions (NICE 2016).

Evaluating and Reporting on Performance and Outcomes

An effective CLDT is there to:

- work with people with learning disabilities to enjoy better health outcomes and health care access, in ways which open up opportunities for independence and inclusion while reducing inequality;
- help people with learning disabilities use ordinary health services that are responsive to the needs of people with learning disabilities and their families;
- ensure opportunities for good health and well-being for vulnerable people; design, develop and deliver high quality local services that reduce reliance on high-cost, restrictive and out-of-area placements.

CLDTs need to demonstrate their value in meeting this agenda and provide evidence of how national minimum standards in relation to recognised best professional and service performance standards are addressed through individual and team performance in relation to a comprehensive set of targeted service activity and quality measures. This will necessitate valuing professional interventions that commonly require more than face-to-face activity.

As a result, commissioners will need to agree a wider range of activity reports and measures related to indirect patient support in line with the 5 essential functions of specialist CLDTs. This work should be in line with NICE and CQC guidance on evidence-based interventions and effective service arrangements, and meeting the varying cultural needs of local communities. They should make sure that services are provided equitably to all who need them, including people with complex disabilities and circumstances, people who may experience known inequalities in relation to other protected characteristics so that people with learning disabilities have positive experiences.

Closing Comments

The importance of the work of CLDTs has been brought to the fore through both the Learning from Lives and Deaths report and the ongoing reports such as Whorlton Hall, Cawston Park and Muckamore Abbey. CLDTs and their commissioners now need to invest considerable energy and the focus of their specialist health service role to achieve change in the status quo. Good outcomes require relationship centred care incorporating person-centred thinking, creativity, commitment, flexibility and clinical expertise balanced by accurate risk assessments and management. Success will only be apparent if this group of vulnerable people live lives with more opportunities, with less exposure to harm; and are healthier for longer more in line with the general population.

NHS commissioners in England retain overall responsibility for the performance and outcomes of the health support available to people with learning disabilities and their families, including any access problems and reducing health inequality.

The vision for CLDTs relevant to the wider NHS agenda is to ensure they enable directly and indirectly, access to high quality effective mainstream and specialist services that are equally accessible to all and designed to meet the needs and aspirations of people with learning disabilities, thereby reducing health inequalities and restrictive practices.

Community Teams should:

- Have clearly agreed measurable and reportable aims and objectives, whereby it is possible to assess whether the Team is succeeding
- Be structured in such a way that each member has independent responsibilities, and knows what these are together with relevant performance and activity measures

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- Be collectively responsible for a clear and identifiable areas of work in line with the 5 core functions, delivering on Building the Right Support (BtRS) and Learning from Lives and Deaths report (LeDeR) or other relevant strategic priorities in their nation.
- Develop and maintain effective workforce plans inclusive of talent and succession plans underpinned by positive workforce practices such as regular supervision, leadership/development wellbeing and support services
- Contain members with a mix with varying degrees of professional skills, abilities, experiences and problem-solving strategies
- Ensure sufficient opportunities for team members to interact and meet both easily and frequently - formally and informally.
- Engage proactively with all other health and social care services to ensure that adults with learning disabilities, their families and carers receive a seamless and effective service that meets their needs and helps them achieve their aspirations.

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