



***Delivering Effective Specialist Community
Learning Disabilities Health Team Support
to People with Learning Disabilities
and their Families or Carers***

**A Briefing Paper on Service Specifications and Best Practice for Professionals, NHS
Commissioners, CQC and Providers of Community Learning Disabilities Health Team**

By the National LD Professional Senate

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'...the competence or capability of local 'mainstream services for people with learning disabilities will...influence the number of people defined as presenting a serious challenge. Well organised and managed services...will show fewer problems'

(Mansell Report, 1993)

'life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management'

(Mansell report, 2007)

'urgent need for systemic change within the NHS for people with learning disabilities' and outcomes were a 'shocking indictment of services which profess to value individuals and to personalise services according to individual need'

(Six Lives: The Provision of Public Services to People with LD, 2009)

'We should no more tolerate people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment. That is why I am asking councils and clinical commissioning groups to put this right as a matter of urgency.'

(Transforming care: A National response to Winterbourne View Hospital, 2012)

'The quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways. Despite numerous previous investigations and reports, many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with learning disabilities. The CIPOLD study has shown the continuing need to identify people with learning disabilities in healthcare settings, and to record, implement and audit the provision of 'reasonable adjustments' to avoid their serious disadvantage.'

(Confidential Inquiry into Premature Deaths of People with Learning Disabilities, 2013)

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Introduction

It is clear that **life today is better for most individuals with learning disabilities and their families. However, there remain particular groups that remain at risk of unnecessarily restrictive lifestyles, poor access to services and opportunities, and serious health inequalities.**

Locally commissioned effective specialist Community Learning Disabilities Health Teams are critical to providing the essential support needed by people with learning disabilities and their families. And their **success can only be judged if this group of vulnerable people live full lives with more opportunities and less exposure to harm, as well as experience health outcomes in line with the wider general population.**

Good practice guidance such as *Services for People with Learning Disabilities and Challenging Behaviour*, first published in 1993, has been available for many years, and many argue that had this been fully implemented it is clearly arguable that Winterbourne View would not have happened. These concerns led to the previous *DH Good Practice Guidance: Commissioning Specialist Learning Disability Health Services* originally issued in 2007, which noted even then:

- ***There is growing concern that some areas of the country have found it difficult to develop commissioning strategies for specialist adult learning disability health services that reflect both current policy and best practice.***
- ***This has led in places to inappropriately funded services, outdated service models including ineffective integration arrangements, the poor development of a community infrastructure and an over-reliance on bed based services (including NHS campuses and distant NHS & independent sector placements). Additionally, the lack of appropriately funded and skilled specialist learning disability health services can be a major cause of failure by social care services that are commissioned by local authorities.***
- ***These, and associated problems, can mean that***
 - ***people with learning disabilities are getting ‘stuck’ in the NHS system or independent health placements often for many years and sometimes many miles from their home and/or,***
 - ***people placed in increasingly expensive and inappropriate social care services that are failing to meet their needs.***
 - ***People experience serious difficulty getting their healthcare needs met and are at risk of neglect and, at worst, abuse.***

It is now clear that the NHS has not met the targets set out in *Transforming Care* and the *Concordat*. Clearly, the existing approaches have proved ineffective, and a different professional and commissioning approach to Community Learning Disabilities Health Teams and services is now needed in line with the challenges noted in for example *‘Winterbourne View: Time for Change’* and *‘Keys to Life’*.

In a similar vein, concerns regarding the effectiveness of existing community learning disability services were noted in Mencap’s 2007 report *Death by Indifference* which described the circumstances surrounding the deaths of six people with learning disabilities who died while they were in the care of the NHS, exposed *‘institutional discrimination’* by wider society and services.

In response, the resulting 2009 report of the Parliamentary and Health Service Ombudsman *Six Lives: The Provision of Public Services to People with Learning Disabilities* reinforced the urgent need for systemic change within the NHS for people with learning disabilities and considered the existing outcomes as a ***‘shocking indictment of services which profess to value individuals and to personalise services according to individual need’***.

The establishment of Learning Disabilities Public Health Observatories in England and Scotland, and the time-limited Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), recommended by the Independent Inquiry chaired by Sir Jonathan Michael, noted ***'We hoped to find that people with learning disabilities were living long and healthy lives to no lesser extent than those without learning disabilities. Our optimism has been quashed'***. The review of deaths that made people with learning disabilities particularly vulnerable to premature death was the relative inattention given to predicting potential problems, and then having to respond to those problems in a crisis.

The main areas highlighted were: firstly, addressing the knowledge that a person is fearful of contact with medical professionals, and secondly, predicting and planning for the future health and care needs of people who were likely to have changing support needs as their condition progresses, or their circumstances change. This involves effective support available from specialist community learning disability teams that enable mainstream health services to respond appropriately to individuals with complex support needs and their families.

The events at Winterbourne View and the CIPOLD inquiry highlight the importance of action to ***'rapidly expand and improve community provision for people with learning disabilities and/or autism who display - or are at risk of displaying behaviour that challenges'*** and ***'supporting people to access health services' through 'providing expert advice, support and training to health and social care providers; providing individual assessment, care coordination and therapeutic interventions for people with learning disabilities; offering advice and support for the provision of reasonable adjustments for people with learning disabilities, including the provision of easy read information.'***

There is now a collective recognition for ***'sufficient skilled support to people across all ages throughout (or at various times in their lives) and at times of crisis to minimise the admission to in-patient facilities'***.

This requires joint action on the part of CCG and NHS England commissioners (working with their Local Authority colleagues, service providers and other stakeholders) to ensure that a good local spectrum of responsive services are available to support people who challenge and present complex support needs and prevent expensive, restrictive and potentially risky out of area placements.

Critical to this are 5 essential elements that commissioners need to attend to for a good local service offer. That is:

- **Sufficient Specialist Learning Disabilities Clinical Capacity** as part of comprehensive and well-integrated community support services, with well-resourced Community Teams, that can readily access responsive specialist professionals
- **Adequate Skilled Community Support and Provider Capacity**, including a range of supported home, education and occupation options
- **Access to Expert** and learning disability informed **Care Management Capacity**
- **Joint Funding Capacity and Panels** to enable delivery of flexible support arrangements and on-going tracking of individual and wider services
- **Appropriate Models for the Integration of Health Care and Social Care Service Provision** so as to ensure a 'seamless service' for the user

To succeed, these components must be **accompanied by strong informed and effective local leadership, with well trained and committed staff** who have the competence, capacity and confidence to respond effectively to complex and challenging behaviour and work with people through all levels of difficulty.

This paper is mainly concerned with the adult health commissioning, health funds and healthcare element of this agenda. We do however recognise that the importance of integrating health care and social care means that this NHS approach must be complemented by specific action involving a review of the role of social workers and other care workers, as well as children's services. This therefore acknowledges that this responsibility of Local Authorities must be discharged in collaboration with NHS colleagues.

This work **applies to health services directly commissioned by CCGs or where these have been delegated through local Pooled Budgets with Local Authority lead commissioners.**

For such services **NHS commissioners retain ultimate responsibility to their regulators for the quality of outcomes achieved for individuals and the local community.** The accountability of Local Authorities to their regulatory bodies and to their electorate is a parallel and vital element in integrated services.

Real changes must take place in the ways Community Learning Disabilities Health Teams specialist health professionals, teams and services work for people with learning disabilities.

Overall, services must be more person-centred and act strategically across health and social care agencies deploying clinical skills, knowledge and time with a view to the long-term needs of individuals, families and communities, rather than continue adopting a reactive and solely individual case work bias.

The wider activities of Community Learning Disabilities Health Teams health professionals must also **be re-focused to give greater emphasis to providing high quality clinical expertise on both an individual and system-wide basis.**

Commissioned Community Learning Disabilities Health Teams must focus on delivering specialist clinical support for both registered patients (in local or out-of-area placements) and wider health promotion/facilitation activities and service improvement programmes.

These recommendations are **in line with the defined responsibilities for CCGs and their equivalents in other nations in relation to NHS funding and commissioning responsibilities and for example the existing NHS England Business Plan** whereby NHS commissioners and regulators must ensure that there are local systems to ensure the needs of people with learning disabilities and their families are prioritised. They must be supported by effective evidence-based positive behaviour support work, at an individual and wider way that ensures people with complex support needs are safe and healthy.

This work has been reinforced by the *Transforming Care Concordat*, *National Audit Office* and *Keys to Life* reviews defining best practice for commissioning community services and innovative responses to effect change, as agreed across all stakeholders in responses to the Winterbourne View Update Review and CIPOLD inquiry findings.

Person-Centred Principles, Culture and Values

Person-Centred Practice and individual service design should be at the heart of the commissioned and provided specialist community learning disability health team practice. This agenda is supported by the DH *Ensuring Quality* Core Principles work that defined those essential capacity elements that must be considered and be place in a local effective functioning health and social care system. This approach has also been adopted by the Improving Lives Team Model, in the individual reviews arising from the *Transforming Care Concordat* as a model of good practice.

The principles are:

- Prevention and early intervention
- A whole systems life course approach
- Family carer and stakeholder partnerships
- Behaviour that challenges is reduced by better meeting needs and increasing quality of life support for communication
- Physical health support
- Mental health support
- Function based holistic assessment
- Support for additional needs
- Positive behavioural support
- Safeguarding and advocacy
- Specialist local services
- Workforce development
- Monitoring quality

Good quality learning disability services have an approach based on strong community support services, planned around people in the environment that they are in, focussing on person-centred care, and looking at each individual's needs. This approach should be applied to all, including people with very complex support needs. Services must be committed to achieving the outcomes of 'rights, inclusion, independence and choice', and to ensuring that they 'stick with' individuals in spite of the difficulties experienced in meeting their needs. These principles have long been re-affirmed in national policies such as *Valuing People Now*, *'Rights, Independent Living, Control and Inclusion'* in England and *Keys to Life* in Scotland.

To do this, **all those supported by specialist community learning disability services should have in place good Person-Centred Plans and brief Personal Profiles describing their essential needs and positive active support plans** (not unread and unused lengthy inaccessible professional reports too often just filed away).

These plans and profiles therefore:

- Build on the best ways to listen to people and their behavior by getting to know each person and developing a picture directly through personal contacts, listening to what records do and do not say, face-to-face interviews/reviews, rather than listening to diagnostic labels and reputations
- Are specific, simple, clear and understood by all those involved, focusing on what works and does not work for individuals in reducing health disparities and restrictive practices
- Address the key areas of a person's life, health and well-being which are most concern and the people who care about them, recognizing individual needs, hopes, desires and capacities
- Have the backing of the person and people around them, with open clarification of constraints

- Do justice to the person in the way it describes individuals and support needs
- Accurately reflect what has been agreed
- Are unique to the individual and so do not package people or service specifications, or focus process and activity at the expense of outcomes
- See people with learning disabilities as valued human beings in need of opportunities
- Involve people getting together and building shared pictures of the way forward
- Check for consensus and disagreement without blame, surfacing and negotiating disagreements
- Record shared action plans with what, who, by when, how know if successful, and fall back positions to manage the inevitable reality when things do not go as planned
- Accept that the support solution today is not expected to last forever, as everyone grows and changes, so reviewing plans is a necessary continuous effort
- Value effective professional health expertise and personalised input

This positive approach towards supporting individuals must also be accompanied by equal attention to the needs of families through the initial adoption of key assumptions that support joint working. That is:

- The **emotional reactions** of families of individuals with disabilities are **normal, necessary and potentially productive** reactions
- Though the **family may need professional assistance in managing effective responses and education**, they are as capable as others in solving other problems without professional input. Their solutions may not be always be our solutions, and often that should be acceptable
- **Professionals must learn to work within the family's system**; this system should not always have to change to accommodate professional input
- Having a child with disabilities may not be the most important problem the family has at a given point in time. It is legitimate for other issues to be given priority, as family needs dictate
- **The family can often be the person's best, most committed, long- term advocate**
- Parents and professionals usually share a common concern for the long-term functioning of the individual with disabilities, although on occasion emotions can cloud appropriate judgements
- **Families usually want to do what is best for the individual and so want/should be actively and productively involved**
- All interventions, diagnostic and otherwise, should be based on clinical and empirical evidence, not on traditional unhelpful assumptions about parental/environmental pathology causes
- **Interventions should fully acknowledge the negative impact of the historical misconceptions of families of individuals with disabilities and common negative experiences families will have faced with services and so should seek to dilute this impact by positive service attitudes and actions**
- Professionals should be fully aware of their own interpersonal strengths and weaknesses. They should continuously strive to avoid inflicting their weaknesses and/or subjective values on the families with whom they work
- **The criterion of the 'least dangerous assumption' should be applied to the selection of interventions or placement decisions. That is, in the absence of conclusive data, decisions should be based on the assumption that if incorrect, will have the least dangerous effect on the individual with disabilities and their family in terms considering out-of-area placements and restrictive clinical practices.**

- Even if very young, a full explanation regarding the possibility of specific disabilities is essential. Parents should be informed explicitly about the concrete features which support a diagnosis, those which do not, and the level of confidence, together with realistic but positive future options
- **Interventions should be sensitive to the unique emotional and practical problems faced by families, and accept their reactions as normal and legitimate reactions to an overwhelming situation**
- **Emotional and other types of support** (e.g. counselling, parent groups, circles of support, person-centred plans, parent advisors/link workers, training) **should be made easily available to the families who want them.** The assumption that all families need professional services should be avoided
- **Other types of support (e.g. respite breaks, leisure/ work activities, transport) which enable the individual to stay at home should be freely available to their families for as long as necessary**
- Interventions should be designed to meet the needs of the child in the broader context of the needs of the family
- **Parents should be recognised as an expert in many areas related to their child's unique history, behaviour and needs.**
- **Therefore, parents should usually have full membership of the multidisciplinary support teams, and should share equally in all team decisions providing a balance to professional expertise, and have the right to request re-evaluations of decisions at any time without receiving hostile responses.**
- **Of course not all families act in their children's best interests, both those of children with learning disabilities and without – and on these occasions formal 'best interest' challenges may be necessary and essential**
- Parents should usually have full access to all diagnostic and intervention information, facilitating individualised, flexible open partnerships
- **Under no circumstances should parents and families hear that 'nothing can be done'.** There may be times when local services run out of practical resources or expertise to resolve a problem, and at these times, **alternative options may need to be explored through open, transparent dialogue.**

Meeting the needs of families both as units in their own right, and as part of the communities in which they live, needs the input of social care services and of professional social work and thus requires effective models of integration.

Many of these assumptions equally apply for specialist learning disabilities community health teams when working with other paid carers and support services, where similar power differentials with professionals are apparent.

Implementing person-centred support on a broader scale is critical but only affordable if services really change fundamentally the way many Community Learning Disabilities Health Teams and services work today.

They must **become both more proactive and pragmatic in making strategic decisions about what they focus on doing within a positive values-based and individual service design framework.** Only then is it possible to achieve high quality, safe and compassionate care in the least restrictive settings and ensure fewer health disparities (i.e. access, quality and outcomes).

Key NHS Learning Disabilities Challenges

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 to two critical priorities for action. That is, **'Reducing Restrictive Practices and Reducing Health Disparities'**.

Learning disability health services have, in the past 25 years, moved from a predominantly bed-based to a community based model of care for most individuals. The intention accepted across society is a fundamental shift in the focus of care from a pathological (illness versus wellness) model, based in large institutions, to a more social (normalisation and inclusion) and person-centred model based in communities, thus improving the life chances of people with learning disabilities and their families.

The key principles adopted in designing, developing and delivering services have focused on the need to put the individual 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 so that they can support all people, including those individuals with the most complex support needs, as close to the person's community as possible.

Services have been directed to plan and intervene early, focussing on safely meeting the full range of needs and opportunities that improve a person's quality of life. At all times people using services should be treated with dignity and respect and should be included in planning and receiving care and treatment, with access to advocacy and independent representation when necessary, and supported by competent staff and professionals with access to continuous professional development or CPD opportunities that lead to better outcomes for all.

For most people with learning disabilities then, life is now better than decades ago and presents more opportunities for individuals and their families with more valued community options and experiences.

However, for one significant group of individuals this has not been so. Despite models of good practice being demonstrated for more than a generation, making this happen on a wider scale for all people with learning disabilities, especially those presenting with behaviours that challenge have continued to involve unnecessary restrictive options and less than an ordinary life experience.

Further, **people with learning disabilities generally experience poorer health than the general population,** with the significant differences in life chances and mortality to a large extent avoidable, and thus representing significant health inequalities that must be attended to.

In 2013, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) confirmed that: **'the substantial health care needs of people with learning disabilities too often go unmet as they can experience both avoidable illness and die prematurely, with symptoms not recognised by either the person or their family or carer leading to late diagnosis and treatment, too low expectations of the treatment they can expect and the therapeutic environment being too often unsuitable with a lack of reasonable adaptations.'**

Sir Jonathan Michael, in 2008, stressed that: **'What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have learned that 'equal' does not mean 'the same' and that 'reasonable adjustments' that are needed to make services equally accessible to people with learning disabilities are not particularly difficult to make'**.

In December 2013, the DH published *'Winterbourne View: Transforming Care – One Year On'* with a Ministerial Forward that noted: **'Winterbourne View was a scandal which shocked and appalled us all. The**

systemic failings there are as bad as those uncovered by Robert Francis in his report into Mid Staffordshire. We are not looking at one or two poorly-trained or malicious members of staff but at something much more insidious. That is why we need this full programme of work to address all the different aspects and underlying causes which allowed this to happen. We must take every step to be as sure as we possibly can be that this will not happen again.'

The NHS England Business Plan 'Putting Patients First' (2014/15 to 2016/17) has confirmed work to address this agenda as a priority action area noting ***'The purpose of this business area is to ensure that people with a learning disability or autism receive safe, appropriate care in a safe environment and they are protected from avoidable harm (in line with domain 5 of the NHS Outcomes Framework). A key aspect of this is ensuring that lessons are learned when things go wrong and action is taken to prevent a recurrence'***.

This means that specialist community learning disability services must be commissioned with sufficient capacity to help support these objectives with access to local specialist health and social care support for individuals across the life-course, and targeted at people with learning disabilities who have additional severe, complex or enduring support needs.

This calls for significant changes in the whole health and social care system to truly *Transform Care* across the lifespan provided through the on-going access to competent, credible, committed, capable Community Learning Disabilities Health Teams.

For this outcome, commissioners of and clinicians in Community Learning Disabilities Health Teams need to:

- secure better practical early support for children and families to tackle issues 'upstream' with staff encouraged to care, connect and deliver practical short full life plans and interventions
- promote good health care support and the well-being of individuals
- ensure that health care and social care services work effectively together
- undertake in-depth person-centred assessments of individuals and their clinical support needs
- flag up possible common co-morbidities and vulnerabilities (e.g. sensory impairments, respiratory conditions, epilepsy, dementia, autism and mental health difficulties), with accompanying education and awareness programmes for families and services
- develop, design and implement support packages using a range of therapeutic approaches
- ensure access to skilled and accessible core specialist professionally registered therapeutic support (e.g. nursing, OT, psychiatric, psychological, speech and language therapy, physiotherapy, dietetics, arts therapies), with support from effective clinical governance and supervision frameworks
- see 'behaviour that challenges and complex support needs in context', thereby responding to individuals by first removing stressors and building on capacity assets, rather than pathologising problems with individuals that require restrictive or 'removal' treatment responses
- support effective care management and resource allocation panel processes, and enable flexible use of health and social care monies and joint funding options
- provide effective skilled care coordination for small numbers of people presenting significant challenges in community and in-patient settings

- put in place positive behaviour and crisis response plans, including detailed challenging behaviour escalation response and emergency management plans that do not focus solely on moving the person elsewhere
- have clear credible on-going senior leadership and commitment to support action informed by a positive community vision and practice principles that avoid a reactive 'easy' placing people away approach
- support access when times get hard, and staying in the community setting is not possible, to short term flexible extra practical assistance and a wider spectrum of support resources (with step-up/step-down pathways that reduce the length of time people spend in in-patient settings and better manage crises)
- support on-going personal and professional leadership development and more robust longer-term work with skilled providers that are committed to demonstrating dignity/compassion/skills /endurance for supporting people with learning disabilities over the long run
- support access to competent local health and social care providers, encouraging multiagency training partnerships and collaborative service improvement programmes

It is important to remember that the DH's Winterbourne View Review found ***'there was a widespread failure to: design, commission and provide community-based services that meet the needs of children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges'***.

Although the past moves away from institutional and hospital models of care through the Valuing People agenda led to a clear need to initially prioritise social care and justice issues in the NHS commissioning agenda, in many cases this has been misunderstood. At times, this has inevitably meant that the valued and essential role of discrete specialist community learning disability teams and services has been inappropriately downplayed.

'Disability-blindness' to the often complex and additional support challenges of individuals presenting with high health and social care support needs is ineffective and will mean mistakes of the past will be repeated. This can be further threatened by the all-too common, but inappropriate, plans in many localities for locality-based integrated generic health and social care teams that limit access to necessary specialist learning disability professional input. Such undermining can be clearly seen as removing the essential 'reasonable adjustment' that specialist community learning disability teams and services provide.

This must be avoided so that **the focus of commissioned specialist Community Learning Disabilities Health Teams health staff is available to providing specialist clinical support (doing things that mainstream health and social care services cannot do) for CCG-registered patients (both in local or out-of-area placements), and wider health promotion/facilitation activities and service improvement programmes.**

Only then can the clear vision be realised, whereby:

'Everyone, with no exception, deserves a place to call home. Person by person, area by area, the number of people with learning disabilities and autism in secure hospitals or assessment and treatment settings will permanently reduce. At the same time local community-based support and early intervention will improve to the point it will become extremely rare for a person to be excluded from the right to live their life outside of a hospital setting.'

The Core Purpose of Community Learning Disabilities Health Teams

National policies have all wanted dedicated specialist NHS learning disability health services to **direct their efforts towards helping people enjoy better health and health care, in ways which opened up opportunities for independence and inclusion.** They have wanted services to **be person centred and show high quality expertise.**

It has also been expected that specialist learning disability health professionals **spend less time in direct work with people with learning disabilities in isolation, and more time on enabling people with learning disabilities use mainstream services and obtain opportunities for good health and life outcomes.**

The sorts of changes envisaged by *Valuing People* were in line with the challenges in **developing extended clinical and practitioner roles crossing professional and organisational boundaries,** and are even more pertinent today than when they were first defined more than 10 years ago.

It is clear that a **comprehensive community support model and infrastructure** requires at a minimum:

- An appropriately resourced Community Learning Disability Team
- Accessible specialist support both from health care and social care professionals
- A range of facilitated physical exercise, education, work and leisure opportunities
- Short breaks and 'respite' for carers (especially those of people with behaviour that challenges)
- Transition arrangements for children moving to adulthood, including addressing the critical loss of full-time education and over-arching medical oversight and annual reviews
- The capacity to access support and respond to crises 24 x 7
- Accessible resources to facilitate effective support for people with complex support needs and behaviour that challenges
- Policies and protocols for the design, monitoring and prevention of placement breakdown
- Effective integration of the components of the service.

For individuals with a wide range of support needs, such as many people with learning disabilities with complex support needs, adult services have too often been seen as confusing and fragmented due to the considerable overlap in professional and service roles. As a result, **Health teams and services should now be organised as fully inter-disciplinary team with sufficient critical mass in each locality to enable to deliver the identified 5 Essential Community LD Team functions required by commissioners** for inclusion in commissioning service specifications, operational policies and reviews. These being:

1. Support at a universal level for positive access to and effective responses from mainstream services
2. Targeted work with individuals and services enabling others to provide effective person-centred support to people with learning disabilities and their families/carers
3. Specialist direct clinical therapeutic support for people with complex behavioural and health support needs
4. Responding positively and effectively to crisis presentations and urgent demands
5. Quality assurance and strategic service development in support of commissioners

Integrated Health and Social Work Community Learning Disabilities Teams

Several factors are creating changes in the demand for both health and social care services for people with learning disabilities and their families:

- Significantly increased numbers of people with learning disabilities, partly caused by people living substantially longer as a result of medical and technological advances, with people needing additional support around illnesses and long-term conditions linked to old age, in particular dementia for people with Down's Syndrome
- Significant changes in the demographic profile with increased numbers of people with complex needs requiring input from specialist health professionals. This particularly applies to young people with multiple disabilities transitioning into adulthood
- Increasing empowerment of people with learning disabilities and their families, resulting in higher expectations and demands for better quality services located nearer to local homes and communities.
- Increasing demand to support people with autistic spectrum disorders with or without learning disabilities to better diagnosis, early identification of need and post-diagnostic support.

Providing health interventions in a social context that fails to match an individual's essential support needs can be ineffective. 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.

As a result, national policies have defined a vision for effective Community Learning Disability Teams supporting:

- fully-integrated professional work across disciplines and agencies, with all health and social professionals jointly accountable for the outcome of their work to local LD Partnership Boards or local Health and Social Care Partnerships arrangements
- social inclusion opportunities and outcomes
- organisational structures which encourage and promote inclusive working, through:
 - single points of access for health/social work referrals;
 - common contact assessment/core client databases;
 - integrated health/social work team management arrangements;
 - shared initial intake assessment allocations meetings;
 - shared common assessment process including essential current and historical information records;
 - common care plan/programme review systems;
 - re-focused multi-disciplinary and professional team meetings enabling reflective practice;
 - joint resource allocation panels supporting personalisation;
 - active team participation in regular multi-agency service development/contract reviews;
 - clear supportive professional leadership provided with a range of effective management, high quality supervision, training strategies and resources;
 - shared team bases and resource centres providing equipped meeting/training rooms and offices.

A clear care co-ordination framework is integral to making this work, with an underpinning principle being to adopt a single integrated health and social care process to deliver continuity of care for vulnerable people with complex needs requiring intensive intervention and/or long-term support. Service users should therefore be provided wherever possible with one integrated assessment process, one principal contact person, one care plan and one review process – including joint documentation, commonly agreed aligned eligibility criteria and integrated information systems. In principle, this is a vision that should be supported.

The 5 Essential Community Learning Disabilities Health Teams Functions

In essence, effectively commissioned specialist learning disability community health services:

- Promote safe, person-centred support and evidence-based practice
- Demonstrate positive outcomes, particularly in regard to reductions in restrictive practices and health inequalities
- Support mainstream practice and directly serve those with the most complex support needs
- Direct people away from institutional responses to crisis and put support around people in community settings
- Integrate planning and development work that promotes individualised local services close to home
- Include staff that offer advice and support to other professionals or services and those who provide day-to-day care, as well as direct interventions with people with learning disabilities and families
- Provide skills to provide specific and responsive care in all settings for people with learning disabilities and their families/carers
- Enable swift access, when needed, to medical, nursing and therapy professionals
- Invest in training and development for specialist professionals, families and front-line support staff
- Support a robust community infrastructure that takes a broad early intervention view on addressing health needs and the range of health and other factors associated with social exclusion and health inequalities to secure better and more inclusive service outcomes
- Fulfilling all legal/safeguarding requirements and ensure the voice of individuals and families is heard, including access to appropriate advocacy, representation and new ways of working to further enhance health care and reduce health inequalities.

1. 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 Community Learning Disabilities Health Teams 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. This should be seen as a non-negotiable component of a Community Learning Disabilities Health Teams service specification, 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.

Community Learning Disabilities Health Teams health professionals should work with mainstream providers, acute liaison, primary care liaison and prison liaison nurses about ways to support the specialist health and complex support needs of people with learning disabilities.

As such, some of the **core training competencies that Community Learning Disabilities Health Teams health staff should have and then also share through an organised local multi-agency training programme in line with best practice guidance** (and where appropriate including service users, families and paid carers as co-trainers) should include:

- Understanding Learning Disabilities
- Person-centred planning and Essential Lifestyle Planning approaches, including for example creative graphic facilitation strategies

- Health Action Planning
- Health Inequalities and Reasonable Adjustments
- General Communication and Listening strategies for people with speech, language and communication needs
- Effective Inclusive Communication strategies, including signs, symbols and accessible communication
- Enhancing Positive Interactions and Building Engagement
- Effective Skills Teaching, including where necessary Training in Systematic Instruction
- Understanding and Responding Positively to Behaviour that Challenges through Positive Behaviour Support
- Understanding and Responding Effectively to Mental Health/Dual Diagnoses Issues (including using PAS-ADD or other tools)
- Understanding and Responding to Autism Spectrum Conditions in Adults
- Applying Sensory Integration approaches positively
- Understanding and Responding to Loss and Bereavement
- Understanding Ageing & Learning Disabilities
- Understanding and Responding to Dementia
- Understanding and Responding to Epilepsy Supporting People with Profound and Multiple Disabilities
- Effective support with Eating, Drinking and Swallowing difficulties, including Dysphagia
- Understanding and responding to sensory impairments
- Special Parenting issues
- Effective Risk Management
- Managing Physical Aggression and Violence in Community Services for People with Learning Disabilities

Community Learning Disabilities Health Teams should provide on-going support, supervision and advice to services (especially primary, community and specialist acute/mental health and criminal justice services) to support them in:

- Establishing joint registers and flagging systems for all known local patients with learning disabilities, thereby enabling the provision of 'reasonable adjustments' and positive support plans that mitigate known health inequality and service access outcomes
- Ensuring regular dialogue and joint training meetings with mainstream health and social care services to discuss any particular general concerns and support plans
- Developing increasing confidence, skills and experience in supporting patients with complex health support needs through training and other service development interventions
- Implementing the Accessible Information standard specification once finalised

This work is necessary, although insufficient alone, in addressing all the barriers faced by people with learning disabilities accessing effective support from mainstream services and housing/support systems which matches an individual with complex needs.

2. Enabling Others to Provide Effective 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 Joint 14+ Transition Work and Liaison Support

An effective Community Learning Disabilities Health Team should be able to:

- **Provide prompt and expert evidence-based practical focused assessments and formulations as to why any problems have or may arise, and interventions to mitigate concerns** that:
 - Address specific learning disability-related concerns
 - Reduce and shorten distress and suffering
 - Ensure that inappropriate or unnecessary interventions are avoided
- **Provide specialist advice, limited support and client-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 individuals with learning disabilities and their families/carers and promote effective integrated working maximising the health and well-being outcomes of individuals and the local community.

A key objective of effective targeted support from a Community Learning Disability Health Team should be to share and develop broader adoption of the 5 Good Communication Standards identified by the Royal College of Speech and Language Therapists. That is, raising awareness whereby:

1. There is a detailed description of how best to communicate with individuals.
2. Services demonstrate how they support individuals with disabilities and communication needs to be involved with decisions about their care and their services.
3. Staff value and use competently the best approaches to communication with each individual.
4. Services create opportunities, relationships and environments that make individuals want to communicate.
5. Individuals are supported to understand and express their needs in relation to their health and wellbeing.

Community Learning Disabilities Health Team health staff should provide targeted individual case-related teaching and accessible materials to people with learning disabilities and family carers about healthy living and specific health topics that enhance support for complex presentations, thereby working with them to develop their skills and confidence in speaking out about health matters, and making complaints or providing feedback to services where necessary to deliver better quality and more responsive services.

Community Learning Disabilities Health Teams support to wider local multi-agency and multi-professional training programmes should be encouraged as part of an agreed workforce development strategy.

The local clarification of training that will be provided as core commissioned Community Learning Disabilities Health Teams as opposed to those elements that remain the responsibility of publically-funded services (in line with their contractual and disability equality duty obligations) should inform an agreed plan. That is:

- Any mandatory health and safety elements as induction and foundation training
- Any core disability awareness training in line with the obligations to provide 'reasonable adaptations'
- Any non-person specific 'specialist disability' training noted as part of their specific care home or professional service offer (such as for example autism, dementia, mental health or sensory disabilities)

There may however be need to agree additional specific 'top-up' funding agreements to support local additional capacity where Community Learning Disabilities Health Teams training and other professional input is necessary to support agencies to meet their core CQC and other contracted responsibilities and obligations, for which they have already been funded as a 'specialist provider'.

Alternatively, there are some localities where there is an agreed top-slicing approach to remove some funding from the commissioned service contracts to enable additional local professional team capacity, training and cross-agency joint service-improvement development work.

In both these later cases, where this 'top-up' funding is necessary, these actions should be **supported in line with the obligation on Community Learning Disabilities Health Teams to support wider Learning Disability commissioning strategies and service-improvement programmes, and not be seen as additional income-generation opportunities.**

This type of joint working can be all the more important for Community Learning Disabilities Health Teams as this work can also **foster a culture of mutual local multi-agency support, sharing and joint investment in local practitioners as shared trainers to link local clinical interventions with training materials and services. This can also maximise the outcomes of other Team work, as well as providing additional information to inform quality assurance, monitoring and intervention compliance** and necessary service adjustments. As such, this type of training should be seen as more than 'train and hope', and instead essential scaffolding.

This function also includes the work of primary care, hospital, mental health and prison service liaison posts, (established as specific adjuncts to generic posts) because of the specific complex presenting disabilities or challenges that individuals can place on mainstream services. They can also assist the setting up and maintenance of 'flagging' registers.

Making equal access and outcomes a reality for people with complex disabilities and support needs often demands additional targeted and at times highly intensive specialist casework, as well as wider sensitive service planning and interventions. In terms of primary and secondary physical healthcare, this requires active roles rather than just signposting. Similarly in terms of mental health services (including forensic services) this requires active roles and breaking out of speciality silos. These types of development should be encouraged as they have been demonstrated to ensure equal access and outcomes in line with the same entitlements to independence, choice, inclusion and civil rights that people with learning disabilities and their families are entitled to.

3. 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 and clinical support)

Community Learning Disabilities Health Teams must be able to support a substantial minority with complex support needs, who because of on-going complex support needs will remain in contact with the Community Learning Disabilities Health Teams for on-going interventions as the intensity of their support needs fluctuates over time.

This can necessitate **specialist care 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 individuals requiring on-going care coordination with options to step-up and step-down matching the changing intensity of problem presentations.

As a result, **some individuals 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.

Community Learning Disabilities Health Teams specialist health professionals with the support of clinical assistants should carry individual specialist caseloads of clients with complex, severe and enduring problems and disorders related to learning disabilities (including people with disabilities and co morbid severe challenging behaviours, mental health difficulties, dementia, dysphagia, long-term conditions, epilepsy, autism, personality disorder 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 Community Learning Disabilities Health Teams specialist health professionals should provide:

- specialist and complex assessments of people with learning disabilities and summary formulations/ diagnosis based upon a good understanding of the person's history and what that person's life has taught. Without this, we are unlikely to provide an accurate person-centred service as we sometimes forget that people's understanding of the world is learned and that, for most people, this learning takes place quite early on.
- recognition and support for histories of abandonment or abuse, or where lives have been socially isolated. Such a learning history that can be overwhelming and the emotional impact of this must not get overlooked by critically understanding the answer to questions such as:
 - Who is this person?
 - What are the person's needs?
 - What are the non-negotiables?
 - What would it take to get those needs met?
- complex individual care plans for the treatment/management of a person's problems
- a range of complex highly specialist clinical interventions, employing methods based on proven efficacy, for individuals, couples and groups, adjusting and refining clinical formulations drawing upon different explanatory models - for individuals and groups
- physical health support
- specialist information, consultation, advice and support to relatives and carers
- skilled evaluations and decisions about treatment options
- specialist responses to complex, sensitive, distressing and emotional information in relation to mental and physical health issues, where there may often be difficulties in terms of acceptance or understanding
- effective communication of confidential and specialist condition-related and personal information obtained through assessments, formulation, therapy and interventions, adapting models sensitively
- complex risk and risk management programmes for individuals presenting vulnerability, self-harm and/or risk of physical, sexual or emotional harm to others
- care coordination, where appropriate, including initiating, planning and review of care plans under CPA/CHC mechanisms
- expert specialist advice, guidance, consultation and support to other professionals in a wide range of settings where care is discussed, planned and organised
- broader theoretical knowledge and specialist clinical skills to develop or support the ability of others
- staff supervision, development and working relationships with relevant statutory, voluntary and community groups and organisations
- access to bed-based services only where health input is highly intensive or unpredictable
- support to any admissions which result in real and meaningful assessment and treatment
- an eclectic range of interventions **beginning from an assumption that ordinary housing and support with specialist clinical health input added on locally (thereby more likely to be the best value and lower cost effective options) is the first option to be explored.** This includes a commitment to using the 'least restrictive alternative', support for the supporters (i.e. well-staffed, managed, trained, clear principles and flexibility built in including time for training), and access to an assertive outreach model taking resources to the person as opposed to removing the person, and expertise in establishing supportive boundaries to enable 'wounds to be healed'.

Community Learning Disabilities Health Teams specialist health professionals need to be tolerant, gentle, patient, empathetic, mature and respectful, and must be open to intense analysis of how their actions or the situations they operate in may be the ‘problem’ that needs addressing rather than adopting a traditional treatment model. This calls for high-quality clinical supervision to enable health professionals to fulfil their tasks. Staff in Community Learning Disabilities Health Teams must be able to ‘step back’ and attempt to analyse what is happening, and take on the critical roles of teachers, mentors and anchors to facilitate an inclusion agenda and avoid out-dated traditional assumptions. This is **best achieved through ensuring some on-going direct clinical and personal contact with people with learning disabilities, even for Community Learning Disabilities Health Team managers.**

Some people need health care support for a very long time. This can be provided in people’s own homes, care homes, or through health care centres and teams. Joint or 100% NHS funding can be provided where the conditions present severe, unpredictable, intensive and/or complex challenges. National guidance is clear that the presentation of behaviours that challenge are not a sole basis for 100% NHS Continuing Healthcare responsibility, especially as in many instances these challenges relate to unmet needs that most people take for granted (i.e. being healthy, happy, busy and recognised).

However, where CHC funding responsibility has been agreed, or where joint funded complex care packages such as S117 aftercare arrangements apply, specialist health professionals within the Community Learning Disabilities Health Teams are expected to:

- Facilitate specialist and community care assessment and care/treatment plans
- Support the completion of any specialist assessments
- Develop detailed individual client-level and service-level specifications
- Undertake a monitoring and service review/assurance function role, recording any key risks and issues.

This type of work has also enabled other quality review and monitoring mechanisms of wider health and social care systems, and so enabled Community Learning Disabilities Health Teams to directly influence commissioning and contracting strategies. Further moves towards pooling budgets will support this.

4. Responding Positively and Effectively to Crisis

It is known that 10-15% of people with learning disabilities known to services present with behaviours that challenge and two thirds of this group can present with more demanding support needs. This equates to approximately 350 people of all ages with learning disabilities known to services in a local population of 100,000, and therefore more than 50 people presenting with behaviours that challenge and an estimated 35 individuals with more complex support needs. Given the common 3:1 ratio between adults to children, **it is likely therefore on average, that 25 adults and 10 children in each 100,000 population will be seen as more demanding with severe reputations of severe behaviour that challenges and at risk of exclusion.**

Community Learning Disabilities Health Teams specialist health professionals must identify and work with all these individuals, and everyone else supporting them, to plan ahead for when things might be difficult. Given most crises are usually predictable, they should try and avoid surprises and stop crises from happening. **If a crisis does happen, they should make sure that the right sort of help is at hand to rapidly defuse and stabilise the situations.**

For all in this ‘core group’ of people often ‘famous for the wrong reason’, there should be in place a well thought out contingency plan which should assist the effective management of emergency and demanding situations.

As such, Community Learning Disabilities Health Teams need to take a multi-faceted approach to rising to the challenge of dealing effectively with crisis, **responding on at least 3 levels:**

- **Proactive crisis prevention**
- **Reactive crisis management and immediate resource deployment**
- **Proactive Strategic planning and service development** (informed by the first 2 levels)

Clearly, **continuing to respond only reactively as crises arise is most likely to lead to high-cost, unnecessarily restrictive and out-of-area placements** (including inappropriate use of Winterbourne View-type options).

The Department of Health published the ***Positive and Proactive Care*** guidance in April 2014, replacing the previous DH non-statutory guidance document on reducing the use of restrictive physical interventions first published in 2002. This new guidance is relevant to the role of Community Learning Disability and Mental Health Teams with the emphasis **on significantly improving care through day-to-day practices that:**

- * **Are based upon Positive Behaviour Support**
- * **Ensure that services provide strong leadership, assurance, accountability**
- * **Are transparent about both the care they provide and when restrictive practices are used**
- * **Provide effective monitoring and oversight through CQC and local professional/service inspections.**

The accompanying Positive and Safe 2-year programme to reduce use of physical interventions will be reviewed to assess the extent to which it results in:

- ending the use the deliberate use of face-down restraint and reduce the use of all restrictive interventions, including physical, medical, chemical, mechanical and seclusion
- working with services to create safe, compassionate, therapeutic health and care environments that are respectful of patients' dignity.

Changing the common scenario of restrictive care away from local areas and restrictive practice critically requires that Community Learning Disabilities Health Teams retain accurate up-to date knowledge about all those locally with severe support reputations and their histories of crisis situations, to avoid surprises.

Both commissioners and Community Learning Disabilities Health Teams should work proactively and take steps to prevent crises from happening, but are dependent on providers being proactive in referring people. If they do happen, Community Learning Disabilities Health Teams must make sure that the right sort of help is at hand at the right time in the right way. This includes ensuring:

- Comprehensive summary assessments are already in place for all clients in transition, families homes and agency placements – critically defining the things that help and make things worse
- Positive health action and behaviour support plans (with potential crisis/emergency situations identified and clear relapse prevention plans) for the on average 50 individuals in each CCG locality with severe reputations at any point in time clearly described and understood by key stakeholders (i.e. what to do if ... and what works and what to avoid)
- On-going monitoring and review systems in place for those with complex support needs
- Having someone to talk to at short notice
- Problem solving learning to see where things go wrong and how they could be put right.
- Having sufficient Community Learning Disabilities Health Teams capacity for responding with extra professional support around the person in situ

- Contingency options of going somewhere else for a period of time as a crisis respite or refuge breaks whilst things get sorted out (such as social crisis and planned respite/breaks service) rather than pathologising/blaming people as in need of treatment
- Access to crisis Mental Health and Learning Disability home treatment and admission to in-patient facility options through stepped care pathways
- Supporting a spectrum of local longer-term service options ranging from supported living/residential options through specialist learning disability nursing homes to the very rare on-going use of long-stay hospitals.

When people are experiencing a serious problem or crisis, it is essential that a service can respond to their needs with appropriate effective advice and intensive support 7 days a week and outside office working hours. As well as improving service accessibility and responsiveness this can positively impact on the number of out-of-area placements, high-cost care packages and inappropriate admissions to in-patient units.

This also means that access to the Community Learning Disabilities Health Teams should also be more than a traditional weekday office-hours service model, as clearly **preventing admissions is not a 9am-5pm task.** Community Learning Disabilities Health Teams should follow the practice being introduced into community mental health services whereby some Community Learning Disabilities Health Teams cover is available from 8am to 8pm weekdays and some day-time access at weekends. In line with Crisis Concordat action plans, **responsive services need to be around when people need them.**

Access to some form of 24-hour emergency on-call and community crisis centre or in-patient outreach resource can be essential, including access to psychiatric cover as part of the agreed enhanced local crisis response system that now needs to be put in place across the country.

As most people's health needs will be able to be met in community settings (and only a small number of people should need to access specialist in-patient beds appropriately), it is **likely that collaborative commissioning across several CCGs will be necessary with respect to the crisis support services and handful of needed short-term crisis access beds and intensive in-reach/out-reach assertive outreach and home support teams.** Given the relative limited need for such a service in any locality, this work requires collaborative commissioning across localities (usually at the level of existing Mental Health Trust or Local Area Team boundaries).

A small number of people with mental health or offending problems need admission to in-patient services for more intensive help than can be provided in the community. These should offer time-limited (no longer than 6 months for non-forensic presentations) active assessment, care and treatment, and then link in with other services to enable a return to the community as soon as possible. For those with mental health or forensic presentations, support should be formalised with specialist mental health services and/or tie them into the developing liaison and diversion schemes to prevent further such needs as much as possible.

While admitted to crisis centres, people should:

- be clear how long they will stay in an in-patient unit or emergency respite resource
- understand what their rights are
- feel supported and safe
- be offered assessment and treatment and effective care co-ordination
- know who is in charge to make sure things get done
- be helped to return home as soon as possible.

Where longer-term admissions are suggested in line with specialist mental health section requirements, these should be subject to regular independent challenges through securing alternative assessments, care and treatment reviews.

In-patient services therefore need to be part of the whole system of service delivery for people with learning disabilities and have a defined place and purpose. Services need to be able to demonstrate their relevance to local needs and not promote or perpetuate inappropriate long-term use of 'out of area' placements, including for respite while more effective wrap-around support options are put in place.

As such, good local services should include interim (*step down/step up*) support mechanisms to assist when people face difficulties and it is no longer possible to return home, and while more permanent less restrictive living arrangements are being developed.

Where people are placed away from their own locality, it is even more important that the Community Learning Disabilities Health Team regularly review services in order to ensure it is still safe, effective and appropriate.

Support networks should also be established to help stakeholders learn from and cope with stresses arising from responding to crisis situations. In particular, regular service dialogue must be apparent between Community Learning Disabilities Health Teams and colleagues in the Acute sector, Mental Health services, Court Liaison and Diversion schemes, and Social Care providers, to ensure effective partnership working relationships remain in place over time.

5. Quality Assurance and Strategic Service Development in Support of Commissioners

Community Learning Disabilities Health Teams health professionals should play an active operational or micro-commissioning role in strategic planning, care package contract oversight and policy development, in support of local commissioners. This service planning and micro-commissioning development role should include activities to:

- Support the involvement of people with learning disabilities and family carers.
- Gather information on individual and wider population health needs and inequalities, including those groups with complex support needs (e.g. autism, challenging behaviour, dementia, epilepsy, long-term and life-limiting conditions, mental health, profound and multiple PMLD, sensory impairments, children and older people)
- Clarify actions to support better health and health care, and the contribution of health services to independence and inclusion (e.g. support for intimate care and community care tasks policies that enable complex care packages in the least restrictive settings with support staff able to access adequate specialist training and supervision)
- Highlight the future impact of early intervention and support for inclusion in services for children and young people with learning disabilities.
- Identify health and well-being outcomes for monitoring, audit and review of service effectiveness
- Develop and apply the best available research evidence and evaluative thinking in all areas of practice, including service contract service specifications and reviews.

Community Learning Disabilities Health Team health professionals should contribute to the design, creation, and monitoring of provider support arrangements for individuals, particularly for those people who need a lot of support from family and community, and a range of agencies. This should mean that there are clear plans and arrangements put in place to deliver on the national learning disabilities commissioning framework for services that place an emphasis on individualised services in community settings (rather than in-patient options) achieved through person-centred planning and informed high quality clinical practice. As such, commissioners should recognise and utilise the knowledge and experience

of specialist learning disabilities community health team professionals in reviewing the performance of commissioned services, especially in implementing care plans and recommendations. On occasion, this may require more active service improvement programmes.

Work related to this will **include professional expert support prioritised to support commissioners ensuring adequate policies, procedures and safeguarding support structures to ensure that the *Transforming Care* agenda can be achieved through which people with complex support needs and behaviour that challenges have their identified needs met through effective local support and care arrangements.**

This will include providing support to design, develop and deliver an adequate local capacity support and development programme with sufficient:

- practical family support
- training/supervision for support staff teams
- transition joint working with children's services, ensuring there is good cooperation and coordination between services, support into adulthood
- access to a spectrum of appropriate supported local accommodation options designed around people's individual needs, together with small local specialist services that can provide residential or nursing care to meet particular needs
- respite breaks/activity arrangements able to meet the needs of people with behaviour that challenges and complex support needs
- agreed crisis-management pathways to prevent placement breakdown
- access to in-patient services in both learning disabilities and mental health services, with admissions that provide skilled and appropriate focused and time-limited support, with a well-defined admission and discharge pathways
- service monitoring and review mechanisms, specifically looking at length of stays in any restrictive settings and use of step-down arrangements (including those placed in secure settings)
- organised support to repatriate people from distant out-of-area and in-patient placements.

As such, **Community Learning Disabilities Health Team specialist health professionals should be expected to be both individually and collectively responsible for ensuring effective care co-ordination related to all individuals who receive long-term funded public services from the Local Authority, the NHS and the Independent Sector.** This thereby enables **monitoring mechanisms to be put in place that avoid 'surprises'.**

Whilst co-ordination/care management is often a major role for social workers and care managers, some **members of other disciplines within Community Learning Disabilities Health Teams may be expected to carry a care co-ordinating role for a limited number of clients (in addition to providing professional advice, and where necessary, therapeutic/remedial interventions).**

This care co-ordinating role should be allocated based on the primary needs of particular clients and agreed by senior health and social work managers in support of the micro-commissioning role. This will require close working with CCG Continuing Health Care and/or Individual Care Package leads, and support through completion of relevant assessment and update reports to support Funding Panels in both the CCG and Local Authority.

More senior practitioners are likely to carry a smaller caseload than their junior colleagues, thereby enabling them to take on a greater focus on service development and training activities. This should mean that **all clients within local services have a named care co-ordinator, involving at least face-to-face contact on a minimum annual basis for reviews of care packages.** This work can be more efficiently undertaken with the inclusion of assistant practitioners and reviewing officers or teams.

Since no two people share identical needs, one element of a good service is that they 'fit' more closely to the person than to a pre-existing model. As a result, the variety of service options increases. This requires Community Learning Disabilities Health Teams to continually develop their capacity to respond to local needs and adapt the skills base to match changing demand. To manage this over time, **careful consideration is needed to critical mass issues**, especially when access to competent specialist health professionals is limited.

It is the responsibility of the service to report any serious health and safety or protection from abuse issue as soon as any concerns arise. All safeguarding issues should be recorded and reporting in line with the local Safeguarding Vulnerable People policies and CQC standards. This care coordination and review work must include the use of outcome evaluation tools such as the Health Equality Framework, as means to providing on-going intelligence to commissioners, operational service managers and public health teams of both good and poor practice and recognition of relevant legislative processes such as the Mental Capacity and the Court of Protection.

Community Learning Disabilities Health Teams are expected to be key agents that support the effective functioning of Local LD Partnerships Boards and Forums, and should play a significant leadership role in the related Better Health sub-groups coordinating and demonstrating action in line with the National Joint Health and Social Care LD Self-Assessment Framework or SAF.

Core Specialist Community Learning Disabilities Team Professional Practice

Community Learning Disabilities Health Teams should operate as fully inter-disciplinary teams which include specialist health professionals who collectively work to support individuals with learning disabilities in respected and high status activities in the community, and provide co-ordinated specialist advice and practical help to accomplish such lifestyles.

At a minimum, this should include sufficient numbers of: registered practitioners and assistant practitioners across all these professions. A Community Learning Disabilities Health Team without easy local access to all these core professional staff resources is likely to be inadequate to the tasks assigned to them. There will need to be a range of staff skills commissioned and recruited as part of these community health infrastructures. **This will include (but not necessarily be limited to): clinical psychologists, learning disability nurses, occupational therapists, physiotherapists, psychiatrists, speech and language therapists, arts therapists).** Although there are a variety of models for Community Learning Disabilities Health Team services, **access should be available from a full range of core registered health professionals working to nationally defined standards for 'fitness to practice'.**

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 *Transforming Care* and *CIPOLD* agenda, there will need to be particular attention to ensuring access to a critical and adequate mass of senior experienced staff with the range of specialist knowledge, skills and capability.

Those team members who are not a registered professional (e.g. behaviour analysts delivering positive behaviour support who are not registered professionals or support workers/ assistants), **must be supervised by a registered professional with clear accountability arrangements clear to all.** In addition to this, in Scotland all non-registered professionals must complete Mandatory Induction Standards for Healthcare Support Workers (HCSW) which has been designed by NES (NHS Education for Scotland) within the first 3-6 months of joining the NHS in Scotland.

The key roles of all Community Learning Disabilities Health Team health professionals are to reduce risks; promote relationships and build capacity and capability. As such, all these health professionals should have a basic understanding of the needs of people with learning disabilities, have knowledge of the role of other professionals and services (eg residential/day/respite) , and know when to escalate issues to the relevant team specialist and/or senior operational and commissioning officers. This is particularly important following procurement programmes resulting in any changes to support plans and working arrangements, as transitions need to be positively managed. Critical here are the recognition and up-to-date understanding of the differential responsibilities of different stakeholders.

This also means valuing the positive contribution and role of learning disability social workers to enable health interventions to work in supportive social contexts. This can include effective social work practice in: responding to complex needs; effective safeguarding and risk management of cases of abuse, neglect and vulnerability; addressing adversity and social exclusion; promoting independence and autonomy through case work and brokerage to empower people to live independently; prevention and early interventions across spectrums of need.

As such, it is expected that key lead professionals will be in place as senior members of Community Learning Disabilities Health Teams, supporting Team Managers across health and social work agencies, and in co-ordinating and managing work to provide high quality practical health guidance and personal support, with a range of effective operational management, supervision and training strategies/resources across teams and for individual professional disciplines to ensure 'fitness for purpose'.

Lead Areas of LD Health and Social Work Professional Activity

Clinical Psychology

- Specialist neuropsychological/behavioural assessments, diagnostic, therapies and wider service support to prevent and reduce the incidence and impact of psychosocial/health difficulties.
- Clinical formulations and support to individuals with severe reputations for presenting with challenging behaviours and the most complex support needs (caseloads will include people with the complex needs involving abuse/trauma/forensic histories, autistic spectrum disorders, challenging behaviours, mental health/physical health difficulties, people who usually present a serious degree of risk of harm to themselves or others, including those who have offended or are at risk of offending). A key consultancy role at both an operational and strategic level, as well as at individual/family/systemic levels. Also clinical supervision of others providing psychological based approaches (such as Behavioural Activation Therapy, PBS and Behavioural Family Therapy)

Nursing

- Specialist nursing practice and public health/well-being support to prevent and reduce the incidence /impact of physical/mental health/challenging behaviours difficulties and health inequalities, including long-term clinical case management and practical support for the delivery of packages of care through collaborative working with colleagues within primary and secondary care in line with the 2014 RCN position statement on the role of the learning disability nurse
- Support to individuals with health facilitation/access issues for people with learning disabilities with accompanying challenging behaviours, mental health and profound multiple physical/sensory disabilities across health and social care communities, and the provision of interventions around complex support needs such as those seen as community-based health-focused healthcare tasks/health action planning with challenging cases

Occupational Therapy

- Specialist occupational therapists deliver personalised assessments and interventions that focus on individuals' occupational needs; specifically barriers to occupation. Barriers can be either 'personal' (cognitive and/or physical); and/or 'environmental' (social and/or physical). People are intrinsically active and creative, needing to engage in a balanced range of activities in their daily lives in order to maintain physical and mental health.
- Support an understanding of the relevance and role of occupation in health and well-being with specific skills in activity analysis, assessment of function, collaborative goal setting and evaluation. By supporting individuals to access a range of meaningful occupations, particularly in relation to leisure, productivity and self-care, the impact of complex health and social issues such as mental illness, multiple sensory/physical disabilities, challenging behaviour and social isolation can be reduced, issues surrounding occupational deprivation addressed, quality of life improved and health inequalities reduced. Specialist occupational therapists utilise a wide-ranging specialist assessment process with an aim to improve individuals' functional abilities, and develop existing and new skills. Occupational therapists contribute to the development of correct care packages by working closely with other health and social care services. This is particularly important at times of life transitions, for example from child to adult services, moving from family home or residential services to supported living and as health needs change such as with the onset of dementia.

Physiotherapy

- Specialist physiotherapy practice and health service support to prevent and reduce the incidence/ impact of complex health issues and profound or multiple physical/sensory disabilities, including clinical case management for the delivery of packages of care through collaborative working with colleagues within primary and secondary care

- Support to individuals with health facilitation/access issues for people with learning disabilities and their carers across health and social care communities, including issues in relation to primary/secondary health care access, and the provision of specialist moving and handling assessments, respiratory /dysphagia/postural care, mobility assessments, specialist equipment/access issues, systematic skills teaching/rehabilitation and complex support needs

Psychiatry

- Specialist psychiatric assessments, diagnoses (where applicable) and interventions to ensure effective evidence-based support for co-morbid presentations of mental health difficulties, challenging behaviour, epilepsy, dementia, and forensic issues relevant to multi-agency protection panels, including community out-patient reviews, and in-patient support in line with the Mental Health Act.
- Support through participation in multidisciplinary gate-keeping assessments for suitability for community psychiatric liaison support, medication reviews, psychotherapy, admissions, discharge and on-going risk assessment/management plans as part of formal CPA and multidisciplinary processes

Speech and Language Therapy

- Specialist Speech and Language Therapists provide person centred assessments and multi-layered formulation and treatment for complex speech, language and communication needs. They reduce the risks associated with limited comprehension, challenging behaviour and difficulties expressing one's self by supporting the best possible understanding between people with learning disabilities, carers and staff, reducing diagnostic overshadowing, and promoting safe, proactive and ethical communication strategies and effective intervention. Improved communication promotes well-being and prevents social isolation.
- Specialist Speech and Language Therapists reduce the risks associated with eating, drinking and swallowing difficulties, improving health in relation to respiration, nutrition and hydration by increasing safety around swallowing, reducing the risks of choking, getting chest and other infections, and preventing hospital admissions.

Dietetics

- Although uncommon as core Community Learning Disability Teams, the needs of people with learning disabilities, and the particular care and social networks in which they live, can be too complex for main stream services alone to succeed despite attempts to make reasonable adjustments. As with Special Care Dental practice, access to specialist dietetic resources in Community Learning Disability Teams resources can in these cases reduce the incidence and impact of complex health presentations, such as dysphagia through collaborative working with primary and secondary healthcare services.

Arts Therapies

Arts Therapies (Art Psychotherapy, Dramatherapy, Music Therapy and Dance Movement Psychotherapy)

- Specialist person centred psychological assessment and therapeutic treatment utilising art, drama, music and dance as a mode of communication with the aim of identifying issues relating to mental health, trauma, abuse, challenging behaviour, forensic histories and complex needs including wider service support to reduce levels of anxiety, distress and challenging behaviour.
- Using predominantly psychodynamic principles provide therapeutic formulations and therapeutic support to all individuals regardless of their level of cognitive and physical abilities thereby giving all individuals a voice, through which they may share their story and experience themselves and others in a different way. By supporting the individual with accessible approaches to self-expression and communication, challenging behaviour, social isolation anxiety and distress can be reduced and quality of life improved. This work is understood in the context of the individual's family/care situation and community in which they live, with contributions to the development and clinical case management of

health treatment packages (for example PBS plans) through close liaison with other health and social care professionals, the family and the individual. Activation of the individual's creativity can extend beyond the therapeutic space and support mental health needs and promote lifelong learning in the community. Arts therapists can act as lead consultancy and offer clinical supervision of professionals wishing to explore their work with people, the meaning of non-verbal behaviour and its relationship to increased mental health difficulties.

Social Work

- Social workers bring a different and complementary set of skills and knowledge to constructing the support package. They see the service user in the context of their human and civil rights and will help to ensure that the process is one of co-production, based on the strengths of the individual and their aspirations for a life as independent as is possible given the circumstances.
- Social workers see the service user in the context of their family and/or the community in which they live and work to ensure that the wishes and needs of the service user and those of the family and the community are balanced. There will be a need to assess in each locality the particular impact of care management demands on the access and availability of social work in lien with this role description.

Community Learning Disabilities Health Teams Eligibility Criteria

Commissioned Community Learning Disabilities Health Teams **must be available to all people with learning disabilities in the commissioning CCG locality and in all locations where CCG- registered patients reside (even where these involve placements out-of-area), with clear feedback mechanisms in place to inform commissioners of any practice issues and concerns.** All professional work must ensure that individuals are safe and healthy, and not subject to restrictive practices and settings, irrespective of the severity of an individual's learning disability.

The detailed information concerning the presenting learning disabilities and complex support needs should be assessed by an appropriate professionally registered Community Learning Disabilities Health Team member with the requisite skills and experience able to develop a formulation about causal, maintaining and risk factors.

The **priority target group for Community Learning Disability Health Teams must include people with learning disabilities and complex support needs**, including all those adults, with issues related to:

- The extent of their intellectual impairment
- Having physical disabilities which severely affect their ability to be independent
- Having sensory disabilities, which severely affect their ability to be independent
- Having a combination of physical and/or sensory disabilities
- Any behaviour that can severely challenge services
- Having a form of autistic spectrum condition
- Having complex health support needs
- Having enduring mental health needs and /or psychological issues
- Having a forensic offending or criminal justice system interface history
- Having receptive or expressive communication difficulties
- Parenting support unrelated to court reports
- And their needs require health or social care organisations to provide on-going support and assistance, no matter how this is funded.

Although Community Learning Disabilities Health Teams often include both health and social care workers, **specialist health services must not be restricted to only those individuals with severe learning disabilities or social care criteria for vulnerable adults. This is not in line with NHS Responsible Commissioner guidance.** Services must be provided on the basis of assessed clinical needs.

Community Learning Disabilities Health Teams are also commissioned in line with national policies such as the 2013 'Who Pays' NHS Responsible Commissioner Guidance in England. These note that ***'The safety and well-being of patients is paramount. The underlying principle is that there should be no gaps in responsibility - no treatment should be refused or delayed due to uncertainty or ambiguity as to which CCG is responsible for funding an individual's healthcare provision'***. As such, the health and social care elements of local jointly commissioned Community Learning Disabilities Teams are likely to be closely aligned, but at times they may operate as separate elements working to different eligibility criteria. This can be a challenge where it becomes necessary to draw distinctions between defining people with learning disability requiring health service support alone and those meeting defined as meeting social care eligibility criteria.

After the events uncovered at Winterbourne View, the need was highlighted for CCGs and their commissioned services to **have in place robust local safeguarding arrangements and communications between services in different areas.** In practice, this clarified **required notification and joint working-funding responsibilities**, which Community Learning Disabilities Health Teams should be aware of and support the local Safeguarding Boards and national Out-of-Area protocols.

Transition of Children into Adult Services

As a practical and pragmatic solution, and in line with the national drive to develop comprehensive life-course long services that minimise unnecessary service transitions, and support the outcomes of the Children's and Families Act and Care Bill (including reference to the SEND reforms requiring combined health, education and social care plans and changes in Annual Health Check criteria), **specialist Community Learning Disabilities Health Teams should be available for joint working with young people with complex health support needs and behaviours that challenge from 14 years +.**

Clearly, there is a need for the recognition of any other local Community Learning Disabilities Health Teams service access age limits, determined in line with locally agreed protocols for transitions from adolescent to adult services and wider moves to all-age services. A parallel paper on Children's Specialist Learning Disability Health Team services is currently being prepared by the National Senate.

There should also be in place **a specific local Transition action plan** that highlights how:

- **local action will resolve any identified problems in the support to young people with complex needs in transition to adulthood** (including reviews of the clinical and other support models in place from local CAMHS and Children's Complex Additional Disability Needs Teams), including:
 - Health action plans and reviews
 - Intimate and/or community care support task policies
 - Practical impact of changes to a full-time structured education programme to a more limited adult daytime, educational and respite options
 - Defining vulnerable individuals with autism or learning disabilities or difficulties that will not be eligible for adult Community Learning Disabilities Health Teams, community mental health or other services in the same way that they had in children's services
- **information and decisions on any complex or high-cost placements** (especially those involving young people aged 14 years+) **involving high-cost or out-of-area education, social or health-funded care**

packages is shared with adult Community Learning Disabilities Health Teams, commissioners and funding panels (especially CHC and Exceptional Individual Packages of Care arrangements).

This work involves a call for significant changes in the whole health and social care system to truly **Transform Care** across the lifespan provided through ensuring the on-going access to competent, credible, committed, capable specialist Community Learning Disability Services.

For this positive outcome to be realised, commissioners of and clinicians across the lifespan need to:

- **secure better practical early support for children and families to tackle issues ‘upstream’** through earlier detection/interventions of emerging problems especially in the transition to adulthood from 14+ and earlier targeted work with families (especially where there may have been long-standing problems and disputes)
- **promote, from point of diagnosis, good health care support and well-being of individuals and their families with access to practical effective support**
- **encourage staff to care, connect and deliver practical short full life plans, interventions and care packages**
- **agree common access to care criteria that recognise the changes in expectations and resource demands from child to adult services.**

As noted previously, the Senate is developing a parallel document clarifying the best practice guidance relevant to the commissioning, operational delivery and evaluation of effective services for children with learning disabilities, their families and other key stakeholders such as schools.

Desired Outcomes of Effective Community LD Health Teams Health Support

“Everybody in this world today needs support of one kind or another. People need support to go ahead and do things whether this support comes from a good friend, parents, a social worker, or guardian. There is no person so independent in the world that they don’t need anybody. We all need support, but with that support, we don’t want somebody coming in and taking over our lives”

Kennedy (1993)

If the core purpose of the NHS is to protect life and maintain health, this applies equally to people with learning disabilities and their families across the lifespan. In many ways, given the past repeated failings whereby the collective actions of services and society resulted in poor care and reduced life expectancy for a vulnerable and marginalised group, the challenge now of responding effectively to the learning disabilities challenge can be seen as a critical test of the effectiveness of the wider NHS.

Community Learning Disabilities Health Teams can then only be seen to be effective if they address two essential priorities for action **‘Reducing Restrictive Practices and Reducing Health Disparities’** through delivering the 5 identified core functions to:

- **Assist people with learning disabilities and those supporting them to better understanding the causes of ill-health and then supporting access to good primary care, community and specialist acute/mental health services, and wider valued mainstream opportunities in society**
- **Practically reduce health inequalities and improving access to a wide range of health supports, including access to annual health checks, screening programmes, diagnostic assessments and health action planning** which:
 - maintain optimum health and reduce dependency on continued intensive health/social care
 - prevent illness and requirements for on-going and extensive health supports

- identify and reduce reliance on medications and restrictive practices where alternative positive behaviour supports are appropriate
- prevent hospital admissions, restrictive services and out-of-area placements
- **Support health and well-being through supported access to a wide spectrum of local supported homes, work and lifestyle options, that also reduce the likelihood of people presenting complex support needs and challenges being placed into inappropriate services and unstructured support arrangements**, through:
 - monitoring effectiveness of personal health/social care packages against agreed specifications and providing feedback through contract review mechanisms
 - designing, organising and reviewing specialist reasonable adaptations and alternative 'non-ordinary' community services where complex presentations warrant this
 - supporting when times get hard, and staying in the original community setting is not possible, access to short term flexible practical assistance and a wide spectrum of support resources

The work of the Learning Disabilities Public Health Observatory IHAL has confirmed the main reasons for poorer health as: (1) increased risk of exposure (and possibly greater vulnerability when exposed) to well established 'social determinants' of poorer health such as poverty; (2) some specific genetic causes of learning disabilities associated with some specific health risks; (3) people with learning disabilities often have communication difficulties and poorer understanding of health; (4) people with learning disabilities less likely to lead 'healthy' lifestyles; (5) people with learning disabilities at risk of being discriminated against when trying to access or use health services. The Health Equalities Framework tool is useful to review the impact of these factors at an individual level and across teams/services, as well as changes over time.

Evaluating and Reporting on Performance

An effective Community Learning Disabilities Health Team is there to: help 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.

Community Learning Disabilities Health Teams 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 community learning disability services. 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 so that there are positive experiences, such that:

- *It is easy to get in touch with services, and they respond quickly to requests for help*
- *It is easy find out where services are and what they do, and the choices people have*
- *Staff talk in a respectful way and work to get to individuals*
- *Individuals get high quality care that is linked in with other support arrangements in people's lives*
- *Service surroundings are clean, comfortable and friendly*
- *Services listen carefully to the views and experiences of people with learning disabilities and their families, using different ways to communicate and provide information*

- ❑ *Services offer people choices about 'where' and 'when' they get help, as well as 'what' and 'how' someone wishes to be helped with*
- ❑ *Services help people make decisions about health matters, providing the right kind of support and they are clear when someone cannot make a decision, and who can best represent them*
- ❑ *Services take care over issues of confidentiality*
- ❑ *Services give people copies of letters written about them*
- ❑ *Services support person-centred plans*
- ❑ *Services build on what people can do for themselves and other people who can help.*
- ❑ *Services are focused on the whole person, being clear about what else is going on in a person's life. They work closely with other people and organisations providing support to a person, so that the right things happen at the right time.*
- ❑ *Health professionals and support staff are trained and good at what they do.*
- ❑ *People with learning disabilities and family carers are involved in teaching them.*
- ❑ *Health professionals and support staff find out what works best and use this in their everyday work*
- ❑ *They are good at working in partnership with people with learning disabilities and their families*
- ❑ *They are good at working in teams and with other agencies supporting people and families*
- ❑ *They are treated fairly by their organisation, and supported to work flexibly for people*
- ❑ *They have good management and professional leadership*
- ❑ *Services focus on getting good results for people with learning disabilities and the community*
- ❑ *Everyone understands that the laws relating to discrimination and human rights apply equally*
- ❑ *Steps are taken to help ensure that people with learning disabilities are safe, and specialist staff know what to do if they are worried about people being harmed or abused in other services*
- ❑ *Services ask for feedback from people with learning disabilities and families about the services they get.*

Closing Comments

The importance of the work of Community Learning Disabilities Health Teams has been brought to the fore through the results of the Winterbourne View review and Confidential Inquiry into Premature Deaths in people with learning disabilities. Community Learning Disabilities Health Teams 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 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 that are healthier for longer more in line with the general population.**

The vision for Community Learning Disabilities Health Teams that are 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 individuals with learning disabilities, thereby reducing health inequalities and restrictive practices.

Evidence and best practice confirms that:

- All individuals with disabilities can and should live in the least restrictive local community settings. The key is the availability of adequate and appropriate skilled and timely support (including knowing people well, anticipating surprises through early proactive detection and managing crisis with contingency plans providing more help to 'survive with dignity', not removal away from families and localities)
- Too often insufficient flexible and planned support has been provided to families and carers (including access to additional funding, social, professional clinical and practical support - especially planned and crisis 'respite breaks' in and out of home). Families and services that report a balance between stressors and resources want to and do keep together well

- When individuals with disabilities or their families/carers are provided with individualised support (and involved in the design, development, implementation, monitoring and evaluation of services) there are greater chances of success and satisfaction
- People with disabilities who move out of large residential environments do better in smaller ones
- When there is sufficient attention paid to a person's individual characteristics and real needs through person-centred planning and positive behaviour support, matched with high levels of technical and emotional support for staff and carers, outcomes are better for all
- People grow and behaviours that challenge commonly reduce in homes that encourage social interactions, vocational development and independence by adopting a 'wrap-around' support and recovery model, rather than attempting readiness 'medical model-based' care assessment pathways or treatment
- In addition to being placed in local community settings, individuals with disabilities need active support to integrate into community and work settings. Change does not just happen, it requires careful on-going thought and planning
- People with disabilities and their neighbours should be encouraged to develop lasting meaningful social mixed heterogeneous relationships as it is safer, less stressful for all and better value-for-money. Grouping people with learning disabilities who challenge together in services increases the likelihood of problems
- Spending lots of money alone does not guarantee good care or support outcomes for people with disabilities and their families
- For redesigning and commissioning or re-commissioning services, equal attention needs to be paid to both clinical and non-clinical evidence and factors (especially leadership and commitment over time in community teams, professionals and services).

NHS health commissioners 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 health inequality outcomes. This applies even where the lead commissioning responsibility has been delegated to Local Authority commissioners and/or Community Learning Disabilities Health Teams are managed through Pooled Budgets.

So while, while **what people in a Community Learning Disabilities Health Team do should be agreed locally, this must be in line with national best practice guidance and evidence-based clinical practice.** As such while, people in Community Learning Disabilities Health Teams will do different things, they should all help to put national policies such as *Valuing People* or *Keys to Life* principles into practice with:

- **sufficient skilled clinical support to individuals with learning disabilities and their families to access respected and high status community opportunities and activities, and**
- **co-ordinated professional advice and practical help to accomplish such lifestyles without being displaced out-of-area or into restrictive settings, and being faced with continued health access and outcomes disparities, as a result of local models of residential living and care options being put in place to meet the full diverse needs of the individuals concerned.**

As such, Community Learning Disabilities Teams should:

- Have clearly agreed aims and goals, 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
- Be collectively responsible for a clear and identifiable areas of work in line with the 5 core functions, delivering on the Transforming Care and CIPOLD agendas
- Contains members and 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

Throughout history, people with learning disabilities, and their families, have been at particular risk of social exclusion with worse health outcomes. As a result, many individuals need additional support to ensure fairness, equity and opportunities. **Community Learning Disabilities Health Teams and services are important in helping face this challenge. To do this, they must focus on the really important goals of ‘Reducing Restrictive Practices and Health Disparities’, acting with professional integrity and flexibility, and continuing to raise the bar of expectations for person-centred valued outcomes for all through delivering effective evidence-based support.**

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Appendix

NHS Sample Service Specification – Community LD Health Team Service – To Follow

Appendix

NHS Sample Service Specification – Community LD Health Team Service – To Follow