



MEDWAY JOINT ADULT LEARNING DISABILITY STRATEGY

CHAMPIONING PEOPLE WITH LEARNING DISABILITIES

CREATED IN PARTNERSHIP WITH THE LEARNING DISABILITY
WORKING GROUP
2019-2024

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Forward

The abuse scandal at Winterbourne View Hospital in 2011, led to a sea change in the way in which vulnerable people with complex needs and challenging behaviour are supported and cared for. National Government requires all commissioners and providers of healthcare to review services provided to people with learning disabilities, autism, complex needs and behaviour that challenges. The pivotal report by NHS England “WINTERBOURNE VIEW – TIME FOR CHANGE”, states ‘it is not acceptable in the twenty-first century for thousands of people to be living in hospitals when with the right support they could be living in the community’ (Sir Stephen Bubb”, (2014)¹.

Medway is already transforming the care and support services it provides for adults with a learning disability. We want to do more. Through active listening to, individuals with learning disabilities; their families; carers; and professionals, we aim to ensure that local services and related interventions, are informed by those that use them and work in them. Our strategy will deliver first-class, high quality services and support that promotes independence and choice for people with a learning disability and allows them to live rewarding and fulfilling lives in their own homes in the community.

Signature here

Councillor David Brake
Medway Council’s Cabinet
Member for Adult Social Care

Signature here

Ian Ayres - Managing Director
Accountable Officer for NHS
West Kent Clinical
Commissioning Group

¹ <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>

Strategic Summary

The Learning Disability Strategy 2019- 2024 is the mechanism by which both Medway CCG and Medway Council articulates its intention to deliver its statutory duty to support people with learning disabilities. This five-year strategy describes the actions that Medway health and social care commissioners, working with key stakeholders from the local community, provider organisations and the voluntary sector, will take. These will ensure that people with learning disabilities are identified and supported to access the services that meet their needs and deliver better outcomes. The key elements of the strategy are:

- Empowering People with Learning Disabilities
- Preventing Escalation of Need
- Integration of health and social care
- Active citizenship
- Improvements in health and wellness
- Improved housing and support options
- Increased capacity of clinical teams
- Workforce development
- Stop over medicating people with learning disabilities
- Improved carers support

Introduction

What is a learning disability?

A learning disability is a reduced intellectual ability and difficulty with everyday activities. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with people. The level of support someone needs depends on individual factors, including the severity of their learning disability.

Why do we need a Learning Disability Strategy?

Research also shows that people with learning disabilities die, on average, 15-20 years sooner than people in the general population. Even more concerning is the fact that many of these deaths are avoidable.²

The 'Medway Adult Joint Learning Disability Strategy 2019 -2024' has been developed to bring together all key relevant statutory and partner organisations within Medway to address inequalities and ensure person-centered accessible services are available for residents.

² <https://www.bristol.ac.uk/cipold/news/2013/19.html>

The Vision

Medway CCG and Medway Council working with the Learning Disability Working Group³, have developed the following vision:

Adults with a learning disability in Medway will be supported to engage in active citizenship by increasing opportunities to exercise choice, control, and independence to live happy and healthy lives free from harm.

Legislation and Policy Context

In 2001 The Department of Health's white paper 'Valuing People'⁴, set-out bold and comprehensive guidance on the future expectations of services in communities for people with learning disabilities. Further legislation and guidelines have continued to develop the agenda:

- The Mental Capacity Act (2005)
- The Mental Health Act (2007)
- The Equality Act (2010)
- Nice Guideline NG11 (2015), NG54 (2016), QS142 (2017), NG96 (2018), NG93 (2018)

Significantly, The Care Act 2014⁵ sets out a range of statutory duties for Local Authorities, including a number related to the prevention agenda. It requires all Local Authorities to, work in partnership to provide, or arrange services, facilities, resources, or take other steps, towards preventing, delaying or reducing the development of needs for care and support. The national plan, Building the Right Support (2015)⁶ also gives a framework within which community services for people with learning disabilities are to be developed. The mandate for the closure of inpatient facilities is supported by a clear vision that sees:

"... adults with a learning disability who display behaviour that challenges, including those with a mental health condition, have the right to the same opportunities as anyone else to live satisfying and valued lives and to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life".

³ Key representatives from different organisations, parents and carers and people with learning disabilities

⁴ Valuing People: A New Strategy for Learning Disability for the 21st Century. (March 2001). Department of Health.

⁵ <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

⁶ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

In addition, the NHS Long Term Plan (2019), ⁷builds on the Five-Year Forward View 2014⁸ and as such has sets out specific actions that the local health and social care economy will need to deliver on in order to improve outcomes for people with learning disabilities including:

1. Acting to tackle the causes of morbidity and preventable deaths in people with learning disabilities;
2. Improving the understanding of the needs of people with learning disabilities across the NHS including the implementation of the national learning disability improvement standards;
3. Reducing waiting times for specialist services;
4. Supporting local providers to move more care to the local community by taking control of budgets;
5. Enabling greater numbers of people with learning disabilities to access personal health budgets;
6. Increasing investment in intensive, crisis and forensic community support; and
7. Improving the quality of inpatient care across the NHS and independent sector

Local Strategic Context

The national legislative and policy context has been translated to the local level by the following:

- **Medway's Council Plan 2016/17 - 2020/21** - describes how the council will ensure that older and disabled people are supported to live independently in the community;
- **Medway Council's Adult Social Care Strategy, 'Getting Better Together'**, states "We will support the people of Medway to live full, active lives; to live independently for as long as possible, and to play a full part in their local communities";
- **Medway Health and Wellbeing Strategy** notes that the lives of all people in Medway 'will be as full, meaningful and healthy as possible'. This will be achieved through the theme including '..., improve mental and physical health and well-being and reduce health inequalities';
- **The Medway Model** - a joined-up approach between NHS Medway and Medway Council brings key local partners together to deliver out-of-hospital services and care in the community and provides a personalised and holistic approach to care that helps people to live independently in their own homes and stay connected to their communities;
- The NHS, social care and public health in Kent and Medway are also working together to deliver the **Sustainability and Transformation Partnership (STP)** agenda. This is radically transforming the health and wellbeing of people in Kent and

⁷ <https://www.england.nhs.uk/long-term-plan/>

⁸ <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

Medway. It is also determining the quality of care people receive by ensuring services are delivered across Kent and Medway in more joined up ways.

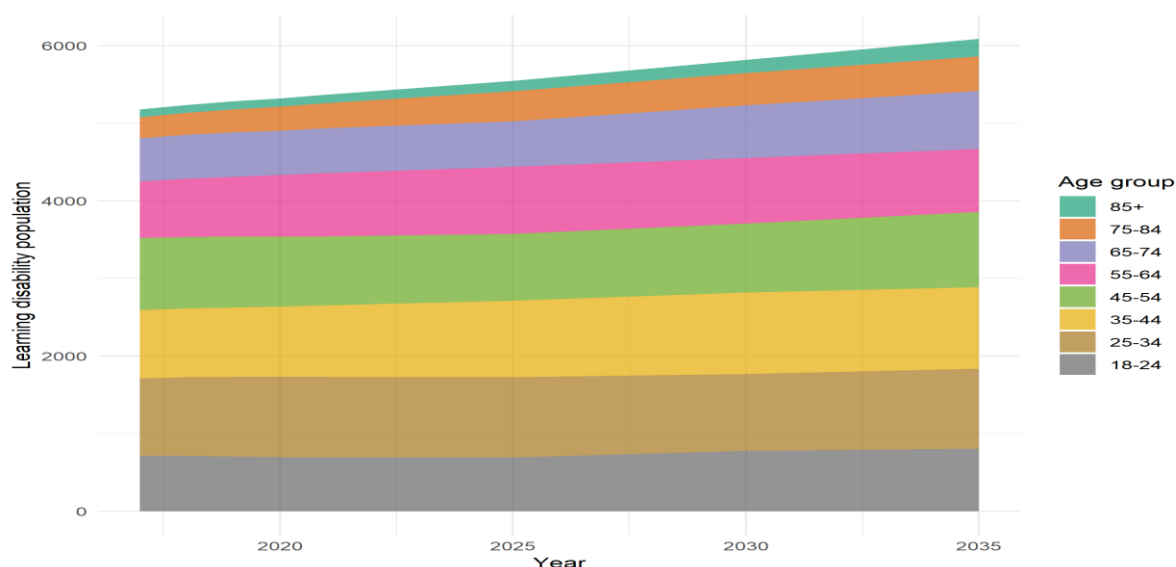
- The NHS Long Term Plan places a requirement on the local area to create one **Integrated Care System (ICS)**, which brings together health and care commissioners, providers and GPs into new relationships. This will mean soon that there will be one Clinical Commissioning Group (CCG) across Kent and Medway and **4 Integrated Care Partnerships (ICPs)**. The ICPs will support the achievement of improved outcomes and greater efficiency. Whilst **7 Primary Care Networks (PCNs)** in Medway will act as the local vehicles for the integration of health and social care services and delivery of primary care (including local care) at scale.

About People with Learning Disabilities in Medway

Population

The population of Medway is approximately 278,000 and is estimated to grow to approximately 330,000 by 2035. As the overall population of Medway grows and more people live longer, the population of people with learning disabilities also grows. According to recent figures, the national average for the prevalence of learning disability for all ages of the population in 2016/17 is 2.6 per 1000.⁹ Medway by comparison has a figure of 2.15 per 1000 slightly lower than the national average. In April 2018, there were 938 people over the age of 18 recorded on GP registers in Medway who have a learning disability. Figure 1 however shows the predicted total number of adults with a learning disability in Medway is significantly larger than those on the GP register.

Figure 1: Predicted learning disability numbers by age group projected to 2035



Source: POPPI and PANSI, Crown copyright 2016, Figures may not sum due to rounding

⁹ <https://fingertips.phe.org.uk/profile/learning-disabilities>

The number of people with a learning disability living past 85 is also predicted to more than double by 2035, this will bring an increase in demand for housing, care and support among this group. Another emerging area of need will be those living at home who survive their parents and as a result need formal care and support.

Mortality

In May 2018 the second annual report for the Learning Disabilities Mortality Review (LeDeR) was published¹⁰. Authors reported that not enough was being done to prevent health inequalities and premature deaths of people with learning disabilities, from avoidable health conditions. Three key themes for action have been identified:

- the need for healthcare coordination for people with complex or multiple health conditions
- the need for effective reasonable adjustments (in all areas) to be made for people with learning disabilities and their families
- the need for mandatory learning disability awareness training for all staff supporting people with learning disabilities

At present further action is required in Kent and Medway to ensure that the investigations required as a part of the LeDeR process are undertaken in a timely manner. Once this in place the learning from the deaths can be systematically translated into local policy and practice.

Health Checks

What we know from a range of sources is that people with LD have substantially higher rates of major health related problems. Annual health checks for people with learning disabilities form a key part of the prevention agenda. The Apple Tree Clinic also provides specialist sexual health provision for people with learning disabilities in Medway. In April 2019, 39% of people aged 18+ with a learning disability on Medway GPs LD registers had had a health check. This represents an increase from previous years however it is still lower than the national average of 63.2 %. Medway CCGs Clinical Variation Team is currently working with GP practices to improve coding issues; however, the current figures mean that there is still a significant number of people with learning disabilities on GP registers who are not receiving annual health checks. In addition, the true number of people with a learning disability who are not on GP registers is unknown and as such there may be a significant unmet need.

Independent living

Over a quarter of disabled people nationally say that they do not routinely have choice and control over their daily lives including with whom and where they live.

¹⁰ <https://www.hqip.org.uk/wp-content/uploads/2018/05/LeDeR-annual-report-2016-2017-Final-6.pdf>

Table 1: Percentage of adults with learning disability who live independently

	National % 17/18	Statistical Nbr % 17/18	Medway % 17/18
Percentage of adults with a learning disability who live independently	77.2	82.6	67.1

Source: Medway Council, Performance and Information Team 2017/18

Table 1 shows the number of adults in Medway with a learning disability who were living independently in 2017/18. The Medway target in this area is 75%. Work has been underway during 2018/19 with local providers to understand and source appropriate accommodation for this cohort. Early indicators for 2018/19 are suggesting improvements in this area. Further strategic work is being explored to ensure that the needs of people with learning disabilities is built into longer term developments across Medway.

Table 2: Care and Accommodation sourced by Medway adult social care for 18-64-year-old with a learning disability during 2016/17

Category	Nursing	Residential	Supported Living	Shared Lives
Learning Disability	5	160	90	20

Source: Medway Adult Social Care Data 2016/17

Table 2 above also shows the number of people in each category of accommodation during 2016/17 in Medway. The data clearly shows that for those being supported by adult social care there is a heavy reliance on residential services. This presentation is characterised by limited capacity in the market and a marked variance in charging policies and practices particularly in relation to older people with a learning disability, where the cost accommodation and support is consistently higher.

Currently in Medway there are thirty-five approved Shared Lives carers. The Shared Lives model has for a number of years formed of the overarching plan to improve access to suitable accommodation and support for people with learning disabilities. In June 2018, Shared Lives Plus the national network for shared living began providing support to the local Shared Lives team to streamline processes, increase the number of carers and promote the service. As a result eleven new carers have been recruited and many more who have expressed an interest in becoming Shared Lives carers are being managed through a speedier process. There is also a planned programme of marketing and promotion that will continue into 2020.

Employment

Research conducted by Watts et al. 2014 identified a number of barriers that make it more difficult for people with a learning disability to get a job, stay in work, and make progress at work.¹¹ It is estimated that 65% of people with learning disabilities would like a paid job.¹² Table 3 below shows that the percentage of people with a learning disability in paid employment in Medway. This is lower than both national and regional levels.

¹¹ Watts et al. 2014; Oilstone et al. 2014; Hall and Wilton 2015; Coleman et al. 2013; Meager and Higgins 2011

¹² [Valuing Employment Now](#)

Table 3: Percentage of people with a learning disability in paid employment

	National % 17/18	Statistical Nbr % 17/18	Medway % 17/18
Percentage of people with a learning disability in paid employment	6.0%	5.7%	2.3%

Source: Medway Council Performance & Information Team 2017/18

There are a number of factors that impact on the ability of people with learning disabilities to get a job and maintain employment. These factors include individuals not having the confidence to apply for a job. They may also have a skills deficit and lack the qualifications or experience to take up employment. These factors are often compounded with some employers not being aware of the capabilities of people with learning disabilities¹³.

Addressing the low proportion of people with learning disabilities in paid employment in Medway is a local priority. The Medway Skills Board has recognised action needs to be taken to tackle this issue. Work is also underway to gain more insight into the specific factors that might be influencing the uptake of paid employment for this population locally. This work will feed into existing programmes and inform new ones. For example there are a range of supported internships available for local people. Medway Adult Education services working closely with the portfolio holder also offer a range of courses and tailored support for people with learning disabilities. The focus of these courses is to help them access paid employment.

Table 4 shows that the largest area of adult social care spend is consistently spent on working age adults of which those with a learning disability make up a significant part.

Table 4. Adult Social Care Expenditure in Medway 2015 -2018

Adult Social Care expenditure	2015/16	2016/17	2017/18	Comments
Under 65's in residential care	£18,450,044	£19,000,491	£19,290,161	4.5% increase since 2015/16
Under 65's in nursing care	£ 1,332,053	£ 1,015,246	£ 1,012,734	Slight decrease in ASC spend
65+ in residential care	£10,370,599	£10,078,461	£10,410,826	0.75% increase since 2015/16
65+ in nursing care	£ 5,355,177	£ 5,087,386	£ 5,998,828	12% increase since 2015/16
Adults in mental health residential care	£ 2,432,633	£ 2,407,113	£ 2,698,847	11% increase since 2015/16
Home Care	£ 9,242,869	£10,211,794	£10,200,200	10% increase since 2015/16

¹³ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/stigma-discrimination>

Health and social care services for people with learning disabilities in Medway

The Mental Health of Learning Disability (MHL) Team, the Community Learning Disability Team (CLDT) along with Adult Social Care (ASC), work in partnership to ensure that health and social care services are focused on meeting the individual assessed needs.

Mental Health of Learning Disabilities Team (MHL)

The Mental Health of Learning Disabilities (MHL) Team is a community-based specialist service for adults with learning disabilities in Medway. The service is provided by Kent and Medway Partnership Trust (KMPT). The service is multi-professional and is made up of nursing, psychology and psychiatry professionals with specialism in learning disability. MHL provides a service for people with a learning disability whose presentation is such that even within a reasonably adjusted environment they are unable to access mainstream mental health services. The care pathway is determined by the needs of the individual, as opposed to the severity of learning disability, i.e. Mild, Moderate, Severe. In keeping with national policy (Valuing People) those individuals who are able to access mainstream mental health services should be actively supported to do so. MHL sits alongside mainstream community mental health teams in Kent and Medway to help ensure that reasonable adjustments are considered that ensures all appropriate pathways are open to people with learning disabilities.

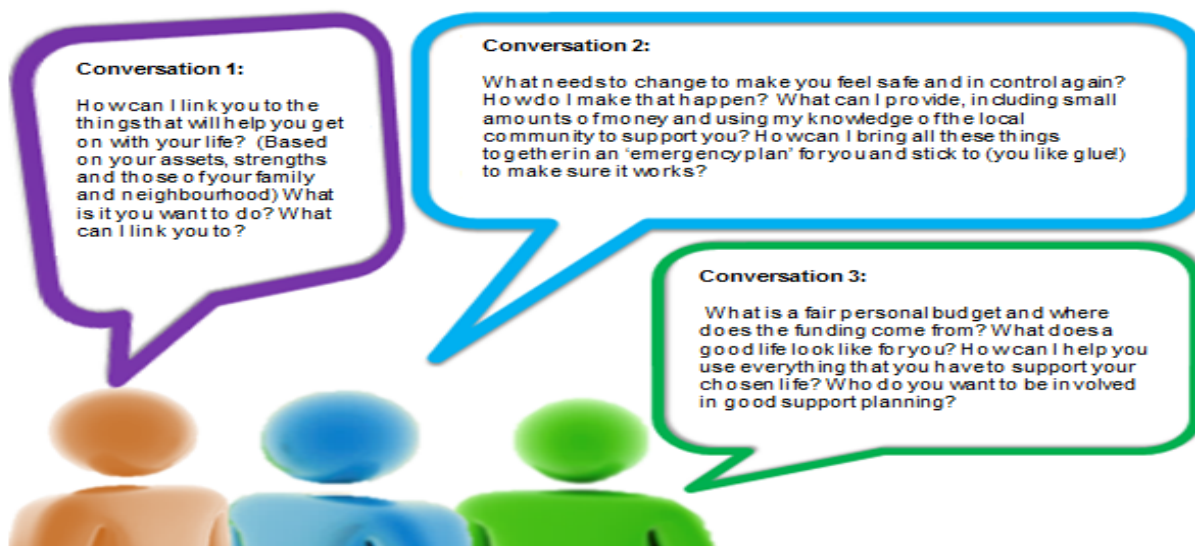
Community Learning Disabilities Team (CLDT)

CLDT provides support to people with a mild to moderate learning disabilities to live healthy and rewarding lives in their local community. The aim of the team is to provide clinical assessment and support interventions that promote physical and mental health well-being and prevent ill health. The team also aims to improve access to a wide range of health supports including annual health checks, screening programmes, diagnostic assessments and health action planning and review. The team is comprised of a nurse, a physiotherapist and speech and language therapists.

A recent review of this service identified the need to increase the level of occupational therapy and nursing resources within this team. Given the increase in demand, the projected increase in resources allocated to this service may not be sufficient to meet the future demands placed upon it. Further work will be required to ensure appropriate capacity and capability is in place to meet current as well as future population need.

Adult Social Care Services (ASC)

ASC provides services and support for disabled people including those with a learning disability. Medway Council's Locality Social Care Teams provide direct support based on the three conversations model detailed below:



Professional staff in the locality teams are responsible for all clients in that locality, instead of previous arrangements where staff teams were based on a categorisation of client need, for example Learning Disability, Older People or Mental Health. This approach allows for greater equity of arrangements to support all clients and a greater appreciation of their overall needs. This approach does require staff to be familiar with a broader range of client need and as such, effective staff development and training programmes are essential to ensure that staff are able to support people effectively. Much work has been done to ensure that all teams have access to specialist learning disability knowledge and support when required, however further development of staff skills specifically in relation to supporting clients with Learning Disabilities has been identified as a priority.

The importance of supporting an effective transition of young people with Learning Disabilities into Adult Services has been recognised as a key priority for the Local Authority. An Adult Services Transitions Team has been created to ensure early support is provided to young adults to maximise their independence.

A key challenge with the local configuration of services is that the three teams are provided by three separate organisations (Kent and Medway NHS and Social Care Partnership Trust, Medway Community Healthcare, Medway Council). Feedback from individuals with learning disabilities and carers has highlighted that this can result in a fragmented and dis-jointed system that can be difficult to navigate. Further work needs to be done to improve the links

between services across health and social care for people with Learning Disabilities in Medway.

Additional more generic support is offered by services like Medway Adult Education who offer an initial assessment to all learners where support needs are identified. Following on from this learners can access a range of vocational courses including Life skills and employability.

Stakeholder Feedback

Statutory duties including The Equalities Act 2010¹⁴, section 142, NICE Quality Standards for patient experience in adult services 2012¹⁵, the NHS Constitution 2012¹⁶ and the Health and Social Care Act 2012¹⁷ all place specific obligations on the Health and Social Care economy to involve patients and the public in designing, commissioning and delivering health and social care services. To this end over the last two years a range of methodologies have been utilised to gain feedback from stakeholders including people with learning disabilities, families and carers as to what's good about the current system of care and support for people with learning disabilities in Medway and what could be better.

Carer Summary

Carers in Medway consistently say not being communicated with is the single biggest challenge they face in supporting their loved ones. Carers report there are long waits for care, support and advice often leading to an escalation in need. This is compounded by the fact that when placements are made, they are far from home and change frequently with little or no prior engagement with family members. Carers also raise the issue of a lack knowledge about learning disabilities amongst staff which has a negative impact on the care and support offered. The "State of Caring" report undertaken each year by Carers UK sets out the range of adverse impacts that this situation can and does have on carers themselves¹⁸.

Stakeholder Summary

Stakeholders in Medway agreed that a lack of investment had led to gaps (including gaps in workforce capacity and capability) in provision and support which were compounded by increasing demand. Stakeholders including professionals, the voluntary sector and paid carers recognised that they lacked knowledge about the range of services available in

¹⁴ <https://www.legislation.gov.uk/ukpga/2010/15/contents>

¹⁵ <https://www.nice.org.uk/guidance/qs15>

¹⁶

https://webarchive.nationalarchives.gov.uk/20130104164106/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961

¹⁷ <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

¹⁸ <https://www.carersuk.org/images/Downloads/SoC2018/State-of-Caring-report-2018.pdf>

Medway. This lack of knowledge impacted on the ability of partners to develop effective working relationships and potentially meant people experienced avoidable delays in terms of access to services. Stakeholders felt that increased opportunities to develop services where it makes sense to do so across the wider Integrated Care System would be welcomed. In addition, stakeholders identified the need, for a multi agency response to impending crisis so that individuals with learning disabilities presenting with an increased need can be averted. Lastly stakeholders' fed back that the system of health and social care needs to be supported by access to appropriate housing and employment opportunities that increase the individual with learning disabilities opportunity for independence.

Priorities 2019 to 2022

The priorities outlined below are reflective of the collective feedback and analysis of the current state. The priorities are realistic, and deliverable based on the allocated budgets, and the legal requirements put on Medway Council and Medway CCG to provide high quality and effective support and services for people with learning disabilities. The priorities below are designed to directly improve outcomes for people with learning disabilities.

1. **Empowering People with Learning Disabilities** – we will develop a communication plan that will serve to keep parents and carers and other stakeholders informed of the wider developments within the world of learning disabilities. We will also develop further specific learning disability information on the Medway CCG and Medway Council websites and ensure the learning disabilities newsletter is distributed to a wider audience.
2. **Preventing Escalation of Need** – At present there is no “complex care response” service in Medway. We will therefore ensure that an agreed pathway of integrated care and support is delivered across health and social care in times of impending crisis.
3. **Integration of health and social care** - we will look at opportunities to develop services where it makes sense to do so, across the wider Integrated Care System. We will ensure this process has ownership and oversight from senior leaders.
4. **Active Citizenship** – we will continue to promote the use of direct payments and develop the wider provider market to offer a more varied range of activities and opportunities. We will develop the supported internships model to include a wider group of young people with learning disabilities and offer more enabling approaches. We will review current employment support provision to determine how people with learning disabilities can better access these universal services.
5. **Improving health and wellness** – will continue to drive up the number of annual health checks by (i) increasing the identification of those with a learning disability on GP registers; (ii) delivering a social marketing campaign (ii) working with the local Commissioning Support Unit (CSU) to deliver the full complement of reviews under the national Learning Disabilities Mortality Review (LeDeR) programme (iv) ensure that

those who are eligible for NHS Continuing Healthcare are made aware of their right to a personal health budget.

6. **Housing and Support Options** – we will maximise opportunities for independence through the provision of good quality and cost-effective local accommodation and support. This will include increasing shared lives placements, supported living and exploring whether the extra care model can be extended to those with a learning disability who are under 55 but who have similar care needs. In addition, we will continue to seek clarification from central government via the Transforming Care Programme of the funding commitment to develop community-based infrastructure inclusive of housing options for those people with learning disabilities who present with complex needs.
7. **Increase the capacity of clinical teams** - to support the needs of a wider range of people with learning disabilities - We will ensure that commissioned health services have the full complement of specialities including occupational therapy and increased nursing and forensic psychology support.
8. **Workforce development** - -we will work with partners across health and social care to provide access to accredited courses that deliver competence-based training in learning disabilities; we will ensure courses are promoted to our commissioned service providers; we will routinely monitor the impact of the courses to ensure staff working with people with learning disabilities have an improved understanding of their needs. Further we will deliver a tiered approach to Positive Behaviour Support (PBS) training with a view to developing Medway as a PBS community. We will grow our own practice leaders through a community of practice approach. PBS training will be delivered across the whole system and will include parents, carers, foster carers, schools, shared lives carers, statutory services and voluntary and third sector partners.
9. **Stop over medicating people with learning disabilities** – we will set up a task and finish group to map out services to enable behavioural support, effective treatment and specialist review of patients across all sectors. We will review findings from Medway audits conducted in primary care to inform actions going forward.
10. **Carers Support** – we support the delivery of the six priorities as set out in the Carers Strategy 2019-2024 being to ensure: that carers are more effectively identified, that they receive good quality information and advice; that they have access and involvement in assessment and support planning; that there is high quality carers support; carers are supported to maintain their emotional and physical health and that respect for the expertise that carers have is recognised and supported.

Delivering the Strategy

The strategy is the result of work done through the Learning Disability Working Group. Achieving the vision and priorities set out in the strategy will require a continuation of the strong partnership and collaborative working that is already being delivered in Medway. This will enable all aspects of commissioning, health and social care policy and other factors that affect the population of Medway and impact on the lives of people with a learning disability to be considered.

The draft LD Strategy Priorities 2019 - 2022 (appendix 1) will be developed further through ongoing consultation, and any new policy guidance and emerging strategies will be reviewed and considered.