

# Lifelong Disability and Autism

Accommodation, Help to Live in West Sussex,  
Support for Carers, Day and Work Opportunities

## The next five years





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## Introduction

West Sussex County Council, alongside our NHS commissioning partners, is producing this Market Position Statement (MPS) in order to give an indication to service providers working in West Sussex or planning to work in West Sussex about how we would like the services for adults and young people (16+) with lifelong disabilities to develop over the next 5 years. We intend this MPS to be a 'live' document and therefore subject to development and refinement over the next few years, taking into account views of all stakeholders.

The current financial position for adult social care and healthcare is extremely difficult and we want to work with service providers to find a way of delivering outcomes for people in a sustainable and affordable way. Although we do not anticipate that our direction of travel, as set out below, will change, we may need to revisit our plans as circumstances dictate. We also recognise that it will take time for both the council and its partners to make the changes we believe to be necessary.

We appreciate that this is a challenging time for all involved in meeting people's health and social care needs and recognise and value the creativity, skills and commitment of service providers. We look forward to working in partnership with you over the next 5 years.

## Principles

This Market Position Statement is underpinned by the following principles:-

**Development of independence:** for some, this will enable individuals to have more choice and be able to undertake some basic self-care; for others it will result in employment, better links with friends and local community and less need for funded social care services.

In line with the **Preparation for Adulthood** work that has been done following the implementation of Children and Family Act, 2014, which we feel applies to all customers 16+, we aim to support with: living independently; gaining employment or voluntary work; being part of their community; and keeping safe and healthy.

**Working with individuals and their families**, where relevant, both in developing their individual plans and in service development. What we have heard from young people and those using services aligns with our principles.

This means we will:

- Commissioning all our services in line with the **Strengths Based Approach**. This draws on the individual's personal skills, strengths and assets and opportunities in the local community to maximise what they are able to achieve and aims to develop greater resilience in individuals and families.
- Taking a positive approach to risk management, supporting providers to offer enabling models of support whilst meeting their registration requirements and maintaining services that are safe and of good quality.
- Using the strengths based approach, positive risk taking and investment in a range of prevention service, including use of volunteers, which will mean that more people's needs can be met without the need for formalised care.
- Work with care providers in all settings to ensure that people are as independent as possible. This will mean actively addressing the communication, environmental and interpersonal issues that may trigger behaviours that challenge, through the application of Positive Behaviour Support and similar approaches to reduce the levels of restrictive care and support. This will be achieved through contracted rates, not as additional payment.
- Commission services to provide "just enough" support, not only due to financial constraints but because we believe that this will support individual development and positive risk taking.
- Commission short-term support with a clear focus on progression. We will be realistic about the tasks that people can complete for themselves. We will commission or organise alternatives to direct support from paid staff where appropriate.
- Ensure residential care is reserved for people whose needs cannot be met in other settings or where this is the most appropriate and cost-effective setting.
- Commission support close to where people live and aim for as many people as possible to travel independently.
- Expect providers to be competent to deliver care to the individuals they support without undue or repeated referrals to health or social care community teams.
- Promote an increased use of **Assistive Technology** in order to increase independence and reduce reliance on formalised care and support.
- Commission services that help lead to people being as healthy as possible in adult life, including ensuring people with a learning disability have their annual health checks and address the health inequalities faced particularly by people with a lifelong disability or autism.

- Work in positive collaboration with the provider market, sharing our plans and developing strategies for the future.

## Current Position

Lifelong Services was established in the summer of 2019 with a vision to deliver a lifelong pathway for disabled and autistic people and their families and carers.

### Pathway for a Lifelong Service



- In 2018 there were around 3,600 people with a lifelong disability identified as within the scope of Lifelong services<sup>1</sup> - 2,700 of these were adults.
- There are currently around 600 adults with learning disabilities living in residential care.
- There are currently around 770 adults with learning disabilities living in their own tenancies and receiving support funded by a personal budget.
- The total social care expenditure on adults with lifelong disabilities is around £95 million. This is made up of the social care element of the Learning Disability Pooled Budget, care costs for those with autism or physical and sensory impairments and social care staff not funded from the LD Pooled Budget.
- There are around 800 people attending buildings based day services. Some of these are 'work based', others predominantly aim to build skills and/or supporting access to community and leisure activities. There is little progression from most day services with the result that most services are near or at capacity.

<sup>1</sup> The scope of Lifelong Services is: all those with a lifelong disability which may be a learning disability, autism, physical or sensory impairment or acquired brain injury. For those who have acquired a disability, through illness or accident, the disability must have been acquired before the age of 25. Where individuals with autism have a severe mental illness, their care will usually be provided by Adult Mental Health Services. Former Children Looked After who require adult social care to support them in adulthood are also included.

- Approximately 50% of people with a learning disability have had their Annual Health Check in 2019.
- We do not yet have a breakdown of expenditure on individuals with autism or physical and sensory impairments but the table below shows how the Learning Disability Budget is spent.

<b>Type of Care</b>	<b>Total Expenditure</b>	<b>Council Expenditure</b>
Residential Care	£47,954,000	£39,083,000
Day Care	£10,383,000	£8,462,000
Supported Living	£21,447,000	£17,479,000
Direct Payments	£6,966,000	£5,677,000
Shared Lives	£2,149,000	£1,751,000
Staffing <sup>2</sup>	£6,518,000	£5,312,000
Prevention	£1,947,000	£1,587,000
Other	£1,202,000	£980,000

## Constraints

### a) Funding

Demand for adult social and health care has been increasing whilst the funding challenge has increased. This creates an imperative to increase focus on prevention of needs escalating to the point where a social or health care intervention is needed. Alongside our NHS commissioners, the council needs to ensure best value in the market and that services are proportionate to need.

Balancing resources against demand has meant that all authorities have had to make savings and prioritise statutory and core services. West Sussex is subject to these challenges and all elements of services are scrutinised and expected to take opportunities to be as efficient and cost effective as possible.

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<sup>2</sup> Includes all specialist health and social care staff, Health Facilitation Team, commissioning and contract staff.

## b) Workforce

Data relating to the whole adult social care workforce (source: [Skills for Care](#)):

- West Sussex has the 4<sup>th</sup> largest adult social care workforce in the South East, both in terms of total number of jobs (22,500) and FTE jobs (16,500).
- 51% of workers are in full-time jobs, below the South East average, and 22% are on zero-hours contracts, roughly average for the region.
- 6% of positions were vacant in 2018, below the average for the South East. The turnover rate of 28% in West Sussex is also lower than the South East average.
- In West Sussex, 23% of workers are aged 55 and over, and 13% are EU nationals.
- The workforce in West Sussex is among the best qualified in the South East, with 52% of workers having a relevant social care qualification.

The council is very aware that in West Sussex there are recruitment challenges and a need to grow the workforce to meet increasing demand. We also recognise that the National Living Wage, other changes to employment law and the uncertainty surrounding BREXIT have all made workforce issues even more challenging.

As part of our strategy for meeting this challenge the Authority will provide strategic leadership around workforce planning and workforce development, to support providers as employers to meet their workforce challenges, including recruitment and retention. Work is underway to promote and increase partnership between health and social care providers, training providers to develop a workforce with the capacity and capability to meet the current and future care and support needs of the people of West Sussex. Partnership and care training activity and work will facilitate partnership working with and between care providers, training providers, NHS partners and other key stakeholders to help develop a workforce with the capacity and capability to meet the future care and support needs of the people of West Sussex.

There will also be a focus on delivering training in Positive Behavioural Support and other Least Restrictive Practices to providers who are meeting the needs of those with most complex needs. A range of autism training will be available to ensure staff have the right training to understand the needs of autistic people and the skills to deliver the most effective care and support.

## Key Objectives

In order to support the principles set out above, we will take the following steps over the next five years:

### a) Prevention Services

The council is in the process of retendering for these Community Based Social Support services and new contracts will start to be in place from April 2020.

The new contracts will focus on 3 separate areas of provision:

- Independent living – continuation of My Network and expanded My Network Plus services which aim to provide support via provision of information, advice and signposting; supporting peer relationships and development of social opportunities; and outreach support either in small groups or on a 1:1 basis for individuals who will need continuing support but do not require a personal budget (or personal health budget).
- Employment support – a stronger emphasis has been put on paid employment in line with the council's intention to support more adults from Lifelong Services to find work.
- Community connecting – this includes support to increase physical and social activities and opportunities; voluntary work; young adult job clubs; and other initiatives aimed at increasing participation, engagement and integration in local community based activities.

Customers in Lifelong services will also be able to access 'Talk Local'. Talk Local's are a series of community locations from which prevention and re-ablement support can be organised and delivered. They are largely facilitated by people from the voluntary and community sectors but have input from trained health and social care professionals where required.

This prevention tier caters for two groups of people:

- Those who do not require care but need something to support them to remain independent of services (for example, equipment, reduce social isolation, ad hoc carer support or benefits advice etc.).
- Those who require interventions for a short time to either recover from a crisis or as part of a re-ablement plan (for example, following a hospital admission or a period of illness).

A new technology enabled care service (TEC) will go-live in April 2020 which will support the council's commitment to support people to remain independent.



- The council is procuring an all-age TEC service and changing to one where eligible customers will be provided with a TEC service as part of a care package.
- The council is moving towards a 'Technology-First' culture and wants to work with providers through Reference Groups to jointly work with the TEC service and appropriate partners to increase the use of existing, and develop new technology to maximise outcomes for people.

Increasing access to wheelchair services and other mobility equipment will also help support independent living and managing care on a daily basis.

A focus on early intervention and prevention will avoid people being admitted to hospital, this includes supporting good physical health as well as mental health and having 'learning disability friendly GP practices.

## **b) Re-tender the Supported Living and Family Support Services Framework**

There is a desire to support more individuals to live as independently as possible within the community, giving them choice and control to live where and with whom they want. Wherever possible this means individuals living within settled accommodation with their own front door. This is dependent on the availability of accommodation.

The current supported living framework comes to an end in March 2021. In planning for the future commissioning of these services the council is aware of the challenges faced by many service providers. These include:

- Being able to pay a wage that is attractive – whereas it was possible for most organisations to pay in excess of National Minimum Wage, the uplifts to this, combined with funding restrictions to local authorities have meant that there are other opportunities at entry and all levels where pay is better.
- Difficulties in recruitment and retention of staff.
- Increasing complexity of some individuals supported.
- Increasing expectations of individual and families.
- Being able to provide outreach services, particularly in more rural areas, for individuals who only require a few hours support at any one time.

We have started working with service providers to identify ways that these challenges could be addressed within available funding.

## c) Day Services

The council intends to update contract arrangements with an emphasis on:

- Reviewing current models and cost structures with a view to increase consistency across West Sussex.
- Promoting 'move on' from buildings based services – we would welcome proposals that will support this in a cost effective way.
- Clarification of the purpose of day services and ensuring that work to develop skills is done within the context of the individual's life within an overall person-centred plan.
- Provision that offers opportunities which enable people to be more ready to progress onto paid or voluntary work.
- Increased use of local provision, reduce transport costs and make more efficient use of peoples mobility allowance.

## Achieving our objectives

### a) Supported living

- Supported living has been increasing slowly (2.3% in the last 2 years) and in 2019 there were 771 adults with a learning disability residing in supported living. In 2019 there were 601 adults with a learning disability living in residential care. We want to decrease the number living in residential care and increase the number in supported living.
- For young adults, supported living will be the default provision. Residential care will be arranged only when there is no suitable supported living service and will be a temporary arrangement other than in exceptional circumstances.
- The council intends to directly commission specialist supported living services where they are required, including for those with the most complex needs as a result of physical disabilities, autism or behaviour that challenges. Capacity in the market will be developed through a new Supported Living Model which will be commissioned in 2021. This will reduce demand for out of area residential placements.
- The new Supported Living Model will encourage supported living schemes that are sustainable and cost effective in relation to the possibility to share support hours and include self-contained flats/annexes.

- We will encourage development of services directed at young people to assist in skill development to enable them to move from children's to adult services.
- Service providers will need to locate services advantageously as the council will be spending much less on transport costs. New services should consider use of public transport.
- We are reducing the number of people with learning disabilities and/or autism with mental ill health placed within a hospital setting and will require supported living delivery models to support more individuals with complex needs to live independently in the community.

## **b) Extra Care Housing**

Extra Care Housing (ECH) is typically a complex of one or two bedroom flats, privately owned or rented where all residents pay towards a low level of background support 24 hours a day. It is then possible for individuals to have additional support, usually on a 1:1 basis.

- Currently there are two ECH schemes where small groups of adults with learning disabilities are living and have additional support commissioned by the council.
- The council is continuing to invest in the development of ECH to include people with a lifelong disability whose needs can be met in this way. There is an increasing focus on making ECH available to younger people.

## **c) Shared Lives**

Shared Lives is where individuals live with carer(s) under a licence agreement. The carer(s) receive payment for rent (via housing benefit), day-to-day living expenses (from the individual placed with them) and for the care they provide (from the council). There is also a payment for management of the scheme and support to carers. These can be highly successful arrangements, particularly where the carer(s) have strong local links and include the individual within family or other social events. There has recently been a drop in the number of individuals supported in Shared Lives settings.

- The council intends to work with in- house and independent sector schemes to increase capacity and so expand this service, both for long and short-term (respite) services.
- The council intends to work with schemes to explore how Shared Lives could support individuals with more complex needs; and how Shared Lives carers could work in time-limited way and focus on development of independent living skills so that individuals can move on to more independent living.

## **d) Support to family and friend carers**

Much of the care provided to individuals with lifelong disabilities is provided by, or co-ordinated by family members, usually parents. There are currently a number of different ways that families are supported to care for their disabled relative including day services, overnight short breaks and provision of 1:1 support including for personal care.

There are limited opportunities to source overnight short-term breaks for individuals with the most complex needs either due to physical disabilities or behaviour that challenges, therefore:

- The council will work with stakeholders to develop additional overnight short break capacity across the county.
- The council will consider the Special Education Needs and Disability (SEND) short break provision to identify other opportunities for short breaks that could be offered to adults.

## **e) Residential Care**

Refocusing support in order to increase independence and opportunities will mean that we need less residential care. Although it is the intention of the council to reduce use of residential care unless there are no suitable support living services and/or this is the most cost effective means of meeting need, the importance of residential care for some people is recognised. For example, good quality residential care can be person-centred and offer an individualised service in a cost effective way for those who are ageing and require constant supervision or access to nursing care.

- We will continue to monitor the cost of care and ensure the council pays a fair price for residential care, through transparent commissioning and contracting arrangements.
- We will work with residential care providers, including those delivered by the council's In-house services, to ensure that people are as independent as possible and consider plans to enable the person to move on where appropriate.
- Where appropriate, for example, to make service improvements and/or reduce costs to the council, we will support de-registration of residential care services.

## **f) Day opportunities**

Refocusing support to in order to increase independence and opportunities will mean that we need less building based day services. The council intends to reduce the demands for centre based day services, through the development of support for paid and voluntary work and increasing opportunities for individuals to use community facilities. There has been a

reduction in the number of young adults attending buildings based day services over the last couple of years but the number of older adults attending remains high. The importance of building based day services as a form of short breaks for unpaid carers is recognised.

- Long-term day service placements will become increasingly focused on those individuals with the most complex needs who require constant supervision.
- We will aim to reduce the amount spent on transport for individuals attending day services through development of local services and an expectation that if an individual chooses to attend an alternative day service they make and fund their own transport arrangements.
- We will work with independent and in-house providers to ensure people receive outcomes focused services, with a move toward time limited placements.
- People who have the potential to gain paid employment or volunteering opportunities will be supported to achieve this goal and move on from funded services.
- We will continue to build and develop access into universal, community based services and support people to build their own sustainable natural networks, rather than attend services.
- We will explore the development of social clubs for individuals that could offer a move on from buildings based day services or a lower cost alternative.
- We will explore how the council can support the development of social enterprise ventures to create work opportunities.

## **g) Direct payments and Individual Service Funds**

These are mechanisms which allow an individual to have the most choice and control over how a personal budget (or personal health budget) is spent. It can be difficult for individuals or their families (who often manage the direct payment on their behalf) to source Personal Assistants (PAs) and it is acknowledged that there are currently a limited number of PAs. The council has developed Pre-Paid Cards which reduce the administrative burden on those managing direct payments. An Individual Service Fund can be paid to a service provider who will use this to meet all of an individual's outcomes including use of other organisations' services.

- We will encourage the growth of the PA market including support for PAs to become self-employed and therefore reduce the demands on those managing direct payments.
- We will develop Individual Service Funds and test out their effectiveness in meeting outcomes in creative and cost effective ways.

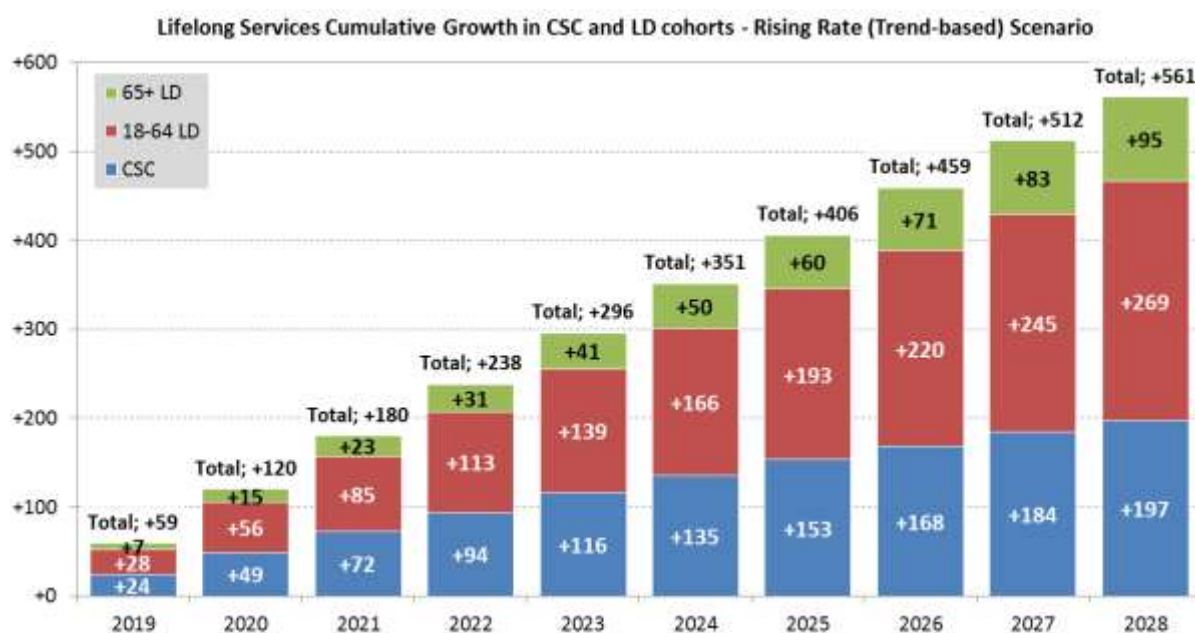
## Demographics

The council publishes a wealth of health and social care data and analysis which is available on the JSNA (Joint Strategic Needs Assessment) [website](#).

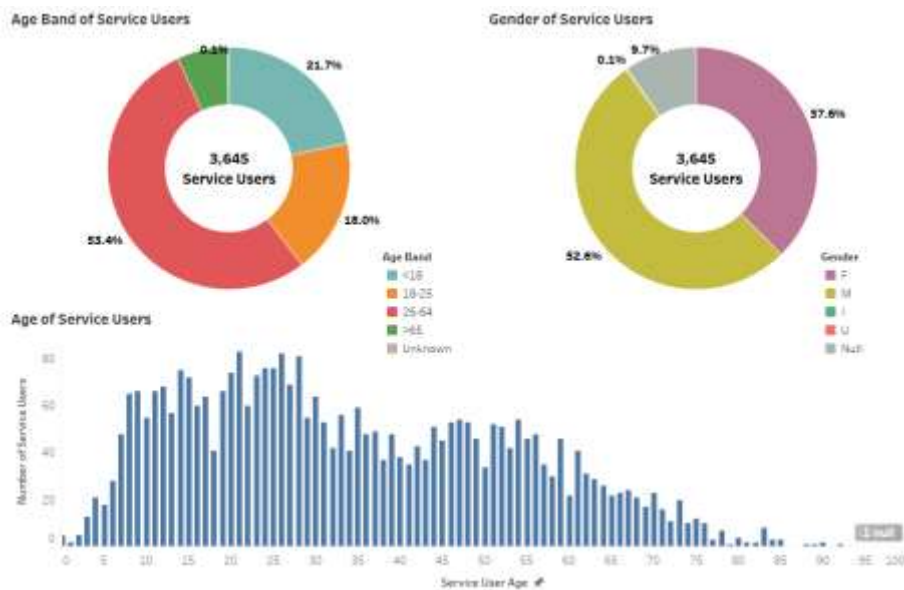
We know that demand for support will continue to rise due to population growth, as more people are living longer including more people with complex needs living into adulthood and:

- The number of people with a learning disability is projected to increase by over 2,000 people by 2035, an increase of 12.8% from current estimates. Within the overall growth, an increase of 300 people with a moderate or severe learning disability is projected, including an increase of 30 people with severe learning disabilities.
- The number of people with Autistic Spectrum Disorders is projected to increase by just under 1,000 by 2035, an increase of 14.0% from current estimates.
- The number of working age (18-64) people projected to have a physical or sensory impairment is projected to increase by around 2,000 from 2019 to 2025, then decrease slightly thereafter. This includes people with a physical disability that impairs mobility, a serious personal care disability, Down’s Syndrome, serious visual impairment or severe hearing loss.
- Over half of our customers are working age.

**Data 1: Projected increases in LD and Children’s Lifelong Services cohorts based on current trends**

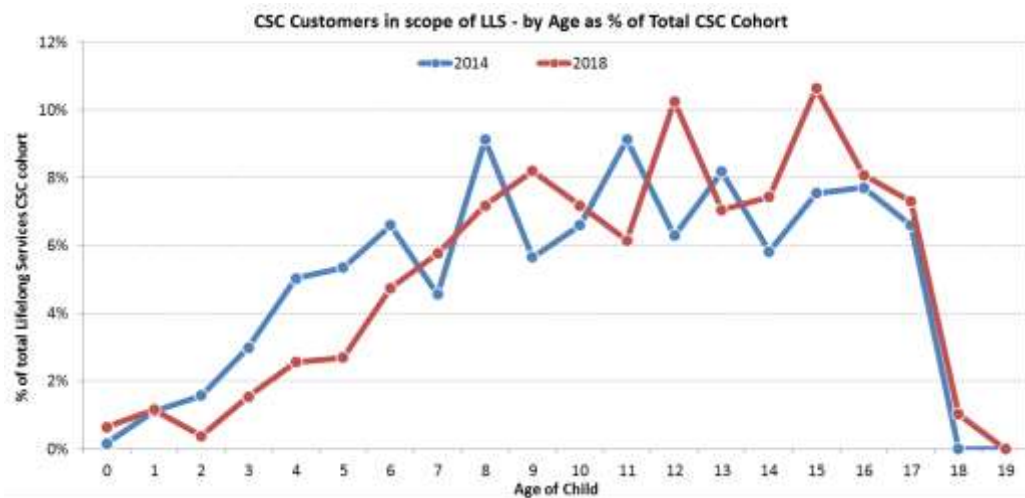


## Data 2: Age and Gender of Lifelong Service Customers



- We will see a 'spike' in young people moving into adulthood over the next 5 years.

## Data 3: Age of Children in Lifelong Services: Comparison 2018 vs 2014



## Quality Assurance

- Both the Learning Disability and Autism Partnership Board's are made up of self-advocates, family and friend carers, representatives from statutory and community organisations, and service providers. The Board's work to improve the lives of both learning disabled and autistic adults and their families living in West Sussex, working together with the health and social care as equal partners in reviewing and planning. Working together in this way ensures that people can have a voice and be informed.

- Quality Checks are carried out each year by self-advocates on subjects close to the Board's heart. Findings and recommendations are discussed at the meetings and are taken into account within our work, in particular in health and social care commissioning.
- We will focus on finding the most affordable price that can deliver us the degree of quality people require.
- We will promote a market which offers a choice of provision that deliver high quality services.
- We will set out our approach to assuring quality in a Quality Assessment Framework.
- Our Provider Forum's for Learning Disability and SEND meet regularly and provide an open and supportive community for Providers to share good practice, concerns and seek information and advice.
- Provider workforce training and development is supported by the West Sussex Learning and Development Gateway which offers the following:
  - An up to date directory of courses from different sectors in one place.
  - Training Pathways for various roles/topics.
  - Online and E-learning opportunities.
  - Facility to book training for self and for staff.
  - Access personal learning record at any time.
  - Alerts for events and opportunities that match individual needs.
- Working together with people with support needs, family and friend carers and stakeholders is at the heart of realising the vision for adults' services. We have committed to coproduction and will do this by:
  - listening to people and treat them as experts of their own experience.
  - involving people at an early stage in service change.
  - sharing ownership of solutions and outcomes.
  - being honest and open with people about what we can change and what we can't .
  - providing people with the information they need, at the right time and in format they can understand, in order for them to be an equal partner in planning change complying with Accessible Information Standard.
  - ensuring that all co-production activity is as local as possible to where people live and that venues are fully accessible.



- Ensuring that we have a full understanding of all individuals, groups and communities that are affected by the issues being considered and that they are supported to fully participate.
- Ensuring that we understand the impact of any proposals upon the responsibilities we have toward people with protected characteristics, as defined in the Equality Act 2010. Any outcomes from the work will take account of those responsibilities.
- Ensuring that the resources for meaningful co-production are available.
- Recognising the contribution of the people we are working with, in line with our payments and reimbursements for customers and carers guidance.
- Giving feedback on outcomes of any co-production work to all who take part.

There is an expectation that services we commission will have similar coproduction values.

## Finally .....

This MPS should be read alongside the MPS for children and older people once published.

There are other strategic documents that influence this work:

- The West Sussex Plan (2017-22);
- Adult Social Care Vision and Strategy (2019-21);
- West Sussex Health and Care Plan (to be published in 2019)
- Procurement Strategy (2019-21).

This MPS describes our strategic direction for our Lifelong Service customers and outlines how Providers might plan for the changing needs of care and support in the future. If you would like to make constructive comments on this document and/or be involved in future versions of this document please contact via the following link:

[lifelongservices@westsussex.gov.uk](mailto:lifelongservices@westsussex.gov.uk)

