

Suffolk Joint Learning Disability Strategy (2015 – 2020)



Image created using words spoken by people at Suffolk Engagement events in April & May 2015



Foreword

This Strategy sets out a clear vision on how we can work together differently to deliver better outcomes for individuals, meeting our Statutory obligations and making best use of the rich and diverse assets we have in our county. Like all other localities, we face challenges in terms of the current climate of reducing financial resources.

Working differently will enable us to harness the resources of people, places and the community of Suffolk. The Strategy is firmly rooted in the reality of the current climate and national policy framework. It sets out the way we can deliver positive change and efficiencies together.

In preparing this Strategy we engaged with people and families and those who support them. This includes people with learning disabilities from the age of fourteen. What we heard, resoundingly, is that people want and need to be supported to live **ordinary** lives.

The aspirations of and for people with learning disabilities are, unsurprisingly the same as for the rest of us; to be listened to as individuals, to have choices about where to live and who to live with, to have relationships and pets, to choose the people who support them and to have opportunities for work and participation in their communities.

People want to enjoy good health. People want to be able to stay up late and have holidays. People want to have opportunities to try new things out, celebrate success and learn when things don't work out as hoped.

There's nothing radical here, nothing extraordinary and nothing that should be difficult for any of us to achieve. Enabling people to have good ordinary lives doesn't need to be expensive and is within the gift of communities, Local Authorities, Clinical Commissioning Groups and organisations who support people.

Anna McCreddie (Corporate Director for Adult and Community Services)

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1. Introduction

Suffolk County Council and the three Suffolk NHS Clinical Commissioning Groups (Ipswich and East, Great Yarmouth and Waveney and West Suffolk) have developed this five-year Strategy detailing how people with learning disabilities (aged 14 and over) and their families should be supported to live good ordinary lives in Suffolk. The Strategy was developed with people with learning disabilities, families, health and social care professionals, supporters and community organisations.

The thoughts and ideas that have been generated are rich; a sense of energy, interest and hope is growing. People have wanted to play a part in making sure a realistic, yet aspirational Strategy is developed to ensure people with learning disabilities live a good life in Suffolk.

It is also important to acknowledge that in recent years there have been numerous examples of people and families not having their voices heard and not receiving the support they needed. This had lead, at the most extreme, to people dying unnecessarily in receipt of poor quality care and support services. Throughout the development of this Strategy many people said they were lonely and isolated. This increases the risk of vulnerability and needs to change. Appropriate safeguarding remains fundamental to good support.

The Suffolk Health and Wellbeing Board have a role in the oversight of this joint Strategy, through its duty to 'encourage integrated working' between health, care, police and other public services in order to improve wellbeing outcomes for Suffolk. Suffolk Health and Wellbeing Board's vision is that, *'People in Suffolk live healthier, happier lives. They also want to narrow the differences in healthy life expectancy between those living in the most deprived communities and those who are better off. To do this we will need to make greater improvements in more disadvantaged communities.'*

This Strategy sets out a Vision, Strategic Intentions with Headline Actions, Key Priorities and subsequent recommendations for action. It also outlines underlying principles to enable the Local Authority and the NHS, to commission and secure the delivery of good support that frees people to live good ordinary lives, within the context of significant financial and capacity challenges. There are, of course, local challenges and variations in practice, for example it is important to remember that the Great Yarmouth and Waveney Clinical Commissioning Group spans two Counties and therefore some recommendations have different relevance in each area.

The Strategy recognises that good support isn't just paid support. It isn't just from services. Good lives happen when we:

- are healthy
- have a place to live of our choosing
- are connected to our communities through relationships, work, and activity
- have good support and a voice that is valued, respected and listened to

Sometimes some people need some paid support to achieve this.

2. How the Strategy was developed

Suffolk Adult and Community Services worked with people from across Suffolk to co-produce the Suffolk Joint Learning Disability Strategy for 2015 – 2020.

A working group, consisting of family members, self-advocates, provider representatives, Adult Social Care and Health colleagues was created to design a series of engagement events, surveys, feedback processes and final draft meetings to ensure that the Strategy was ready for the Health and Well Being Board scheduled for July 2015.

The highly interactive, challenging and creative events were well supported by a wide range of stakeholders. Approximately four hundred and fifty people shared their thoughts, concerns, hopes and ideas for the future. Listening with integrity and working to reflect the voices of many, requires a delicate balance between what people want and need - and the challenges faced in the current environment. This Strategy does not shy away from this challenge.

Thank you to each and every one of the people who contributed to creating this Strategy. Together you have created a vision for the future. Now, working together we must all deliver the vision.

There will be challenges, there will be less money, but working together with honesty and integrity will enable good things to happen.

The following details the events and activity leading to this Strategy.

1 Engaging people to appreciate the 'as is' and agree a Vision and actions for the future

- Three community-wide Engagement Events. Attendees included, family members, self-advocates, providers representatives, health and social care colleagues and community agency colleagues
- Online Survey
- Social Media campaign #goodlifesuffolk2015
- A workshop with The Learning Disability Partnership



2 Checking out what was heard at the Engagement events

- A report of Feedback from Engagement Events and surveys along with initial recommendations was presented to all three Clinics



Commissioning Groups and Adult and Community Services Management Team for comment

- An event inviting people who attended the Engagement workshops to come together to hear what was learnt and to review, amend and strengthen the recommendations
- A 'Providers Day' – Health and Social Care and Universal Service providers invited to come together, hear about the Vision and to start the conversation about what their role can be in achieving the vision and strengthening the recommendations
- Further meetings with colleagues in Health and Social Work Services and others, following a gap analysis of engagement to date
- A workshop with Suffolk People First (a group representing people with learning disabilities from all over the county) to seek views on the Engagement Report

3

Finalising the Strategy

- The drafts of the Strategy were circulated to the Learning Disability Partnership, the Working Group, Clinical Commissioning Groups and Adult and Community Services Management Team. Comments, corrections, additions were invited
- Presentation of the draft to: Clinical Commissioning Groups, the Learning Disability Providers Forum, Supporting Lives Connecting Communities Progress Group, Adult and Community Services management team and the Learning Disability Partnership
- Following all of the above a number of emails were received, sharing thoughts and ideas for strengthening the Strategy. It's worth noting that much of the feedback received will be helpful when co-producing the detailed implantation plan and therefore may not all be reflected in this high level Strategy paper



Here is just a little of what we were told:

'There isn't enough good support to help people get work. A lot of courses but little progress to real jobs. Need to get to know more employers to create opportunities.'

'Many people are not aware of housing possibilities - and future housing planning with individuals is weak.'

'The Acute Liaison Nurses are brilliant – but we need more of them!'

'Communication between Health and Social Care is poor.'

'People want increased opportunities for lifelong learning. Community courses, not always specialist 'Learning Disability' courses.'

'Be honest with us about the money – then we can all find creative ways of delivering the vision'

'Good support is about relationships. I get you, you get me and together we can figure out what is needed to support people to live a good ordinary life!'

'People need better access to information and advocacy.'

'Support should be like elastic, supporting yet stretching people to be brave and try new things. Someone listen to me! People are LONELY and poor support can cause this. Good support frees people.'

'Continuing Health Care does not work at the moment – people aren't easily able to access it and wait long periods of time for support while Local Authorities and Clinical Commissioning Groups decide.'

'Families of children and young people in mainstream school are concerned about the lack of inclusive cultures and consequently young people leave school isolated'

'People find quality of support from General Practices varies greatly'

'Find a way of providers sharing what they offer to meet the wishes and needs of people supported by other agencies'

'People want more flexibility and choice to plan their social life, not to just do what support staff control.'

'There is some good planning with young people and families but it's not available for all'

'My staff say I can't.... go to that group, stay up late, have my friends over...'

'Stop competitive tendering – move to Personal Budgets – it will allow us to be creative and work together to innovate, encouraging joined up working and sharing of ideas and action'

'It's really hard to get a social worker to help make changes like moving house or changing my support'

'The support me and my son (aged 16) get from the Community Psychiatrist and Learning Disability Nurse keeps us going and my son out of hospital. They see us as people first, not a diagnosis'

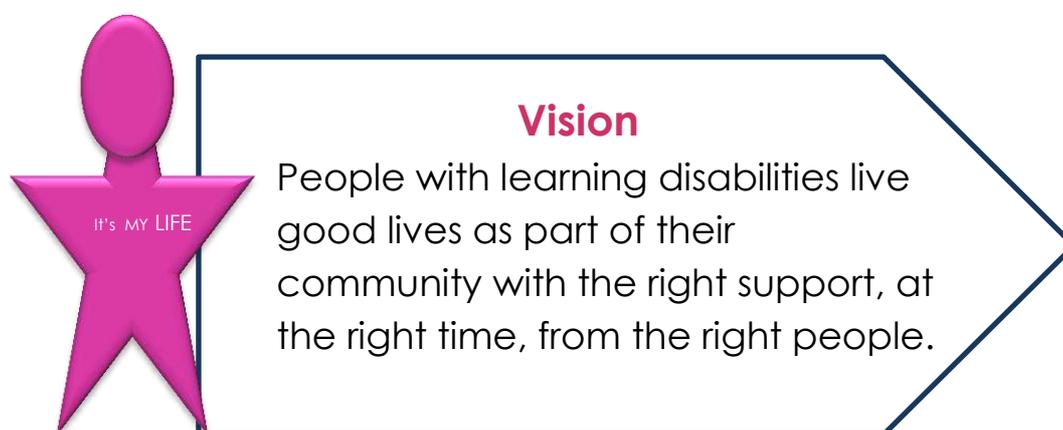
'My family are my greatest supporters. My person centred meetings make sure I am heard. My family supervises my own staff team'

'Communication between Health and Social Care is sometimes poor'

'More information about money, benefits and Personal Budgets is needed. 'We don't know how it works!'

3. The Vision

Suffolk NHS Clinical Commissioning Groups and Suffolk County Council want people who have a learning disability to live good lives as part of their community with the right support, at the right time from the right people.



In the following sections, unless the context suggests otherwise, the use of the word “we” means all key stakeholders including of course, people with learning disabilities and family carers, and reflecting the necessity for joint ownership – achieved through co-production.

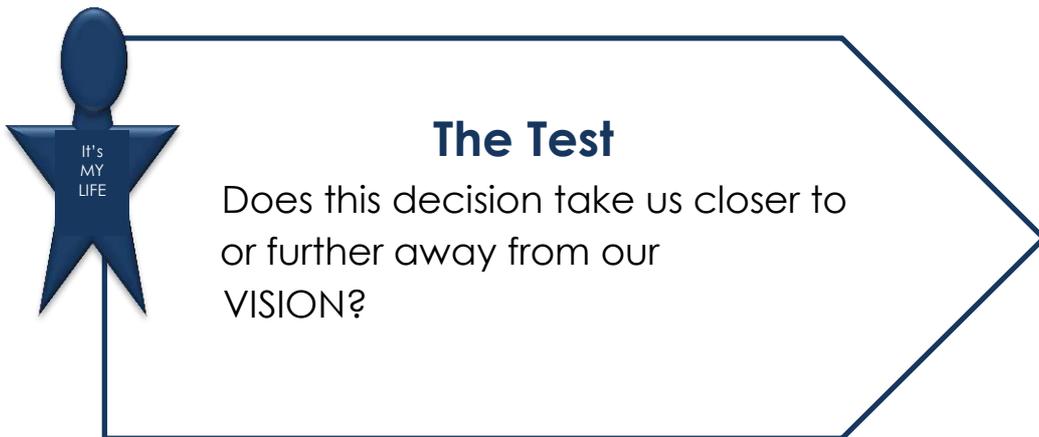
We will build on the skills, resources, and abilities that people and communities already have, rather than focusing on what they can't do. Working with people and communities to harness and build on their existing pool of resources and use them more effectively can offer more affordable and value for money solutions and better outcomes for individuals.

We will simplify the social care and health system, making it more personal, flexible, accessible and accountable to people who need to use it.

In order to do this we will provide information and advice so that people know how to get the right support at the right time, from the right people.

We will be flexible and responsive, enabling people (aged 14 and over) to move between different levels of support, building on their individual strengths and capacity so that people live as independently as possible. This is about supporting independence and focusing on preventing people reaching crisis.

To implement the Strategy and make real the priorities with integrity, decisions must be tested against this fundamental question; does this decision take us closer to or further away from our Vision? If it takes us further away from, we shouldn't be doing it.



4. Strategic Intentions

In order to achieve the Vision, we know we need to do things **differently**. This means changing the way we work with each other in our organisations and with our partners. We also know the Council and the Clinical Commissioning Groups are facing significant financial and capacity challenges. This makes it even more important for us all to be agreed on the strategic direction and to work together differently to deliver a clear vision.

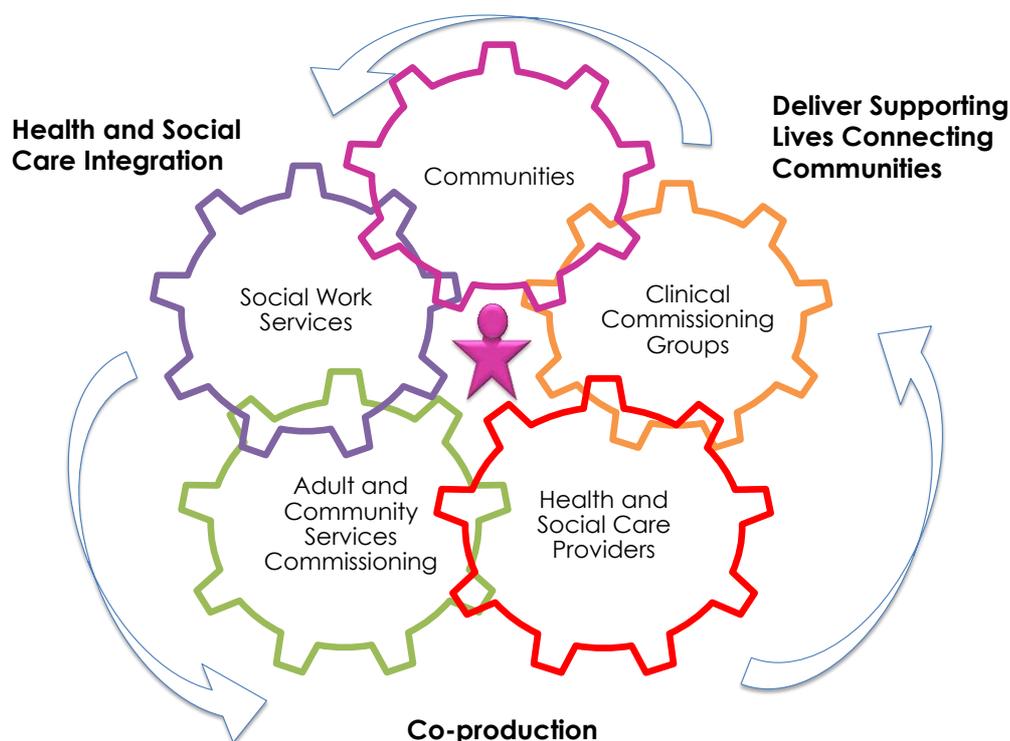
The Strategy was developed in co-production with people with learning disabilities and families, community organisations and Health and Social Care commissioners and Providers.

We need to be brave and challenge each other when we see behaviours or a decision being made that moves us away from the vision or away from the commitment to co-production reflected in this plan. Remember the test!!

In order to deliver the vision we need to recognise the 'whole systems' approach to change. We need to understand the interdependencies between each of our roles, departments and organisations. If one part of the system doesn't change, it delays or stops progress in other areas. Similarly if one part of the system streaks ahead of the rest, it can cause problems for another area.

We need to manage the delivery of the Strategy to support the **whole system**. We need to ensure that we are using our resources; people, community and money, in the right way to make sure each "cog" drives the next, so the whole system works together. (See below).

Cogs in our whole system



The Cogs

- **Social Work Services** – Working alongside people, families and communities to deliver Personal Budgets through assessments, reviews and robust support planning. A fundamental element of the Strategy is the move to individuals having control of their total resources through the implementation of Personal Budgets and personalised support plans
- In parallel – **Suffolk County Council Adult and Community Services Commissioning** teams continuing to move away from block contracts and tendering processes and focusing more on market growth, and innovation (-e.g. community commissioning), provider reviews and quality
- **Providers** –Social Care and health providers (- including Primary Care, Community Health and the Norfolk and Suffolk NHS Foundation Trust) working collaboratively and with integrity, innovating and delivering flexible, person centred services
- **Clinical Commissioning Groups** – continuing to secure community based responses to the physical and mental health needs of people with learning disabilities that are flexible, accessible, person centred and joined up. This should include -further maximising choice and control by working to increase the uptake of Personal Health Budgets
- **Communities** – supported to flourish, grow and support people with learning disabilities in a variety of ways, (- this might mean using resources differently)

The Mechanisms for Delivery

1. Supporting Lives, Connecting Communities

Suffolk County Council Adult and Community Services recognises that good lives happen for people when they are supported in their communities. This means being connected to people and places in neighbourhoods and beyond.

Through its Supporting Lives, Connecting Communities initiative, Suffolk County Council Adult and Community Services aims to support people to work towards being as independent as they can, promoting progression wherever possible throughout a person's life. This initiative is entirely in line with the new requirements set out in the Care Act 2014 and as such is considered to be a Value for Money and affordable approach to enabling people to plan their paid and unpaid support.

Supporting Lives, Connecting Communities has been developed in line with the National best practice and policy guidance. It has been cited as an excellent example of how local authorities can deliver good services, whilst still delivering value for money.

The 2014 Care Act gives Local Authorities a new statutory framework to support people. Supporting Lives Connecting Communities will enable these requirements to be met.

Suffolk County Council will continue to deliver support through this three-tier Supporting Lives Connecting Communities approach. This is fundamental to the success of The Strategy.

Tier 1 – Helping people to help themselves

Tier 2 – Providing help to people when needed as a short-term measure

Tier 3 – Providing on-going support for those who need it

2. Health and Social Care Integration

Policy and Guidance, including the Care Act 2014, says that Health and Social Care teams should be integrated where this will deliver better outcomes for people. There is also evidence to suggest that integration delivers value for money.

During the development of this Strategy people said that there is poor communication between Health and Social Care teams and providers and that this leads to greater health inequalities, poor support and unmet need.

Suffolk is committed to developing integrated models of support that are holistic across health and social care and are embedded within communities and neighbourhoods.

3. Co-production

The co-production of public services has been defined in a variety of ways, for example

co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours (New Economics Foundation).

Co-production as a method or approach is a very different way of working and can be challenging to implement. However it can make the system more efficient, more effective and more responsive to community needs.

In line with national Guidance and legislation the Suffolk Clinical Commissioning Groups and Local Authority have committed to co-production as a powerful and successful way of redesigning, developing and commissioning support and services for all.

Suffolk's co-produced definition (see Appendix two) of Co-production is that: "*Co-production is people, carers and professionals working together as equal partners to: design, develop, commission, deliver and review services, information and advice*"

Headline Actions

There are some HEADLINE ACTIONS that need to be considered immediately, in order to get the cogs working to deliver the KEY PRIORITIES (see Section 4)

1. Set up mechanisms and structures for Governance (Governance proposals currently being coproduced) that puts the Learning Disability Partnership as a key mechanism for delivery, accountability and audit of The Strategy – embedding co-production from the start
2. Designate, or clarify who will have responsibility for driving the Strategy within each of the NHS Clinical Commissioning Groups and Suffolk County Council. Consider identified Clinical Leads
3. Explore the feasibility and efficacy of a jointly funded Programme Manager
4. Establish robust, co-produced, creative Health and Social Care Providers Forum to strengthen communication, shared learning and innovation
5. Continue to work towards integrated Health and Social Care teams located in the community
6. Work with people with learning disabilities, their families and other partner agencies to co-produce the Implementation Plan for this Strategy
7. As per the Joint Strategic Needs Assessment (JSNA) develop accurate demographic data sets for planning and reporting.
8. In co-production, explore, develop and implement a set of Key Performance Indicators based on the Making it Real 'I' Statements and/or Quality of Life Standards, designed to cross reference with the Key Priorities, to drive up quality in provision
9. Map people and tasks to check whether the right people are in the right place doing the right thing to maximise use of resources
10. To ensure value for money and efficiency, consider mapping and improving meeting flow to ensure that key meetings in different agencies don't clash in order to support full participation. This will allow for the right people to be at the right meetings to make well informed and timely decisions.

5. The Key Priorities.

The key Priorities set out below have been identified through a process of engagement and form the basis of the Strategy. The recommendations for action under each Key Priority can be found in Section 10. These are based on what people told us was important and will enable us to deliver value for money solutions.



6. Underlying principles

At the very heart of the Strategy are the principles of empowerment, choice and control. These principles must be held strong if the Strategy is to be delivered in the current climate and with the current financial challenges in order to change people's experiences and enable people to live good ordinary lives.

These principles will underpin every work stream, approach and decision



Co-production is understood and evidenced at all levels. Honesty, trust, openness and transparency throughout



People have choice and control over their lives



We are brave, innovation is encouraged and we learn together when things don't work out as anticipated



Organisations, systems and professionals value and include families, communities and the importance of relationships in freeing people to live good ordinary lives



We have compassion and respect for each other as we work towards the vision



People are free to live good ordinary lives whilst having the appropriate support to be safe and well



The vital role support workers play in the lives of individuals is valued and nurtured



We celebrate together

7. The National Policy Context

It is important that we keep up to date with good practice and what is happening across the Country. Some of this is policy and legislation we must follow, some is about an approach to quality we choose to follow, as we want to ensure we offer the best possible health, support and opportunities for people with learning disabilities. We know we need to share with and learn from others to achieve this.

This document is informed by a number of national legislative and quality developments relevant to the commissioning of care and support and healthcare for people with learning disabilities. This Strategy enables Suffolk to deliver its statutory and other responsibilities as outlined in national policy and guidance as well as meeting the challenges of the current climate.

The Care Act sets out new requirements and also makes clearer what Local Authorities are required to fund via the implementation of the new national eligibility criteria for adults in need of support as well as their carers.

See Appendix One for summary information on the:

- The Care Act 2014
- Winterbourne View Joint Improvement Programme
- Driving Up Quality Code
- Quality of Life Standards
- No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions (Green Paper March 2015)
- Think Local Act Personal – Making it Real
- Children and Families Act 2014
- The forward view into action: Planning for 2015/16 - NHS England December 2014
- Individual Service Funds (ISFs) and Contracting for Flexible Support Practice guidance to support implementation of the Care Act 2014 – Think Local Act Personal, June 2015
- Moving forward with personal health budgets: a CCG development programme – NHS England 26th May 2015

8. The Local Context

The following information comes from the 'Health and Social Needs Assessment of People with Learning Disabilities in Suffolk' November 2014. The assessment shows that there are an estimated 13,700 people in Suffolk with a mild, moderate or severe learning disability and this is projected to rise by 5% to around 15,000 by 2030. Of this, there are an estimated 2,800 people with complex or severe learning disabilities. However, less than 2,000 people with learning disabilities are currently recorded as being in receipt of care by Suffolk County Council (SCC) and NHS primary care Learning Disability registers are incomplete.

The difficulty in calculating an accurate picture of the number of people with learning

disabilities living in Suffolk reflects similar difficulties nationally. The gap in numbers suggests a significant amount of unidentified and unmet need. It may be that there are 80-85% of people with learning disabilities not receiving specialist learning disability support.

The [Learning Disability Joint Strategic Needs Assessment 2014](#) contains further information.

Support currently being provided to people with learning disabilities in Suffolk

- There are approximately 175 'supported living schemes' and 'supported housing' services across Suffolk. These services provide care and support for approximately 670-700 people.
- There are currently 43 residential care homes for people with learning disabilities in Suffolk, with a total of 464 rooms between them. A total of 225 of these places are purchased by Suffolk County Council, who also purchased an additional 83 places outside of Suffolk
- Between 70 and 100 young people with learning disabilities are estimated to transfer to adult services in 2015-2017
- 48% of people with a learning disability receive 'Home Care' directly commissioned by the Local Authority
- 52% of people with learning disabilities receive Direct Payments to pay for support to live at home
- 507 people with learning disabilities are receiving direct payments which equates to one third of the total number of adults in receipt of direct payments
- There are currently 4368 council funded home care services for all adults in Suffolk; of these, approximately 20% of people receiving home care support are people with a learning disability
- 29 people are receiving support within Shared Lives settings
- There are approximately 20 people living in Out of County Assessment and Treatment Units
- There are currently 1548 people attending day care services at 138 different locations across Suffolk; of these, 52% of people have a learning disability
- 132 people have care packages that cost over £1400 per week or more
- In terms of age groups, peaks of learning disability social care activity occur between the ages of 18-24, and 40-50 years. Numbers of people using services decline after the age of 55, potentially reflecting reduced life expectancy. Use of services in the age group 18-24 has increased as a proportion of the total consistently over the period 2009-2013 (13.7% to 16.7%). This may reflect an increase in the numbers of people being diagnosed with a learning disability in childhood. The higher number of people with learning disabilities in the 40-50 year age bracket than in the 25-39 age bracket may be indicative of people seeking social care support when their family support network may break down.
- For NHS care, the number of people receiving residential/inpatient care from Norfolk and Suffolk Foundation Trust has reduced markedly in the past five years. While in 2009/10 664 people received residential/inpatient care, this had dropped to 54 people in 2013/14. As noted above, this reflects national policy in the period.

The number of people receiving community-based care from NSFT has remained stable in the same period (1,195 in 2009/10 and 1,036 in 2013/14).

- In terms of secondary NHS care, over the five year period 2009/10 to 2013/14 numbers of admissions were relatively stable (between 877 and 945 admissions annually). A high proportion of admissions related to the chromosomal disorders often associated with learning disabilities. The high volume diagnostic areas most amenable to preventative interventions or improvements to healthcare access or practice were diseases of the respiratory system, injuries and poisoning.
- Despite this increased risk of physical and mental health disorder, access to screening and health check services for people with learning disabilities is markedly lower than for the general population. The 2013 Suffolk learning disability profile suggests that in comparison to the general population, uptake of cervical screening in people with learning disabilities is 41% lower than for peers without learning disabilities, and for breast cancer and bowel cancer screening it is 14% lower. Additionally, the 2013 Self-Assessment Framework submission suggests that only 36% of people who were eligible attended their GP for a Learning Disability Annual Health Check.
- The uptake of the annual health check is markedly lower in Suffolk than in statistical neighbour counties. Where the Improving Health and Lives Learning Disabilities Profile suggested as few as 19% of eligible individuals had a health check and the 2013 Self – Assessment Framework submission suggested that the figure had risen to 36%, statistical neighbours reported figures of 70% plus. Improving the uptake of this intervention may help address health inequities in this population in terms of treating illness earlier
- However, the 2013 Suffolk Learning Disability Profile does suggest that people with learning disabilities make up a lower proportion of emergency secondary care admissions than the national average and comparator counties. The rate of admission for ambulatory care sensitive conditions is also lower than the national average.
- It is clear that while there are mechanisms in place to try and address health inequalities for people with learning disabilities, uptake in Suffolk can be improved. While mortality rates for cancer are similar for people with learning disabilities and the general population, people who die of cancer die younger when they have a learning disability co-morbidity. Initiatives such as screening and health checks should enable earlier detection of conditions such as cancer so it is vital that access is better facilitated for people with learning disabilities.

9. The financial context

Increased financial pressures make it even more important to have a clear, joint strategic plan and to work collaboratively to make best use of resources and harness innovation. The best evidence available (Appendix 3) in relation to delivering services to people with social care needs and their family carers, shows that working inclusively with people, families and communities to create individual and community led and mainstream solutions both enhances people's quality of life, meets statutory duties and shows value

for money.

This Strategy proposes the way that Suffolk can deliver change, better outcomes for individuals, as well as efficiencies. Supporting Lives, Connecting Communities, Health and Social Care Integration and Co-production are key mechanisms and are integral to implementation.

Having choice and control, core to good ordinary lives, does not mean being entitled to increased funding. It does mean being supported to:

- get the best from the money you are eligible for
- receive services you are entitled to
- value and maximise the non-paid natural support from family, friends and community

The number of people with a learning disability in Suffolk is increasing and, understandably this leads to increasing demand for services. This is expected and in line with national trends.

In recent years Adult and Community Services spend on services for adults with a learning disability has increased by about 5% a year. This is in contrast to spend on services for older people, which has been relatively flat. However between 2013/14 and 2014/15 the rate of increase in spend on learning disability services has decreased to 2.5% (over inflation) and the spend per head has decreased - indicating that the growth is due to increased numbers of people being eligible for funded services.

The expected spend by Suffolk County Council Adult and Community Services in 2015/16 on services for people with a learning disability is £62m. The spend by the Clinical Commissioning Groups is c. £9.5m.

Over the last six years Suffolk County Council Adults and Community Services Directorate has consistently achieved savings on the totality of spend - amounting to a recurring saving of £59m over that period (c. £10m a year.)

The consequence of these trends is that the amount spent on services for people with learning disabilities requires an increasing share of the total Adult and Community Services budget. This reflects the position in many other local authorities.

There is some evidence that Suffolk Adult and Community Services spends a little more per head of population than similar authorities. Further exploration is required to understand the detail behind this.

The premise in this Strategy is that, working together with people who use services, family carers, providers and community groups in the context of Supporting Lives Connecting Communities and effective partnership working with health commissioners and providers will create the innovative solutions necessary to achieve both improved outcomes and better value for money.

10. The Key Priorities and Recommendations for Suffolk

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult Care Service colleagues and other stakeholders. Under the Key Priority headings is a summary of what people told us and some recommended actions, some of which require further exploration.

The financial situation for the Clinical Commission Groups and the Local Authority is challenging and the delivery of this strategy will require strengthened joined up working and collaboration. Multiagency integrated working is key, as is a broader understanding of each organisation's cross cutting priorities. For example people's health is not the sole responsibility of the National Health Service.

It is important to note that at this stage these are high-level strategic recommendations. This Strategy does not identify which individuals or agencies are responsible for taking forward recommended actions. For example, it should not be assumed that all Good Support recommended actions are the sole responsibility of provider agencies. It may be that for some recommended actions different agencies have shared responsibility to deliver.

The range of stakeholders involved in developing the Strategy need now to co-produce a robust, five-year implementation plan having clarified and prioritised the recommended actions.



1. Information, advice and advocacy

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

What we heard:

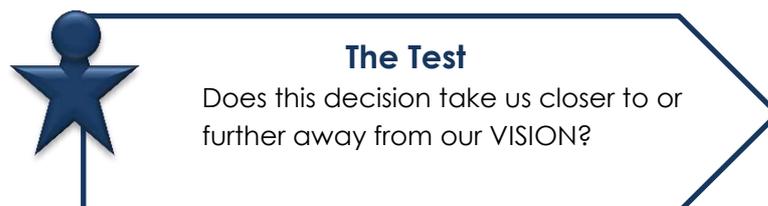
Whichever Key Priority Area people spoke to us about they told us that access to Good Information, Advice and Advocacy was important, whether that was to do with Health, Housing, Work, Support etc.

- People need access to information and advocacy to make good decisions about their health
- Advocacy and support to Speak Up is really important. More is needed
- Access to information, advice and advocacy needs to be better
- It's essential to have better access to information to support people to make choices and understand what is possible
- More information about money, benefits and Personal Budgets is needed. 'We don't know how it works!'
- Accessible information about what is 'out there' in the community not just service land is needed
- We heard that people often didn't understand or know about different initiatives despite efforts of organisations to communicate
- People need access to advocacy to help them understand what good support is and then to help them get it
- There is a sense that providers are not sharing information and wanting to hold on to their 'Service Users' and provision
- People have very limited access to information and support about personal and sexual relationships. People need information and advice from supporters that is open, confident and non-judgmental

Recommended action:

- a. Ensure a full range of advocacy support is available to people e.g. Statutory, Community, Self-Advocacy, Independent Mental Capacity Advocacy and Care Act Advocacy
- b. Ensure support is available to help people plan life changes (for example

working age benefits, end of life support)
c. Ensure that parents with learning disabilities have access to appropriate information, advice and advocacy
d. Ensure appropriate and accessible information, advice and advocacy is available to members of the community from black and minority ethnic groups
e. Ensure open referral systems to access Advocacy
f. Provide easy to understand information about the Mental Capacity Act to ensure people know their rights
g. Consider using the Quality of Life Standards to create Key Performance Indicators to support people to choose support agencies
h. Consider developing Mental Capacity Act champions across the County to support other colleagues
i. Co-produce mechanisms to develop and share clear, engaging, accessible information about community, support, learning and employment possibilities
j. Consider how to improve access to community based lifelong learning opportunities
k. Ensure support is available to support people to make their own decisions
l. Further develop http://infolink.suffolk.gov.uk/kb5/suffolk/infolink/adult.page?adultchannel=0 to increase accessibility. This should include information about 'Who's Who' in Health and Social Care in each locality



2. Choosing where I live and who I live with

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

What we heard:

- Many people are not aware of housing options or possibilities and the planning of future housing solutions with individuals is weak
- People think that general housing can't meet the needs of people with learning disabilities
- There is a need to ensure people can choose where they live, whom they live with and who supports them
- Housing departments in Districts and Boroughs, Residential Social Landlords and Adult and Community Services are not engaging with each other and there is a lack of robust, creative, housing solutions
- People and families need support to help them see that moving on is a positive, not the result of family failure
- There is a misunderstanding of Supported Living (Support for Living)
- Too often people are told they can't have pets. This is wrong.
- Different ways of drawing down capital should be considered.
- Adult and Community Services have communicated a belief that it is their responsibility to house people
- Social Workers want fixed pricing and terms and conditions in contracts with providers
- Need to make sure support is focused on increasing independence e.g. of those in Residential Care to ensure people are supported to move onto more independent living

Recommended action:

- a. Ensure the needs of people with Learning Disabilities are addressed in the Housing Strategy including a full range of housing options e.g. shared ownership, shared lives, private tenancies
- b. Make sure there is good support for people to maintain tenancies in general housing
- c. Research and develop creative approaches to funding housing e.g. Family run housing associations, philanthropy, see [Cameron Trust Lets for Life](#)

d. Manage 'voids' in a way that respects people's rights and ability to choose who they live with and who supports them
e. Work more closely with District and Boroughs and Housing Associations/Social and Private Landlords to meet identified housing needs and to develop a range of innovative housing options and solutions
f. Develop a shared understanding of the principles, applications and service specification of Supported Living. Principles of choice and control should underpin all. From choosing where I live, how I decorate, who I live with and who supports me
g. Work with housing providers to review tenancies to ensure people are able to have friends/partners to stay and can keep pets if they choose
h. Develop a new specification for Supported Housing
i. Investigate working with providers to develop a Letting Agency



Vision

People with learning disabilities live good lives as part of their community with the right support, at the right time, from the right people.

3. Staying healthy and well

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

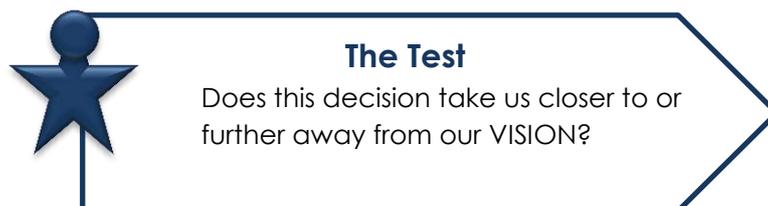
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What we heard:

- Acute Liaison Nurses are brilliant and that one per hospital is not enough - and that this role needs to be available in other health settings
- Communication between Health and Social Care is sometimes poor
- People find quality of support from General Practice varies greatly
- Home visits by psychiatrists, anaesthetists etc. needed
- Fewer people are making complaints to NHS, Advocacy or Social Care complaints systems. Why is this?
- The lack of Speech and Language therapy is shocking and communication support is a real problem
- Supporters should be better at ensuring people understand their medication and treatment
- Training for staff about health support SHOULD be specific to the person/people they support
- Continuing Health Care does not work at the moment – people aren't easily able to access it and wait long periods of time for support while Local Authorities and Clinical Commissioning Groups make decisions
- The Mental Capacity Act is not well understood in hospitals and by some health colleagues. People's rights are not always upheld
- Where there are Learning Disability community teams (Integrated Delivery Teams / Neuro Developmental Pathway) (IDT – NDP) the support is good, however people report that this is patchy across the County
- People living in Assessment and Treatment Units are being supported to move on where they can
- There is a need to further develop community support options for people with learning disabilities experiencing mental ill health
- People need access to information and advocacy to make good decisions about their health
- People need support to manage medication and long term health conditions
- People with learning disabilities want support to make healthy food choices and

with keeping active
Recommended action:
a. Ensure people with learning disabilities are supported to access community opportunities for staying healthy and well
b. Learn from what's worked well and explore increasing the number of Liaison Nurses and consider their role in General Practice, Community Health as well as hospitals. Find ways to increase the skills and awareness of all staff to better support patients with learning disabilities.
c. Co-ordinate efforts to increase uptake of annual health checks for people with learning disabilities
d. Consider making use of support to develop a full local offer around Personal Health budgets that extends to people with learning disabilities
e. Review the screening appointment invitation process for people with learning disabilities to increase screening uptake
f. Working with local partners e.g. Advocacy services and providers, tackle health inequality in General Practices – communication, awareness, training co-delivered by self-advocates
g. Work to ensure the specific health needs of people with learning disabilities from black and minority ethnic groups are understood and met
h. Integrate Health and Social Work teams to ensure coordinated approaches to meeting health and care needs and equality of access to community support, with a full range of support available e.g. Learning Disability Nursing, Physiotherapy, Occupational Therapy, Speech and Language Therapy, Dentistry, Podiatry, Clinical Psychology, Positive Behaviour Support etc
i. Develop integrated teams embedded in community locations
j. Continue to jointly commission the new Norfolk and Suffolk Foundation Trust support service and co-location of Health and Social Care teams to deliver enhanced community based support to people with learning disabilities – reducing demand for assessment and treatment beds
k. Ensure parents to be with learning disabilities receive appropriate antenatal and postnatal support
l. Work towards people having named Care Coordinators to liaise across organisational boundaries
m. Adult and Community Services, Clinical Commissioning Groups and providers work together to ensure smooth processes for accessing Continuing Health Care. Join this up with Children and Young People's Health and Social Care Services so that families can plan better for adulthood
n. Work to implement the roll out of holistic Health Action Plans for all, including detail of the named person responsible for actioning and monitoring the plans
o. Implement Hospital Passports for people with additional communication support needs
p. Ensure written handovers when people move between support, health care and education providers

q. Ensure the robust implementation of the Mental Capacity Act, including appropriate training
r. Continue to develop a range of responsive community solutions for people who challenge and/or have periods of mental ill health
s. Continue to develop opportunities for people (young people and adults) to take up Personal Health Budgets
t. Ensure that Community Mental Health Teams and Acute Psychiatric Services are able to appropriately respond to the needs of people with learning disabilities. This includes access to crisis response and Home Treatment teams
u. Ensure people with learning disabilities are given the right tools and support to manage long-term health conditions, and so reduce health inequalities.



4. Choice and control over my life, my support, my money

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

What we heard:

- Advocacy and support to Speak Up is really important. More is needed
- People are struggling to shape their own lives as services have limited flexibility and people feel they have to 'fit into' groups.
- A number of people talked about not being 'allowed' to do something different so providers can keep hold of a persons funding
- We need to ensure people can choose where they live, whom they live with and who supports them
- It's essential to have better access to information to support people to make choices and understand what is possible
- People are confused about Personal Budgets and most people don't have one
- People don't understand the principles and application of the Mental Capacity Act
- Support should be more individualised. Listen to people!
- Support needs to be available for people to get help if they are struggling with managing their money
- People need to know how much money they have, to plan
- More information about money, benefits and Personal Budgets is needed. 'We don't know how it works!'
- People's individual support needs to be planned better so the right budget and support is secured
- The Independent Living Fund is coming to an end – what happens next?
- Most people with learning disabilities still rely fully on paid support and support that is commissioned for them
- Families and people feel that the Council doesn't trust them to manage Personal Budgets. Council staff sometimes reinforce this message
- Providers want to administer Individual Service Funds, but don't always feel ready

<ul style="list-style-type: none"> • Providers sometimes 'hold on' to people as a source of income or 'we know best, nobody else can support this person.' • Funding for equipment and assistive technology to develop and maintain independence must be secured
Recommended action:
a. Work to develop mechanisms, knowledge and skills to ensure Personal Budgets for all those eligible, maximising the use of Direct Payments and Individual Service Funds to give people choice and control. This will see Adult and Community Support commissioners move away from block tendering processes.
b. Enable people who are eligible for NHS Continuing Health Care to take up Personal Health Budgets when they choose to. This could be as a notional budget, a third party arrangement or a Direct Payment
c. Explore possible solutions and ways of developing capacity to ensure people have access to timely skilled assessments and reviews that lead to person centred, creative support plans being developed and implemented
d. Explore joining up the Direct Payment and Personal Budget approach with Children's Services so that young people get experience of it from the age of 16
e. Ensure access to information, advice and advocacy to people for assessments and reviews and to enable people to plan their support that is appropriate for the stage in their life
f. Ensure there is easy access to information, advice and advocacy in relation to Personal Budgets from the age of 14 along with support to manage employment and finance
g. Get young people involved in their support plans from the age of 14 so that they build up experience of being in control and having choice
h. Ensure providers and others to encourage people to develop networks, circles of support and use of community resources to enhance quality of life
i. Explore Local Area Coordination, Brokerage and Asset Based Community Development approaches and consider how such approaches could benefit people in Suffolk
j. Continue to introduce Individual Service Fund options to focus on true freedom, choice and control
k. Seek evidence that families are involved in the development of person centred support plans
l. Work with providers to demonstrate how they maximise choice and control for people they support
m. Support people to take positive risks and understand how to manage these
n. Ensure that people actively engage in the development of their support plan have a copy of their support plan in a format that they can understand
o. Providers to review policies and procedures to ensure these don't get in the way of people living ordinary lives

5. Good Support

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

What we heard:

- There needs to be support for people who are bullied at school and college
- Support should be like elastic, supporting yet stretching people to be brave and try new things.
- Someone listen to me!
- People are LONELY and poor support can cause this.
- Good support frees people.
- Flexible support that I can access as and when needed. This is about relationships with trusted people. So if someone is seen as a Tier 1 support they must be able to contact someone they know. Otherwise Tier 3 may be needed! Strangers aren't suitable.
- It should be about being asked what you want and getting help to find it. NOT...this is what you can have
- We get too much 'you can't'. This needs to turn into 'yes you can' whilst supporting me to understand my impact on others
- Staff training should be designed in response to the needs of the person supported, not just national minimum standards
- People are generally still not choosing their own support staff and this must change
- People and families don't always know what good looks like so they accept what they have. People need to know what is possible!
- Good support is about relationships. I get you, you get me and together we can figure out what is needed to support you to live a good ordinary life!
- There needs to be more positive approaches to risk
- We should celebrate support staff and the gift that is their job
- We want a place to access Personal Assistants who are credible
- Communication between agencies isn't good.
- Social workers don't respond when we need them to
- Where contracts are defined too closely there is a tendency for people to say 'it's not our job.'

<ul style="list-style-type: none"> • There needs to be strong, supportive monitoring of contracts and quality. There is disagreement about where responsibility lies and concern about how this is resourced • That families need support to continue to support and care for their family members and to keep them in the community • You have to be in crisis and then wait a very long time to see a social worker
Recommended action:
a. Develop ways to value and celebrate support staff
b. Consider creating a support workers network to share good practice, develop skills, reflect and drive innovation
c. Develop more flexible approaches to people receiving the right support, at the right time, from the right people
d. Consider the development of Community Circles to expand people's natural support networks and strengthen community presence
e. Ensure there is appropriate support to family carers to enable them to continue to provide care and support
f. Research and consider the development Personal Assistant banks, "Slivers of Time", Skills Swap Schemes etc. – employing/engaging people across a range of communities and age groups
g. Develop a joined up approach to monitoring quality and contracts – it is everyone's responsibility. This will ensure sound approaches in terms of holistic support and communication in relation to safeguarding
h. Strengthen approaches to safeguarding including Systems for recording safeguarding referrals, alerts and action plans. Whilst ensuring freedom to live a good life whilst the essential foundations of support are in place
i. Consider developing a strategic and innovative, partnership approach to work force development
j. Continue to develop a wider range of Short Break options to offer people and families choice
k. Explore solutions to ensure all providers work toward offering flexible support for people to stay up late and be free.
l. Review the length of grants and contracts to ensure they are of sufficient length for outcomes to be achieved and enhance providers business planning
m. Transform commissioning approaches to reduce competitive tendering and support collaborative working amongst providers
n. Enable people to develop and sustain interests and friendships. This includes positive approaches to risk and implementation of the Mental Capacity Act
o. Ensure all Support Plans identify people's interests and how these will be supported including culturally specific needs
p. Ensure people, families and supporters themselves, have a good understanding of the Mental Capacity Act

6. Family, friends, pets and relationships in my community

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

What we heard:

- People want increased opportunities for lifelong learning. Community courses, not always specialist 'Learning Disability' courses
- Accessible information about what is 'out there' in the community not just service land is needed
- Transport, or lack of transport, is a real problem for many
- Lack of Changing Places and toilet facilities limits people's access
- Members of the community are not always welcoming. This makes it hard for people
- There is a need to reduce reliance on 'specialist services' and funded care as a mechanism for support. 'Real life' options and not service land.
- Suffolk has a rich and diverse community in lots of areas and people really value the coastline
- The 'community' of people who care about people with learning disabilities is strong and supportive
- There are lots of community assets that many people don't know about
- People want more flexibility and choice to plan their social life. Not to just do what support staff control, or to be 'thrown together with people' you haven't chosen to be with
- People still find accessing mainstream opportunities difficult
- People want to connect with others who share their interests
- People supported often can't stay up late or go out in the evening and weekends due to organisational practice
- It's people and relationships that make a good life. A life not a service.
- Support to help people understand and develop the range of relationships that make a good life needs to improve
- There needs to be a more positive approach to risk. Life should have risks or it's dull. The rollercoaster of life becomes flat!
- We want to be supported in a way that helps us learn from our mistakes – not all

<p>relationships work out in the way we want</p> <ul style="list-style-type: none"> • Families input should be sought and valued by all • Pets are really important to many people and sometimes they are told that they can't have them • When people choose to, they must be supported to live close to friends and families not far away from them • People have very limited access to information and support about personal and sexual relationships. Need information and advice from supporters that is open, confident and non-judgmental • People are lonely, this creates vulnerability and dependency – this needs to stop
<p>Recommended action:</p>
<p>a. Ensure workforce development enables support staff to develop the skills and strategies to connect people with their communities. This includes positive approaches to risk</p>
<p>b. Work with communities to develop opportunities and to welcome people. Consider Local Area Coordination, Community Connectors and Brokers</p>
<p>c. Explore opportunities to further develop "Changing Places" facilities in local communities</p>
<p>d. Work to ensure contract renewals include the need for providers to evidence how they support people to develop their community networks and relationships</p>
<p>e. Re-invigorate community mapping and access to information, advice and advocacy re community resources. This should include locality directories and further developing the 'Infolink' and other websites</p>
<p>f. Work with transport providers to address barriers faced by people when using public transport</p>
<p>g. Continue to work with the Culture, Library, Sport and Communities team to enhance community opportunities for people with learning disabilities</p>
<p>h. Research and consider the implementation of community led commissioning and community led social work</p>
<p>i. Organisations, systems, structures including Clinical Commissioning Groups and Local Authorities to value and recognise the importance of human relationships in terms of continuity</p>
<p>j. Work alongside and support families, recognising that the support and love offered by family and friends enhances the quality of life and reduces dependency on services</p>
<p>k. Ensure that parents with learning disabilities have access to support in their role as parents</p>
<p>l. Ensure that families and friends are involved in the development of person centred Support Plans</p>
<p>m. Develop opportunities for community members to volunteer</p>
<p>n. Share resources and knowledge to enhance quality</p>

7. Work and purpose

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

What we heard:

- Many people have the desire to work but are struggling to secure employment
- There isn't enough good support to help people get work. A lot of courses but little progress to real jobs
- There is lack of regular, reliable transport e.g. public buses create a barrier to people gaining paid employment and/or voluntary work. The bus passes can't be used at particular times of day
- People need better access to apprenticeships – practical, job related experience and learning
- Young people need pathways to employment
- There is a lack of real job opportunity once you are ready for work. Need to get to know more employers to create opportunities
- General lack of innovative approaches to employment e.g. self-employment

Recommended actions:

- a. Develop innovative employment support e.g. social enterprise, self-employment, apprenticeships and internships
- b. Join with local mainstream developments to maximise opportunities for people to work (for example "MyGo")
- c. Continue to transform day opportunities, away from building based services for the majority, to people living full lives as members of their community
- d. Make use of Personal Budgets from the age of 16 to help people access work opportunities
- e. Develop schemes such as, Skill Swaps and "Slivers of Time", so the skills of people are valued as assets for the community even if no monetary payment is received
- f. Learn from approaches to employment and occupations in other countries e.g. Sweden
- g. Ensure Government employment support is maximised e.g. Access to Work and Job Centre Plus

8. Family centred support as I move into adulthood

During engagement and co-production we heard from people with learning disabilities, their families, providers, community organisations, Health and Adult and Community Services colleagues and other stakeholders.

Below is a summary of what people told us and recommended actions. Please note these are in no particular order and many need further exploration before decisions are made. It is important that this exploratory work and decisions about implementation are co-produced. The range of stakeholders involved in developing the Strategy now need to work together on all the recommended actions to co-produce a robust, five-year implementation plan.

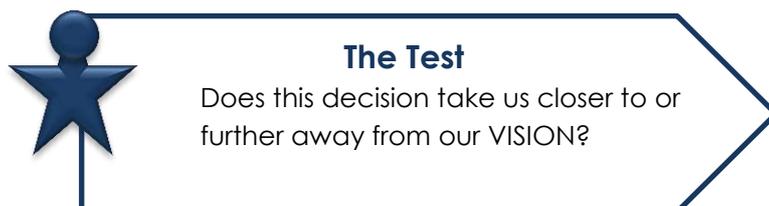
What we heard:

- Families of children and young people in mainstream school are concerned about the lack of inclusive cultures and consequently young people leave school isolated and without connections and are immediately reliant on paid support
- Training for all staff in mainstream schools is needed so they are not condescending to people with disabilities
- Staff in mainstream and specialist education provision need to have greater ability to understand the needs of children and young people in order to assess and provide appropriate support
- Young people in mainstream schools are not being included and face loneliness at school. This can increase once they leave school
- There is some good planning with young people and families but not available for all
- Suffolk Communication Aid Resource Centre aids for children are well funded but not followed or developed into adulthood
- Planning is failing people. People's choices are not heard
- Many people still feel like they are falling off a cliff at 18. This has to stop
- Step down support needs to improve to achieve potential through developing confidence and skills

Recommended actions:

- a. Embed the 'Transition to Adulthood – a lifespan approach' commissioning strategy, and hold all of the organisations involved in young people's lives to account for delivering it
- b. Understand and include the specific needs of young people with learning disabilities in all plans and strategies
- c. Implement Education Health and Care Plans to maximise opportunities for joined up and person-centred planning and action
- d. Ensure transition to adulthood planning starts from the age of 14 with Young People and Families, and is informed by clear information about adult health and social care services, plus community and work opportunities
- e. Providers and others consider linking with schools to explore with young people

and families what a good life can look like for people with a range of support needs
f. Ensure health, education and social care practitioners and clinicians respond to transition to adulthood plans with opportunities for young people to become more independent, confident and healthy throughout their lives
g. Ensure young people are supported to learn how to understand and look after their health as they move from the care of paediatric services to adult universal services
h. More robust, person centred and creative pathways to employment
i. Develop clear, engaging, accessible information about community, support, learning and employment possibilities for young people

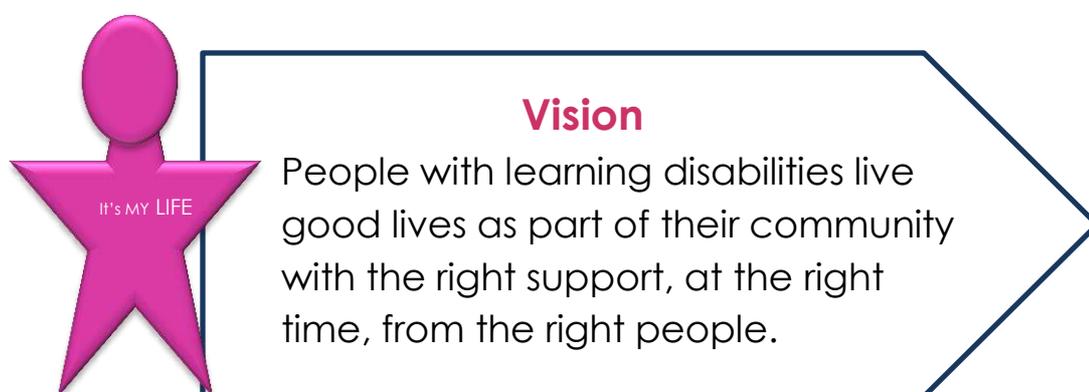


12. Moving forward

This Strategy represents the thoughts and aspirations of many people. Its creation is the first stage towards achieving a vision of good lives for people with learning disabilities in Suffolk.

However, it is the action that must follow now is that will bring the Strategy to life. To sustain energy, commitment, ownership and momentum, the Headline Actions need to be reviewed, decided and acted upon.

The most pressing of these are agreeing the governance structures, the establishment of programme leads and the co-produced development of the implementation plan.



Appendix One

- **The Care Act 2014**

The Care Act 2014 represents the most significant legislation in adult social care in over 60 years, and aims to develop a clearer, more person centred and fairer system. It brings together law that has grown incrementally over the years into a single statute and makes important changes to the way the care and support system works to promote people's wellbeing, prevent and postpone needs for care and support, and put people in control. This includes putting carers on the same legislative footing as those they care for. Thirdly it introduces funding reform, legislating for a cap on care costs to limit what people would pay for their care over their lifetime.

- **Winterbourne View / Transforming Care Joint Improvement Programme**

The Winterbourne View Joint Improvement Programme has been refreshed and is working in local areas to provide swift and lasting action across the system to ensure that the services that are commissioned throughout people's lives are personalised, safe and local. The Local Government's Association and NHS England's joint improvement programme will provide leadership and support to transform services locally, building on current good practice. National partners have committed to a programme of change to transform health and care services and improve the quality of the care offered to children, young people and adults with learning disabilities or autism who have mental health conditions or behaviour that challenges to ensure better care outcomes for them.

This should result both in a movement away from the use of long stay, large-scale hospital services and also lead to real change in the attitudes and culture.

- **Driving Up Quality Code**

The Driving Up Quality Alliance has developed a code for providers and commissioners to sign up to, to demonstrate their commitment to driving up quality in services for people with learning disabilities.

The code has a particular focus on people with challenging behaviour who have longstanding and complex support needs but can be applied to all people with learning disabilities, including those who have autism.

It outlines what good support looks like and provides examples of good and bad practice.

- **Quality of Life Standards**

The Quality of Life standards have been written by over 650 young people and adults with learning disabilities and autism alongside their peers with disabilities. The standards, cover all areas of a person's life from where they live, to where they work and how they are an equal member of the community, are intended to raise the aspirations of people with

learning disabilities and their families from around the country so they can both speak out and take action when people with learning disabilities are not being supported to live as equal citizens.

Locally the standards are being used by commissioners in a range of ways: they have embedded them into social care provider contracts so standards set by local disabled people have become a contractual obligation; they have used them to shape care planning so the person with the disability is at the centre of the planning process and in control of the major decisions which affect their lives.

- **No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions (Green Paper March 2015)**

No voice unheard, no right ignored: a consultation for people with learning disabilities, autism and mental health conditions states that all people with disabilities, mental or physical, should have access to the same life and career opportunities as anyone else.

The consultation, which closed on 29th May 2015, set out some pertinent questions around how services can be strengthened to see a person's potential – not just be limited to a narrow focus on conditions. The proposed measures set out place a clear emphasis on personal independence, choice and community provision.

In summary, the Department of Health (DH) is consulting on:

- Putting people in charge of their life, supported by family and friends - not treating them as passive recipients of decisions about their care. The consultation proposes a named professional in charge of sharing information with individuals, families or carers, including their right to challenge care decisions.
- Strengthening the challenges in the system to people being sent to hospital - making it much harder to admit people to institutions by default and offering better support in the community.
- Helping people live independently and be part of their communities. The consultation asks for views on a specific duty for local authorities and clinical commissioning groups to think about how to ensure there is enough community based support and treatment services.
- Making sure people receive the right care in the right place by putting their needs at the heart of the decision making process.
- Giving very clear accountability and responsibility throughout the system so there can be no excuse for people falling through the gaps between services.
- Whether there should be changes to the Mental Health Act in the way it applies to people with learning disabilities and autism.

To help drive this change, the consultation also proposes a model of shared funding to help posit an expansion of the right to personal health budgets for more people with learning disabilities or autism.

- **Think Local Act Personal**

Are a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support.

The partnership spans

- central and local government,
- the NHS,
- the provider sector,
- people with care and support needs, carers and family members with whom we engage via the National Co-production Advisory Group.

The work of the partnership is coordinated by a small core team with programme leads responsible for pooling resources from different partnership members. This arrangement puts us in the unique position of bringing together people who use services and carers with national organisations.

The TLAP partnership is open to any national organisation not represented through one of the umbrella associations already involved that is willing and able to make a specific commitment of support.

Personalisation is fundamentally about better lives, not services. It means working with people, carers and families to deliver better outcomes for all. It is not simply about changing systems and processes or individualising funding through personal budgets and direct payments, but includes all the changes needed to ensure people have greater independence and enhanced wellbeing within stronger, more resilient communities. That includes all the work done in the work streams set out below.

They work on:

- Advice, information and brokerage
- Self-directed support and personal budgets
- Workforce development
- Integrated Care
- Quality
- Making it Real
- Building Community Capacity
- Co-production

The Making it Real 'I' Statements are useful outcome measures.

- **Children and Families Act**

Section 19 of the Act sets out the general principles that local authorities must have regard to when supporting disabled children and young people and those with SEN under Part 3 of the Act. Local authorities must pay particular attention to:

- the views, wishes and feelings of children and their parents, and young people;

- the importance of them participating as fully as possible in decision-making and providing the information and support to enable them to do so; and
- supporting children and young people's development and helping them to achieve the best possible educational and other outcomes.

Importantly Education Health and Care assessments and plans replace statutory assessments and statements of special educational need.

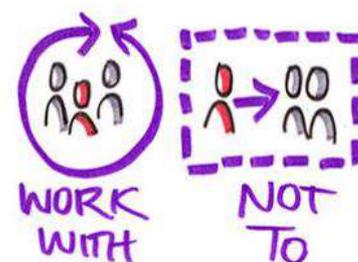
Section 25 of the Act places a duty on local authorities to promote integration between educational and training provision, health care provision and social care provision.

- **The forward view into action: Planning for 2015/16 - NHS England December 2014**
- **Individual Service Funds (ISFs) and Contracting for Flexible Support Practice guidance to support implementation of the Care Act 2014 – Think Local Act Personal, June 2015**
- **CCG Bulletin: Issue 85 – NHS England**
- **Moving forward with personal health budgets: a CCG development programme – NHS England 26th May 2015**

Appendix Two

Definition of co-production for Suffolk

Co-production is people, carers and professionals working together as equal partners to: design, develop, commission, deliver and review services, information and advice. This will often be facilitated by voluntary and community sector organisations who will link commissioners with people.



Co-production is central to achieving the objectives of personalising services and increasing choice and control for users and carers.

Principles:

- Co-production puts the focus on getting results (outcomes) rather than just thinking about services and how we do things.
- This means that people and organisations work together on the issues that are important to people.
- There is a difference in what is important **to** people and what may be important **for** people.
- People are involved **throughout** the process – from beginning to end.
- People feel safe to speak up and are **listened** to.
- It's **clear** how decisions are made.
- People's skills and experiences are **used** in the process of change.
- Meetings, materials and venues are **easily** understood and are **appropriate** for people's needs and abilities. (accessible)
- Progress is evaluated through looking at the **actual** changes in people's lives.
- Different people who are interested in the work (stakeholders) are **actively** involved, not just one set of voices or experiences.
- These interested people (stakeholders) work **together** as equal partners on a shared goal, task or vision, including a shared understanding of what success looks like.

Questions people may ask themselves which show what is important to them:

- What do people like about me?
- What is important to me now?
- What is important to me in the future?
- How do I want people to support me?
- How do I communicate and how do people communicate with me?
- People are involved **throughout** the process – from beginning to end.
- People feel safe to speak up and are **listened** to.
- It's **clear** how decisions are made

(Definition & Principles of Co-production in Suffolk – 01 June 2015. The definition was developed by people in Suffolk, acknowledging resources of SCIE and NDTi for the Principles.)



Appendix Three

The following documents and resources are a brief snapshot providing evidence and rationale for the approach taken in the Strategy, specifically Supporting Lives, Connecting Communities, Health and Social Care Integration and Co-production. It is not a comprehensive literature review.

- **Care Act** (2014)
- **Use of Resources in Adult Social Care** - A guide for local authorities. John Bolton, Department of Health (2009)
- **Individual Service Funds (ISFs) and Contracting for Flexible Support** Think Local Act Personal (TLAP June 14)
- **Moving forward with Personal Health Budgets** (a CCG development programme) (May 2014)
- **The Challenge of Co-Production: How equal partnerships between professionals and the public are crucial to improving public services.** David Boyle and Michael Harris. NEF and NESTA (2009)
- **Getting Value for Money from Procurement** *National Audit Office and Office of Government Commerce (2013)*
- **Oversight of special education for young people aged 16–25** National Audit Office for Department for Education (2011)
- **Benefits realisation: assessing the evidence for the cost benefit and cost effectiveness of integrated health and social care.** Turning Point (2010)
- **A Problem Shared: Making best use of resources in adult social care** (TLAP 2007/8)
- **What is the evidence on the economic impacts of integrated care?** Ellen Nolte, Emma Pitchforth. The King's Fund, 14 October 2014

