

Meaningful Lives Matter

Our plan for a more inclusive Essex





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Foreword by Councillor John Spence

As someone who has been blind for over 30 years, I know at first hand how others can – quite understandably – focus on what disabled people cannot do, rather than what we can.

From their earliest days, disabled children may experience protective parents concerned for their welfare. They may experience challenges in understanding how best their challenges can be met, whether in school or in their voluntary activities. Moving on to higher education and the workplace can be quite a challenge.

Yet my overall experience, when thinking of all those whom I have met, and with whom I have worked and played, is that those who are disabled want to live in exactly the same way as all those around them. They want to enjoy quality of life and, where possible, live independently of others; to progress in their chosen workplace and leisure activities; to have people offer respect because of what they do, rather than sympathy or sadness.

At the heart of the County's disability strategy is this ambition. Our vision is for people with disabilities to live the best lives they can. In this strategy document, Essex County Council sets out how we will work with individuals to achieve a series of goals. We understand that this strategy needs to be the platform on which world-class plans are achieved and delivered. We need to work constantly to ensure full integration both with other County Council pieces of work, such as the carers strategy; and with all the plans being delivered through other strategic and voluntary organisations at national, county and district levels.





Introduction

People with disabilities have the right to the best life they can have. But right now they often get left out of things.

The things that are important to us, and make all our lives meaningful, do not always happen for people with disabilities. We believe that people are disabled by barriers - things in the world around them that stop them from living a normal life - instead of by their health problem or how they are different from other people. We want to remove barriers so that people can live better lives.

We are already helping lots of people in Essex to live the best life they can. We need to make sure this is the case for every person. We want to help people get what they want and expect from their lives. To do this, we will support people by understanding who they are as a person and what they might need across the whole of their life.

The number of people who have a disability and who might need help from social care is going up. We need to use our money carefully to make sure we have enough to help people in the future.

66 This plan will set out the change we want to bring about. It will make a commitment to people in Essex who have a disability. It will show where we can work better together with others. **99**

The <u>Meaningful Lives Matter</u>¹ work is already helping to make life better for people with learning disabilities and autism in Essex. Now we want it to help make life better for people with sight and hearing loss and physical disabilities too.

What is this strategy about?

This strategy will help us plan what needs to change.

It will include:

- how things are being done now
- how people feel about things now
- what we need to do in the future to make things better

This strategy is for people in Essex who have:

- a learning disability
- a physical disability including people with brain injury
- a sensory impairment part or full loss of eyesight and/ or hearing.

This includes 'invisible' disabilities that are not easy for others to see.

The strategy covers people who have more than one disability. It covers people who have autism as well as one of these disabilities or who consider their autism itself to be a disability. The strategy does not cover everyone who has autism or neurodivergence, as these do not always mean a person has a disability. People with autism might also be interested in our <u>All-age autism</u> <u>strategy</u>², which was developed through the Essex All Age Autism Partnership. People with mental ill health might be interested in the Mental Health Strategy, which will be published later this year.

We recognise that language is important when talking about disability and autism. Different people prefer different terms. For example, some people use the terms 'autistic people' and 'disabled people', 'neurodiverse, autistic or disabled community', 'people with autism' and 'people with disabilities', or others. In this document, we will be using the terms 'people with autism' and 'people with disabilities'.

Some people have support from social care. Other people are not in contact with social care.

We are looking at the things that help people in life. This will include:

- where people live
- who they spend time with
- what they do for work or in their free time
- health services
- social care services

To write this strategy we have spoken with lots of people with disabilities and listened to their experiences and ideas. We have spoken with families and carers. We have spoken with other organisations.

We learnt that for a good strategy:

- we need to keep talking and working with people
- we need to be creative and bold
- we need to measure whether we are making things better and how much.

The We but

The strategy is for the next 4 years. We cannot do everything in 4 years, but we can make a good start.

How does this strategy link to other strategies?

The Disability Strategy will work towards the **Everyone's Essex plan: our plan for levelling up the county**³.

The plan has four areas of focus: the economy; the environment; children and families; and promoting health, care and wellbeing for everyone who needs support – this last one is a very important part of the strategy.

Our plan for levelling up has a focus on children and adults with learning disabilities. We know that these groups, along with some others, need extra help to access opportunities.

This strategy will work together with other things we have to do and choose to do:

- Equality Act 2010⁴
- <u>Accessible Information Standard 2016</u>⁵
- <u>The Care Act 2014</u>⁶

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- Levelling Up Essex 2022⁷
- Essex Mental Health Strategy
- Essex SEND Strategy 2022-2027⁸
- Essex All-age autism strategy 2020-2025⁹
- Essex Carers Strategy 2022¹⁰
- Essex Ageing Well approach
- Essex Joint Health and Wellbeing Strategy 2022-2026¹¹
- Essex County Council Housing Strategy 2021-2025¹²



Why is this strategy important?

There are more people with disabilities living in Essex every year. About 1 in every 6 people in Essex has a long-term health problem or disability.

There are also more people with disabilities who need help every year. This is partly because some people did not get the help they needed during the pandemic. Other people feel more alone and are less independent since the pandemic.



The number of people with sensory impairment is set to grow from **340,000** (in 2020) to **410,000** (in 2030).¹³



The number of people with learning disabilities who need help from social care will likely go up by **8% by 2030**. Some people get help from social care. Some people get help from other places. We want to make sure everyone gets the help they need. Where we can, we also want to stop people's needs getting worse.

Lots of people with a learning disability tell us that they have enough social contact. Many also say that they can spend time on things they enjoy. But this is not true for everyone.



Over 30% of people with physical or sensory needs tell us they do not have enough **social contact**.



Over 40% of people with physical or sensory needs say they **cannot do the things they want to do**.

It is getting harder to pay for all the things we would like to. It is not clear how much money we will have in the future or what it will need to cover. Because of this we need to spend money carefully.

Adult Social Care in Essex

In Adult Social Care we want to help people and communities to live the best lives they can.

This strategy will help us work towards the things we want to make happen for people. We want people to:

- have friends and have people around them that they love
- be independent and feel good about themselves
- have choice and control over their lives
- be able to work if they choose to
- access meaningful activity
- get the same good health and care service as everyone else
- have a comfortable home
- be involved in their local community
- be safe.



This strategy will also be guided by how we work in Adult Social Care:

- We work together with many different organisations
- We make sure our care and support is right for each individual person
- We do everything we can to support people as close to where they live as we can.
- We are always trying to improve what we do
- We work with you to decide what is needed and what works best.
- We always try to deal with problems as soon as we can, before things get worse.





There are some extra things that are important for people with disabilities:

- Individuals should feel their disability is fully understood by the people around them,
- Support should change when needs change.

Section 2

We have talked with lots of people with disabilities.



We have learned that:



people want to have good relationships.



people want to live somewhere that **feels like home**.



people want to stay healthy, well and safe.



people want to do things that are **important to them and their community** and that help them to feel part of something. This might include working in a job or learning new things.

We will look at each of these things in more detail. There are links that go between each of them and some ideas that keep coming up in all of them.

For example, people want to:

- / make choices
- get the care and support they need when they need it
- be seen as they are and for what they can do as well as what they cannot
- / be treated with respect



What you told us

You told us that you want to grow and keep good relationships in your life.

Many people said they like to spend time with people that they get on well with. People want to love and be loved and have people around them who understand them and their disability too. Sometimes you also need help from other people. You might get help from your family or friends, or from a person whose job it is to help you.

Some people feel left out from the normal things that others do together. You might find it hard to access local places or not know about groups you could join. Some of you do not feel safe going out alone or lack confidence. Because of this you might feel lonely or have difficulties with your health and wellbeing. The COVID-19 pandemic has made this worse for lots of you.

66 It's really hard to meet up with other people like you. So that makes you feel very isolated and alone. I don't know if there is any groups for disabled people in my local area. And I wouldn't have a clue where to find that information either... **99** **5** I tend to find myself either decline invitations or [say] yeah, yeah, I'd really love to come and then cancel at the last minute, because it's just too much hassle and overwhelming. **99**

Some people only have a small group of people who are there for them. This means that the carers they need help from have to work very hard.

Carers and support workers do not always understand disabilities. This might mean people do not get support the way they need it. Other people you meet often do not understand disabilities, especially disabilities that are harder to see. Some of you feel judged by others because of this.

• People see me in that snapshot in a shop... they think 'what's wrong with her'?...but they don't know I've had to go and lie down for like the rest of the day. **99**



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What else do we know?

People with disabilities are more likely to feel lonely than other people. Over 30% of people with physical or sensory needs told us they did not have enough social contact. Lots of people in society do not understand how certain health problems or disabilities affect people. Some people do not have the right help to be able to communicate with others or to go out to places to meet people.

Lots of people who have help from social care have good conversations with their social worker. They are seen for who they are. But there are not enough social workers and people sometimes wait a long time to see one. Social workers are busy and can be rushed. They spend less time face-to-face with people than they used to. This sometimes means they do not have time to help people plan for the future.

We found out lots about what carers need when we spoke with them. This can be seen in the **Carers Strategy**¹⁴.

Over 30%

of people with physical or sensory needs told us they did not have enough social contact.

Where do we need to focus?

We will make sure that in the future:

- more people have the chance to love others and be loved
- people feel more a part of their local community
- people feel closer to other people who like the same things they do
- people feel better understood by those around them.

Some people need help to go out, make connections and to see friends. We want to make it easy for people to find and get the help they need to keep up or make new relationships.

We are making changes to how people who work in social care help people. They will:

- understand that everyone deserves to have loving relationships
- help people to stay close to their friends and family
- help people make new friends if they want to
- understand every single person is different. This includes understanding different disabilities and understanding trauma
- help people with their communication.

To do this, we will look at how we find the right staff within our services and the services we pay for. We will support staff to have the right skills and to have the time to meet with people face-to-face. We will support all staff to think about the good relationships we need and how we help people find and keep these relationships at different times in our lives. This includes for young people as they come into adulthood.

We will also work with communities. Communities are found in local places like the village or town where you live or where people who enjoy the same things come together. They might include groups of people who meet up to talk about a shared interest or do activities they enjoy together. We will help communities to learn more about disabilities. We will ask them to welcome and include people with disabilities. We want community spaces to be easy to access and feel safe.

66 We need to listen to and work with people with disabilities more. This will help make sure change makes things better. 99



What you told us

You told us that where you live is important. You want to live in a safe place that feels like home. You need your home to work for you.

This means you can move around and do things within your home. It may also mean it is close to transport that you can access and places that you can go out to.

You want to have a choice in where you live. Some people want to live on their own. Most people want to live close to family and friends and feel part of their local area.

The right care and support is important to making your home work for you. Some people have to go a long way from their local area to find the right place to live with the right support. It can also take a long time to find the right place.

66 We've basically been in that position for the last four years, we've had about four different assessments done. And we're kind of still just stuck in a position where the living conditions aren't brilliant. **99**

What else do we know?

20% of people with physical or sensory needs tell us that their home does not meet all their needs. There are not enough of the right places to live for some people with complex needs. There are not enough care workers with the right skills in some areas.

In October 2022, 215 people with learning disabilities were living in out-of-county supported living or residential care. This is too many.

Some people could live more independently than they do now. People do not always have information on what is available.

Services are not always set up to help people to progress.



17% of people could live in a more independent setting.

Where do we need to focus?

We will make sure that in the future:

- more people have their own home if they want this. This might be a private home or in <u>Supported Living</u>¹⁵. This will help them to be more independent.
- more people have short-term help to learn independent living skills. This could be through living with a Shared Lives host. Or it could be another option, such as a short-term residential services.
- there will be suitable housing options for adults with very complex needs.

To do this we are making changes to how social workers and care staff help people. They will:

- work to help people to be more independent
- focus on what a person can do instead of what they cannot
- help people to make choices and plans.

We will also work with the care market to increase the choice of places to live within Essex. We want as many people as possible to have their own front door. We will help to make sure people have the information they need to find the right home for them.

The right technology and equipment can help people to live in their own home or access the community independently. It can also help to keep people safe and reassure families without being too intrusive. We will help to make sure there is enough of this and that it is easy to find.



Staying healthy, safe and well

What you told us

You told us that looking after your health is important. You would like to stay well and be able to get help quickly if you are unwell. You also want to feel safe.

You do not always have the right information to know about what could help you, especially early on in adult life. This makes it hard for you to keep yourself well. Sometimes there is a long wait for services. When you do use services, you may have to repeat the same information about yourself lots of times. You may find your preferred methods of communication are not recorded.

You would like to feel more in control of your health and care. Getting an illness or disability can change your life and be difficult to deal with. If you need help with your mental health, you need this to be from someone who understands your disability.

Some people find it hard to plan for the future. Many do not think about how their health might change over time or as they get older. Lots of people are worried about money. Having a disability can come with lots of extra costs. The benefits system can be complicated and stressful to use. Lots of people need extra help with this.

What else do we know?

Over 30% of people with disabilities say they do not feel as safe as they would like.

Disability can be a result of illness. Disability also makes poor health and mental illness more likely.

The number of health checks for people with learning disabilities has been increasing year on year and continues to do so. More people also have a Health Action Plan.

Yet many people with learning disabilities die earlier in life than other people. They are more likely to be unwell with physical or mental illness and not get the right treatment quickly enough. People with learning disabilities on average **die 15 – 20 years sooner** than other people.

Poor health and disability increase the need for social care. People often do not plan ahead for changes in their health.

More people feel alone or have had mental illness since the pandemic. The things that help them may have stopped or had delays. Lots of people are finding things hard because of the cost of living.

We know that services like health and social care are not always joined up. Services can be hard to access.



Where do we need to focus?

We will make sure that in the future:

- more people feel that their physical and mental health is good
- more people know how to feel even better
- people have the technology and equipment that helps them to live their lives
- people can get information and support to help them with their finances.

To do this we will work with partners like the NHS to:

- grow skills and awareness around disabilities
- help stop people getting unwell where we can
- diagnose people quickly and make sure their needs are known about
- help people recover their health or increase what they can do after an illness or injury
- make sure services help people with disabilities to be active and healthy
- give people control over their own health and care records
- help people to plan ahead for changes in health and finances

This will include sharing information, costs and staff to make sure services join up.

To do this, we will take action on things that make it more likely for people to get unwell. For example, where people do not have a job or enough money, or live in poor housing.

We will help people get the information and treatment they need to get well and stay well. This includes young people who are leaving school or college. All services should meet the <u>Accessible Information Standard</u>¹⁶.



What you told us

You told us that you like to do things that are important to you and your community. You want to feel part of something.

Some of you would like to have a job or keep and develop the jobs you have. Some of you want to learn new things or help other people. You want to play a role in the world around you, spend time with other people and have fun.

However, it can be difficult to find a job or information about what it is like to have a job, the support available and how having a job will impact benefits. There are also barriers in both applying for jobs and getting to work. You might feel limited in the types of jobs you can apply for.

6 But I'm at the point now where I would like to do something, but trying to get a job, with the conditions I've got and the fact that I'm probably not that reliable...its quite hard to get a job. **99**

Some people have low confidence in their skills and abilities. Lots of people feel that those around them have low expectations of them.

What else do we know?

People with disabilities are less likely to have a job than other people. If they have a job, they are less likely to be paid for the work that they do.

Lots of people do not understand how certain health problems or disabilities affect people. This can make it harder to work with a disability.



Where do we need to focus?

We will make sure that in the future:

- more people who want to work will be able to work
- people who already work feel supported in their job and able to progress
- people have choice and control over what they do every day.

To help more people with disabilities start and stay in a job, we will:

- make sure this is part of conversations with social workers and support workers
- include a person's family in conversations about getting and keeping a job
- focus on what people can do instead of what they cannot do.
- talk to businesses about why they should give more paid jobs to people with disabilities, and help them to do this
- help people to access transport to get to work.

We help young people to get ready for their adult lives. An important part of this for lots of young people is getting ready to get a job and go to work.

For people who cannot work right now, we will help them to do other things that are important to them. They might like to go out in their community or visit new places, volunteer or learn a new skill or hobby.





How we will make it happen

We recognise that everyone with a disability has different lives, strengths and ambitions.

We will need to do different things for different people to meet our ambitions.



The Meaningful Lives Matter project is working towards the four goals in this strategy in the following ways:



For good relationships

Local Linked Support teams are helping people with learning disabilities and/ or autism to build relationships with others. We would like to expand this kind of support to people with a physical or sensory need. Our "Bfriends" peer support and mentoring service is being piloted. If that goes well, we could expand this across Essex.



For a place to feel home

We have "Move On Workers" to help adults move to the most suitable home for them. We are looking at developing purpose-built accommodation for people with brain injuries.



For staying healthy, safe and well

We are working with health services to make it easier for people to use services. We want to make sure staff understand, and are well trained to look after people as they get older. We are making changes to the Essex Sensory Service. This is so it will have better advice and guidance and shorter waiting times.



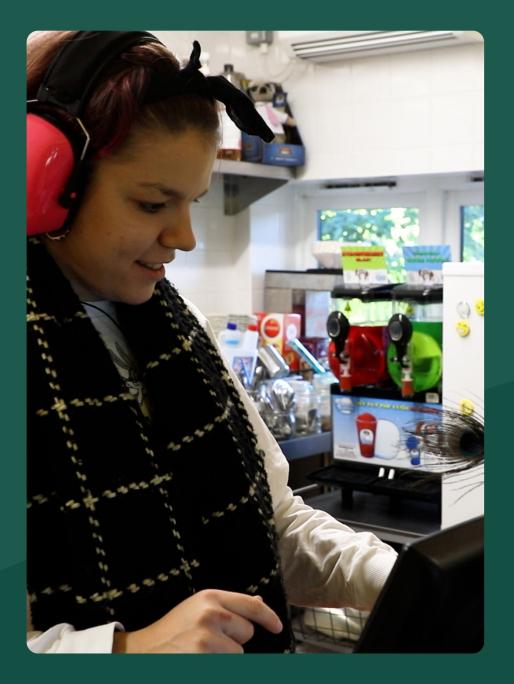
For being active

We are working hard to help people get and stay in paid work. We work with local businesses to get them to give paid jobs to people with a learning disability and/or autism. We have one of the biggest inclusive employment services in the country. We are looking at how this service can grow even more. We want to work with care providers to make sure activities help people to learn new skills. We also want activities to connect people to their communities.



Between April – September 2022 an average of 23 people a month

were supported into inclusive employment.



We will continue to empower people with disabilities and their carers and families to work with us as partners in making sure people get the care and support they need.

We will continue to make these planned changes but also:

- think about the order in which things need to happen and what is most important
- continue to empower people with disabilities and their carers and families to work with us as partners in making sure people get the care and support they need
- keep people up to date on what is happening, using the Meaningful Lives Matter programme
- test new ideas before rolling them out
- spend money carefully and on the right things
- consider how our work can help protect and reduce harm to the environment

We will make sure that other work going on supports this strategy. This includes work around:

- social care practice and workforce
- the different services that are on offer. For example, helping to make more places suitable for people with disabilities to live.
- joining up health and care services. For example, asking health partners to look at how their plans can keep people healthy
- technology
- data and information





We will think about other ways we can make changes. This could include:

- teaching people to be more aware of disabilities and how to make sure services are easy to access
- working with a range of organisations like the police, job centres, leisure centres and teams that plan new places
- sharing information with people and communities

The Adult Leadership Team at ECC will oversee what needs to happen in Adult Social Care. This group has directors for different parts of Essex. It also has other senior people from ECC.

How we will know it has worked

We will look to talk with people with disabilities about how things are going in their lives. We will also look at data. We want to understand how things are changing. We want to make sure things get better over time.

We will aim to measure things like:

- the number of adults we have helped to move from a residential home to community care. We want this to go up.
- the number of adults who have received a learning disability health check and health action plan from their GP practice. We want this to go up.
- the % of adults who had all their needs met by Local Linked Support. We want this to go up.
- the % change in adults' 'happiness index' after using Local Linked Support. We want this to go up.
- the number of new Shared Lives placements. We want this to go up.
- the number of people living in residential care or supported living outside Essex. We want this to go down.
- the number of people with disabilities who have a paid job. We want this to go up.
- the % of people with disabilities who live in a care home. We want this to go down.

- the % of people who have help from social care who are moving towards their personal goals. We want this to go up.
- the % of people who have help from social care who have three or more 'good' relationships in their life. We want this to go up.

Where we can, we will look at how things are changing in different parts of Essex. We will also look at how things are changing for people of different race, gender, and sexual orientation. This is because we want things to get better for everyone. We want the change to be fair.

We want things to get **better for everyone**.

We want the change **to be fair**.



Section 4

The budget

Essex has £835m in the budget to spend over the next 3 years on services that support adults with a physical, sensory or learning disability and/ or autism.

There is also £45m to support young adults aged 18-25 within the Transitions service, and £15m for in-house services such as Shared Lives, Short Breaks respite care and Short-Term Enablement.

Within the context of financial constraints, increasing demand, pandemic recovery and closer working with health partners, adults with disabilities are a priority for Essex County Council.

A key part of this strategy will be delivering good outcomes efficiently within the financial resource available against rising demand.

Any investments needed to support the action plan to deliver the strategy will be subject to a separate decision.



Endnotes

- 1 https://www.facebook.com/MeaningfulLivesEssex
- 2 https://www.snapcharity.org/wp-content/uploads/2020/06/All-age-autism-strategy-EasyRead-2020-2025.pdf
- 3 https://www.essex.gov.uk/everyones-essex-our-plan-for-essex-2021-2025
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- 13 These sensory figures are from the NHS Hearing Loss Data Tool and RNIB Sight Loss Data Tool
- 14 https://assets.ctfassets.net/knkzaf64jx5x/6k7lTuiQFl8oo4oDCO8uQQ/6b3f4e0deebee1055db863c460be77a0/ Essex-All-Age-Carers-Strategy-2022-2026.pdf
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Contact us: DisabilityStrategy@essex.gov.uk

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