

Living My Best Life

**A Life Course Strategy for People with a
Learning Disability in Stoke-on-Trent
2021 - 2026**



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FOREWORD

On behalf of the Learning Disabilities Partnership Board in Stoke-on-Trent, we are proud to present our “Living my best life” strategy.

We have developed this strategy during a particularly challenging period in the history of Stoke-on-Trent with the Covid-19 pandemic and subsequent lock down. We are pleased we have been able to adopt an approach based on co-production during this time, listening to children, young people and adults with a learning disability, parents, carers and other stakeholders such as care providers and health, education and social care staff.

This knowledge and insight will enable us to improve outcomes and support for children, young people and adults with learning disabilities with a focus on dignity, choice and respect across the life course.

Acknowledgements

We want to say a big “thank you” to those who were able to help us shape this strategy. In particular the parents, carers, children, young people and adults living with learning disabilities who created some brilliant pieces of art and poetry to show how you want to live your best life. We look forward to continuing this work with you as we move forward.



Margaret Mason,
Co-chair
Stoke-on-Trent Learning Disabilities Partnership



Councillor Ally Simcock,
Co-chair
Stoke-on-Trent Learning Disabilities Partnership

STOKE-ON-TRENT HEALTH & WELLBEING PRIORITIES

The Health and Wellbeing Plan 2020-2024 identifies the key priorities and outcomes for the city. This strategy contributes to the themes and priorities below.

Themes	Priorities
Start well	Getting the most healthy start in life
	Developing well into adulthood
Live well	Promoting good physical health
	Promoting good mental health
	Supporting people to maintain independence
Age well	Living well into old age
	Providing the best end of life care
Healthy city	Building strong communities
	Living in a healthy home and environment
	Supporting sustainable employment, skills and local economy



EXECUTIVE SUMMARY

Introduction

Welcome to our Life Course Strategy for People with a Learning Disability in Stoke-on-Trent.

We have developed this strategy during the Covid-19 pandemic and we are pleased we have been able to adopt an approach based on co-production during this challenging time, listening to children, young people and adults with a learning disability (LD), parents, carers and other stakeholders such as care providers and health, education and social care staff.

We believe all people in Stoke-on-Trent should be able to reach their full potential, living as independent a life as possible within the community in which they live. This strategy aims to ensure that children, young people, adults and older people with a LD experience equal rights and have the same opportunities as those who do not have a LD.

We have developed a Vision that summarises through a person-centred lens, what we are trying to achieve:

I am my own individual. I want to be safe, healthy, independent and happy and have opportunities that are enjoyable and fulfilling, having choice and control, help or support where needed to be able to live my best life which is purposeful and meaningful to me, throughout my life.

Outcomes and ambition

This strategy focuses on the five outcomes that children, young people and adults with LD, their carers and their families told us were important in supporting them to live their best lives. We have structured the strategy against each of the five outcomes, exploring what this means across the life course.

For each outcome we:

- **Identify** current issues through data analysis and engagement feedback
- **Celebrate** what we are doing well and can be proud of
- **Acknowledge** what needs to change
- **Describe** what change looks like
- **Develop** measures that will evidence outcomes are being achieved and change is happening

The Five outcomes

				
I feel safe	I am healthy	I achieve my goals	I love where I live	I enjoy my life
I feel safe within, and valued by, the community in which I live and the environments I am in.	I have equal opportunities to good health and wellbeing	I am aspirational in my life goals which are purposeful and valued	I live in a home that I choose, with who I choose, that meets my needs.	I have equal opportunities to a good quality life, to feel included in my community and enjoy my life.

I feel safe

Social contacts and access to community life are important to people living with LD and people want to feel safe and welcomed within their community and the environments they find themselves in. Our ambition is to ensure people with LD remain living safely within their community for as long as they want to, this extends to physically safe streets, good quality housing and public transport.

Children and young people were often keen to explore and get out and about, and parents want to ensure they are safe to do so.

Keeping people with LD safe in their homes and communities requires a joined-up response from key agencies such as schools, police, criminal justice and the city council as well as support from local communities. This will help people with LD feel and stay safe where they live and when travelling around the city.

I am healthy

People with LD currently have poorer physical and mental health, with life expectancy lower than the general population. Health inequalities for people with LD also extend into palliative and end of life care and have been further highlighted during the Covid-19 pandemic.

Annual Health Checks and screening can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish trust and continuity care. Some people with LD find hospital appointments and screening daunting or scary with some families reporting individuals being anxious, which sometimes led to failed or cancelled appointments and deterred the individuals from future screening.

People with LD told us mental health is very important and that their needs cannot be “pigeon-holed” as single issues, i.e. mental health or LD and should instead be seen as intrinsically linked and requiring a multi-dimensional response.

I achieve my goals

Children and young people with LD told us that inclusion in school life and education achievement is very important to them. They are aspirational for their life ambitions and want to have a job and the independence that this brings.

Adults with LD told us that whilst they aspired in their childhood, they did not always feel they had the same chances as everyone else as they grew into adulthood. Too few adults with LD find meaningful employment in our city and there is an over reliance on staying in continued education provision.

People with LD want to choose if they work and want the right support to help them find and keep meaningful jobs and not be judged if they do not work.

I love my home

Parents worry about where their child will live as an adult .They want to encourage independence and choice whilst recognising and managing risk taking. Older carers worry about where their loved one is going to live in the longer term.

Adults with LD felt they had a choice over where they lived and felt safe and supported by care staff, family and friends. They want to be able to watch their favourite football team and go to the local pub.

For people with the most complex needs, we will continue to improve access to care in the community, so that more people can live in or near to their own homes and families.

I enjoy my life

People with LD want to live happy and fulfilled lives, within a family and community setting as much as possible. Often, people come to the attention of social care when the individual or the carer is at crisis point for a range of reasons. Sometimes all that is needed is short term support and small changes. At other times, significant change may be required to return a sense of enjoyment in life.

Children and young people told us they enjoy activities such as scouts and feel that key milestone events in their lives such as school proms are important. Parents want their children to have more opportunities to socialise and mix with others.

Cross Cutting Themes

We found there were two recurring themes when co-producing the strategy.



Integrated approaches and workforce development

It is difficult to determine how many people with LD will need care and support, personal circumstances will have a bearing on specific requirements. Person-centred, joined up approaches across multiple organisations will contribute to enabling people to live the life they choose.

We want individuals living with LD to be supported by a workforce that employs their own skills and knowledge and uses their own personal abilities to further the health and wellbeing of a person with care and support needs, using an assessment as a meaningful intervention not as a gateway for services. We need to invest in training & awareness programmes for professionals and carers as part of continuous development.

Parents and Carers

Carers are critical to the health and wellbeing of individuals with LD and we need to consider parents/carers in the same way as the paid workforce in providing support, training, information and a break from their caring role and involving them in the care of the person with LD.

There are a number of carers with their own health issues and support needs and as such, a family based approach to support would be more beneficial.

Supporting those with learning disabilities who are parents or carers

The exact number of parents and carers with learning disabilities living in Stoke-on-Trent is not known . There is also a wider group of parents/carers who do not have a formal diagnosis but are considered to have learning difficulties, as a result of which they may struggle with some aspects of parenting. People with LD may also be caring for their parents and siblings informally as part of family life.

How will we achieve this strategy?

Our approach will be based on what children, young people and adults with LD are saying is happening to them and how this makes them feel and act. Keeping people with LD safe, healthy and happy in their homes and communities requires a multi-agency approach that will ensure a whole system, joined up approach that enables a combined response across health, social care, housing, employment, justice and beyond.

We need to take a holistic approach to supporting families, recognising the role and responsibilities of each person in the family and where there may be support needs for carers.

We will make sure that our strategy links in with other council and health plans across Stoke-on-Trent and we will report to the Health and Wellbeing Board on our progress.

Leadership will be provided by the Learning Disabilities Partnership Board and the Inclusion Partnership Board. Each outcome will have a lead and co-chair (someone with LD). We can't make all the changes needed all at once, but by co-producing delivery plans for each outcome and cross cutting themes, we will be accountable about what we will do, who will do it and when.



How we will make a difference

Safe

- support people to speak up about hate and hate crime
- check that communities are accessible and welcoming
- expand Safer Places from the age 14 onwards
- build strong links to community teams
- make sure that people are safe from abuse at home

Healthy

- support people to speak up about health
- support people to eat well, live well, age well
- provide support with physical and mental health
- help more people to have personal health budgets

Achieve

- support people to speak up about ambitions and plans
- develop work experiences for young people
- develop career opportunities for young people
- develop partnerships with employers and education
- support people to be financially independent

Live

- support people to speak up about life choices
- support young people to become independent adults
- support carers when and for as long as they need it
- develop more choices for places to call home
- explore opportunities for home ownership

Enjoy

- support people to speak up about what they enjoy
- review activities and short breaks across the life course to ensure they are fun, interesting and help develop new skills and make connections
- support people to have more opportunities to make friends and have places to go
- improve digital connectivity across the life course
- increase prevention work (low level housing, employment, health advice etc.)

Living my b

I am my own individual
have opportunities
help or support u
purposeful an

Community First



I am h
and h
to loo
my we



I feel safe
and people in my
community care
about me

Commissioners aim to move to a system
Commissioners will improve commission
innovative solutions to care that focus n

Best life in Stoke-on-Trent 2021 - 2026

Individual. I want to be safe, healthy, independent and happy and
that are enjoyable and Fulfilling, having choice and control,
where needed to be able to live my best life which is
and meaningful to me, throughout my life.



that is focused on improving the outcomes that matter to people living with a learning disability.
Planning and market development to ensure good quality, cost efficient services that work together and find more
more on preventative services and self management

INTRODUCTION

We believe all people in Stoke-on-Trent should be able to reach their full potential, living as independent a life as possible within the community in which they live. This strategy aims to ensure that children, young people, adults and older people with a learning disability (LD) experience equal rights and have the same opportunities as those who do not have a LD. This means living the life they choose, having their voices heard, being valued and treated with respect and seeing the barriers created by society removed.

We have worked closely with partners and stakeholders, including people with a LD, their families, carers, advocates, health and social care professionals, education services and the wider community to co-produce this strategy. We have based our strategy on a person-centred, strengths-based approach, with a focus on the outcomes that people living with LD told us were important to them and they have shared their stories to illustrate what it is like to live in Stoke-on-Trent.

The strategy is the high-level strategic document that sets out our vision and intentions for improving life in Stoke-on-Trent over the next five years, from 2021 to 2026. It links to the Inclusion Partnership Strategy as we take a whole life approach; from childhood into adolescence, adulthood and older age. Our focus is in line with the Children and Families Act 2014, Care Act 2014 and the Health and Social Care Act 2012 in:

- Supporting young people in preparing for adulthood
- Creating better physical and mental health and social care outcomes for people living more actively in their local communities
- Generating greater satisfaction for people using services and their carers

This strategy is an exciting plan for us and must lead to real change. It will inform delivery plans and commissioning intentions (where applicable) so that the outcomes are achieved. For our strategy to be a success, we will continue with an approach of co-production which will ensure the work we do is integrated and supported across the city council, health, education, providers, third sector partners, individuals with LD and the communities in which they live.

This strategy links to and is informed by the following key strategies for Stoke-on-Trent:



The strategy is also guided and supported by wider national legislation and other local strategies and procedures¹.

WHO IS THE STRATEGY FOR ?

The strategy is for any child, young person, adult or older person who has a learning disability (LD).

LD is defined as:

“A reduced intellectual ability and difficulty with everyday activities; for example; household tasks, socialising or managing money, which affects someone for their whole life.”²

Some people with LD can also have physical and sensory impairments.

Children and young people with LD may also have special educational needs and disabilities (SEND). A child or young person may be classed as having SEND if they require more help to learn and develop than children and young people of the same age³. A new Inclusion Partnership Board is being developed to oversee the development and delivery of improvements for children and young people with SEND, this will include the development of an Inclusion Partnership Strategy for Stoke-on-Trent⁴.

It is estimated that around 4 in 10 autistic people have a LD⁵. We are developing a separate life course Autism Strategy⁶ that should be seen as a complement to this strategy.

This strategy adopts the social model as a way of understanding learning disability. This model is supported by disabled people and promotes a view that disability is not caused by an individual's health condition or impairment but by the way society treats people and creates barriers for them. The barriers tend to fall into three categories:

- **the environment** – including inaccessible buildings and services
- **people's attitudes** – stereotyping, discrimination and prejudice
- **organisations** – inflexible policies, practices and procedures

Removing these barriers creates equality and offers disabled people more independence, choice and control and encourages society to become more inclusive.

“

In real life a learning disability is when someone learns to do things slower. Someone may find it difficult to understand complicated words or to concentrate for a long time. But we can still do what other people can do. We are experts and can check how things are working. Co-production is important because we can teach you and you can learn from us. People are not a problem to be fixed, we are all part of the solution

Reach Parliament member

”

OUR PRINCIPLES

We have developed four key principles that will underpin the delivery of the strategy for Stoke-on-Trent:

Community First

- Living within the community where appropriate.
- Access to community activities and community life.
- Support services easily available when help is needed.



Equality

- Needs are understood and reasonable adjustments made
- Equal opportunities e.g. access to health services, learning, employment, housing, social and leisure activities
- Equality and Diversity is respected and valued.



Strengths based



- Focus on what people can do, not what they can't. Thinking what's strong, not what's wrong.
- Involvement of families and carers and prioritising carer's needs



Person Centred

- Everyone is treated as an individual with their own needs, ambitions and desires.
- Everyone is treated with dignity and respect and able to make their own choices.
- A flexible approach which means pathways and services are coordinated around the needs and wishes of the person





OUR VISION

It is only by putting people with learning disabilities at the centre of our strategy that we will be able to deliver its ambition. We have developed a Vision that summarises through a person-centred lens, what we are trying to achieve.

I am my own individual.

I want to be safe, healthy, independent and happy and have opportunities that are enjoyable and fulfilling, having choice and control, help or support where needed to be able to live my best life which is purposeful and meaningful to me, throughout my life.

STRENGTHS BASED APPROACH

The strength based approach starts by looking at a person's strengths - what someone can do, not what they can't do. This means having good conversations with the person to find out what are their concerns, what have they already tried and what else might help. Once their situation is understood properly, people can be supported to find good solutions that work for them .

Community led support is the strength based approach that we are adopting in Stoke-on-Trent. It is a programme that will change how we work and change our culture too. It is based on seven principles:

- Co-production brings people and organisations together around a shared vision
- There is a focus on communities and each will be different
- People can get support and advice when they need it so that crises are prevented
- The culture becomes based on trust and empowerment
- People are treated as equals, their strengths and gifts built on
- Bureaucracy is the absolute minimum it has to be
- The system is responsive, proportionate and delivers good outcomes

The Resource Wheel (developed by NDTi)



OUR OUTCOMES

Our strategy is focused on the five outcomes that emerged from our co-production with people living with LD in Stoke-on-Trent. These are important for them to live their best life. We will know we have been successful in delivering our strategy when people can say with confidence that they:

SAFE	Feel safe within, and valued by, the community in which they live and the environments that they are in.
HEALTHY	Have equal opportunities to good health and wellbeing.
ACHIEVE	Are aspirational in life goals which are purposeful and valued.
LIVE	Love where they live, who they live with, in a home that meets their needs
ENJOY	Have equal opportunities to a good quality life, to feel included in my community and enjoy my life.

Translated into a person-centred focus, the outcomes look like this.

Living my best life



I feel safe



I am healthy



I achieve my goals



I love my home



I enjoy my life

A detailed breakdown of each outcome across the life course can be found at Appendix 1. In addition, we also identified two cross cutting themes and these are explored later in this strategy

- Integrated approaches and workforce development
- Supporting those with learning disabilities who are parents or carers.

DEVELOPING THE STRATEGY

We adopted an approach of co-production in developing the strategy, overseen by a steering group with representation and linkages to children, young people and adults living with LD. We revisited the engagement work undertaken as part of the development of the Carers Strategy⁷ and the Inclusion Partnership Strategy⁸ to ensure feedback shapes this Life Course Strategy. We tapped into existing networks and brought together online focus groups and used one-to-one sessions to encourage a two-way dialogue. We also received written responses, case studies, art work, video and poems from people willing to share insight into their lives.

We spoke to other partners and stakeholders; professionals such as social workers and health staff who support people with LD and also care providers, short break providers, local charities, the police and commissioners at Stoke-on-Trent City Council and Stoke Clinical Commissioning Group (CCG). The draft strategy was shared with those who had contributed and also more widely through a public consultation exercise. This dialogue provides the key learning that is the golden thread throughout the strategy and our approach to co-production will continue to underpin the delivery of the strategy as we move forward.

We have structured the strategy against each of the five outcomes, exploring what this means across the life course.

For each outcome we:

- **Identify** current issues through data analysis and engagement feedback.
- **Celebrate** what we are doing well and can be proud of
- **Acknowledge** what needs to change
- **Describe** what change looks like
- **Develop** measures that will evidence outcomes are being achieved and change is happening.

We have identified measures that are already in place and acknowledge others may need to be refined or developed to demonstrate progress. We will work to develop detailed delivery plans and agree targets against which we can measure and evidence our progress.

Woven into this narrative are some of the stories and case studies we gathered during our engagement work⁹. We had such an excellent response that we were not able to include everything in the strategy so we have published all feedback and contributions on the “Equal People” website¹⁰ and CCG website¹¹.

COVID 19 AND THE IMPACT OF PANDEMIC

As our engagement took place during Covid-19 pandemic lockdown, we asked people to share their experience, concerns and hopes for the future.

We heard about the importance of human contact. Children, young people and adults have spent time thinking about family and friends, about getting back to school and to jobs and about how and when things will start up again and routines will be back in place. They have been keeping busy during lockdown staying in touch with friends using technology. There has been an increase in chatting with neighbours from a safe distance. TV and radio, gardening and a range of hobbies have kept people busy. There was also some elements of boredom and a break in usual routines.

We heard concerns and anxieties about going out of the home. Everyone was mindful of safety measures in place from washing hands to wearing masks. We heard that mental health has been impacted by the pandemic lockdown and worries over contracting Covid-19.

Lockdown particularly highlighted issues around access to digital technology. The lack of access to and ownership of technology as well as the ability to use it has further isolated some people and meant they may have missed out on the resources, support and information provided to the general population. This extended to links with the outside world, what was happening in the local community and keeping in touch with family and friends. The increase in amount of time spent gaming and staying safe online were highlighted both positively and negatively and, especially for children and young people, we found online friendships have been developed as people found new ways to connect and new group activities were taking place on line. The Aiming High programme moved some activities on line so that children and young people didn't miss their short break. Other services also moved support on line and via telephone. Using online methods for keeping in touch was greeted with enthusiasm by some and disliked by others.



Case study – Chelsea

Chelsea and her family struggled with lockdown and mum asked for additional support from Aiming High who tried to get Chelsea involved with virtual sessions. Mum was apprehensive, thinking Chelsea wouldn't join in. Mum joined in with the virtual quiz along with Chelsea who liked seeing the Aiming High staff and the other children. Chelsea asked if there could be a Peppa pig round at the next virtual quiz. Mum has seen how the virtual activities work and booked Chelsea onto some of the other online activities.

Case study -Jennie

When all this ends I'm really looking forward to seeing my boyfriend again and going for a coffee with my friend. I'm looking forward to going shopping too, I miss that. I want to get back to work too, I miss that a lot. I want to meet up with my family, my mum. I'd like to be able to talk to my friends on the phone more, like I've been doing now, didn't do that before and I like it. I want to find more time to listen to music, I watch TV music channels now, didn't do that before. I also want to try to cook more, I really enjoy that. I need to call my cousin more, I don't speak to her that much, think I should try to speak with her much more.

Schools, further education colleges and training programmes all closed. There has also been a major impact on the economy and jobs, with the whole population affected. People with LD are already disadvantaged in the labour market and they expressed concern that this is likely to worsen if the economy contracts as a result of the pandemic.

Adults with LD and their carers felt the negative impacts of pandemic lockdown more than parents of children and young people. Most day centres have been closed, as has respite provision. Carers were facing additional stress as they were not getting a break from their caring role and were having to stay inside all the time. This could make family life difficult.

Most local health services have been closed for face to face contact, this includes 'Able', our health support service. The team instead have provided outreach support in the community and have been making weekly welfare calls to the people who usually attend in person.

Social care and NHS teams felt that whilst lockdown had been challenging, they had been able to continue to work with colleagues from other teams during lockdown, doing their best to keep in touch and keep people safe. Some care providers reported feeling isolated as the council sought to adapt to new ways of working and respond to the pandemic.

The NHS England, Learning Disabilities Mortality Review (LeDeR)¹² report into deaths of people with LD during Covid-19 tell us that there are differences between people with LD that died from Covid-19 and people without LD. More than half the people with LD who died during this time, died from Covid-19. These reports also found that people with LD were much more likely to die from Covid-19 in hospital than people without LD. The Care Quality Commission¹³ analysis also showed that people with LD who died from Covid-19 were on average much younger than other people. In Stoke-on-Trent, 13 out of the 30 deaths reviewed between April 2020 to June 2020 for people with a LD were linked to Covid-19.

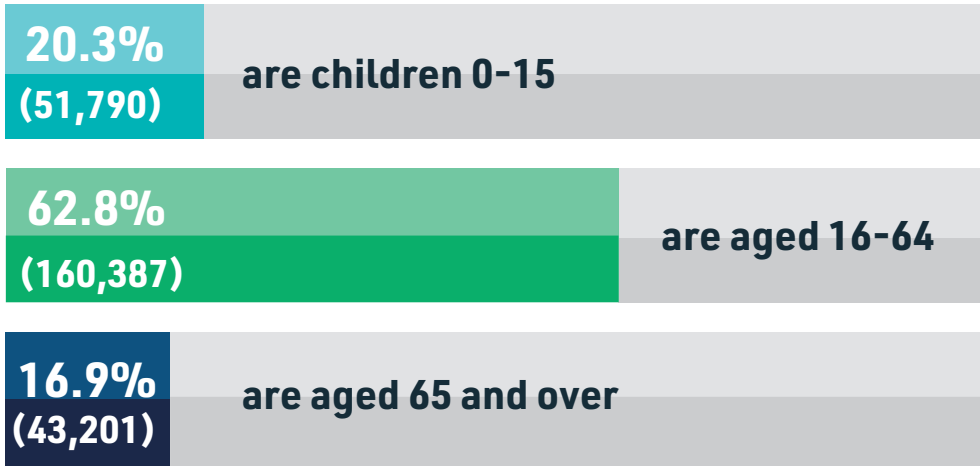
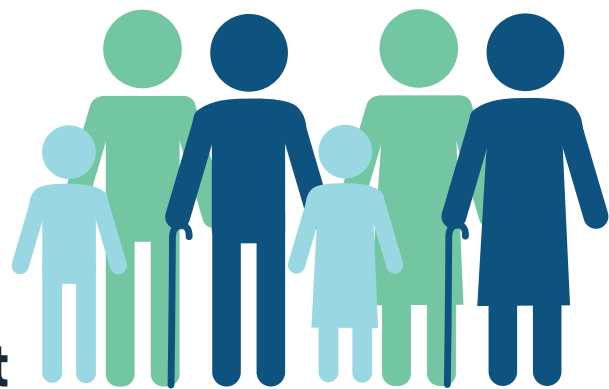
Both Stoke CCG and the city council acknowledge the impact of Covid-19, including the availability of and access to vaccinations and will pursue the opportunities that learning from the pandemic offers as we reflect, review and reset in order to move forward.


WHAT WE KNOW ABOUT STOKE-ON-TRENT

The below demonstrates the demographics for Stoke-on-Trent:

POPULATION

255,378
people live in Stoke-on-Trent



 **Around 3,300**
babies born a year

20.2%
of people are from minority ethnic groups

2.36% (4,698) of the total population of Stoke-on-Trent who are over 18 have a Learning disability.

There are more than 2,500 under 17 year olds who have a learning disability in Stoke-on-Trent

In total about 2.8% (7,198) of all people in Stoke-on-Trent have a learning disability. This is likely to be more as many adults were not assessed in the past.

17.2% (6,957) of the total school population are SEND pupils. 1,668 of these pupils have an Education, Health and Care (EHC) plan.

Moderate learning difficulty accounted for 33.5% of the EHC cases.


49 children in Stoke-on-Trent's care system were recorded as having either a learning disability, Autism or both This is 4.92% of Stoke-on-Trent's children in care population (March 2021).

Learning Disability
Please see the Joint Strategic Needs Assessment¹⁴ for more details.

OUTCOMES EXPLORED

We have, as much as possible, aligned what people told us with the five outcomes.

Their key messages were:



We want to be listened to.

Life is about fun, family and friends.

We want support to do things and to be independent.

We want more choices.

Accessibility is important for everyone.



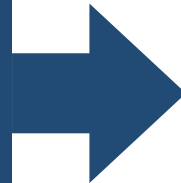
OUTCOME 1 – I FEEL SAFE



I'm in an area that's not got that many villains. I feel safe here. I don't want to live anywhere else. I've been helped to stay here. I've lived here a long time. My neighbours, they come and talk to me. I can talk to them if I've got a problem. And my social worker.

Children & young people

- I am happy and safe at a school that is as close to home as possible.
- I feel valued as an individual , cared for and respected by the community.
- I am free from bullying and know how and who to ask for help if it happens
- I feel understood by the police and justice system if I come into contact with them

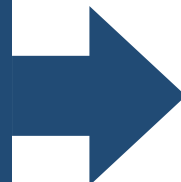


I feel safe

I feel safe within, and valued by, the community in which I live and the environments I am in.

Adults & older people

- I can get around freely and safely.
- I feel valued as an individual , respected and cared for by the community.
- I am able to access community activities and facilities and connect with other people.
- I am free from hate and hate crime and know how and who to ask for help if it happens.
- I feel understood by the police and justice system if I come into contact with them.



Issues that affect people living with a learning disability

Social contacts and access to community life are important to people living with LD and people want to feel safe and welcomed within their community and the environments they find themselves in. Our ambition is to ensure people with LD remain living safely within their community for as long as they want to, this extends to physically safe streets, good quality housing and public transport.

Community safety

Parents told us they want their children to be more actively involved safely in their community and some had created their own “safe spaces”, educating their children where to go and who to speak to if they need to feel safe out in their community. Children and young people were often keen to explore and get out and about and parents want to ensure they are safe to do so.

Social care teams told us that sometimes residential homes are seen as the only option when adults with LD can't be kept safe in the community, even if they don't have particularly high levels of need. The teams identified concerns for some of their clients around harmful sexual relationships, with three sexual exploitation cases reported to the safeguarding team during 2019/20.

People with LD may be at higher risk of criminal exploitation and radicalisation¹⁵ and children with LD are at higher risk of neglect¹⁶. Data from our social care teams shows that neglect and acts of omission and physical abuse are main areas of concern for safeguarding adults, with higher numbers of males than females experiencing abuse.

The number of individuals with LD involved in safeguarding enquiries per 1000 people on the GP LD registers in Stoke-on-Trent is 31.4. This is slightly higher than the West Midland average of 30.8 but much lower than the national average of 50.9. We will continue to work to reduce this figure for people with LD in Stoke-on-Trent.

Bullying

Research suggests that children and young people with LD are potentially more likely to be subject to bullying¹⁷. Locally, we heard that bullying was sometimes a problem within groups of children and young people with SEND. Sometimes this was not deliberate, but where the behaviours of one child triggered behaviours in another. It was suggested grouping a range of SEND children together was not helpful in managing the often specific needs of individual children as it was felt to be contributing to deliberate bullying and indirect “knock on” impact on children and young people, especially those with heightened sensory reception. This was identified by some parents as an issue within special schools and the short breaks programme. . Our Inclusion Partnership Strategy will further challenge how environment, culture and attitudes affect SEND children and young people so they feel happy, safe and are able to take part in community life.

Over 7 in 10 adults with LD have experienced some kind of hate crime in the United Kingdom¹⁸. Locally, Challenge North Staffs¹⁹ supports those who come forward to report incidences of Disability Hate Crime. There was a significant reduction in the number of incidents covering physical/sensory disability, autism, LD and mental health reported from 2018-19 to 2019-20²⁰. Analysis for 2019/20 showed all victims were targeted at home, often for a protracted length of time. Challenge North Staffs believe there is a significant under reporting from individuals with LD and that the reduction is not because hate crime has reduced²¹.

Case study – Rob

Rob, living with multiple impairments, including physical, learning & mental health issues, was targeted by neighbours who he says wanted to drive him out of the street. Over a 6-12 month period, there were 26 reported incidents, relating to anti-social behaviour, disputes, harassment, nuisance and verbal abuse. The Challenge North Staffs team helped Rob to identify what it was that was making him feel vulnerable and the Police Community Support Officer (PCSO) liaised with Rob's neighbours to raise awareness of how their behaviour impacted Rob. With some small adjustments by neighbours and the help and support of the Challenge North Staffs team and PCSO there have been no further incidents.

Challenge North Staffs

People with learning disabilities and the criminal justice system

Young people with LD appears over-represented in the youth justice system²². For adults, the Bradley Report²³ highlighted the disproportionately high number of people with LD and mental health problems in the criminal justice system. These problems may have gone undiagnosed prior to entering prison. Twenty-five per cent of the prison population²⁴ have problems communicating or handling complex information, although they might not strictly meet diagnostic criteria for a LD and consequently, are unlikely to be eligible for support.

Work is ongoing to establish enhanced sentencing for all protected characteristics²⁵ (previously only available for racially and religiously aggravated victims). This now requires the courts to be aware of hostility shown towards the victim based on their sexual orientation, disability or because they are transgender or that it was the motive for the crime.

What are we doing well?

There are a range of initiatives and examples of good practice to address community safety and encourage independence in Stoke-on-Trent.

Safe Places network

We have worked hard to ensure that there is an established Safe Places network²⁶ across the city. Safe places are areas in the community that are 'LD friendly' e.g. cafes, shops, libraries and community centres. This helps to broaden horizons, build confidence and enables people to get out and about. Future plans for Safe Places in Stoke-on-Trent mean it will become increasingly localised, including local community venues and widening availability across the life course as it expands to young people aged 14+. National improvements include the Safe Places app which can be used when visiting anywhere in the UK.

Supported Living

We have a supported living offer which provides opportunities for people with LD to live within a community and access local facilities safely. We will further develop and expand the options available so people have more choice over where they live and whom, if anyone, they live with.

Police liaison

Work is underway to raise awareness within the police to ensure that people with LD are supported through identification of additional needs and/or communication behaviours this will ensure that recognition and the offer for support is sought at every opportunity. An approach of continuous improvement through analysis of incidents will further enhance awareness within Staffordshire Police.

Case study – Jason

Jason was being targeted by a drugs dealer which was causing issues for the local community where he lived and making him unhappy and scared. His supported living team liaised with the police and the local community to increase police patrols and encourage neighbours to look out for Jason and make him feel part of the community. The drug dealer stopped targeting Jason and he is able to enjoy his life in his home, within a community that he feels safe and respected in.

Jump2Independence

What needs to change?

Supporting people with LD to be safe in their homes and communities requires a joined-up response from key agencies such as schools, police, criminal justice and the city council as well as support from local communities. Work is required so that agencies will be more aware that what is required for 'proof' of harassment and bullying to enable them to act, is often considerably more than what can be provided as evidence. Our approach will be based on belief in what children, young people and adults with LD are saying is happening to them and how this makes them feel and act. We will work to raise awareness of what hate and hate crime is and how to report it.

Joint initiatives such as Community Led Support and locality based approaches will support a more inclusive experience and will raise awareness to ensure better understanding and empathy from neighbours and the community. This will help people with LD feel and stay safe where they live and when travelling around the city. We will also strive to address stigma around LD, dispel myths and build social cohesion.

Through the Inclusion Partnership Board, we will address bullying, support inclusion in school life and support children to stay close to home for their education. This includes addressing issues around SEND in young people who are known to the youth offending team.

ACTIONS WE WILL TAKE

- Support communities and local services including schools to be welcoming and accessible to people with LD
- Expand Safe Places to cover from age 14 through to older age
- Build stronger links to the Community Safety and Community Cohesion teams
- Ensure people are safe from abuse in their home. Expanding the choice of accommodation and support available to stay safe
- Develop our community led support programme



We will use the following measures to demonstrate progress

- Incidences of bullying in schools
- Number of children in out of area school placements.
- Reporting of hate and hate crime
- Number of Safe Places offering support
- Reporting of safeguarding concerns
- Reporting of concerns of sexual exploitation
- Baseline survey



OUTCOME 2 – I AM HEALTHY



I've got my carers that come in once a day. They clean me up, help me have a wash. They make me toast and a cup of tea. I go to Smallthorne Health Centre . The staff there, they give me advice about staying healthy. I got support and advice from my brother as well.

Children & young people

- I can use high quality health services that are co-ordinated in ways that meet my needs.
- I am happy and fulfilled, feeling physically, mentally and emotionally well.
- I am able to make informed choices about healthy and safe lifestyles as I get older and given lots of opportunities to be physically active.

Adults & older people

- I can use high quality health services that are co-ordinated in ways that meet my needs.
- I am happy and fulfilled, feeling physically, mentally and emotionally well.
- I am socially connected.
- I expect to live as long as other people that don't have learning disabilities.



I am healthy

I have equal opportunities to good health and wellbeing

Issues and things that affect people living with a learning disability

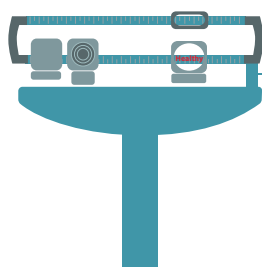
People with LD currently have poorer physical and mental health²⁷ and life expectancy is lower than the general population²⁸. Nationally, there has been no significant change in life expectancy for people with LD between 2014 and 2019 and this situation is reflected locally.

Life expectancy for people with learning disabilities



Weight issues and learning disabilities

Obesity is **twice as common** in people aged 18 - 34 with learning disabilities



Being underweight is **twice as common** in people over 64 with learning disabilities

Epilepsy:

In 2018-19, epilepsy was 26 times more common in people with LD than the general population.

Dementia:

People with LD are 5 times more likely to develop dementia compared to the general population. People with Down's Syndrome have a specific additional risk of developing dementia. For them, this often happens at ages from 35 to 45 onwards.

A number of national reports suggest that preventive health care can avoid a number of deaths. The NHS England Confidential Inquiry into premature deaths of people with a LD (CIPOLD) enquiry²⁹ highlighted that 34% of deaths of people with LD were from treatable medical causes, compared to 8% in the general population, a four-fold difference.

Stoke-on-Trent's rate for the extent to which local authorities are providing long- term support to the individuals identified by GPs as having LD is lower than both the regional and national averages (Stoke 42.5%, regional 44.7%, national 50.7%).

Annual Health Checks can identify undetected health conditions early and ensure that people are getting the right treatment and build trust to ensure continuity of care. Alongside this, screening appointments can help to reduce the inequality in life expectancy. Locally, we found that some people with LD find hospital appointments and screening daunting or scary with some families reporting individuals being anxious, which sometimes led to failed or cancelled appointments and deterred the individuals from future screening. Whilst reasonable adjustments are already in place, more training will be provided around further adjustments that can be made to enable people to attend their health screening appointments and participate in their treatment plans. For example, some feedback for breast screening highlighted that physical adjustments and clearer explanations as to what screening involved would increase the rate of breast screening uptake for individuals with LD³⁰.

Flu and respiratory conditions

We know people with LD have a higher risk of dying from respiratory conditions³¹. There is significant work ongoing in our Primary Care health team in Stoke-on-Trent to increase the uptake of the flu jab for people with LD. Health facilitation and acute liaison services who are commissioned by the CCG have provided continuing professional development events for primary and acute care. University Hospital North Midlands (UHNM) are working on a pathway development for respiratory illnesses in order to improve outcomes.

Mental health

UK Population-based estimates suggest that 36% of children and young people and 40% of adults with LD experience mental health problems at any point in time³². These rates are much higher than for people who do not have LD.

Children, young people and adults in Stoke-on-Trent told us that mental health is very important and that their needs cannot be “pigeon-holed” as single issues, i.e. mental health or LD and should instead be seen as intrinsically linked and requiring a multi-dimensional response. Stoke CCG is working coproductively with health providers to implement a single point of access and single referral form, meaning that a person only needs one referral to access linked services e.g. LD and autism.

End of life care

The Care Quality Commission (CQC) published a thematic review³³ into inequalities in end of life care for people with LD. The review identified that people with LD ‘sometimes experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs’. The CIPOLD Enquiry into premature deaths of people with LD found that for many people with LD who were dying, end of life care was not co-ordinated and the support for the person and their families could have been improved.

Older carers of people with LD tell us they worry about their own health as well as that of their loved one. They felt a more rounded “family” care approach would be more beneficial rather than people seen in isolation.

What are we doing well?

Case Study – Shabnam

Shabnam has a mild learning disability and bipolar affective disorder. Shabnam lived with her elderly parents and began to struggle, leading to an admission to the Assessment & Treatment Unit. The team completed a thorough assessment of Shabnam's mental health and encouraged Shabnam to see her family, support workers and to still do the things in the community that she enjoyed and that gave her a sense of purpose, supporting her to make a full recovery. The team put in place a positive behaviour support plan and relapse prevention plan and Shabnam now lives in supported living and is better able to access services safely, adopt healthy behaviours and communicate her needs and wishes effectively.

LD champions

We have over 200 champions to support health checks and reasonable adjustments for people with LD. This has been rolled out to primary care, acute care and community services.

Annual health checks

In Stoke-on-Trent the proportion of eligible adults with a LD having a GP Health Check for 2018/19 was 54.9%; this is significantly higher than the West Midlands proportion of 46.1 and the National Average of 52.3. For 2019/20, this figure is 62%. Whilst this is good progress, we aim to jointly increase this uptake further for people aged over 14 years with LD, so that at least 75% of those eligible have a health check each year by 2024.

Dementia

The number of people in Stoke-on-Trent with a diagnosis of dementia and LD is low. We expect this will increase over time but not significantly. LD support is provided to the memory clinic at North Staffordshire Combined Healthcare Trust (NSCHCT) in a joint initiative to determine how best to support an individual with LD who develops dementia.

Hospital Passport and digital flags

The Hospital Passport was developed after consultation with local people with LD. This initiative links to a LD acute liaison nurse (ALN) who works at the hospital (UHNM) to improve the experience of people needing hospital care³⁵. UHNM also has an established Flag and Tracking System in place for the identification of individuals with LD who may have extra needs and an email alert now notifies the NSCHCT LD service of an admission. The system also has an alert to prompt hospital staff when a patient with LD is admitted, along with recommended reasonable adjustments.

Hospital Checklist

The ALN implemented the Hospital Trigger Questions and Care Checklist, helping to identify people's hospital passport and using a checklist to make sure timely referrals to specialist services occurs.

Case study – Mr Smith

The team at Able telephoned Mr Smith as part of their outreach contact during the pandemic lockdown. Mr Smith's brother informed the team that Mr Smith had been admitted to hospital and he was extremely anxious as he was unsure how Mr Smith would cope in hospital due to having a LD and family being unable to visit.

Mr Smith's brother had tried calling the ward for updates and to speak to Mr Smith, but it was constantly engaged or ringing out.

The 'Able' team contacted the LD liaison nurse based at the hospital and explained given the lockdown restrictions Mr Smith couldn't be supported by family to express his needs and wishes. It was also established Mr Smith did not have a hospital passport. The Able team contacted the social work team, who then liaised with Mr Smith's brother and supported him to put together a hospital passport for him. This eased Mr Smith's brothers' anxieties and supported Mr Smith's nursing team to know all about him.

Able

We have a dedicated health support team "Able" for adults which has recently relocated to the central library, Hanley, to provide increased opportunities for people across Stoke-on-Trent to access health, safety and wellbeing support. Able helps to develop friendships, confidence, skills, new activities and training.

Mental health

To improve access to mental health support for children and young people with mild LD, NSCHCT recruited LD nurses to ensure children and young people accessing mental health services did not fall between service provision.

Case study – Sarah

Sarah has been unable to access her regular face to face mental health facilities during lockdown. She was experiencing voices and having suicidal thoughts and had at times drunk large amounts of alcohol to try to cope with her feelings. She regularly messaged the team at Able asking for someone to ring her as she couldn't cope. Able supported Sarah to access an online relaxation programme and Sarah has said this had helped her to remain occupied and cope with her feelings.

Able

Medication

Psychotropic medicine is more likely to be inappropriately prescribed to people with a LD or autism. Stopping over medication of people with a learning disability (STOMP) , autism or both-Supporting Treatment and Appropriate Medication in Paediatrics³⁶ (STAMP) are national NHS programmes. The CCG have worked collaboratively with NSCHT to develop a care pathway to reduce inappropriate psychotropic drug prescribing in LD services³⁷ and this continues to be a priority for Stoke-on-Trent.

Screening

Health facilitation nurses have been looking at making screening programmes more accessible locally and a number of Health Promotion events have been led by the Community Learning Disability Team ((CLDT).. The team are currently supporting an easy read invite letter and information sheet for breast screening.

Transforming care and personal health budgets

Under the transforming care agenda, by March 2023/24 inpatient provision will have reduced to less than half of 2015 levels³⁸ and the CCG will workwith the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint for all patients in inpatient settings, particularly for children and young people.

Drawing on learning from the New Care Models³⁹ in mental health services, local providers will be able to take control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out of area placements. In addition, where possible, people with LD, autism or both will be enabled to have a personal health budget.

Case Study – Juan

Juan had recently returned to Stoke-on-Trent from a residential school setting and was living in supported living. Juan's behaviours had deteriorated considerably, displaying violence and aggression, absconding and showing high levels of anxiety which was having a detrimental effect on his health, wellbeing and quality of life. The care provider felt his needs exceeded what they were capable of delivering and so Juan moved to live with his mother. The IST remained in a supporting role, offering emotional support, advice and liaised with the city council to find him a suitable home.

The IST worked with Juan's new care provider, providing extensive knowledge, training and skills to Juan's new staff team and ensuring that his new environment was suitable for his needs. Without IST support it would be highly likely that Juan would have been admitted to hospital and his future options would have greatly been reduced.

What needs to change?

We will ensure whole system approaches that enable joined up responses across health, social care, housing, employment and beyond to tackle some of the wider determinants of poor health⁴⁰. We have recently been accepted into the NDTi “Small Supports” pilot which will enable individual tailored support to those with significant LD who are still living in hospital settings or who are at risk of hospital admission⁴¹.

The city council will work with commissioned LD care providers to have hospital passports for all their residents to cover wider health issues, in effect “health passports”

We will continue to strengthen alternatives to inpatient admission for someone in crisis and continue to improve crisis planning to prevent escalation, this includes better trained care staff, positive behaviours support is key training that is being rolled out The Intensive Support Team (IST) are pivotal in supporting this.

For those at risk of, or already admitted to inpatient units, we will review and look to strengthen the quality assurance and representation for existing Care, Education and Treatment Review and Care and Treatment Review policies, in partnership with people with LD to assess their effectiveness in preventing and supporting discharge planning.

The CCG will further invest to ensure that children with LD have their healthcare needs met and that the needs of children and young people are included in reviews as part of general screening services and are supported by easily accessible, ongoing care.

The Community LD Team have a dedicated Children’s Team and also represent the complex LD pathway of the CAMHS services. The team work with children and their families in a variety of settings including home, school, college and the community to meet specific psychological, social and emotional needs⁴².

Key workers will help to coordinate individual care packages for children and young people with the most complex needs and influence mainstream services to improve accessibility.

Issues over weight management need to be addressed through public health messages on healthy diet. Care providers need increased awareness as to better choices around diet, healthy choices, exercise and mental wellbeing to support healthy lifestyles.

For end of life, the CCG will work with health providers to implement the NHSE Guidance⁴³ to support people to be in control of planning end of life care

By 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standards⁴⁴.

ACTIONS WE WILL TAKE

- Increase health literacy
- Ensure that the physical and mental health needs are identified and addressed in an accessible and timely manner
- Support individuals with LD and their carers to take positive steps to keep healthy , eat a balanced diet, exercise and maintain a healthy weight and to age well
- Accelerate the roll out of Personal Health Budgets to give people greater choice and control over how care is planned and delivered.



We will use the following measures to demonstrate progress

- LeDeR review findings.
- By 2023/24 children and young people with LD, autism or both with the most complex needs will have a designated key worker.
- Number of NHS staff accessing mandatory LD awareness training.
- Reasonable adjustments for access to health and social care.
- Annual health checks for people with LD.
- Numbers having the flu jab.
- Access to health screening services.
- Number of people with LD flagged within UHNM
- Life expectancy and quality of life.
- Uptake of Personal Budgets
- Hospital passports and the number of hospital staff reviewing them.
- Baseline survey.



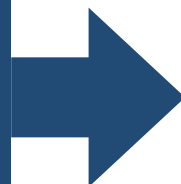
OUTCOME 3 – I ACHIEVE MY GOALS



I like learning things, getting certificates. I do think I plan for the future but right now, I don't know what the future holds!

Children & young people

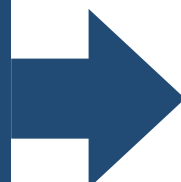
- I have opportunities to develop my education and skills and am encouraged to make the most of my abilities.
- I have a past, present and future with people who are important to me.
- I get the right support to help me influence and make choices about my life and the future.



I achieve my goals

Adults & older people

- I can choose to have a job.
- I can volunteer and contribute to the community, if I choose.
- I have opportunities to continue developing and using my skills and make the most of my abilities.
- I have a past, present and future with people who are important to me.
- I know where I can get help or support to make informed choices about my life.
- I am supported to be financially independent



I am aspirational in my life goals which are purposeful and valued

Children and young people with LD in Stoke-on-Trent told us that inclusion in school life and education achievement is very important to them. They are aspirational for their life ambitions and want to have a job and the independence that this brings. To help them prepare for moving into adulthood and regardless of education setting, they want more opportunities around work experience and good quality careers advice.

The majority of parents felt that mainstream schooling was the best way of educating their child and the majority of EHC plan pupils are in mainstream schools, with around 760 children and young people attending special schools. More than half of these attend special schools that are outside of the city; these may be just over the border in Staffordshire.

Adults with LD told us that whilst they aspired in their childhood, they did not always feel they had the same chances as everyone else to achieve their life goals as they had grown into adulthood. Too few adults with LD find meaningful employment in our city and there is an over reliance in staying in continued education provision. At present, students completing a supported internship and not entering employment re-enter the education system at a cost of between £14,100 (foundation in Further Education) and £19,100 (special) per year. In cases with complex needs this figure can be as high as £40-50,000. The gap in the employment rate for people with LD (aged 18-64), across the city in 2018/19 was 67.6%. This is likely to be impacted as a result of Covid-19 as the economy contracts and businesses fail.

2.4% of working age (18-64) individuals who received long-term support during the year 2018-19 with a primary support reason of LD support, were in paid employment. This ranks Stoke-on-Trent City Council 117th out of 152 Local Authorities in England and against a National Average of 6.38% and West Midlands average of 4.3%. Those who we spoke to who were in employment told us how much they enjoyed their job and liked the people they worked with. People also told us they wanted to be able to choose if they worked or not and felt strongly that this required the right support to help them keep a job.

Adults told us they wanted choice and control over their lives, staying close to family but also being able to explore opportunities to increase independence and try new things. There was a view from social care that day opportunities were limited and didn't offer much choice, but people we spoke to told us they liked their centres and activities.

Case study – Abdul

Abdul had accessed the Aiming High short breaks programme as a child. As he became too old to qualify for the service, he began volunteering, helping set out activities and be part of the team running the sessions, learning new skills and making a positive contribution.

Aiming High

What are we doing well?

Education

Plans are being developed to keep children in or around Stoke-on-Trent for their education by developing alternative provision capacity. The development of free schools will help to meet a shortage of places for secondary age students with social, emotional or mental health needs.

Employment

We will continue to offer more opportunities for people with LD. Supported internship opportunities within the NHS targeted at people with LD, autism or both will increase by 2023/24, with at least half converted to paid employment over the first five years of the Long Term Plan. The number of NHS internship and employment programmes/sites delivered through 'Project Search' and 'Project Choice' will increase as will the number of NHS organisations making the Learning Disability Employment Programme pledge.

A Supported Work-Based Training Team (SWBT) based in Learning Services at the city council will bring together employers, education providers, the EHC team and careers specialists to create a high-quality, cost-effective, city-wide service to support young people into sustainable paid employment. This pathway is an umbrella term covering all DfE-approved training courses developed from the belief that any individual who wants to work is capable of doing so, if the correct support is in place. This includes supported internships, inclusive apprenticeships/traineeships and supported employment programmes. Properly delivered SWBT Pathways offer an individual tailored in-work support from a skilled and qualified job coach to help a young person learn a job and adapt to the workplace.

The adults LD employment team is now embedded within the mainstream JET(Jobs, Enterprise and Training) service to support an integrated approach. Work is ongoing with Department for Work and Pensions and their programme for "Disability Confident Employers". Part of the supported employment for vulnerable groups is about training and supporting employers to work with those groups, offering work experience, work placements, permanent employment.

Case study – Riptide café

During 2017/2018 a partnership was developed with Fenton Manor Riptide Cafe and the Holiday Inn hotel chain. The partnership provided job ready training, hospitality and catering qualifications, on the job work based learning and employment for a group of people who had a keen interest in the industry. An additional offer for people to volunteer rather than become employed initially has enabled people to develop their confidence and achieve their aspirations



Case study – Annie

Annie had a dream to become a weather presenter. A partnership was established with 6 Towns Radio which is managed and run by volunteers and Annie joined the team, volunteering for three years on the Monday morning show, reading out the weather report. She developed her team working skills, made new friendships and learnt how to use the information technology

What needs to change?

An improved offer for children and young people is needed to expand their horizons into the world of work. Consideration needs to be given to an additional “C -Careers” into the EHC planning process, so that training and skills is factored into planning and preparation for adulthood as early as possible. This will raise the aspirations of children and young people and support the planning of opportunities for work experience, apprenticeships and jobs. By capturing the person’s strengths, abilities and limitations at an earlier stage this helps in creating a career pathway, identifying occupational interests, determining educational and training needs based on the person’s assets, interests, skills and abilities.

We will limit the use of Out of Area residential education placements so that children and young people remain in the city, able to make friends and linkages to their community.

We will work with day opportunity/short break providers to develop age appropriate person-centred activities that provide opportunities for learning and skills. We will also explore suitable work or volunteering opportunities within these programmes.

We will develop a Graduated Approach with input from all stakeholders for children and young people (CYP) 0-25 years old. This Graduated Approach will provide access to a range of services to support educational settings in ensuring that the needs of CYP with SEND are identified correctly and that the correct provision is put in place in a timely manner. This will lead to better outcomes and ensure that CYP with SEND reach their potential within a mainstream setting.

Economic independence

We need more flexible ways of accessing money for those whose money is held by the city council and a way of online ordering of large household items (hoovers, fridge/freezers, TV’s, phones membership cards to parks etc.) to ensure that the individual has the same opportunities as those whose money is not held by the council.

ACTIONS WE WILL TAKE

- Develop work experience opportunities for young people in special schools
- Increase career & volunteering opportunities for school and college leavers.
- Increase career, training, volunteering & work experience opportunities for adults
- Ensure people are financially independent



We will use the following measures to demonstrate progress

- Education attainment.
- Number of people with LD in paid employment.
- Number of apprenticeships.
- Volunteering opportunities.
- Baseline survey.



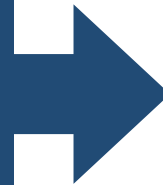
OUTCOME 4 – I LOVE WHERE I LIVE



I've always chosen where to live. I don't ever want to move or leave this area, I've got good neighbours here. I've lived in lots of different places but this one is the best, here is my favourite, I really like it here.

Children & young people

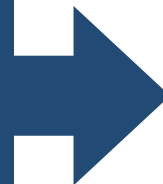
- I live with family/carers or in another environment that meets my needs and where I can thrive
- I am able to choose who and where I live as I get older.



I love where I live

Adults & older people

- I have choice as to where and with whom I live, family/ carers/ Independent/supported living.
- I have as much independence as I choose.
- I feel safe, cared for and I can thrive.



I live in a home that I choose, with who I choose, that meets my needs.

Issues and things that affect people living with a learning disability

Too many children and young people with SEND are placed in residential settings (including schools) that are outside of Stoke-on-Trent. As well as the high economic cost, this means local linkages, family relationships and the ability to form life-long friendships are severely limited.

For adults, our accommodation offer is limited and we are too reliant on residential homes. This is reflected in our position nationally, illustrated in the table below.

Indicator	England National Average (%)	West Midlands National Average (%)	Stoke-on-Trent
Adults with a LD who live in stable and appropriate accommodation	77.4	72.4	66.5
Proportion of Supported working age adults with LD living in unsettled accommodation	17.9	22.3	29

According to the Adults Social Care Outcomes Framework⁴⁵ (ASCOF 2017/2018) people with LD are more likely to be in a care setting in Stoke-on-Trent than most Local Authorities. The above ranks Stoke-on-Trent City Council 140th Nationally out of 152 Council in England.

Children and young people told us they are, on the whole, happy living in Stoke, happy where they live and with their family.

The adults we spoke to felt they had a choice over where they lived and felt safe and supported by care staff, family and friends. They want to be able to watch their favourite football team and go to the local pub. Social care recognised that people with LD want to be independent, but not lonely and wanted friends, not Personal Assistants. Being able to stay in the same home was important to people as they got older, but sometimes the property did not meet their requirements as their needs changed and could make life more challenging.

Parents worry about where their child will live as an adult and whether they would be able to cope with supported or independent living. They want to encourage independence and choice whilst recognising and managing risk. Where social care is involved, having a social worker is a good thing, parents don't want to be judged and be made to feel by other professionals that they weren't a good parent. Older carers worry about where their loved one is going to live in the longer term.

What are we doing well?

After consultation with people and carers, it was apparent there was a need for alternative accommodation models. Shared Lives and Abbots House have been developed as a result. These enable people to live independently with personalised support.

Shared Lives not only provides people with a home but also provides the support to live an independent life. Carers are recruited from within Stoke-on-Trent therefore upskilling local people to undertake the Shared Lives Carer role and employing local people to provide a home for a local person.

Abbots House provides people with their own apartment and support to live independently within the multi-apartment hub living environment. People are supported to access the community, volunteer, continue or begin employment, shop and be part of social activities. Abbots House has seen people access employment, leisure activities and with the development of assistive technology people have been able to stay connected with family and friends.

We have reviewed respite following workshops and carried out a survey of older carers and how we can support their loved ones to stay in the family home for longer.

What needs to change?

Taking an asset based approach, we need to understand what is available in our communities and develop/adapt where there are difficulties accessing community activities. People with LD wanted more activities such as craft clubs and social events for people with learning disabilities, this should include being able to access local leisure and recreation facilities.

There needs to be choice and control over where you live if you have LD, that meets your needs as you get older. This includes exploring HOLD (home ownership LD (mortgages)) and keyring projects⁴⁶ with our own internal housing provider and expanding the offer for individuals to live independently.

For people with the most complex needs, we will continue to improve access to care in the community, so that more people can live in or near to their own homes and families.

ACTIONS WE WILL TAKE

- Supporting young people to become as independent as possible as adults
- Provide support to carers when they need it and for as long as they want it.
- Continue to develop the choice of places to call home



We will use the following measures to demonstrate progress

Measures

- Individuals choose where to live, including supported living, across the life course
- Percentage of people with an LD living in stable and appropriate accommodation.
- Number of children in out of area school placements
- Access to community activities
- Baseline survey



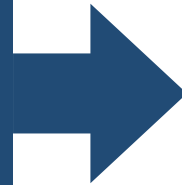
OUTCOME 5 – I ENJOY MY LIFE



We like to sit out on the balcony when it's nice. Talk to the other residents. Singing and dancing as well. Every week people go outside and have a sing and dance. The staff and other residents. I like that

Children & young people

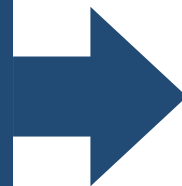
- I have a wide range of social and leisure opportunities and activities to choose from.
- I have friendships and relationships that are good for my wellbeing.
- I am able to connect with friends in person and on line.



I enjoy my life

Adults & older people

- I have a wide range of social and leisure opportunities and activities to choose from.
- I have friendships and relationships that are good for my wellbeing.
- I am able to make my own decisions even if they are considered unwise or risky by others



I have equal opportunities to a good quality life, to feel included in my community and enjoy my life.

Issues and things that affect people living with a learning disability

People with LD want to live happy and fulfilled lives, within a family and community setting as much as possible. Often, people come to the attention of social care when the individual or the carer is at crisis point for reasons such as financial pressures, changes in behaviour, lack of provision, family crises i.e. grief, divorce or changes to the carer's health. Sometimes all that is needed is short term support and small changes. At other times, significant change may be required to return a sense of enjoyment in life.

Children and young people told us they enjoy activities such as scouts and feel that key milestone events in their lives such as school prom are important.

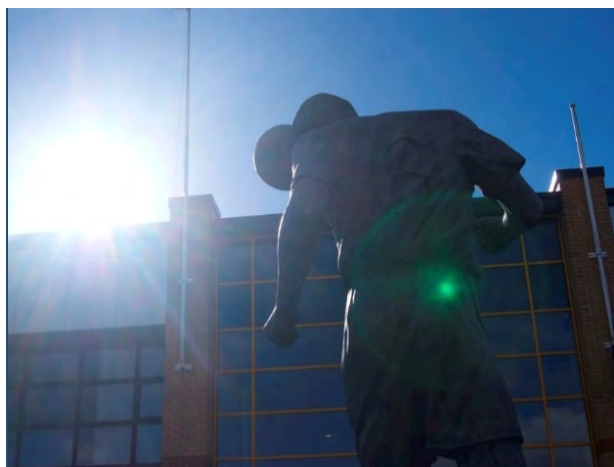
Parents want their children to have more opportunities to socialise and mix with others.

Adults with LD told us they want to be able to do what everyone else takes for granted; access community activities, go to concerts, visit local markets or pubs and restaurants without being stared at or bullied. They don't necessarily want to be segregated into LD day opportunities.

What are we doing well?

We currently have a range of provision across the life course and according to the level of need that is accessible, sometimes without the need for a social care assessment, such as the Aiming High short breaks provision for children and young people. We have also made some significant changes and progress over the last few years to support young people prepare for adulthood with a "Preparation for adulthood" working group and team dedicated to supporting young people aged 14-25, with a focus on a person-centred approach which looks at the holistic needs of the young person.

The adult social care team sometimes find that there has been no involvement from children's social care because families have not needed support. This means that referrals are made as the young person is nearing 18 years old and the family feels they may need support. The team are becoming more proactive in contacting colleges to identify the potential referrals earlier so that families and the individual get the support they require, to help them prepare for moving into adulthood.



Case study – Steve

Steve wanted to watch his football team on a Saturday, but lacked confidence and became anxious in large crowds. Port Vale F.C and Vintage Volunteers found him a "match buddy", Kevin, who supported Steve to attend the home games and introduced him to his friends. Steve's confidence has grown and he now volunteers at Port Vale FC as a groundsman. Steve and Kevin continue to attend football matches together. The success of the buddy system has encouraged Stoke City FC to look setting up a similar initiative.

What needs to change?

Needs should be identified at an early stage whilst in primary education and support services put in place to encourage independence and minimise issues that arise as young people prepare for adulthood. This includes opportunities to make friends and develop hobbies and interests.

Access to technology and digital opportunities needs to be improved, particularly for older adults.

There needs to be more opportunities to make friends and explore ideas such as “Gig buddies” so that people are not reliant on Personal Assistants and care staff as their main source of social life.

Accessibility across the city needs to improve, to include training for public transport driver’s/staff and more accessible transport at all times of the day. LD/Autism friendly drivers would help ensure confidence both in the client and the taxi driver.,

There needs to be an increase in Changing Places toilets across the city.

A focus on preventative work such as low-level housing advice, advice on documentation such as letters and bills could prevent crisis situations from occurring, reducing anxiety and maintaining a level of independence.

More social opportunities for people with differing levels of LD are needed. Some of the opportunities that are already available for adults are well received for the level of ability that they are provided for. We need to ensure that groups and activities are set up to support people with differing levels of ability and that the level of ability is identified and discussed to ensure that groups/opportunities are appropriate and inclusive. These activities should be seen as an opportunity to identify early potential concerns or emerging issues to prevent deterioration in people’s wellbeing and reduce crisis.

ACTIONS WE WILL TAKE

- Review the range of activities and short breaks across the life course to ensure they are personalised, fun, interesting and help develop new skills and make connections.
- Support opportunities to make friends and have places to go
- Improve digital connectivity across the life course
- Increase prevention work e.g. low level housing, employment, health advice etc



We will use the following measures to demonstrate progress

- Changing Places facilities.
- Neighbourhood/community Safe Places.
- Baseline survey,

CROSS CUTTING THEMES

Our engagement exercises suggested there were a number of cross cutting issues and themes that should be prioritised.

INTEGRATED APPROACHES AND WORKFORCE DEVELOPMENT

“

Through my experience as a Housing Needs Officer, there are clear gaps in information sharing which, if filled, could take pressure off both social care and housing teams and ensure quicker responses and less chasing for clients and those that assist them

”

Issues and things that affect people living with a learning disability

It is difficult to determine how many people with LD will need care and support. Personal circumstances will have a bearing on specific requirements.

Getting the right care and support in the community needs to start at a young age. Families need to have the right support to help them care for their children at home when they first feel t extra help is needed, with quick access to specialist support in a crisis. Support in the community can prevent people becoming distressed and in some cases, suicidal or violent. When people reach this ‘crisis point’, hospital is often the only option left⁴⁷. Person-centred, joined up approaches across multiple organisations will contribute to enabling people to live within a community of their choice and avoid admission to an institution.

We need improved information recording and sharing between council departments, health, education and providers/support groups. People told us about the lack of consistency of approaches by social care, education and in healthcare. Staff from different services don’t always accept each other’s assessments and this can impact on the length of time assessments can take and affect support being put in place. Integrated assessment and planning, with all relevant professionals feeding in and listening to the aspirations of the person as the starting point.

Parents and carers don’t feel they are updated regularly with regards to care services. They felt more joint working is required within and across the support groups. They would like digital carer platforms and carer specific chat rooms.

What are we doing well?

Professionals from different services work collaboratively, but there is room for improvement especially in information sharing and planning.

For the city council, training regarding communication and approaches have been identified as a learning need specifically for the Children with Disabilities' assessment team. Work is ongoing to devise an appropriate training plan in relation to this in order that learning needs can be met.

What needs to change?

We want individuals living with LD to be supported by a workforce that employs their own skills and knowledge and uses their own personal abilities to further the health and wellbeing of a person with care and support needs, using an assessment as a meaningful intervention not as a gateway for services.

A multi-disciplinary approach would help in identifying and mapping out a well-planned pathway for the individual. Such teams or approaches need to comprise of Health/Occupational Therapy services, education, social care, housing, the individual/family/carers to ensure support services are offered at an early age.

Parents and carers' views and information about their family member with LD needs to be captured and understood during appointments and assessments and when support is put in place by health, social care or education.

Training & Awareness programme for professionals and carers as part of continuous development. More staff will be supported/trained in alternative communication techniques, such as Makaton, British Sign Language, picture communication to enable confident use of different communicative techniques with individuals and their families.

The NHS aims to have an additional 4,000 people training in mental health and LD by 2023/24, supported by increased funding for clinical placements. This will ensure increases to the current LD workforce within Stoke-on-Trent.

Parents and Carers

Carers are critical to the health and wellbeing of individuals with LD and we need to consider parents/carers in the same way as the paid workforce in providing support, training, information and a break from their caring role and involving them in the care of the person with LD, in line with the recommendation from MAZARs48.

Carers' own health and wellbeing needs to be supported to avoid crisis for families. There should be choice to ensure that the family and individuals within the family receive the most appropriate support for them. In Stoke-on-Trent, we have a Carers Strategy and provision in place that offers advice and information, respite, befriending and informal support.

There are a number of carers with their own health issues and support needs and as such, a family approach to support would be beneficial in this situation and where appropriate, additional support for carers and families who have individuals with multiple illnesses within the home.

Our actions to improve the health for people with LD will mean that as people live for longer, it may alter their end of life care needs. The Carers Strategy will address support needs as people with LD live longer and the event older carers are unable to continue their care provision.

ACTIONS WE WILL TAKE

- Develop a comprehensive, multi-disciplinary LD training package
- Develop multi-disciplinary teams
- Community directory to ensure good quality, accessible information, advice and guidance
- Introduction of mandatory LD training for all NHS staff



We will use the following measures to demonstrate progress

- Inpatient admissions.
- Numbers trained.
- Complaints, comments and compliments.
- Baseline survey.

SUPPORTING THOSE WITH LEARNING DISABILITIES WHO ARE PARENTS OR CARERS

Issues and things that affect people living with a learning disability

The exact number of parents and carers with learning disabilities living in Stoke-on-Trent is not known but it is likely that, as a result of moves away from institutional living over recent years, more people with learning disabilities are becoming parents. There is a wider group of parents who do not have a formal diagnosis but are considered to have learning difficulties, as a result of which they may struggle with some aspects of parenting⁴⁹. People with LD may also be caring for their parents and siblings informally as part of family life.

Parents and carers felt there was too heavy a focus on having a diagnosis if they needed help because of their LD, when the focus should be on need, on a whole family approach. Because thresholds in children's social care are quite high, some children are not known to services nor receive any support until they are adults and parents themselves. This, in some cases, leads to child protection issues and children being removed.

Social care told us that parental capability is sometimes being misunderstood and misdiagnosed as LD and this is preventing families getting the support they need.

What are we doing well?

We have a strong self-advocacy service known as Reach that brings together people with LD to share their experiences.

Joint approaches within social care have been developed to support those with LD who are parents or carers. This has included workshops with social care staff from both the children's services and adults' service. This has helped to address issues when the Family Court had instructed Care Act assessments.

What needs to change?

We need to take a whole family-based approach to supporting families, recognising the role and responsibilities of each person in the family and where there may be support needs.

We need to recognise parent abilities may be affected by their learning disability.

We need to support people with LD who may be caring for parents or siblings.

ACTIONS WE WILL TAKE

- Expand support for individuals with LD who are caring for children and young people and/or parents.
- Identify individuals with LD who are parents/carers who need support.

ADVOCACY

Advocacy is about enabling people who have difficulty speaking out to speak up and make their own, informed, independent choices about decisions that affect their lives. Advocacy is not about giving advice or making decision for people. In Stoke-on-Trent, we have independent advocacy⁵⁰ provision for children, young people and adults with learning disabilities, offered on a direct one to one basis. We also have group advocacy for adults⁵¹ and plan to extend this to children and young people.

To support the delivery of the outcomes, self-advocacy and group advocacy will be strengthened. We will work to ensure that people with LD understand and feel confident to:

- Speak up about hate and hate crime
- Speak up about health
- Express, explore and discover aims and ambitions
- Speak up about the lives they want to live
- Speak up about what they want to do and what they enjoy
- Feel confident to speak up about being a parent or carer

HOW WILL WE BE ACCOUNTABLE ?

Why accountability is important

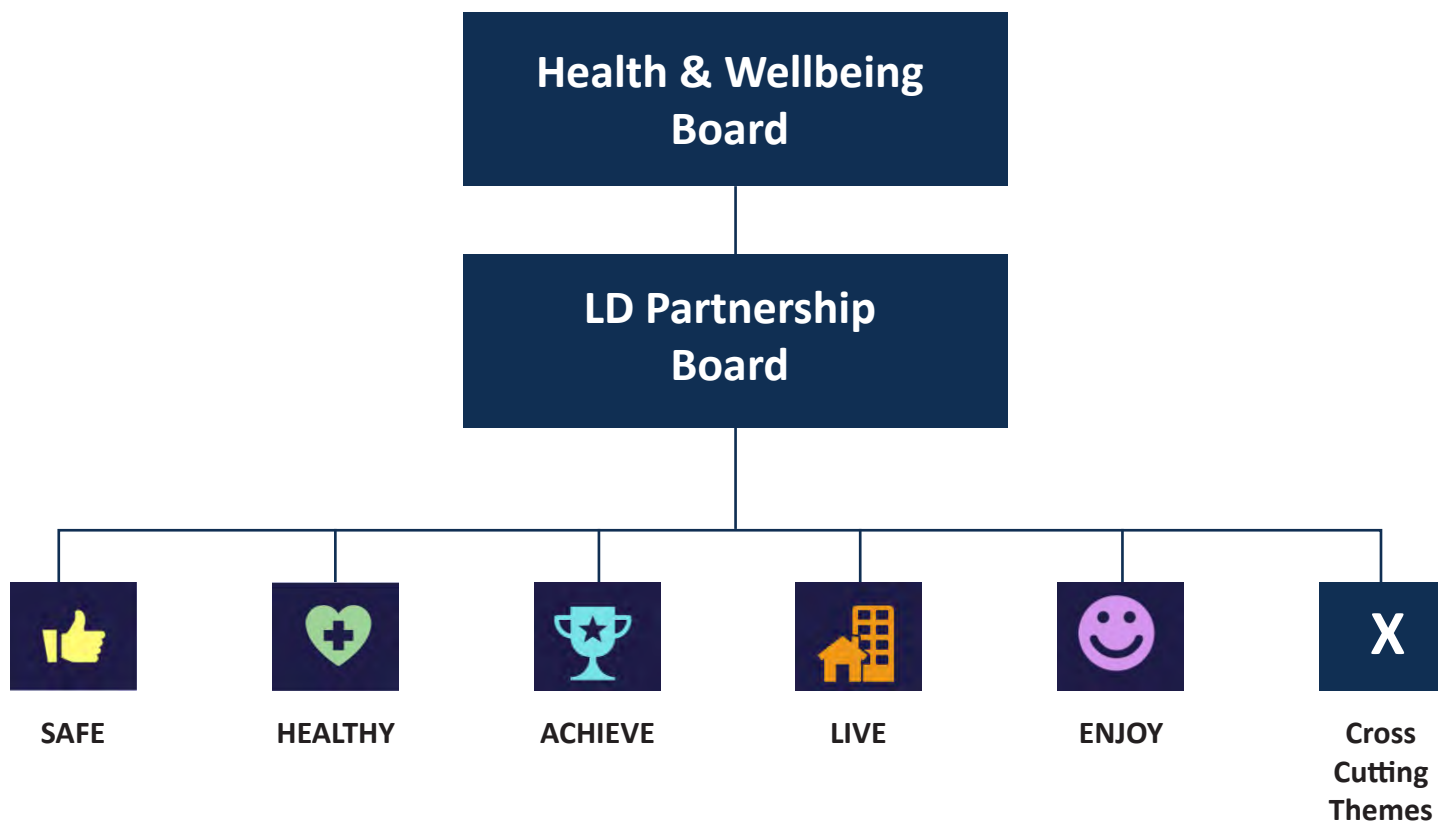
We need to understand the current situation individuals find themselves in in order, to create a baseline against which we can measure improvements and identify quickly where we are not meeting any of the outcomes. We also need to acknowledge the concerns, perceptions and experiences of children and young people, adults and their carers. Older carers particularly, whilst agreeing with the outcome's matrix, feel disadvantaged and that their lived reality is very different and somewhat challenging after years of budget cuts and service reductions.

How accountability will work

We will make sure that our strategy links in with other council and health strategic plans across Stoke-on-Trent and we will report to the Health and Wellbeing Board on our progress.

Leadership will be provided by the Learning Disabilities Partnership Board and the Inclusion Partnership Board. Each outcome will have a lead and co-chair (someone with LD). They will be experienced in the respective area of work and be able to lead and drive change. We will regularly review the membership of the Learning Disabilities Partnership Board and outcome leads to ensure the right people are involved. We will publish the notes and actions from Board meetings and the delivery plans. <http://www.equalpeopleinstoke.org>

Governance structure



Cross cutting themes:

1. Integrated approaches and workforce development
2. Supporting those with learning disabilities who are parents or carers

At an individual level, accountability will be via client feedback and satisfaction surveys within services and via self and group advocacy so that children, young people, adults and older people can tell us what is changing for them. The baseline survey will be repeated bi-annually.

WHAT THE FUTURE SHOULD LOOK LIKE

With an aging population, an increase in demand for services and a reduction in budgets, those organisations that are responsible for commissioning provision in Stoke-on-Trent need to explore more efficient ways of working to deliver the outcomes in this strategy. The cost of providing lifelong support services to a person with LD has been estimated at between £1M and £4.5M. Commissioning is the processes which include assessing the needs of people in an area, designing and then achieving appropriate outcomes. Any subsequent service provision may be delivered by the public, private or civil society/third sector.

To maximise the impact of the monies spent we need modern services, utilising assistive technology and other empowering approaches. We recognise the need for early help and intervention, particularly during childhood and early adulthood and then in later life to help keep people independent for as long as possible, living their best life. We will apply an asset based approach focussed on an individual's strengths, talents and circles of support.

Children, young people and their parents want a stronger focus on choice, independence and equality into adulthood. We propose , therefore, move away from the term “transition” and focus on removing barriers and delivering improved outcomes across the life course.

By working collaboratively, we intend to prevent the need for long-term care services. Our engagement and consultation exercises showed that that most people with LD do not actually need or want this kind of ongoing dependence. We also recognise the need for a whole family approach, to recognise and support carer capacity and capability as a parent and as an individual in their own right, especially when these people may also have LD themselves. We acknowledge that as we improve health outcomes for individuals with LD, then support needs as they get older will change as age-related issues such as dementia become a risk.

We will utilise continuous steps to promote social inclusion and increase an individual's ability to become an active citizen within their local community, to make their own choices, and have control over their own lives so that they can reach their full potential.

This will mean changing how we do things and we will need an effective workforce to help us. We can't make all the changes needed all at once, but by co-producing delivery plans for each outcome and cross cutting themes, we will be accountable about what we will do, who will do it and when.

Co-production

For many years, individuals with learning disabilities living in Stoke-on-Trent have been speaking up about what a “good life” looks like and we will continue to work with individuals , their carers and the people that support them to deliver the strategy. We will also use government reports, national strategies and the law to inform our work and learn from regional and national self-advocacy groups.

Co-production means different things to different people and we will build on the approaches we adopted to develop this strategy, linking to the Community Led Support principles to ask people how they want to be involved, whether this is by attending meetings, producing videos, poems and art or by being part of group and one to one discussions. Co-production is a two way process and we must also find accessible ways in which to report back on achievements and the impact and change that has happened as a result.

We should not underestimate the time and continual effort that will be required to form and maintain local partnerships and develop the strong and trusting relationships required for success. We will produce an engagement strategy to support this approach and a communication plan to show how we will keep in touch.

CONCLUSION

We want to improve outcomes for people with LD, across the life course. The outcomes in this strategy are all connected, if people feel safe then they feel connected in their community and will have a life that is fun, happy and healthy.

The values and principles in this strategy are important to the outcomes. People, regardless of their age, want to be listened to and to be treated with respect. They want freedom to choose their best life, a connected life with purpose and peace of mind. We heard that Stoke-on-Trent is a beautiful place to live with places to visit and meet friends. We heard that parents and carers want to ensure a positive future for their loved one. We heard and felt the goodwill and eagerness from professionals to work together to bring about the change required. There are many elements of change needed and we need to present this in a tangible and simple way, so partners and stakeholders can understand how and when we will be focussing on key areas so children, young people, adults and older people with LD in Stoke-on-Trent **Live their best life**

CONTACT US

If you want to tell us something about the Living My Best Life strategy or you would like to get involved you can contact us:

commissioningandpartnerships.sp@stoke.gov.uk , putting “LD consultation” in the subject heading

APPENDIX 1

Life course outcomes matrix

Outcomes	Children & young people	Adults & older people
Safe I feel safe within, and valued by, the community in which I live and the environments I am in	I am happy and safe at a school that is as close to home as possible. I feel valued as an individual, cared for and respected by the community. I am free from bullying and know how and who to ask for help if it happens. I feel understood by the police and justice system if I come into contact with them.	I can get around freely and safely. I feel valued as an individual, respected and cared for by the community. I am able to access community activities and facilities and connect with other people. I am free from hate and mate crime and know how and who to ask for help if it happens. I feel understood by the police and justice system if I come into contact with them.
Healthy I have equal opportunities to good health and wellbeing	I can use high quality health services that are co-ordinated in ways that meet my needs. I am happy and fulfilled, feeling physically, mentally and emotionally well. I am able to make informed choices about healthy and safe lifestyles as I get older and given lots of opportunities to be physically active.	I can use high quality health services that are co-ordinated in ways that meet my needs. I am happy and fulfilled, feeling physically, mentally and emotionally well. I am socially connected. I expect to live as long as other people that don't have learning disabilities.
Achieve I am aspirational in my life goals which are purposeful and valued	I have opportunities to develop my education and skills and am encouraged to make the most of my abilities. I have a past, present and future with people who are important to me. I get the right support to help me influence and make choices about my life and the future.	I can choose to have a job. I can volunteer and contribute to the community, if I choose. I have opportunities to continue developing and using my skills and make the most of my abilities. I have a past, present and future with people who are important to me. I know where I can get help or support to make informed choices about my life. I am supported to be financially independent

Outcomes	Children & young people	Adults & older people
Live I live in a home that I choose, with who I choose, that meets my needs.	I live with family/carers or in another environment that meets my needs and where I can thrive. I am able to choose who and where I live as I get older.	I have choice as to where and with whom I live, family/carers/ Independent/supported living. I have as much independence as I choose. I feel safe, cared for and I can thrive.
Enjoy I have equal opportunities to a good quality life, to feel included in my community and enjoy my life.	I have a wide range of social and leisure opportunities and activities to choose from. I have friendships and relationships that are good for my wellbeing. I am able to connect with friends in person and on line.	I have a wide range of social and leisure opportunities and activities to choose from. I have friendships and relationships that are good for my wellbeing. I am able to make my own decisions even if they are considered unwise or risky by others.

REFERENCES

- ¹The learning disability improvement standards for NHS trusts (June 2018), High impact actions for service improvement and delivery by Transforming Care Partnerships (published November 2016), Building the right support (published October 2015), Children's Commissioning Strategy, Transforming Care for People with Learning Disabilities – Next Steps; progress report (published July 2015), The Care Act 2014, Children and Families Act 2014, The Health and Social Care Act 2012, SEND 2018 Protocol, Winterbourne View – Time for Change 2014, The Housing Act 1996; Out of sight – who cares?: Restraint, segregation and seclusion review CQC 2020 www.cqc.org.uk/publications/themed-work/rssreview
- ²www.mencap.org.uk/learning-disability-explained/what-learning-disability
- ³www.mencap.org.uk/advice-and-support/children-and-young-people/send-system
- ⁴Inclusion Strategy.
- ⁵www.autistica.org.uk/what-is-autism/signs-and-symptoms
- ⁶Link to Autism Strategy.
- ⁷Stoke on Trent Carers Strategy put link
- ⁸Inclusion Partnership Strategy put link
- ⁹People's real names are not used and composite case studies are sometimes used to illustrate a point
- ¹⁰www.equalpeopleinstoke.org
- ¹¹Insert link to Engagement on CCG website
- ¹²www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder
- ¹³www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability
- ¹⁴www.stoke.gov.uk/directory_record/333579/joint_strategic_needs_assessment
- ¹⁵www.gov.uk/government/publications/prevent-duty-guidance/revised-prevent-duty-guidance-for-england-and-wales
- ¹⁶HM Government (2010) Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children. London: Department for Children, Schools and Families
- ¹⁷A report from Warwick University published in 2015 (Bullying Experiences of disabled children and young people in England) found that 80 per cent of young people with learning difficulties reported experiencing bullying
- ¹⁸Dimensions UK Autism and Learning Disability hate crime survey, 2016
- ¹⁹challengenorthstaffs.org
- ²⁰During 2019-20, 124 incidents, covering physical/sensory disability, autism, learning disability and mental health, were reported by five individuals. All except one were older males. This was a substantial decrease on 2018-19, when 444 incidents were reported by 28 individuals
- ²¹Reasons include: not understanding they are subject of a hate crime; incidents being classed as anti- social behaviour; a belief that agencies and organisations will not be able to do anything therefore negating the point of reporting. There is also a sense of isolation and resignation, with the individuals affected being of the view that they just have to put up with it, especially when problems have been going on for many years.
- ²²It is estimated that 25 to 30 per cent of children and young people in the Youth Justice System (i.e. not necessarily in custody) have learning disabilities, and that around 50 per cent of those in custody have learning difficulties (HM Government, 2009).
- ²³It has been estimated that the proportion of people in prison who have learning disabilities or learning difficulties that interfere with their ability to cope with the criminal justice system is around 20-30%.
- ²⁴The Revolving Doors Agency, a charity specialising in the criminal justice system
- ²⁵www.cps.gov.uk/crime-info/hate-crime
- ²⁶www.safeplaces.org.uk/member-schemes/stoke-on-trent/
- ²⁷Eric Emerson, Susannah Baines Lancaster University, UK "Health inequalities and people with learning disabilities in the UK" 2011
- ²⁸digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019

²⁹NHS England, the Healthcare Quality Improvement Partnership (HQIP) and the University of Bristol led the world's first national programme to review – and ultimately reduce – premature deaths of people with learning disabilities (June 2015).

³⁰phescreening.blog.gov.uk/2018/11/21/supporting-women-with-learning-disabilities-to-access-breast-screening/

³¹Respiratory disease - Public Health Profiles

³²Raj, D., Stansfeld, S., Weich, S., Stewart, R., McBride, O., Brugha, T., ... & Papp, M. (2016). Chapter 13: Comorbidity in mental and physical illness. In S. McManus, P. Bebbington, R. Jenkins, & T. Brugha (Eds.), Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. Leeds: NHS Digital

³³www.cqc.org.uk/news/stories/different-ending-our-review-looking-end-life-care-published

³⁴The latest LeDeR 2019 Annual report highlights recommendation 4 – Coordination of Care “Consider the recommendations from the ‘Best practice in care coordination for people with a learning disability and long-term conditions (March 2019).

³⁵In line with MENCAP 2007 Report

³⁶www.england.nhs.uk/publication/stomp-stamp-pledge-resources/

³⁷This includes:

- Developing Positive Behaviour Support clinics to enhance medication monitoring
- Training staff across the LD Directorate to provide patient centred care
- Undertaking a comprehensive functional assessment and created discharge plans
- Intensive Support/Community LD team supports patients following a discharge

³⁸On a like for like basis and taking into account population growth. For every one million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit. For children and young people this will be no more than 12 to 15 children with a learning disability, autism or both.

³⁹NHS five year forward view (Forward View) Oct 2014

⁴⁰poverty, poor housing conditions and unemployment.

⁴¹Small support organisations have a number of things in common including: planning and delivering in a truly person centred way; person led staff recruitment and training; structuring and using funding around the person; a separation of housing and support; strong partnerships between the individual and family, commissioners, and providers; and staying small.

⁴²Challenging and self-injurious behaviour, Sleep difficulties, developmental difficulties including the acquisition of skills such as continence and dietary/feeding issues and psychological and mental health conditions

⁴³www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability

⁴⁴improvement.nhs.uk/documents/2926/v1.17_Improvement_Standards_added_note.pdf

There are 4 aspects to this : 1. Respecting and protecting rights 2. Inclusion and engagement 3. Workforce 4. Specialist learning disability services

⁴⁵digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof

⁴⁶www.keyring.org/what-we-do/support-networks

⁴⁷Out of sight – who cares?: Restraint, segregation and seclusion review CQC 2020. www.cqc.org.uk/publications/themed-work/rssreview

⁴⁸Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015 December 2015

⁴⁹www.researchinpractice.org.uk/children/publications/2019/april/supporting-parents-who-have-learning-disabilities-strategic-briefing-2018/

⁵⁰For children and young people - CGL www.changegrowlive.org/stoke-staffordshire-childrens-rights/independent-advocatesforadultsAsist <https://www.asist.co.uk/>

⁵¹Reach reach-advocacy.com/



