

My Life, My Choice

A strategy for people with learning disabilities in Cheshire East

2018-2022

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Executive Summary

Introduction

The 'My Life, My Choice' strategy sets out the vision, ambitions, and commissioning intentions for people with learning disabilities of all ages living in Cheshire East. The main aim of the strategy is to ensure that all individuals can live a healthy, happy and independent life with choice and control over the care that they receive. It will mean a shift in the way we do things here at Cheshire East, from a professionally led model of care and support which sees the individual and their families as recipients of service, to a truly collaborative model where the professional is an equal partner to the individual and their carer. As suggested in the NICE guidelines [1] we will be taking a 'whole life' approach from early childhood onwards which will help enable smooth transitions into adulthood, whilst still addressing the needs of different age groups.

Who is the strategy for?

The 'My Life, My Choice' strategy is for everybody who lives in Cheshire East who has a learning disability. A learning disability is defined by the Department of Health 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].

SEN (Special Educational Needs)

Throughout the strategy, we will use the term SEN when referring to a child or young person with learning disabilities. A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her [3].

The 0-25 SEND Partnership is a multi-agency partnership arrangement which leads and drives developments around support, processes and provision for children and young people with Special Educational Needs and Disability (SEND) aged 0-25 years in Cheshire East. For more in depth information in relation to improvements for children and young people with SEND, please see the SEND Developments section of the Cheshire East Local Offer for SEND. This includes information on the 0-25 Partnership, the Children and Young People with Special Educational Needs and/or Disabilities Joint Strategy and the Cheshire East Written Statement of Action for SEND. However, the overarching principles in the 'My Life, My Choice' strategy remain the same in that we will ensure that support is person-focused, inclusive and within local communities wherever possible.

In order to ensure that this strategy, and the consequent commissioning intentions which will stem from it, has a

focused target group, we have decided to focus on learning disabilities and not physical disabilities and autism spectrum condition. We wanted to ensure that services are designed around the needs of the individual and are not a 'one size fits all'. However, autism will be referenced within our ten areas of priority, as we recognise that autism and learning disabilities are closely linked and around four in ten people with autism may also have a learning disability [4]. Strategies for both physical disabilities and autism spectrum condition will be produced in the near future.

We recognise that people with learning disabilities can often struggle with mental health issues alongside their disability diagnosis and a separate mental health strategy has been produced in conjunction with this strategy to support individuals with their mental ill-health.

We appreciate that in order for the strategy to be a success and truly embedded into our practices, we must work with our partners collaboratively and ensure the work we do is integrated with our health colleagues, education and neighbouring authorities.

Financial Challenges

With an aging population, an increase in demand for services and a reduction in budgets, we need to explore more efficient ways of working in order to help reduce costs. We will utilise assistive technology and modernise services where possible and we will emphasise the need for early help and

intervention, particularly during early childhood in order to keep people independent for as long as possible. By encouraging and supporting individuals to take control of their own life and refrain from using services unless absolutely necessary, we will be able to support the most vulnerable people in our society to live long and fulfilled lives. We will continue to meet our statutory requirements and will adhere to the policies set out in the legislation including The Care Act 2014, The Children and Families Act 2014 and the Mental Capacity Act 2005.

Co-production

In line with the NICE guidelines and the Cheshire East Council Commissioning Framework, the strategy has been co-produced with parents, carers and individuals with a learning disability as we are committed to listening to the user voice and incorporating it within our strategy and future commissioning intentions. We will continue to work with a variety of people who are involved in the care received by people with learning disabilities as we work through the proposed areas of focus which will be discussed later. However, the individual with learning disabilities will always remain at the centre of all planning and provision, with their best intentions being at the heart of everything we do at Cheshire East.

Gathering data to feed into the strategy has been one of the main barriers which we have faced and this is an area that we

would like to work on in order to inform our future commissioning intentions. The systems and processes used in children's services differ significantly to adults' services and we will aim to align these processes to ensure that the data is accessible and accurate. A Joint Strategic Needs Assessment (JSNA) for Learning Disabilities will be produced in 2019/20 which will look at our current and future health and care needs in Cheshire East.

Our Vision

The Cheshire East Council Learning Disability strategy 'My Life, My Choice' supports the National Model Vision Statement as defined in: **Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition**, which states:

Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life [5].

In addition to this, we want all our children and young people with special educational needs to be **HAPI: Happy and**

healthy, **Achieving** their potential, a valued **Part** of their community, and supported to be as **Independent** as possible and to make choices about their own future [6].

We want to empower individuals to make their own choices on the support that they receive from our commissioned services rather than being fitted into a particular service with no say in the matter. We will take an assets based approach where we build on the strengths of our community and look at what people can do, as opposed to what they cannot do.

We want employees from across the Health, Education and Social Care sector to continue to work together and build on these relationships so that individuals with learning disabilities only have to tell their story once. Our vision applies to everybody who lives in our borough who has some degree of learning disability, no matter how small or big. This includes those individuals who may not be known to Social Care as we want to support them to remain living independently for the rest of their lives.

Our approach will emphasise the importance of accessing universal services such as health, housing, schooling, further education and leisure which others may take for granted. We want to focus on early help and prevention with specialised services only being used where most needed. By promoting independence and universal services we will be able to focus on enhancing the lives of the most vulnerable people in our community.

Learning disabilities are lifelong disabilities. The primary function of the Cheshire East Council Learning Disability Service is to enable as many people as possible to achieve their maximum autonomy and independence to the point where they no longer need to rely on adult social care intervention and support. Where individuals have reached their maximum level of autonomy and independence, but still need to rely on publicly funded support, then this will continue lifelong [7]. For individuals who have more complex needs we will celebrate the small steps that they take towards maximising autonomy and enhancing their lifestyle.

The Government's White Paper 'Valuing People Now' states that all local authorities should have a Learning Disability Partnership Board. The aim of the Partnership Board is to improve the lives of adults with learning disabilities and to help make sure that the needs of people with learning disabilities in Cheshire East are met. The membership of the Cheshire East Learning Disability Partnership Board is currently lacking and we will aim to rectify this by reviewing the board and ensuring that the terms of reference are being met. We want the Partnership Board to be a powerful and effective forum for people with learning disabilities and a catalyst towards positive change.

Our Priorities

In order for us to meet the ambitions of our vision, we will focus upon ten key areas:

1. Community Inclusion

We will ensure that all individuals with learning disabilities have the opportunity to fully integrate within their local community with access to universal services. We will raise awareness about learning disabilities so that our residents can be welcoming and inclusive of all individuals with varying needs and do not discriminate against those with additional needs.

2. Early Help

We want to make sure that there is early help and diagnosis for parents of a child with learning disabilities and provide the right support from the outset.

3. Life Changes (Transition)

We will ensure a seamless transition for children entering adulthood and will encourage independence from an early age so that individuals do not become dependent on services and are able to live a fulfilled life with the same opportunities as anybody else.

4. Education & Employment

We will support individuals in seeking both paid and voluntary work, including supported internships across a range of sectors. We will ensure that schooling is inclusive, effective and close to home.

5. Short Breaks

We will improve our offer for parents, carers and people with learning disabilities so that they can access a range of short breaks which are enjoyable, fulfilling and stimulating.

6. Assistive Technology

We will ensure that we utilise assistive technology where possible and lead the way with innovative applications and devices which help promote independence and keep individuals safe.

7. Housing

We will ensure that everybody has the opportunity to live in their own home, within a community setting, their own front door and access to local amenities. We will improve the housing offer available and seek to provide choice, opportunities and support with transition into adulthood.

8. Workforce Development

We want to actively promote careers in Social Care and create development pathways into more senior roles within the sector. We want our workforce to be equipped with the skills to effectively interact with people with learning disabilities and constructively manage behaviour that challenges. We will ensure that

our workforce encourage engaging interaction and activities which are age appropriate and take into consideration the needs of the individual.

9. Mortality, Health and Transforming Care

We will address the health inequalities faced by people with learning disabilities and improve both physical and emotional wellbeing to ensure that individuals are not disadvantaged. We will work with our health colleagues to ensure that the delivery of the transforming care programme is successful.

10. Autism

We will ensure effective pathways are in place for children and young people with autism and unreasonable waiting times are addressed. We will also produce an all-age autism strategy and refreshed JSNA to inform the future commissioning intentions for Cheshire East Council.

How will we measure success?

The success of the learning disability adult service will be judged by its contribution to the following indicators:

- 1) The service budget will be committed to support individuals wherever possible within the indicative budget generated from the Care Act assessment.

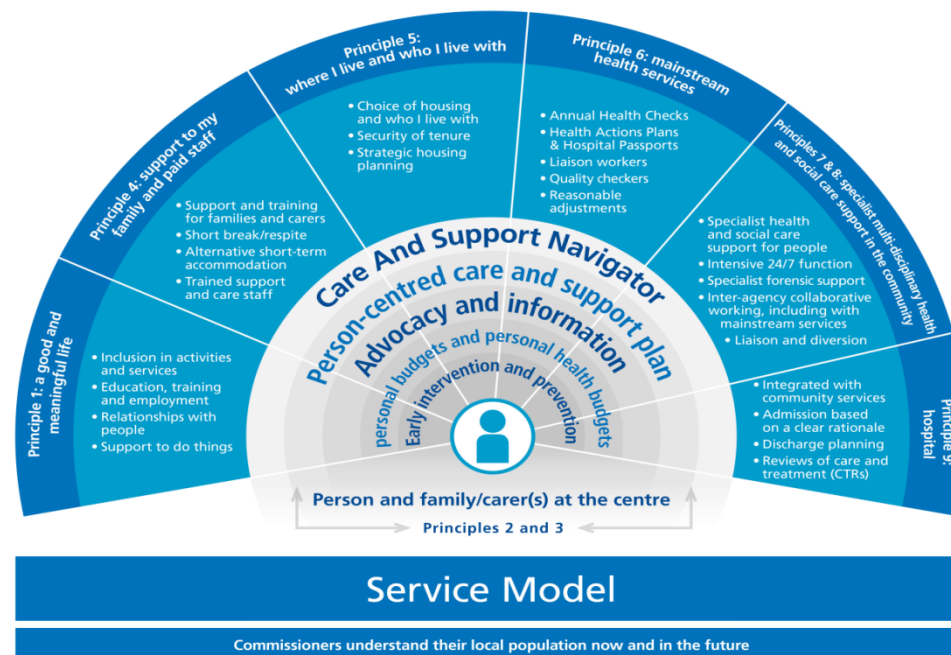
- 2) The number of assessments of people aged 18 between April 1st and March 31st, the following year will be completed before they reach their 18th birthday.
- 3) The number of adults with a learning disability in settled accommodation
- 4) The number of adults with a learning disability in employment
- 5) The number of carers who have had an assessment, either jointly or separate to the service user. [8]

For children and young people, the following sources will be used to inform us on how well we are performing, what's working well and what we need to take action on to achieve change:

- 1) Multi-agency audits will be developed to evaluate the quality of our work to support families across the partnership. Findings from these will be reported to the 0-25 SEND Partnership Board
- 2) A SEND scorecard is in place which is reported to the 0-25 SEND Partnership Board for scrutiny. This scorecard considers a variety of information, such as the number of children and young people with Statements of SEN and EHCPs by primary need, age group and locality, the number of requests for EHCP assessments and the timeliness of completion, and where children and young people access education.

- 3) Feedback surveys, consultation events, work with the Cheshire East Parent Carers' Forum, and feedback on the Local Offer will continue to inform further service developments. Mechanisms for gaining feedback on EHC Assessments and Plans, and our Local Offer (both our provision and the quality of support) will be developed and established.
- 4) Practitioners' views will continue to be sought through consultation events. [9]

The following nine principles from the National Service Model will underpin the strategy and the services commissioned from Cheshire East. They will also act as the success criteria for the services we deliver.



Where are we now?

National Context

There have been some significant changes in national policy in recent years, in particular The Children and Families Act 2014. The Act takes forward the Government's commitment to improve services, life chances, and choices for vulnerable children and young people, and to support strong families [11]. It supports the idea that all children and young people can succeed, no matter what their background. The Act also extends the SEND system from birth to 25 which highlights the importance of taking a 'whole life' approach with children's services and adult's services working closely together and aligning processes to ensure a seamless transition into adulthood.

The Government's Mandate to NHS England 2014-5 states:

"One area where there is a particular need for improvement, working in partnership across different services, is in supporting children and young people with special educational needs or disabilities. NHS England's objective is to ensure that they have **access to the services identified in their agreed care plan**, and that parents of children who could benefit have the option of a **personal budget** based on a **single assessment across health, social care and education**".

Need in Cheshire East

There are an estimated 378,800 people living in Cheshire East, with approximately 75,800 children under the age of 18 and 303,000 adults [12].

Cheshire East Council has a JSNA for children and young people with special educational needs and/or disabilities that was published in July 2017 and a JSNA for people with autism that was published in December 2017 (see Appendix for links to both documents).

3,566 children and young people receive SEN support in Cheshire East and 1,891 children and young people aged 0-25 in Cheshire East have specialist needs and have an Education, Health and Care Plan (EHCP) or a statement of SEN [13]. A number of children will have their needs met through universal support within Quality First Teaching and Learning or First Concerns.

Currently there are 1,138 adults with a learning disability known to Cheshire East. However, it is likely that there are many more adults with learning disabilities living in the wider community who do not receive support from the council and are therefore not included in these numbers.

Cheshire East has an ageing population which means that there is a significant increase in the number of people in the older age groups, and a decrease in the number in the

younger age groups. By 2020, over a quarter of the Cheshire East population will be aged over 65, greater than the UK average [14].

Profound and Multiple Disabilities

In addition to our aging population, due to advances in medicine and care, more young people are living longer with complex disabilities, therefore we need to ensure that our services can accommodate for this change in demand.

There is a lack of adequate services for people who have learning disabilities as well as physical disabilities and people with learning disabilities whose needs are related to ageing [15]. The council needs to support the older population with learning disabilities and ensure that individuals are not disadvantaged in any way.

Where needs are so complex and rare with only few numbers of people requiring a specific type of specialist support, Cheshire East Council will endeavour to joint commission services with neighbouring authorities who also need to cater for a similar small group of individuals. This collaborative approach will ensure that the individual receives the best quality of care possible to meet their profound needs.

Our Priorities

Community Inclusion

Historically, people with learning disabilities have been removed from their communities and institutionalised in buildings which offered little or no option to integrate with the community around them. We have come a long way over the years to take positive steps to change the direction of social inclusion but we still have a long way to go.

We want to ensure that people of all ages who have a learning disability are fully integrated within mainstream society and do not face stigmatisation or fear. We will support individuals as much as we possibly can to equip them with the skills needed to help live a fulfilled and independent life.

We will build on the community assets we have here in Cheshire East, such as green spaces, parks and swimming pools. We will also promote and signpost people with learning disabilities to the local community groups that we have to offer which help people to build relationships and facilitate a variety of life skills. There are already a vast amount of community and youth groups on offer for people with learning disabilities which can be found on the [Live Well](#) website.

Early Help

According to Mencap there are 15,000 children born each year who have a learning disability. Children with learning disabilities are more likely to face issues such as poverty, physical and mental health problems and difficulties at school [16].

As a local authority, Cheshire East will ensure that through early help and intervention, we will support children and their families in the early years in order to reduce the chances of children developing further issues later on in life. As soon as the needs are identified, appropriate support should be offered to families and carers in order to assist the child to remain happy, independent and living at home.

One way in which we will support parents is through our first point of contact. We will provide good quality information and signpost parents to universal services which can be accessed within the community. We will ensure that the Live Well website pages are up-to-date and a true reflection of the services on offer in Cheshire East.

In addition to Live Well, a requirement of the Children and Families Act 2014 is that every local authority needs to publish a Local Offer for SEND. The [Cheshire East Local Offer](#) includes information about the support and provision that families can expect from a wide range of agencies for children and young people with SEND from birth to 25 years

old. We encourage our families and professionals to utilise this tool so that they can gather clear, comprehensive and up-to-date information about the available provision and how they can access it. We also encourage families and professionals to provide feedback if there is anything you feel is lacking or that needs updating.

We recognise that financial hardship is one of our main barriers to successful early intervention and prevention; however it is important that we invest in this cohort of people from the outset so that families feel supported, children are living fulfilled lives and the risk of dependency is reduced.

Mainstream services like nurseries and schools must be inclusive for children with a learning disability, with early years professionals trained to meet a wide range of needs [17]. Activities must be stimulating and tailored to the needs of the individual.

The Cheshire East Council Parent Carer Forum is a useful opportunity for parents to come together and discuss any issues that they may have and also to share good practice. Our parents of children with learning disabilities in Cheshire East have expressed that the current forum is largely focused on autism and attention deficit hyperactivity disorder (ADHD) and it is therefore difficult for some parents to have a voice at times. We will aim to rectify this by reviewing the current parent carer forum, refreshing the terms of reference and ensuring that agenda items are specific and varied. We will

ask our parents and carers for feedback to ensure that the proposed changes have been effective.

Life Changes (Transition)

Cheshire East Council recognises that transition is a vital area that we need to get right for our young people with learning disabilities. Transition is an ongoing and developing process that enables young people to be better prepared for adulthood. It is not a single event or meeting but happens over a period of time between the ages of 14-25. Our vision is that: *all Cheshire East young people with Special Educational Needs and Disabilities (SEND) will benefit from a seamless transition process, which builds on high aspirations as they become citizens.*

Education, Health and Social Care work together with young people and their families to ensure that there is early planning not just from 14 but also in the early years. This planning must build on children and young people's strengths, needs and desired outcomes around preparing for adulthood (PfA). These outcomes are: employment, independent living, participating in society and being as healthy as possible. There is a strong governance structure in place through the SEND Partnership Board and the Preparing for Adulthood work stream which is developing pathways to improve these outcomes for young people. It is important to plan for this transition period by sharing information in a timely manner and working collaboratively to identify any gaps in need and

ensure that the right support is in place which will meet young people's needs in the long term. We will work with young people and their parents/carers to guide them through the transition period explaining the importance of the young people being involved in decisions about their support and their capacity. Other changes such as financial assessment and charging for care and support when the young person turns 18 will also be explained. The local authority uses data from public health and internal departments to forecast and plan to ensure sufficiency of provision e.g. opportunities to learn independent living skills. By focusing on what children are good at from a young age this promotes their independence and means that everyone can work together to ensure that they are happy young adults who are valued members of the community. This gradual approach will enable young people to achieve their full potential.

We accept that one of the barriers for successful transition is the lack of creative commissioning that we currently have at Cheshire East and we intend to offer more choice and improve our local offer so that people entering adulthood can experience independent living and everything that comes with it such as cooking, cleaning and ironing before they reach 18. We hope that by offering and encouraging such taster sessions, our children and young adults will be excited by the prospect of adulthood and any anxieties they may have will be reduced.

We also recognise that transition does not always refer to young people entering adulthood and there are other forms of transition which need to be supported too. For example, an individual with learning disabilities who has lived with parents all their life and suddenly their parents pass away. Appropriate plans should be in place for such events and individuals will need to be supported effectively throughout this transitional period in their life.

In addition, people with learning disabilities who transition into parenthood will also require effective support and guidance. The exact number of parents with learning disabilities 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 [18].

The **6 Ts** show in a simple format what staff need to be able to do (and the resources that need to be available) to work well with parents with a learning disability.

Time

Extra time is needed to get to know parents and communicate appropriately with them. Parents need more time to take on board information/new skills/knowledge.

Trust

Parents and practitioners need to trust each other for the support to be effective; time is needed to develop this trust.

Tenacity

Workers need to keep working on issues with parents over the longer-term, as necessary.

Truthfulness

Practitioners need to be honest with parents and be really clear what the issues are.

Transparency

Practitioners need to be really clear about what is happening, when and by whom.

Tailored Response

Working with parents in a way that works for them. [19]

We know that change can be difficult to handle for anybody, let alone those with additional needs, so it is crucial that they are actively involved in decision making and that they have the right information to make informed decisions. If the person lacks capacity to make a decision, then the Mental Capacity Act 2005 applies.

What people with learning disabilities have told us?

I don't like sudden changes, it makes me feel scared

My mum is 75 and my dad is 82 so I need to think about where I will live when my parents are not around

How will we measure our success?

- Post 14 years Education, Health and Care plans and subsequent transition reviews will reflect PfA outcomes
- Increase in SEND learners in supported internships, apprenticeships, supported or open employment
- Reduction in SEND Not in Education, Employment or Training (NEET)
- Increased numbers of successful transitions into Adult Social Care (assessment and support in place in a timely manner with no gaps in service and good outcomes for young people)
- Percentage of Care Act eligible young people who have an assessment of their needs before 18

[20]



Employment

National figures show that there are more people in work than ever before (32.39 million) and the employment rate is 75.6% which is the highest since records began in 1971 [21].

However, unfortunately the picture is not quite as positive for individuals with disabilities. The disability employment rate currently stands at 32.2% equating to 3.8 million disabled people not in work. The Government manifesto pledge is to halve the disability unemployment gap by the end of this Parliament. According to National Government estimation, 65% of adults with learning disabilities want to work and locally this equates to around 591 people with learning disabilities known to Cheshire East Council Adult Social Care who want to work. We want to support these people as much as possible whether it is through voluntary opportunities in the first instance, supported internships or paid work from the outset.

1
1

We know that work opportunities promote health and well-being, contribute to a sense of identity and personal achievement as well as offering a social network of support, among many other benefits [22]. We appreciate that work is not for everybody but the option should always be there and nothing should ever be assumed.

Currently, 11.6% (106 individuals) of the people with learning disabilities known to Cheshire East are in paid employment. Although this is better than the national average of 5.7%, we

recognise that it is still worryingly low. We want to align locally with the national pledge of halving the disability gap which would mean supporting a further 316 social service clients with learning disabilities into work by 2020. We recognise that this will be a challenge but one with extremely positive outcomes for the individual, the employer and Cheshire East Council.

As a local authority we will take an asset based approach and look at what people can do, as opposed to what they cannot do. We accept that learning complex tasks may be more difficult for individuals with additional needs, but it is by no means impossible with the right support. We also realise that for the first few months, or perhaps longer, people will need additional support and guidance.

As you can see from the figures below, the vast majority of our adults with learning disabilities are not being paid or seeking work (722 adults). One way that we aim to minimise the growth of this figure is via support to transitioning cohorts. We aim to boost the numbers of people taking up supported internships in Cheshire East. Supported Internship schemes place individuals with learning disabilities into an unpaid internship for a minimum of 6 months. The scheme equips individuals with skills that they need for work, through learning in the workplace and supports people to go on to secure paid employment after the internship is complete.

The Council have recruited a Supported Internship Coordinator to manage this.

	Gender		
Employment Status	Female	Male	Grand Total
Paid, under 16 hours	28	28	56
Paid, 16+ hours	15	35	50
Not Paid, seeking work	8	13	21
Not Paid, not actively seeking work/retired	287	435	722
Unknown	33	28	61
Grand Total	371	539	910

Table 1



In 2017 the Council formed a Welfare to Work partnership for the Cheshire East area. This is a partnership of all organisations that have any input into supporting disadvantaged people into work. The work of this group has focused on coordinated employer engagement, transition coordination, reducing service/geographical service gaps/overlaps and the production of a directory of services. One of the clear messages from the partnership is the severe lack of available support for people wanting paid work of less than 16 hours a week. This key piece of information has been fed into sub-regional discussions regarding the intended focus of unallocated ESF money (£2.9m available in measure 1.4) and will also be fed into the future commissioning intentions of the Council.

People with learning disabilities have told us

I love volunteering at Brownies and I have become a leader now. I would love to have paid work too but nobody will give me the support I need

I would love someone to support me into paid work for six months or so until I feel settled. They could gradually stop supporting me after that. I just want a chance

Education

95% of schools in Cheshire East are currently judged Good or Outstanding by Ofsted [23]. The national figure is 89% so we have a good foundation to build from.

The Cheshire East Toolkit for SEND outlines the provision and support that Cheshire East Council expects to be in place in all educational settings which support Cheshire East children and young people aged 0-25 with Special Educational Needs (SEN), and forms an important part of the Cheshire East Local Offer for SEND. Its purpose is to provide detailed guidance on how educational settings can identify children and young people with different types and levels of

need (as visualised by the Cheshire East Continuum of Need for SEN), and information on appropriate steps and strategies to support them. It provides clear information about when a request for an Education, Health and Care needs assessment, or specialised services, may be required.

The Toolkit describes our graduated approach to meeting special educational needs and outlines our expectational needs and outlines expectations for reasonable adjustments to be made in order to ensure that the majority of children have their needs met through mainstream provision (in line with The SEND Code of Practice January 2015). This will support the ethos of community inclusion and allow children with special educational needs to enjoy their lives and experience the same opportunities as their peers. We want to ensure that Cheshire East pupils with SEND are exceeding the national average across the board for all attainment measures.

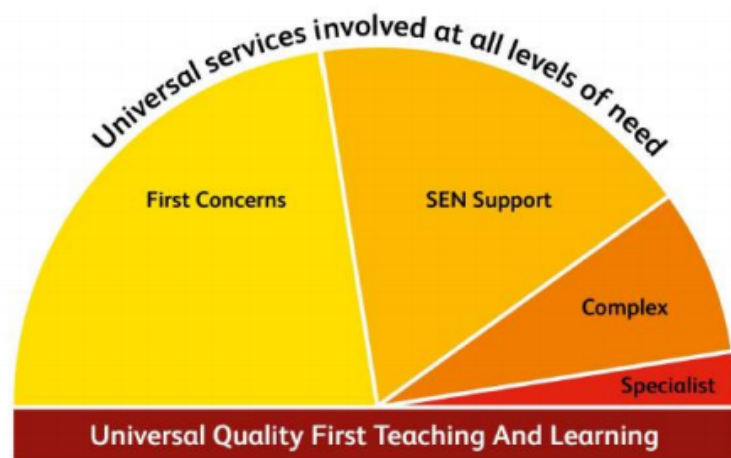


Diagram 2 [24]

Where children and young people require specialist educational provision (in line with our Continuum of Need for SEN and graduated approach as described in our Toolkit for SEND), we will aim to reduce travel times and bring them back closer to home. However, for those individuals who are able to receive education in a mainstream setting, it is crucial that the education system supports these children and that staff within settings have access to appropriate resources and training that enable them to meet the needs of our children and young people with SEND.

Short Breaks

The Care Act 2014 stipulates that local authorities are required to assess a carer's needs for support which means that more carers are entitled to an assessment. It also states that the local authority needs to decide if the carer's needs are "eligible" for support from the council and agree the best way to meet those needs. This could be by providing support directly to the person they care for.

Cheshire East Council are currently reviewing the short break offer for adults as we recognise that there are gaps in the services we currently provide to both carers and the cared for. We want to move towards a more personalised and flexible way of providing short breaks to our families and people with learning disabilities and in a recent survey that was carried out by the local authority, some carers said that they would like an alternative to bed based residential provision.

What has Cheshire East proposed?

Our vision for Cheshire East Adult Respite/short breaks is for an effective range of support services to be available to the cared for person and carers where appropriate, offering a range of personalised options, appropriate to meet the needs of many and offering best value.

The service must focus on providing timely and appropriate support to the cared for person and carers, which enables them to achieve a healthy balance in their role as a carer and where suitable, providing support to the cared for person which promotes their independence and wellbeing.

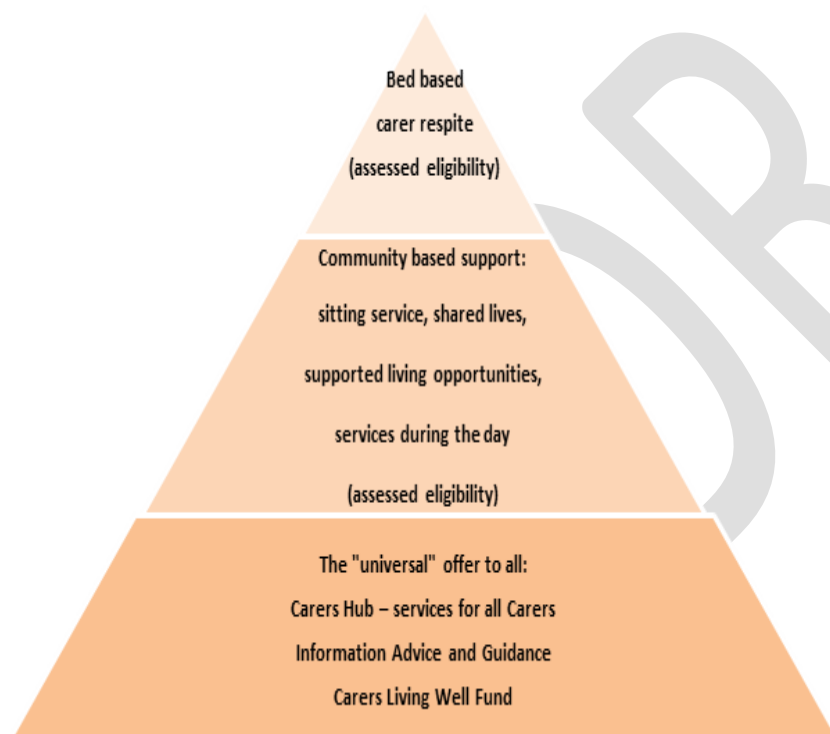


Diagram 3

Diagram 3 displays the new model for short break support in Cheshire East. The universal offer will be available to all and should provide timely and relevant support to carers. The middle tier of support will focus on enabling people to remain at home and retain their independence for as long as possible. The top tier focuses on those with the greatest level of need which can only be met in a bed based setting.

As you can see from the model, there is only a small amount of bed based provision with an emphasis on the community based tier as well as the newly mobilised Carers Hub. The community based offer could include a variety of services such as sitting services in their own home which would allow carers to attend social events on an ad-hoc basis to ensure that they get a much deserved break from their caring responsibilities.

Low occupancy levels show that the residential bed based offer was not being utilised to its full potential. We hope that the new offer will provide a variety of choice for people with learning disabilities which both the carer and the cared for will benefit from. We will continue to work with parent carers over the next few months to ensure that demands are being met effectively.

For children and young people, a similar, more flexible approach to our short break offer has been established. The number of children and young people receiving short breaks

in Cheshire East has steadily grown to approximately 1000 at the end of 2016-17. Short breaks provide children and young people with:

- Positive and safe things to do and places to go
- The opportunity to spend time with friends, to develop personally and socially, and reduce isolation
- The chance to undertake new activities and have new experiences

In addition, they provide parents and families with a necessary and valuable break from their caring responsibilities. They can take place in a community setting; the child's own home, the home of an approved carer or in a residential setting.

Cheshire East Council have commissioned an increased range of short break services, including weekend, after-school and school holiday activities, overnight breaks; and breaks within the home.

Feedback continues to emphasise that the biggest impact is made where families are supported in a flexible way with services tailored to their needs. The reasonably wide variety of activities currently on offer enables building of independence and social skills and reduces isolation. The offered services are easy to access and of good quality and we want to build on this and improve where possible in order to meet the demand of our children and young people.

[25]

Assistive Technology

The 2004 amendments to the Assistive Technology Act of 1998 support the need to improve the provision of assistive technology to individuals of all-ages with disabilities [26]. We know that technology has enhanced exponentially over the last ten years and we want to ensure that as a local authority, Cheshire East are leading the way with these innovative technologies and putting them into practice where possible.

Assistive technology ranges from low to high tech and there are a number of benefits to their usage:

- Promotes independence and allows people to make choices about their life
- Allows people to feel safer in their home as well as out and about
- Effective communication, reduced isolation
- Helps people become a valued member of their local community
- Enables people with learning disabilities to experience more privacy
- Supports individuals to achieve better standards of personal care

[27]



We are currently utilising some of these creative technologies here at Cheshire East such as various android applications, the Amazon Alexa and biometric bands. However, we recognise that the distribution is minimal and inconsistent and this is something we need to work on. We will aim to have a set of clearly defined guidelines in place for the eligibility criteria of assistive technology so that there is clarity on who is entitled to support through such technology.

There have been a number of applications developed to assist people with learning disabilities with various aspects of their day-to-day life such as travel training support, health and wellbeing advice and dental hygiene. One in three adults with learning disabilities and four in five adults with Downs syndrome have unhealthy teeth and gums [28] so the demand for this kind of support is prevalent for people with additional needs. Travel training has been a reoccurring theme at the Learning Disability Partnership Board meetings and service users have expressed that they would like to receive support

on how to access public transport to help them become more independent. A downloadable 'App' which helps to facilitate this process has been created and this is one example of assistive technology which we would like to promote and support people in using, among many other applications.

We appreciate that there are financial restrictions on assistive technology under the current economic climate. However, where there are opportunities for reducing care packages whilst promoting independence, Cheshire East would like to embrace this and provide people with the opportunity to pilot the various technologies before putting them into place on a permanent basis.

We also appreciate that in order to encourage individuals to use such technologies, support and training will need to be given in how to use the products and this is something that needs to be factored in to the process. We will include our families, carers and cared for at every step of the process as we appreciate that their input is vital to its success.

A catalogue of products, applications and innovations which are readily available for individuals with learning disabilities will be listed on the Live Well website so that our service users know what assistive technology is out there and how they can access it.

Housing

We want to encourage independent living for individuals with learning disabilities by ensuring that everybody has the opportunity to live in their own home with their own front door. Improving the housing offer is important to us, so we will continue to work with providers, stakeholders, carers and people with learning disabilities to ensure that there is a range of housing types to improve choice. Currently we have 123 adults with learning disabilities living in a permanent residential setting in Cheshire East and we will aim to reduce this number by ensuring that a residential placement is always the last resort and encourage independent living where appropriate. Our 2020 ambition is that 85% of adults with a learning disability will be living in their own home with their family [29].

We recognise that dependency on a certain type of accommodation can stem from childhood so we will ensure that as soon as a child or young person moves into a residential setting, a plan is developed for how they will progress towards returning to their family home and towards greater independence. This plan will be reviewed every six months to check that progress is being made and outcomes are being met. Cheshire East council will also ensure that the child or young person continues to be supported to meet the outcomes identified in their education, health and care plan [30].

NHS England state that children and young people with a learning disability, autism or both should, wherever possible, receive the support and services they need to continue to live with their family, in their own home or close to home. Out of area placements should ordinarily be avoided [31].

We would like to incorporate a Hub and Spoke Model into our accommodation offer which would allow individuals to have their own front door and private space, whilst also providing a communal area for people to socialise and interact with others should they wish to.

People with learning disabilities have told us

I live with my mum but I want to live on my own

My name is Sarah and I live on my own. I have two support workers and my mum and dad live fifteen minutes away. I can walk to the shops and I love being independent

Workforce Development

We want to work with providers to ensure that appropriate training and upskilling of staff is encouraged in order to ensure that people with learning disabilities are getting the best care possible and are encouraged to do things for themselves wherever they are able.

Practitioners who work with children, young people and adults with a learning disability and behaviour that challenges, and their family members and carers, should get to know the person they support and find out what they want from their lives and not just from services [32]. It has been suggested that staff should have an understanding of the specific condition and the best way of assisting the person as an individual in order to assist the person into living independently [33].

We would like to see a core group of our staff undertaking specialist training in working with individuals with learning disabilities. This would help enable the best possible outcomes for people with additional learning needs, with more specialised person-centred care and support.

We also want to work with schools' and colleges to encourage young people to pursue a career into Social Care from an early age. We recognise the stigma that is attached to careers in Social Care with its low pay and challenging duties. However, we need to highlight the benefits of working in such a rewarding role and the doors it can open into more senior positions such as Nursing and Social Work.

In addition to this, we would like to explore ways of recruiting students into Social Care roles to gain work experience during summer holidays or whilst on placement. We recognise that this will be a short term arrangement but we would hope that

some students will decide to stay or pursue a career in the sector once their studies have finished.

We will use a plethora of platforms to reach out to our community in relation to the workforce development initiatives including social media, Live Well and by attending careers fairs in schools, colleges and universities. We will provide case studies and success stories of people who have gone on to achieve great things in a Social Care career and have positively contributed to the lives for individuals with learning disabilities.

Currently the Adult Social Care offer to people with a learning disability is shared amongst the generic community teams whose primary workload consists of older people. As a consequence of this, expertise and knowledge in the needs of learning disabilities has become diluted, lacking leadership and coherence. The generic approach also acts as a barrier to effective engagement with learning disability providers of care that has to establish working relationships with a wide number of teams. Cheshire East Council is now committed to creating a new learning disability social care team which will develop enhanced and specialist knowledge of the needs of people with a learning disability as well as create new and in depth relationships with the provider market.

Mortality and Health

People with learning disabilities have been proven to have poorer levels of health and shorter life expectancies than individuals without a learning disability. This includes higher rates of respiratory disease, gastrointestinal conditions, mental ill-health, dementia, epilepsy, diabetes, poor oral health, osteoporosis, sensory impairments and obesity [34].

In addition to this, between 25 and 40% of individuals with learning disabilities also experience mental health problems [35]. For children and young people with learning disabilities, the prevalence rate of a diagnosable psychiatric disorder is 36% compared with 8% of children and adolescents without a learning disability. These young people are also 33 times more likely to be on the autistic spectrum [36]. We therefore need to ensure that as a local authority, support pathways are in place for dual diagnosis and early action is taken for individuals with mental health problems so that we can prevent a crisis from occurring.

Annual health checks are for adults and young people aged 14 or over with a learning disability. An annual health check helps people to stay well by talking about their health and detecting any problems early so that individuals can receive the right care as soon as possible. Some people are invited to annual health checks and do not attend. Studies have shown that this can be improved through nurses or health facilitators

encouraging attendance with follow up phone-calls and reminders [37].

Public Health England says that every day approximately 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for [38]. Children and young people are also prescribed them. Overuse of such drugs can cause serious problems with physical health among other side effects and the national initiative STOMP (stopping over medication of people with a learning disability) has been introduced to help prevent this from happening. We will work with our health colleagues to promote this project and ensure that Cheshire East are leading the way.

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) reported that 37% of deaths in people with a learning disability were avoidable [39]. The Learning Disabilities Mortality Audit 2013-15 published by Cheshire East Council found that 26% (9 deaths) could have been avoided and a further 15% of the cases might have been avoidable however, the panel could not come to a unanimous decision [40]. We recognise that this is a worrying statistic and we accept that actions need to be taken from both the Health and Social care sectors in order for this to change. However, it is important to note that we have come a long way over the years and significant improvements have been made to allow individuals with learning disabilities to live long and fulfilled lives.

The Learning Disabilities Mortality Audit put forward several recommendations which aimed to help reduce morbidity and mortality in people with learning disabilities in Cheshire. The 'My Life, My Choice' strategy will incorporate these recommendations into the action plan to ensure that they are acted on and officers are accountable for the outcomes. Some of these recommendations have already been picked up within the 9 priority outcomes.

- The handover process from children's to adult's services needs a full and rigorous review, to improve the transition experience of the young adult and their family and potentially reduce the frequency of deaths in young adulthood. An improved transition process could start earlier in adolescence and include more intensive service input which lasts into the mid-twenties
- Ensure that capacity assessments and consent discussions are recorded in sufficient detail.
- Ensure that the severity of learning disability is coded accurately across all agencies and that any referral letters detail the severity of the learning disability, to enable reasonable adjustments to be made by all agencies.
- Consider how to improve data sharing across relevant agencies in Cheshire, for instance by improving the Cheshire Care Record.
- All agencies involved in cancer screening programmes, at a national and local level, need to consider how to

improve the participation rates in people with a learning disability.

- Review the role played by carers, such as care home staff and foster carers, in supporting the person in attending their appointments, and ensure that carers themselves are well-supported and adequately prepared for the appointment.
- All professionals involved in the care of people with a learning disability need to sensitively challenge the understanding and documentation of the lasting power of attorney, in order to safeguard this group.
- Ensure that independent mental capacity advocates are always used when necessary, and their involvement is not delayed.
- Greater testing of mental capacity is necessary, for all care or treatment offered.
- Extra efforts need to be made by all agencies to identify those adults who are most vulnerable and offer early intervention and extra support where needed.

Transforming Care

The government and leading organisations across the health and care system are committed to transforming care for people with learning disabilities and significant progress has been made since the events at Winterbourne View [41].

However, we recognise that too many people with learning disabilities are still admitted to hospital when admission could have been avoided and this is something we aim to address here in Cheshire East. In line with NHS England, our efforts will be focused on:

- A substantial reduction in the number of people placed inpatient settings;
- Reducing the length of stay for all people in inpatient settings;
- Better quality of care for people who are in inpatient and community settings;
- Better quality of life for people who are in inpatient and community settings.

[42]

To achieve those ambitions, we will pursue a number of streams of work:

- Empowering people and families
- Getting the right care in the right place- both by ensuring that the current care system works for patients and families, and by designing and implementing changes for the future
- Regulation and inspection: tightening regulation and inspection of providers, strengthen providers' corporate accountability and responsibility, and their management, to drive up the quality of care.
- Workforce: improving care quality and safety through raising workforce capability.

- Data and information: underlying all the workstreams above will be a focus on making sure the right information is available at the right time to the people who need it.

[43]

Sir Stephen Bubb's Winterbourne View report emphasised that people with learning disabilities and/or autism should be given the 'right to challenge' their admission or continued placement in inpatient care. In support of this, NHS England intends to provide a Care Treatment Review (CTR) for any inpatient or inpatient's family who requests one.

The CTR review process is carried out by independent expert advisers and asks whether the person needs to be in hospital and, if there are care and treatment needs, why these cannot be carried out in the community. The individual and their family are at the heart of the process and the review team will meet with them to understand the individual as a central part of the review.

[44]

For more information on Transforming Care please visit

www.england.nhs.uk/learning-disabilities

Autism

Similar to a learning disability, autism is a lifelong condition. Autism is sometimes referred to as a spectrum, or autism spectrum disorder (ASD). There are three common features of autism, which might affect the way a person:

- Interacts with others in a social situation
- Is able to communicate with others
- Thinks about and deals with social situations

Every autistic person is different. Some individuals are able to learn, live and work independently but many have learning differences and co-occurring health conditions that require specialist support [45].

Autism is **not** a learning disability, but around four in ten autistic people may also have a learning disability. [46]

There are 700,000 people in the UK who are on the autism spectrum and more boys are diagnosed than girls [47].

Asperger's syndrome is a form of autism which may also affect the way a person communicates and relates to other people. People with Asperger's syndrome may experience challenges such as specific learning difficulties, anxiety or other conditions. However, people with Asperger's syndrome **will not** have a learning disability, as they will have an average or above average intelligence.

In March 2018, Ofsted and the Care Quality Commission (CQC) carried out a joint local area inspection of Special Educational Needs and Disabilities (SEND) in Cheshire East. The inspection outcome letter was published in May 2018 and highlighted both strengths and areas for development in the work carried out by all agencies in Cheshire East.

As a result of the inspection, Cheshire East has produced a [Written Statement of Action](#) (WSOA) that explains how the local area will tackle the following areas:

- The timeliness, process and quality of EHC plans
- The lack of an effective ASD pathway and unreasonable waiting times

In addition to the WSoA, an all-age autism strategy is in the process of being produced and will aim to address the issues outlined in the Ofsted report. There will also be a refreshed [autism JSNA](#) produced in conjunction with the strategy.



Next Steps

Proposed Areas of Focus

1. Life Changes (Transition)

- 1.1 Build on the intentions set out in the Preparation for Adulthood plan and ensure that children's and adult's teams work together and share data in a timely manner so that plans can be put in place for our young people entering adulthood. One option would be to produce quarterly reports with an update of who is coming through the system.
- 1.2 Improve local offer so that young people can experience a taster of what it is like to live independently.
- 1.3 Increase numbers of successful transitions into adult social care- assessment and support in place in a timely manner with no gaps and good outcomes for young people.
- 1.4 Ensure plans are in place for adults living with parents to avoid a crisis should one of the parents pass away.

2. Employment & Education

- 2.1 Reduce the numbers of SEND not in education, employment or training (NEET).
- 2.2 Increase numbers of people with learning disabilities in both paid and voluntary work.

- 2.3 Increase the number of SEND learners into supported internships (recruitment of supported internship coordinator).

3. Assistive Technology

- 3.1 To produce a set of guidelines for the eligibility of assistive technology in order to improve consistency of implementation.
- 3.2 To produce a catalogue of various assistive technology innovations and Apps and promote on the Live Well website.

4. Workforce Development

- 4.1 To work with providers to ensure that appropriate training and upskilling of staff is carried out for employees working with LD clients.
- 4.2 Work with schools to encourage young people in Cheshire East to pursue a career in Social Care.
- 4.3 Explore ways to support our providers in recruiting students into care roles whilst on placements/summer holidays.
- 4.4 Use a variety of platforms to reach out to our community about the workforce development initiatives such as social media so that our community know what is going on and can help spread the word.

5. Mortality, Health and Transforming Care

- 5.1 To follow up on recommendations set out from the Mortality Audit and allocate actions to specific managers so that somebody is held accountable for the implementation.
- 5.2 To work with Health colleagues to promote the STOMP initiative and allocate a STOMP champion for Cheshire East
- 5.3 To improve the uptake of Annual Health checks and increase consistency of the offer across Cheshire East
- 5.4 To reduce the numbers of people with learning disabilities placed in inpatient settings

6. Autism

- 6.1 To take on the actions set out in the Written Statement of Action, ensuring effective pathways are in place and waiting times are reduced
- 6.2 To produce an all-age autism strategy
- 6.3 To refresh the autism JSNA

7. General

- 7.1 Cheshire East Employees to work collaboratively and continue to build on relationships with health colleagues, Education, CCGS and neighbouring authorities.
- 7.2 To align the processes used in both the children's and the adult's teams in relation to data inputting and ensure that all data is accurate and accessible.

- 7.3 Reduce travel times for people travelling further afield to receive education and bring children and young people closer to home.
- 7.4 Provide good quality information and signposting to parents and carers of children with learning disabilities and ensure that the Live Well website is up-to-date with all of the community services on offer in Cheshire East.
- 7.5 To carry out a review of the Parent Carer Forum to ensure that the meetings are inclusive of parents with children who have learning disabilities and meetings are not targeted heavily towards autism and ADHD
- 7.6 A more varied short break offer to be implemented with creative alternatives to bed based provision.
- 7.7 To redesign the Learning Disability Partnership Board and ensure that agenda items are service user led and relatable to their lives. For example; safeguarding, staying up late, dating etc.
- 7.8 To ensure a vibrant provider market to raise quality, promote choice and control for individuals, and provide commissioners with flexible and innovative providers.
- 7.9 To produce an all-age JSNA for individuals with learning disabilities in Cheshire East.

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Appendix

Abbreviations

A number of abbreviations have been used in this document:

NICE	National Institute for Health and Care Excellence
JSNA	Joint Strategic Needs Assessment
CTRs	Care and Treatment Reviews
SEND	Special Educational Needs and/or Disabilities
SEN	Special Educational Needs
EHCP	Education, Health and Care Plan
ADHD	
PfA	Preparing for Adulthood
NEET	Not in Education, Employment or Training
NHS	National Health Service
STOMP	Stopping over medication for people with a learning disability
CIPOLD	The Confidential Inquiry into Premature Deaths of People with Learning Disabilities
CCGs	Clinical Commissioning Groups
ASD	Autism Spectrum Disorder
WSoA	Written Statement of Action

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Cheshire East Council Learning Disability Partnership Board

CVS Cheshire East

NHS Eastern Cheshire Clinical Commissioning Group

NHS South Cheshire Clinical Commissioning Group

NHS Vale Royal Clinical Commissioning Group

Key Documents

Cheshire East Council Special Educational Needs and Disabilities JSNA

[file:///ce-userdata/cehomedrive\\$/AP918L/Downloads/sen-jsna-final-jul17%20\(4\).pdf](file:///ce-userdata/cehomedrive$/AP918L/Downloads/sen-jsna-final-jul17%20(4).pdf)

Cheshire East Council Autism JSNA

Cheshire East SEND Partnership Children and Young People with Special Educational Needs and/or Disabilities Joint Strategy 2017-2019

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