Cambridgeshire & Peterborough
Integrated Care System

Learning Disability and Autism Improvement Programme

Progress Update on LDA for Cambridgeshire County Council Health Scrutiny Session

Thursday 14th December 2023

Introduction and context

The ICB has commissioned a scoping piece of work to understand what a long-term improvement programme for people with a learning disability and/or autism would look like

- There are ~**17,000 adults with a learning disability** living in Cambridgeshire and Peterborough, representing just over 2% of the total population. There is also an estimated **~3,000 children with a learning disability** living in Cambridgeshire and Peterborough, and a further population of adults and children with autism.
- There is a strong **history of successful work to improve the complex landscape of services** accessed by people with a learning disability and/or autism across Cambridgeshire and Peterborough, and during the Covid-19 pandemic we worked well as a system to innovate services and improve access, experience or outcomes
- However, we all know there is **more to do to better meet the needs of people with a learning disability and/or autism**, as evidenced by our JSNAs and LeDeR report: we have not revisited our service model in recent years and we have different service provision across our two geographies
- The **ICB has commissioned a piece of scoping work** to understand what a long-term improvement programme for people with a learning disability and/or autism would look like, thinking about the aims and scope of a programme, the key strategic questions to answer, and how to carry out service model design
- The **long-term improvement programme has started with a health focus**, but acknowledges that people with a learning disability experience a wide range of services across health, care, and beyond – so we must consider the full journey for these people and their range of interactions
- We have spoken with a **wide range of stakeholders** across Cambridgeshire and Peterborough involved in the delivery of health, care, and wider services for people with a learning disability and/or autism, to understand the priorities for improvement or service model redesign, and who should be involved in service model design
- On the basis of this, we have a set of **emerging outputs from the scoping phase** to test with you today – these show the current thinking on what a piece of service model design for people with a learning disability and/or autism could look like on the basis of engagement to date, and will continue to be live and updated as we speak to you and others

Initial engagement as part of the scoping phase

Initial conversations were had with individuals across a range of system partners to develop an understanding of the current state, including main challenges and opportunities for improvement to shape the case for change. Individuals were also asked their vision for a long-term programme and what it should achieve.

Organisation	Named individuals
ICB	Carol Anderson (Chief Nursing Officer), Karlene Allen (Deputy Chief Nurse/Deputy Director of Maternity and Childrens Commissioning), Madeleine Coddington (Head of Learning Disability and Autism Commissioning), Karen Chopping (Children's Lead Commissioner for Transforming Care, LDA and SEND), Hannah Brookes (LAC and Senior Lead for LeDeR programme and Health Inequalities Senior Manager), Dr Nandini Mukhopadhyay (CCPL in LDA), Rowan Procter (Nursing Director), Kate Hopcraft (Director of Performance and Delivery)**,** Paula Marshall (Care (Education) Treatment Review Manager)
Public health	Jyoti Atri (Executive Director of Public Health), Emily Smith (Public Health consultant)
CCC	Patrick Warren-Higgs (Executive Director for Adults, Health and Commissioning), Donna Glover (Service Director, Adult Social Care, Adults Health and Commissioning), Will Patten (Service Director for Commissioning), Jill Johnson (Lead Service Manager, LDP), Shauna Torrence (Head of Commissioning for Adult Social Care), Rebecca Ford (Lead Nurse, LDP), Martin Purbrick (Executive Director for Children, Education and Families), Jonathan Lewis (Service Director for Education)
PCC	Debbie McQuade (Service Director for Adults and safeguarding), Oliver Hayward (Service Director for commissioning), Sarah Croxford (Senior Commissioner for Adult Social Care), Tracey Bean (Lead Nurse), John Gregg (Executive Director for Children's Services), Chris Baird (Service Director for Education)
CPFT	John Webster (Deputy Chief Executive), Elaine Deazley-Morgan (Director of Improvement and Operations for MHLDA partnership), Debbie Smith (Director of Operations and System Partnerships/COO), Stephen Legood (Director of People and Business Development), Catherine Maxey, Dr Soumya Ghosh (Consultant Psychiatrist), Dr Frances Marshall (Clinical Community Psychologist), Kaeron Dodson (Transformation Manager, in-patient services), Ree Wood (Service Manager, in-patient services), Dr Shahid Zaman (Clinical Lead for LD), Dr Caroline Meiser-Stedman (Clinical director for Adult Specialist Directorate), Dr Venkat Reddy (Clinical Director of Children's Services), Laura Barnes (HCP lead for the 0 – 19 service), Sharon Daniels (Clinical nurse specialist, community paediatrics)
CCS	Steve Bush (Director of Children and Young People's Services), David Vickers (Medical Director), Dr Jacqueline Taylor (Clinical lead, community paediatrics), John Peberdy, Debbie Marshall (Specialist practitioner for additional needs and disability, covering C&P)
NWAFT	John Rooke (Managing Director of North Place ABU), Jack Stevens (Deputy Chief Nurse), Sue Bates (LD nurse advisor), Emily Fidoe
CUH	Amanda Small (Deputy Chief Nurse)
Voluntary sector	Fiona Kerr (VCSE Sector Influence and Participation Manager for the MHLDA ABU), Lois Sidney (SUN Network C.I.C)
Lived experience	Liz Taylor (CEO of Red2Green), Kate Bunting (Speak Out Facilitator, Voiceability)
Criminal Justice	Vicki Evans (Assistant Chief Constable)
Regional work	Sue Fox (Regional Lead for Learning Disability and Autism), Wendy Scott (Head of Quality for Mental Health, Learning Disability and Autism, SNEE)

Key themes: Across the system

Engagement highlighted a number of key themes and sentiments felt by stakeholders across the system.

Current delivery of services

There is a **disconnect** between the desire to deliver **needs-led** services and some services requiring a diagnosis, acting as a **barrier to access** and increasing pressure on waiting lists for diagnosis.

There is **limited preventative / proactive care** for this cohort, resulting in higher acuity need and more people engaging with services when in crisis.

Transition points are a particular challenge, both between children's and adult's services, and transitions between providers.

The current system relies on the **passion and goodwill of dedicated staff** who often go above what is expected of them to support individuals, which is not sustainable.

System working

The system can feel **disjointed**, with key stakeholders working in isolation instead of working as a system.

There has been a lot of **positive work** in C&P in recent years (including the LD Summit) that should be built upon and that cannot be lost.

There has been a lot of **change and restructuring** across the system which has resulted in a lack of clarity on who key **decision makers** are.

Different partners have their own **priorities** which do not completely align

Supporting the needs of people with LD&A requires a **holistic approach** to service provision with input from **wider than just health.**

Key themes: Across the system (continued)

Engagement highlighted a number of key themes and sentiments felt by stakeholders across the system.

Enablers	Inequalities
There is the need for **improved information flow** across the system and more **joined up systems** and processes.	Consideration needs to be made to improving access to services for **underserved groups**, for example the growing population in C&P for which English is their second language.
Stakeholders already understand the main challenges due to **strong evidence base** (LeDeR programme and Health Needs Assessments). This evidence base must be core to any redesign work.	Whilst there is a lot of talk about reasonable adjustments for mainstream services, there is **variation in reasonable adjustments** and a lack of understanding on recognising where they are needed and how to make them effectively.
There is a need for **increased visibility** on what is already available in the system and who provides it.	There were concerns for the **'hidden' population** of people with learning disabilities and autistic people who are **not accessing services they need**.
There is a need for improved **data capture** to understand the **level of need** and **measure impact** of initiatives on outcomes.	Particular concern for the cohort of individuals with the **most complex needs**, recognising the need for input from multiple teams and effective care coordination.
There are **recruitment and retention challenges** for LD specialist staff, exacerbated by less people entering the profession.	

Key themes: Adult’s services

Engagement highlighted a number of key themes and sentiments felt by stakeholders across the system.

Across both Cambridgeshire and Peterborough

The environment of in-patient facilities (**The Hollies**) is **not fit for purpose**, with a lack of clarity around what it should be used for.

There are concerns that the market of providers is particularly **saturated** with increasing instances of providers **‘cherry picking’** cases based on complexity of needs.

Variation in commissioning and service provision between Cambridgeshire and Peterborough results in an element of ‘**postcode lottery’** that is exacerbating **health inequalities**.

Specifically for autism, **demand is outweighing capacity** for diagnostic services and there is a **lack of post-diagnostic offer** when people do have a diagnosis.

Cambridgeshire	Peterborough
The **MDT approach** mean there is ‘one way in’ to the LDP, providing wrap around care with input from health and care staff and a streamlined experience for people receiving care.	There is **no MDT working** in Peterborough meaning services are more **fragmented.** There is a lack of link up between what is provided by CPFT and what is provided by the council with different referral routes for different services.
Whilst the LDP requires joined up service provision, teams within the LDP are working on different digital systems that do not link up/interface with each other making the **flow of information challenging.**	There is a **lack of clarity around commissioning** with the LD psychiatrist providing support to people with a learning disability outside of their commissioned work.
No Intensive Support Team commissioned for Cambridgeshire, meaning staff members are picking up crisis/out of hour support on a need-by-need basis.	The **Intensive Support Team** provides effective support to those in the area.

Key themes: Children’s services

Engagement highlighted a number of key themes and sentiments felt by stakeholders across the system.

Across both Cambridgeshire and Peterborough

With the establishment of academies and schools not all being under the local authorities, there is **variation in what is provided in schools**. Some schools have capacity to assess cognitive function whilst others do not, resulting in variation in access and more people being referred to community services.

Whilst there is a desire to be **needs-led** across the whole system, there is a **misconception that some services require a diagnosis** to be able to access them meaning that more people are seeking a diagnosis (with the view that this is largely driven through the advice given by schools).

Both nationally and locally, waiting lists for neurodevelopmental assessments have increased substantially, emphasising **the need for ‘waiting well’** whilst families are waiting for their assessment to reduce the risk of children reaching crisis and needing higher acuity support before obtaining a diagnosis.

For autism diagnoses, staff have observed **inequalities between the number of girls and boys being diagnosed**. Research suggests that girls are more likely to mask whilst in school, resulting in a larger proportion of girls in school that have a need for additional support but are not known to services.

Due to **inequalities of experience** for people with learning disabilities, a number of children go to their community paediatrician who they have a relationship with instead of their GP. Whilst this forms a strong positive relationship, this poses a risk when they are no longer under the care or responsibility of the community paediatrician and no one in the system has a close relationship with them (can lead to a drop off in care).

There is a need for more consideration for those with the **most complex needs**. It was felt that there is a risk that there is more focus on the needs of the individuals who are more vocal and advocate for their needs more loudly, meaning the individuals who don’t do this are at risk of being overlooked.

Children would benefit from **earlier identification** of their needs and earlier access to **targeted interventions** to meet their needs. The role of schools was highlighted as invaluable in this.

Transition was highlighted as a particular concern, noting that the level of support tends to ‘drop off’ when individuals start to use adult services. This challenge is compounded by services covering different age ranges which makes it more likely that people can ‘fall through the cracks’.

There is a need for more **robust case management** for children with complex needs (especially in Peterborough), as these individuals are often interacting with a number of different services at any one time (each with different safeguarding requirements) which can make effective joined up working challenging.

Key themes: Desired outcomes and key design principles

Engagement highlighted a number of key themes and sentiments felt by stakeholders across the system.

Key considerations/principles for the long-term Improvement Programme	Required outcomes from the long-term programme/goals over the next 12 months
There is a willingness to be **ambitious** when thinking about what is possible with regards to redesign.	Move towards being completely **needs-led** instead of diagnosis driven for LD&A services across all ages to **reduce pain points for transition** and people not being able to accesses services they need.
A **joint system approach**, with all key organisations around the table is essential to changes having lasting positive impact.	**Consistency in commissioning and service models** between Cambridgeshire and Peterborough, keeping the areas of good practice from both current states, reducing geographic variation and 'postcode lottery'.
The **voluntary sector** is invaluable to the support of people with LD&A and autistic people in C&P and must be engaged with/bought-in to any redesign work.	**Increased maturity** of the MHLDA ABU, with delegated responsibility in place. The ABU used as the structure for **alignment of priorities** and **joint decision-making** moving forward between key stakeholders.
Clinical and service leads must input into the programme to ensure its success and impact.	Changes must reach **wider than just specialist LD&A services**, with a plan in place for education/upskilling of staff across **mainstream services** on the needs of people with LD&A.
Work should **leverage existing networks/meeting structures** to avoid unnecessary duplication.	A **measurable reduction in health inequalities** for people with LD&A and autistic people around access, experience and outcomes.
Any redesign must incorporate the input of those with **lived experience** and ***meaningful* co-production** at all stages of the programme.	
There is wide variation in need within the LD&A population that needs to be catered for, emphasising the need for **person-centred design**.	

Programme approach and overview

To address the themes raised in the 1:1 engagement in the scoping phase, we are moving into a service model design phase

This phase

Our scoping and mobilisation phase will guide the service model design phase

Stage 1: Scoping and mobilisation

4 weeks, Nov 2023

- Review **current landscape** and agree **outline case for change**, key **opportunities**, and **strategic questions** to be answered locally
- Develop **stakeholder mapping and engagement** plan, including clinical involvement and options for co-design and patient/user involvement
- **Mobilise** programme and bring stakeholders together to agree **scope**, **purpose** and **success factors**, aligned around a **roadmap for delivery**

Indicative only

The service model design phase will guide what we need to do to implement

Stage 2: Service model design and delivery planning

Approx. 3-6 months, Jan 2024

- Developed of outcomes framework and shared vision
- Further development of case for change, review of population needs, and variation in current arrangements driving potential inequalities, set out end-to-end pathways required to respond to the case for change, meeting population needs and aligning to local and national strategy
- Linking in with implementation of the all-age autism strategy

Indicative only

Stage 3: Implementation and roll-out

6 months or more, June 2024

- Agree financial and workforce implications of re-designed pathways, feeding into service specification, contracting and commissioning arrangements for LDP and other potential areas
- Agree digital and estates implications of re-designed pathways, feeding into capital planning
- Develop and deliver system-wide plan for continuous governance and delivery of re-designed pathways, ensuring governance and enablers in place

Aims and objectives

Our aspiration is to transform our services so that they are fit for the future, redesigning how we work, and our service models to better match the needs of our citizens

Our overarching aims for services for people with a learning disability and/or autism:

- Improved **access, experience and outcomes** for people with a learning disability and/or autism - both through **specialist services and improved access** to mainstream services
- **Eliminating geographic variation** and providing equitable care across our ICS
- Addressing **health inequalities** for people living with learning disability and/ or autism
- Working towards an **integrated service model** that wraps around individuals, working across traditional organisational boundaries to meet their needs
- Addressing the specific areas of need and **improvement identified in our JSNA and LeDeR** reports
- **Voice of service users, carers and families embedded** into how we design, develop and deliver services through ongoing co-production

By November 2024, we aspire to have:

Common understanding of what good looks like

- All stakeholders in the system signed up to a **digital-first vision** on the future of services for people with a learning disability, including mainstream services
- A service specification for an **any commissioning or contractual changes** as a result of the service model redesign

Collaborative transformation and service development

- A **small number of affordable and high-impact priorities for transformation** – which all system stakeholders are signed up to, are progressing, and have visibility of progress
- A small number of **quick-wins** identified and realised, with all system stakeholders working together
- Clear actions underway to improve the access to and **use of data** underpinning integrated LDA services

Partnership working

- Clearly understood **leadership and governance** arrangements for commissioning and improvement of LDA services embedded through the MHLDA ABU – developing collective responsibility for LDA across the ICS
- A **proactive approach to funding** services and understanding of funding arrangements which that works to avoid traditional reactive approaches
- **Service changes co-produced** with people with learning disabilities and/or autism, their families and carers

Programme scope

The LDA improvement programme is an all-ages approach focused on health with consideration of the interactions into wider services, looking at service model redesign for people with a learning disability and/or autism

In-scope for the LDA long-term improvement programme:

- **All ages:** Services used by people with a learning disability and/or autism throughout their lives
- **Health-focused with links into wider services:**
  - Full range of preventative, proactive, and reactive health services in scope
  - Actively consider the wider services people with a learning disability and/or autism will frequently interact with: social care, case management
  - Understand the links into wider services people with a learning disability and/or autism may interact with: criminal justice, employment, accommodation
- **Person-focused:** Looks at both the services specifically for people with a learning disability and/or autism , and the interactions with mainstream services
- **Equity of service provision:** Across Cambridgeshire and Peterborough
- **Prioritised approach to mainstream services:** Focus on services particularly relevant to people with a learning disability or autism - mental health, annual health checks, health and justice, respiratory
- **Grounded in recommendations from JSNAs and LeDeR:** Considering the service model changes needed for long-term delivery of the LeDeR and JSNA action plans
- **Commissioning changes:** Key inputs for service specification needed for commissioning changes for LD services
- **Data, workforce, and estates:** Consider the enablers required to deliver pathway transformation

Out-of-scope for the LDA long-term improvement programme:

- Redesign all care and wider services for people with LDA
- Detailed review of all pathways and assessment of current state performance

Source: Current LDA areas of work taken from MHLDA Partnership Update, October 2023

Overarching strategic questions to answer through this work

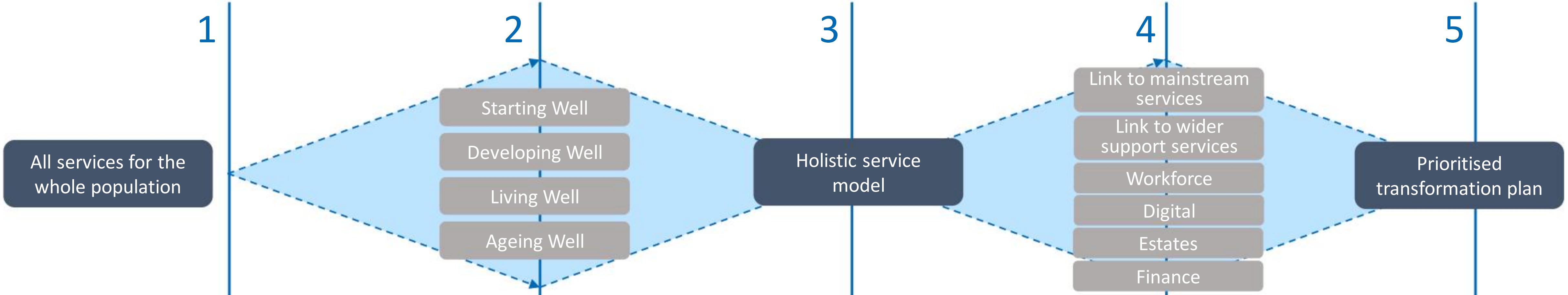
To address the case for change and deliver a sustainable service model for people with a learning disability and/or autism, the LDA Improvement Programme is set up to answer 10 key questions

Learning from our evidence base of the LeDeR report and the Health Needs Assessments:

1. What are the **outcomes** we want to influence for people with a learning disability and/or autism, and how can we measure these using the voice of people with lived experience?
2. How can the **needs** of people with a learning disability and/or autism be **identified early** to enable access to support, and receive a diagnosis where needed to address inequalities experienced by this population?
3. What does a **needs-led, digitally-enabled, integrated, service model** look like to support people with a learning disability and/or autism to be enabled and stay well at home?
4. What is the optimal model of support for people with a learning disability and/or autism **before, during, and after, a period of crisis** in their physical or mental health, including inpatient care?
5. How can people with a learning disability and/or autism be supported through **transitions between different stages** of their lives?
6. How can mainstream services be supported to provide **reasonable adjustments** for people with a learning disability and/or autism?
7. What is an **equitable provision** of learning disability and autism services across Cambridgeshire and Peterborough?
8. What **commissioning changes** are required as a result of the service model redesign and what do these look like?
9. What is the **role of each system partner, people with lived experience, and the MHLDA ABU** in the ownership and delivery of the new service model?
10. How can the system **use and share data** to enhance service delivery and measure impact of service changes and promote digital inclusion?

Service model design: design approach

The approach is based on the 'double diamond' – designed to enable development of a unified service model and to define in detail what this means for LDA services and reasonable adjustments to mainstream services



1

All services for the whole population

Articulate a vision and principles for future services.

Based on: best practice, LTP commitments, Joint Forward Plan

2

Starting Well

Developing Well

Living Well

Ageing Well

Define what this means for services for people with LDA using life-course approach

Based on: Population health metrics and future projection, LeDeR and JSNA recommendations, best practice, co-production

3

Holistic service model

Bring together and agree overall LDA service model

Test and iterate emerging plans, focusing on transitions and interface between organisations

4

Link to mainstream services

Link to wider support services

Workforce

Digital

Estates

Finance

Translate into implications for mainstream services, enablers and delivery requirements

Agree interface with mainstream services. Implications for workforce, estates, digital and finance, contracting

5

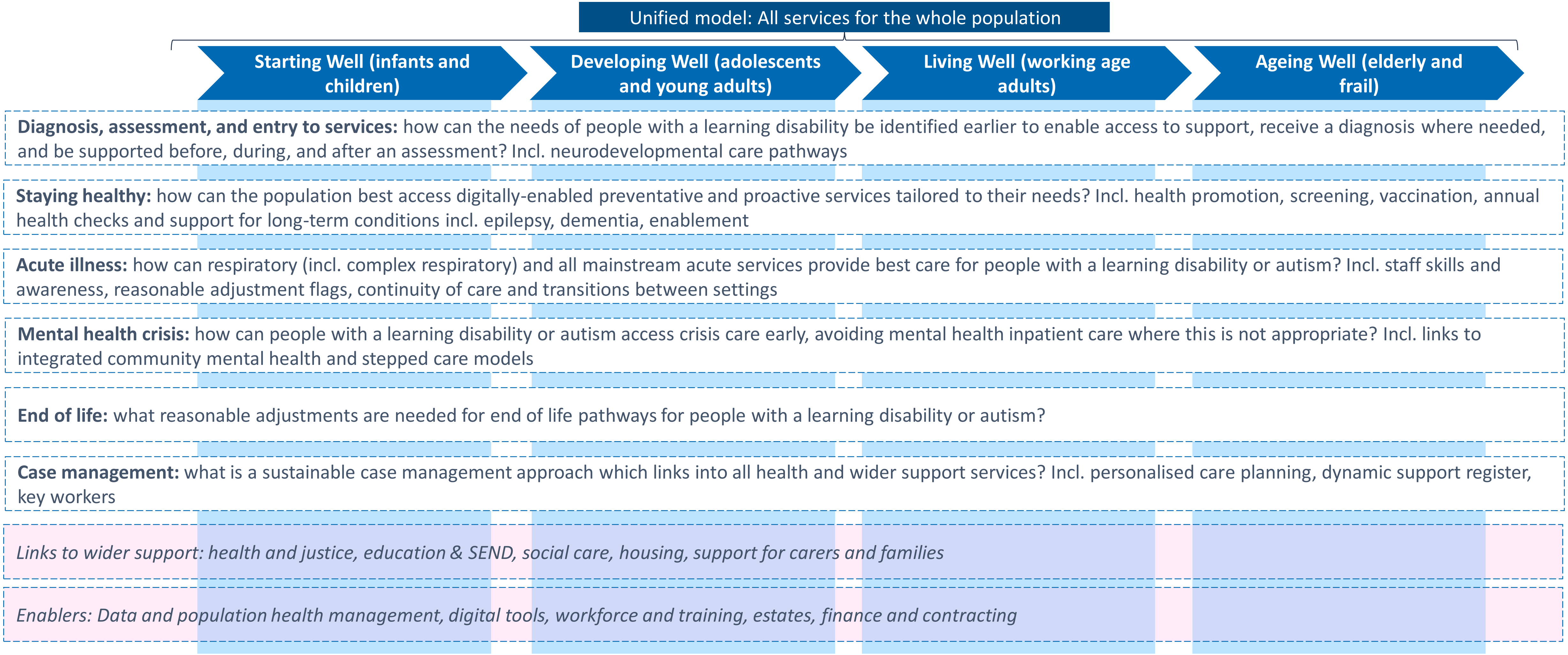
Prioritised transformation plan

Transformation planning and prioritisation

Agree joint priorities, timelines and milestones and change management approach. Leads to ongoing implementation

Service model design: themes and areas to be addressed

Life-stage working groups will tailor the overall model to the needs of their population, ensuring they consider and address the key themes and areas of need identified



Unified model: All services for the whole population

Starting Well (infants and children)

Developing Well (adolescents and young adults)

Living Well (working age adults)

Ageing Well (elderly and frail)

Diagnosis, assessment, and entry to services: how can the needs of people with a learning disability be identified earlier to enable access to support, receive a diagnosis where needed, and be supported before, during, and after an assessment? Incl. neurodevelopmental care pathways

Staying healthy: how can the population best access digitally-enabled preventative and proactive services tailored to their needs? Incl. health promotion, screening, vaccination, annual health checks and support for long-term conditions incl. epilepsy, dementia, enablement

Acute illness: how can respiratory (incl. complex respiratory) and all mainstream acute services provide best care for people with a learning disability or autism? Incl. staff skills and awareness, reasonable adjustment flags, continuity of care and transitions between settings

Mental health crisis: how can people with a learning disability or autism access crisis care early, avoiding mental health inpatient care where this is not appropriate? Incl. links to integrated community mental health and stepped care models

End of life: what reasonable adjustments are needed for end of life pathways for people with a learning disability or autism?

Case management: what is a sustainable case management approach which links into all health and wider support services? Incl. personalised care planning, dynamic support register, key workers

Links to wider support: health and justice, education & SEND, social care, housing, support for carers and families

Enablers: Data and population health management, digital tools, workforce and training, estates, finance and contracting

Source: Themes developed through 1:1 discussion with Steering Group members and tested against JFP, C&P, November 2023

Service model design: life stage working groups

Working Groups will bring together partners from across the system to discuss key strategic questions related to each life stage, working across traditional organisation boundaries and develop person-centred and integrated models to solve system challenges

Starting Well (infants and children) → **Developing Well (adolescents and young adults)** → **Living Well (working age adults)** → **Ageing Well (elderly and frail)**

	Each Working Group will include representatives from							
Organisation	**ICB**	**Cambridgeshire**	**Peterborough**	**Voluntary Sector**	**Lived Experience**	**Wider services**	**Life stage specific**	**MHLDA ABU**
Roles	• Commissioners • Clinical lead • LeDeR programme • Complex case management	• Commissioners • Social care team leads (adults and children) • Public health • LD nursing • Therapies leads (OT, SALT, Arts) • Service leads (community, out-patient and in-patient services) • Clinical leads (psychiatrists and psychologists) • Community paediatric nursing • Primary care representatives from integrated neighbourhoods • Selected clinical leads in acute providers • LD liaison nurses		• Representation from the significant number of VCSEs working in the LD&A space in C&P	• Individuals with LD&A • Parents and carers representatives	• Representation from system partners that interact with this cohort on a wider basis (e.g. criminal justice, education, housing)	• E.g. Healthy Child Programme leads for Starting Well	• Programme delivery and governance

Service model design: co-production approach

It is essential that this work takes a genuine co-production approach to service design, following the NHS’ 10 principles of co-production to ensure best practice

NHS’ 10 Principles of Co-production

1- Ensure people and communities have an active role in decision-making and governance

2 - Involve people and communities at every stage and feed back to them about how it has influenced activities and decisions

3- Understand your community’s needs, experiences, ideas and aspirations for health and care, using engagement to find out if change is working

4 - Build relationships based on trust, especially with marginalised groups and those affected by inequalities

5 - Work with Healthwatch and the voluntary, community and social enterprise sector as key partners

6 - Provide clear and accessible public information

7 - Use community-centred approaches that empower people and communities, making connections to what works already

8 - Have a range of ways for people and communities to take part in health and care services

9 - Tackle system priorities and service reconfiguration in partnership with people and communities

10 - Learn from what works and build on the assets of all health and care partners – networks, relationships and activity in local places.

What this means for Cambridgeshire and Peterborough

Working with existing voluntary, community, and social enterprise sectors:

- Pinpoint
- VoiceAbility
- Family Voice
- Family and Carer Forums
- Healthwatch

Engaging with people with learning disabilities and/or autism, their families, and carers in best practice ways:

- Using existing forums to share input and identify relevant people
- 1:1 engagements where appropriate
- Focus groups and other engagement approaches with existing forums
- Aligned to renumeration policy
- Emphasising choice and working together to design questions
- Accessible materials prepared well in advance
- Clarity in expectation re level of involvement needed for co-production

Ensuring people with learning disabilities and/or autism, their families, and carers are key participants (and option to co-facilitate) in:

- Understanding the current experience of health and care services
- Service design workshops
- Implementation governance

Next steps

The critical next steps are to schedule the upcoming set pieces, put enablers in place, and start co-production approaches

- Finalise details of **governance** for the next stage of the Learning Disability and Autism Improvement Programme
- **Agree membership** and **schedule** launch event, workshops, Task and Finish Groups, and data stakeholders
- Continue **engagement with wider range of front-line and clinical stakeholders, including integrated neighbourhoods,** to build in-depth understanding for life-stage and key question, current state pathways and best practice approaches
- Commence **engagement with key VSCE organisations for people with lived experience** to arrange workshop representation and hold focus groups
- Confirm **enabling support** from data teams, front-line and clinical stakeholders, and project delivery resources
- **Align the LDA Improvement Programme with the LeDeR report and Health Needs Assessments Action Plan** – incorporating the recommendations and actions which would be best taken forwards through a service model redesign