



**Bedfordshire, Luton  
and Milton Keynes**  
Integrated Care Board

# BLMK Learning Disabilities and Autism Strategy 2023/2026 (FINAL)

October 2023 v.7



Trust



Respect



Integrity



Accountability



Care and  
Compassion

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# A Quality Improvement (QI) approach was used to develop the Learning Disabilities and Autism Inequalities Strategy

The BLMK Learning Disabilities and Autism (LDA) Equalities steering group met for the first time on 5<sup>th</sup> January 2023, and we agreed to work on a system-wide LDA Equalities strategy.

The steering group included partners working with people with learning disabilities and autistic people across the BLMK Integrated Care System (ICS).

The group has adopted a QI approach, using the below sequence to develop the strategy

1. Choose a population segment

2. Identify Assets and Needs

3. Create a Governance Structure

4. Develop a purpose and change theory

5. Develop a measurement plan

6. Start testing changes

# What is Quality Improvement (QI)?

“Quality improvement (QI) is about giving the **people closest to issues** affecting care quality the time, permission, skills and resources they need to solve them.

It involves a systematic and coordinated approach to solving a problem using specific methods and tools with the aim of bringing about a measurable improvement.”

(Health Foundation, 2021)

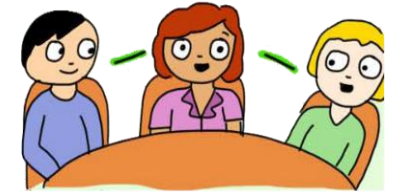


**People closest to the issue**

**Permission**

**Skills**

**Resources**



**Not jumping straight to solutions!**



# Step 1 – Choose a population segment

Things to consider when choosing a population:

- Is there a segment of the population that is failing to thrive, where there might be some apparent inequity?
- Is the population segment an achievable size to target effective testing?
- Is existing work taking place and is this work a priority to those in the system?
- Are there other partners who share responsibility for this population that are willing to partner with us in this work?
- Is there readily available data that people are willing to share?

1. Choose a  
population  
segment

2. Identify  
Assets and  
Needs

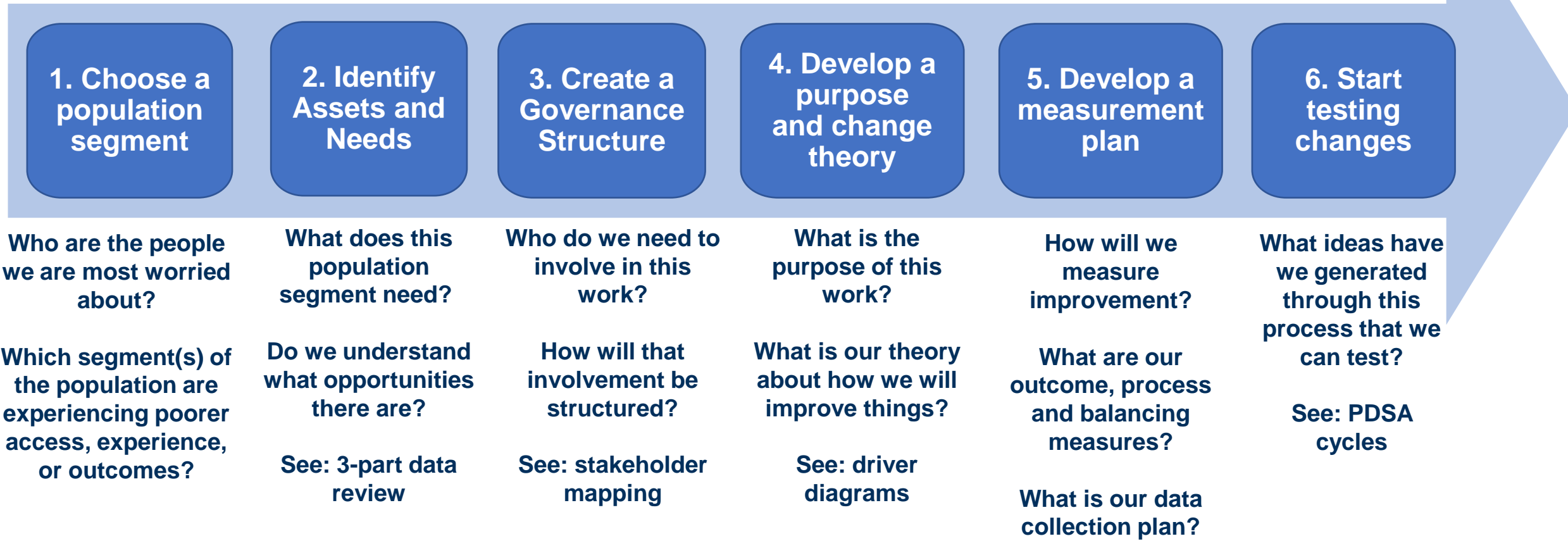
3. Create a  
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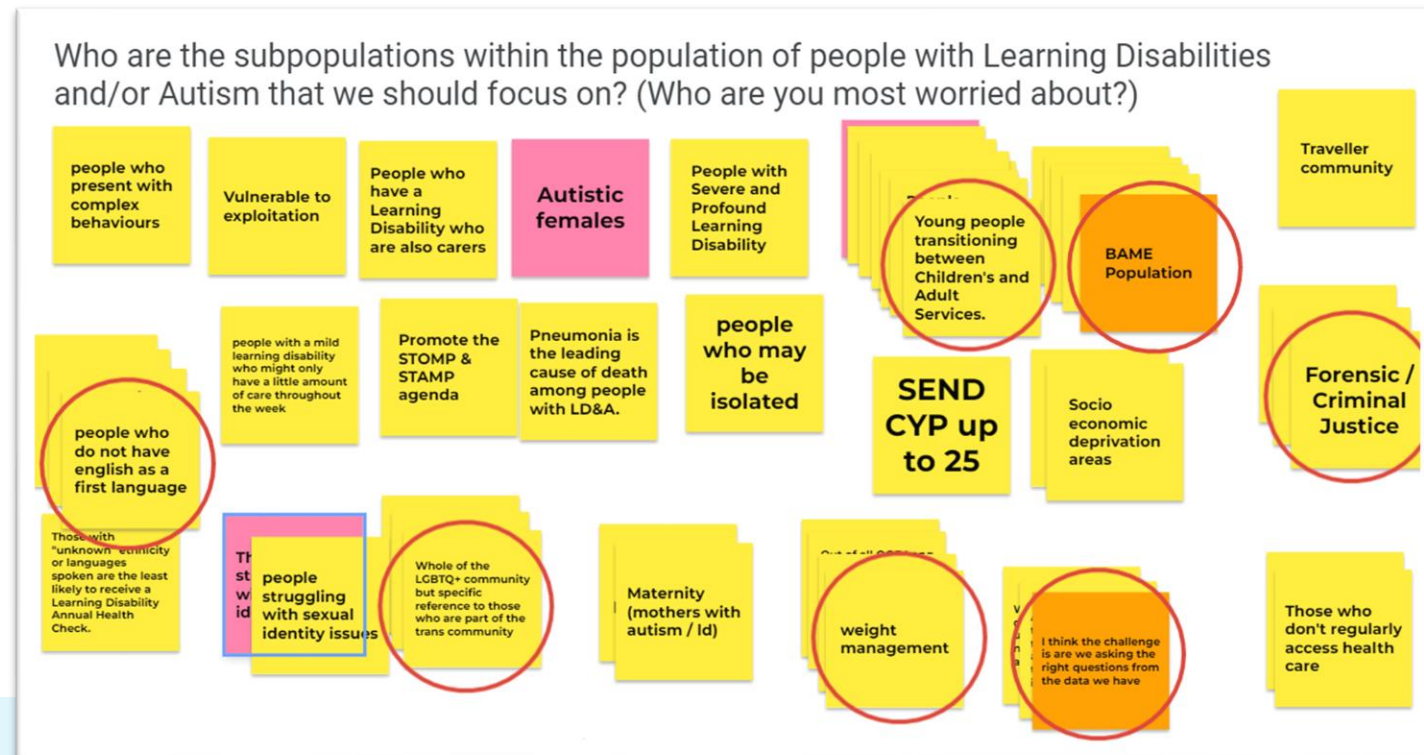
# Detailed Overview of the QI Sequence Used



# Step 1 – Choose a population segment

Our population segment is **adults with Learning Disabilities and Autistic people in Bedfordshire, Luton and Milton Keynes (BLMK)**. As well as health challenges faced by this group, there is also an unequal spread of health within the population.

We thought about which **groups** within this population that need extra focus (the groups we were most worried about.)

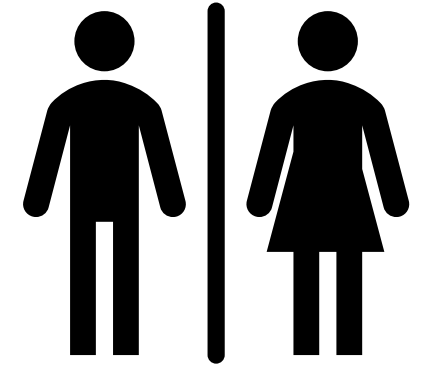


# Step 1 – Choose a population segment

The groups of people with Learning Disabilities and Autistic people we felt needed extra focus were:

- People who don't speak English as a first language
- LGBTQ+ community
- Young people transitioning to adult services
- Ethnic minority groups
- Forensic/criminal justice population
- People requiring weight management
- People experiencing comorbid mental illness or complex behaviours

**Males** with a learning disability are **less likely** to have an annual health check than females.



People with learning disabilities of **Black ethnicity** are **less likely** to receive an Annual Health Check compared to the rest of the population.

# Step 2 – Identify Needs and Assets

**The work should derive from meeting the needs and maximising the assets of the population we serve.**

Needs are typically defined as problems or barriers experienced by the population that require an intervention.

Assets are the collective resources that people and communities have at their disposal, which can help promote health and wellbeing. These can include:

- Individual – personal resilience, individual talents
- Community – Community groups, social clubs, resident’s associations
- Organisational – Faith groups, coffee shops, community hubs, health and social care services

1. Choose a population segment

2. Identify Assets and Needs

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# Step 2 – Identify Needs and Assets

## 2. Identify Assets and Needs

1. What does the **data** say?
2. What do people who **work closely** with the population say?
3. What do people with **lived experience** say?

To identify the needs and assets of people with a learning disability and autistic people in BLMK, we undertook a 3-part data review. This meant following 3 steps:

1. Review the data already available – quantitative and qualitative
2. Seek input from those working with, and supporting, this population
3. Learn from people with lived experience

# Step 2 – Identify Needs and Assets

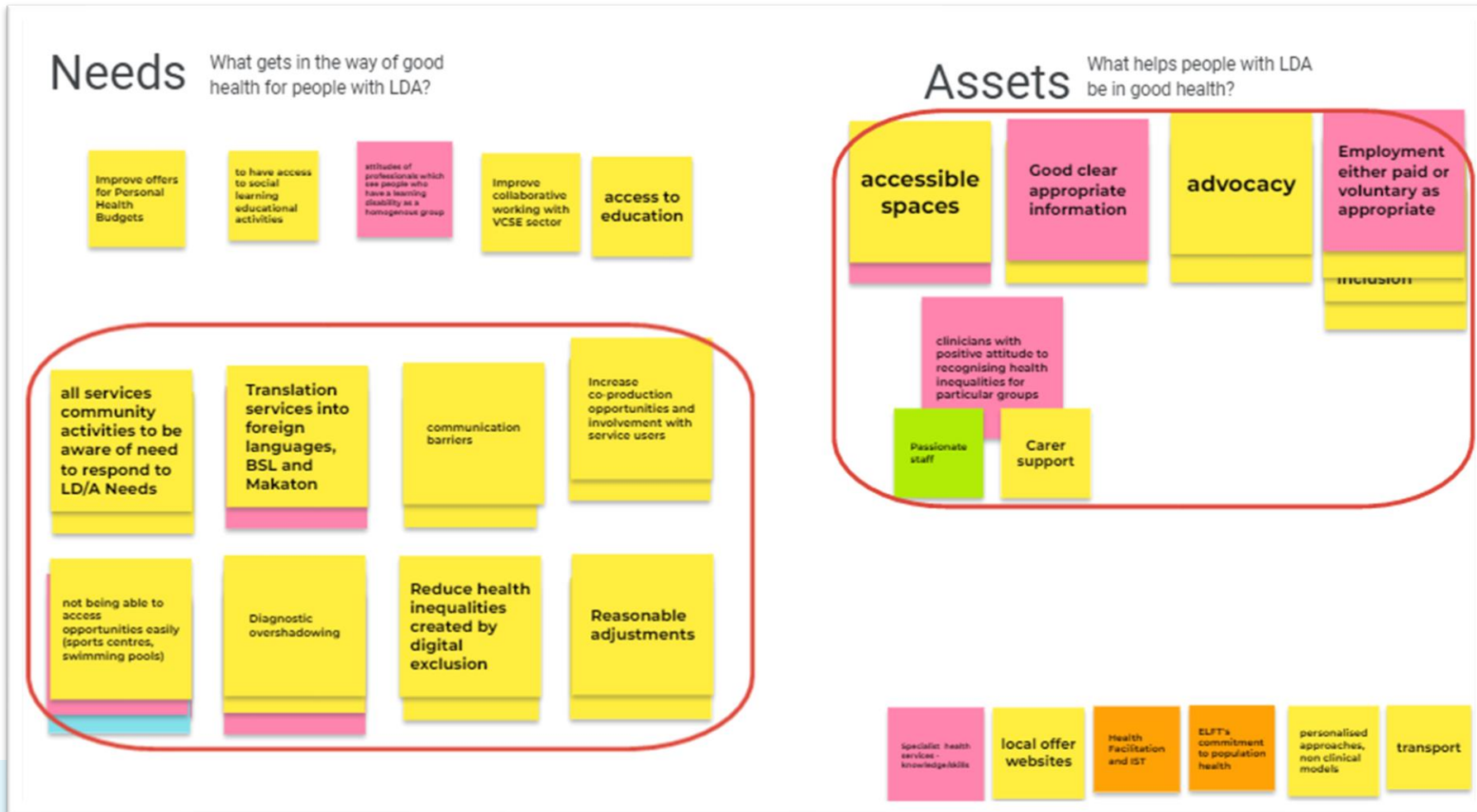
- The number of people recorded on the **BLMK learning disability register increased by almost 6%** between March 2022 and March 2023.
- The proportion of people with a learning disability in BLMK with a **comorbidity increased** from 2022 to 2023. The largest comorbidity increases were observed within Non-Diabetic Hyperglycaemia, Obesity, Hypertension, Depression, Diabetes, and Asthma.
- People with a learning disability in BLMK were found to be **24% less likely to receive Bowel Cancer Screening**, 15% less likely to receive Breast Cancer Screening, and 3% less likely to receive Cervical Cancer Screening compared to the population average.
- Autistic people in BLMK were found to be **16% less likely to receive Bowel Cancer screening**, 10% less likely to receive Breast Cancer Screening, and 7% less likely to receive Cervical Cancer Screening compared to the population average.
- **Males are less likely** to receive a learning disability **Annual Health Checks** than females.
- People with an ‘**unknown**’ severity of learning disability are 4% less likely to receive an **Annual Health Check** compared to the rest of the population.
- People with an ‘**unknown**’ ethnicity are almost 8% less likely to receive an **Annual Health Check** compared to the rest of the population.

2. Identify  
Assets  
and Needs

1. What does the  
**data** say?

# Step 2 – Identify Assets and Needs

We thought about the key needs and assets of people with a Learning Disability and/or Autism in the LDA Equalities steering group. The key themes are in the red boxes.



2. Identify Assets and Needs

2. What do people who **work closely** with the population say?



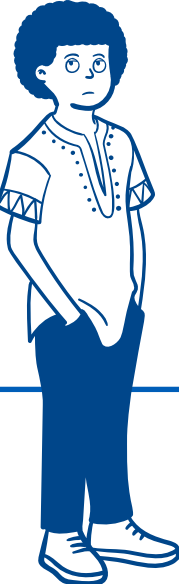
# Engagement Sessions

- We held three focus groups with people with Learning Disabilities, Autistic people, and their carers and families: one in Bedford, one in Luton, and the third in Milton Keynes.
- These are in addition to the extensive engagement work done as part of the Denny review, which along with the work of the collaborative, will support development of the strategy further to Place level.

2. Identify  
Assets  
and Needs

3. What do  
people with  
**lived  
experience**  
say?

# Access to Primary Care



“I go to the Walnut Surgery and need to go twice a month. I struggle with the automated phone system. There are too many options. I forget which one I need. It’s a struggle to get an appointment.”

***Access to primary care was one of the most commonly mentioned challenges for people with learning disabilities and autistic people in BLMK.***

**Phones were not an option** for a lot of people, a barrier to accessing care (particularly primary) especially if no carer/support to use phone for them

(H) “I struggle on the phone. My mum makes my appointments for me. I want to do it myself, but I find the phone system frustrating”.

(J) “ When you get a call back from the Doctor’s, they come from withheld numbers. I don’t answer those calls.”

Being unable to access primary care **leads to people attending A&E**, which is a **stressful environment** for people with learning disabilities and autistic people

“There is nowhere to go except A&E if my need is not urgent, but I can’t get a GP appointment, for example for my diabetes or for antibiotics.”

BLMK LD registered patients with a **QoF comorbidity** was 58.9% in 2021/22; in 2022/23 the figure is 61.3%, reflecting **more complex health care needs** in people with a learning disability.

6.59% of the BLMK LD Register aged 14+ did **NOT** receive a LD Annual Health Check between April 2021 – March 2023



# Oral Health: the impact of reasonable adjustments **NHS**

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**“Going to the dentist is (quite the) experience for an autistic person when you consider the sensory sensitivities of being tilted backwards in the chair, the taste of the mouthwash, the tools used, the noises from the tools, the lighting from the lamps that shine in your face and also people being in your personal space.”**

We heard lots of **positive** experiences of dentists making **reasonable adjustments**:

**(H) “My dentist is in Woughton. It’s private. It’s very friendly. The staff know me. Mum comes with me for re-assurance, to make sure I understand what’s being said.”**

**(J) “My dentist is at Eaglestone which is part of the hospital at Milton Keynes. The staff always have a chat with me. They let me bring in a CD of relaxing music which is what I need.**

**“[The Luton Dental Centre has] good communication, procedures explained in a way I understand, they were open even during Covid, and are very good at helping with my anxiety.”**

**Negative experiences** were mentioned less frequently, but they made a **lasting impact**:

**“Due to previous experiences of the dentist. I haven’t been since I was fifteen [now early thirties] I would go to the dentist if it was absolutely necessary, but I’d have to be in pain to actually go.”**

**One in three** adults with learning disabilities have **unhealthy teeth and gums**

Children and young people with a learning disability, autism or both have higher levels of **untreated tooth decay**.





# Broken Trust

**“It’s very off putting and makes me not want to go back.”**

**We consistently heard about the lasting impact of impressions that have been made in healthcare settings.**

**Broken trust builds anxiety and ultimately leads to avoidance:**

**“Some reception staff have been rude. It’s very off putting and makes me not want to go back. You feel like you’re wasting people’s time. You can end up feeling pretty worthless.”**

One person’s journey to being referred for an autism diagnosis took a long time, several years. GP initially refused to refer him; was constantly **‘shot down’**. This led to depression and now he **‘won’t go to GP unless absolutely necessary’**. He has not been to a GP since 2019.

Someone recalled her experience of being asked to participate in groups with the previous Milton Keynes CCG in 2015, where she felt her time and contribution had not been valued: **‘treated as if I hadn’t got a brain’**. This made her cautious of participating in future engagement activities.

Autistic people were **over seven times** more likely to report that their senses frequently overwhelm them so that they have trouble focusing on conversations with healthcare professionals.

In addition, they were **over three times more likely** to say they frequently leave their healthcare professional’s office feeling as though they did not receive any help at all



# Addressing fear of the unknown

(J) “I went to a breast cancer screening and took my support worker with me. I was nervous. I didn’t know what to expect. In the lead up to the appointment my mind was full of ‘what if’ scenarios. It was scary. It’s the ‘unknown’s’ you worry about.”

When we asked people if they would attend a screening appointment, most people said they **would not attend**. **Fear of the unknown** caused a lot of anxieties:

It’s ‘Scary, I won’t know what to expect.’

‘Panic... thinking “What if ...?”’

‘Really concerned about the results.’

‘Crowds’

‘How long will I be there for?’

People were very positive about ideas presented on **familiarisation**, such as open days, videos and easy-read information:

“Having videos sent out after sessions would be good because everyone learns in different ways. Autistic people process information in their own time. Videos would be helpful to assist in processing information and to refer back to if needed.”

“An open day would be very helpful.”

People with a learning disability in BLMK were found to be 24% less likely to receive **Bowel Cancer Screening** and autistic people 16% when compared to the population average.

# Why is it important to you to be healthy?

When asked this question, **everyone told us their health was important to them.**

People told us that **not being well stopped them doing things they enjoyed**, which led to **mental health** being negatively impacted.

**(H) Mental and physical health matters to me. If I feel healthy, I feel positive. I feel happy. If I wasn't healthy, I wouldn't be able to do what's important which is to go to my social groups and my employability group. Without these groups I'd feel emotional, bored, and lonely.**

**(K) I used to enjoy kickboxing, but I can't do it now due to various physical health situations. I think it's harder for autistic people to integrate with society if they are unhealthy and this leads to depression.**

**(M) I think my mental health is more important than my physical health. I need that time for 'me' during the day. If I don't get it, I get depressed. I wouldn't get out of bed if I knew I wouldn't get any 'me' time on a particular day.**

**(J) My physical health is very important to me. If I am unwell, my daily routines are taken away from me. I feel depressed when this happens. My mental health takes a downturn if I'm stuck in bed. I need to be around people. Daily routines are extremely important for autistic people.**

**Research shows that autistic people are significantly more likely to experience a mental health diagnosis than those without**

# Zoe's Story

I am Zoe, a young adult living in Bedfordshire. I have cerebral palsy and I am a wheelchair user.



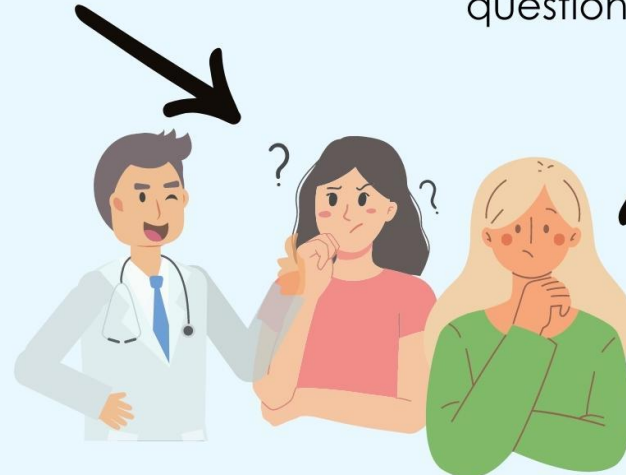
Zoe went to see her doctor with the support of her carer.



Zoe's carer told the doctor that Zoe can understand and that they should direct their questions to Zoe.

Health care professionals should not make assumptions about people's abilities and disabilities.

Speak with people to understand how best to communicate and what support or reasonable adjustments may be required.



When the doctor arrived, he did not look at Zoe and spoke directly to Zoe's carer.



The doctor then raised their voice and shouted the questions to Zoe. Zoe replied that she can hear people perfectly well.

# Pauline's Story



I am Pauline, and I'm from Bedfordshire. I have a learning disability.

Pauline takes medication for her health needs.



She does this herself, using the colour, shape and size of the tablets to recognise what she needs to take and when.

Pauline collects her prescription from the pharmacy. She assumes she has the same medication as usual.



When Pauline gets home, she realises that the tablets have a different colour, shape, and size.



Now Pauline doesn't know which tablets to take and when. This made Pauline anxious and she had to seek support.

If Pauline was advised that the tablets were different, this would have given Pauline the opportunity to ask questions and understand the differences. She could have continued to take her medication independently.

**Health professionals must take the time to communicate about things which affect them and help enable independence.**

# Key Takeaways



We were consistently told that people experienced low levels of access to primary care, which is leading people either to not access care or to use emergency routes (a stressful sensory experience)



There are longstanding issues with trust due to previous negative experiences accessing healthcare



'Fear of the unknown' is a big contributor to anxieties about attending health appointments, for example cancer screening



There are a small number of champion dentists which people reported positive experiences with, while a smaller number of people have negative experiences of dentists which stops them going regularly



People really cared about their health, and being in poor health stopped them doing the things that made them happy

# Step 3 – Create a Governance Structure

Who do we need to involve in this work?

How will that involvement be structured?

1. Choose a  
population  
segment

2. Identify  
Assets and  
Needs

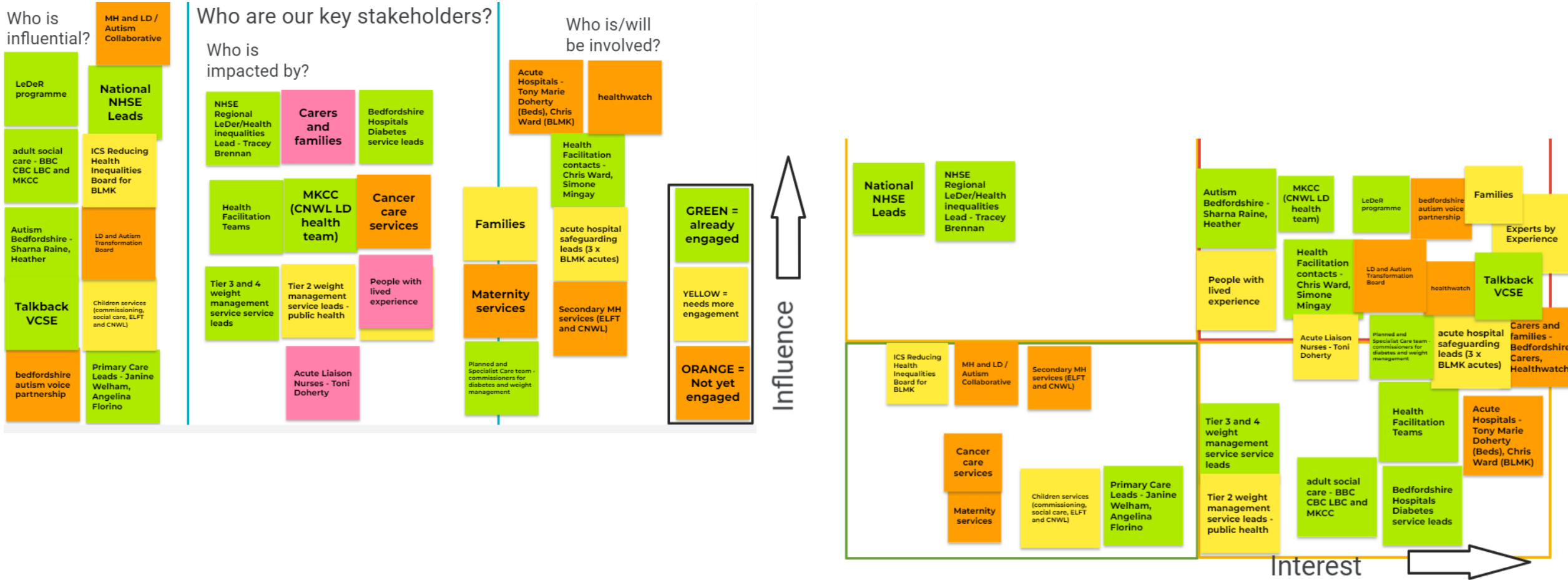
3. Create a  
Governance  
Structure

4. Develop a  
purpose  
and change  
theory

5. Develop a  
measurement  
plan

6. Start  
testing  
changes

# Mapping our stakeholders



# Engagement – Organisations that contributed to the development of this strategy



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1.	Autism Bedfordshire	20.	Carers in Bedfordshire
2.	Autism Early Support	21.	Carers Bucks and Carers MK
3.	Be Active Bedfordshire	22.	Camphill MK
4.	Bedfordshire Community Dental Services – CIC	23.	Central Bedfordshire Council
5.	Bedfordshire Hospitals NHS Foundation Trust	24.	Community Action: MK
6.	Bedfordshire RCC	25.	Community Dental Services – CIC
7.	Bedford Borough Council	26.	Disability Resource Centre
8.	BLMK Adult Specialist Autism Practitioner	27.	East London Foundation NHS Trust
9.	BLMK Forensic Officer	28.	Healthwatch Bedford Borough
10.	BLMK Integrated Care Board – Children’s Commissioning and Transformation	29.	Healthwatch Central Bedfordshire
11.	BLMK Integrated Care Board – Learning Disabilities and Autism Strategic Commissioning	30.	Healthwatch Milton Keynes
12.	BLMK Integrated Care Board – Learning from Lives and Deaths	31.	Leap With Us (Active Partnership Bucks and MK)
13.	BLMK Integrated Care Board – Mental Health	32.	Luton Borough Council
14.	BLMK Integrated Care Board – Planned and Specialist Care Commissioning	33.	Milton Keynes University Hospital
15.	BLMK Integrated Care Board – Primary Care Commissioning	34.	Mind (BLMK)
16.	BLMK Integrated Care Board – Primary Care Transformation and Improvement	35.	Public Health
17.	BLMK Integrated Care Board – Quality	36.	Talkback
18.	BLMK Integrated Care Board – Strategic		
19.	BLMK Integrated Care Board – Transforming Care		

As we implement the ideas in this strategy, we will continue to engage with system partners across BLMK

# Engagement Workshops



No.	Locality	Group / Host	Focus Areas	Date
1.	Milton Keynes	Talkback – Christ The Cornerstone Church, Milton Keynes	Experiences of accessing local health and care services	13 03 2023
2.	Bedfordshire	East London Foundation Trust LD Service User Participation Group – St. Andrews Church, Bedford	Let's talk about better healthcare	11 04 2023
3.	Luton	East London Foundation Trust LD Service User Participation Group – Luton Irish Forum	Let's talk about better healthcare	24 04 2023
4.	BLMK	Voluntary and Community Sector Enterprises (VCSEs) – Virtually, via MS Teams	LDA strategy purpose and focus areas	25 07 2023

Great interactive session

A well structured ICB workshop with knowledgeable professionals!

Thank you for listening

# Engagement – BLMK Steering Groups

No.	Group	Focus Areas	Dates
1.	LDA Health Equalities Steering Group	Initial LDA strategy discussion, including BLMK wide engagement	08 02 2023
2.	LD Steering Group	LDA strategy purpose, focus areas and engagement	03 04 2023
3.	LD Annual Health Checks Task and Finish Group	LDA strategy purpose, focus areas and engagement	04 04 2023
4.	LDA Health Equalities Steering Group	Review of outline draft: Sub-populations within the Learning Disabilities and/or Autistic community that we should focus on (or are worried about); what gets in the way of good health for these groups (needs); what helps people with learning disabilities and/or autistic people to be in good health (assets); purpose (why we are doing it) and aims (what we are going to do) of the LDA strategy	12 04 2023
5.	LDA Health Equalities Steering Group	Review of 2 <sup>nd</sup> draft: refining areas above, taking account of engagement feedback	14 06 2023
6.	ASD Steering Group	Review of LDA strategy engagement feedback, themes, purpose and focus areas	18 05 2023
7.	LDA Health Equalities Steering Group	Review 2 <sup>nd</sup> draft, incorporating themes derived from engagement feedback	12 07 2023

# Step 4 – Develop a Purpose and Change Theory



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**What is the purpose of this work?**

**What is our theory about how we will improve things?**

**Driver Diagram & change ideas**

1. Choose a population segment

2. Identify Assets and Needs

3. Create a Governance Structure

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5. Develop a measurement plan

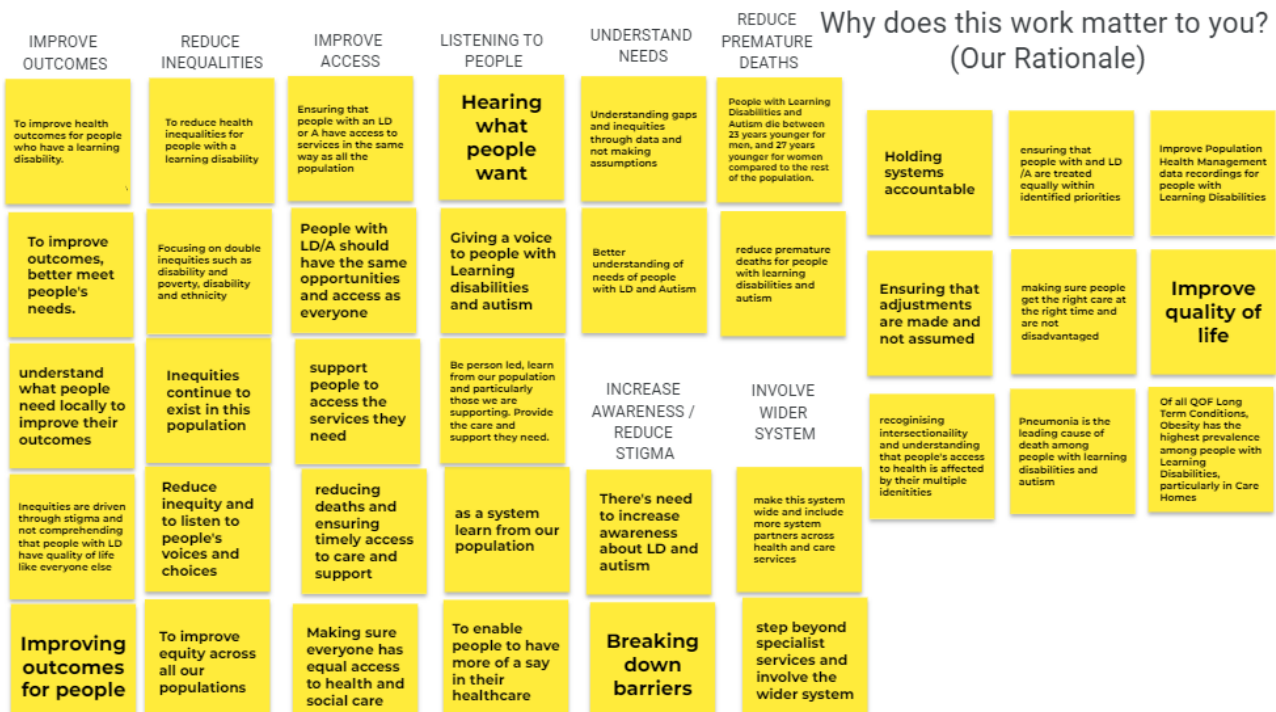
6. Start testing changes

# Interdependencies

- National strategy for autistic children, young people and adults: 2021 to 2026
- NHS Long Term Plan, Learning Disabilities & Autism
- Learning from Lives and Deaths programme (formally known as LeDeR)
- Dynamic Support Register and Care (Education) and Treatment Review Policy and guidance, January 2023
- Place Based Priorities (BBC, CBC, LBC & MKCC) covering Learning Disabilities & Autism
- Special Educational Needs and Disability (SEND)
- BLMK Reducing Health Inequalities Programme
- BLMK Learning Disabilities Annual Health Checks
- BLMK Section 117 Programme

# Our Purpose

“Mental and physical health matters to me.  
If I feel healthy, I feel positive, I feel happy.”



We will work in partnership to reduce inequalities for people with Learning Disabilities and Autistic people by listening to people and increasing awareness of their needs. Our overall aim is to improve access, improve wellbeing outcomes and reduce premature deaths.

# Our Strategy: 5 Asks

**“If I feel healthy, I feel positive, I feel happy”**

Aim: We will work in partnership to reduce inequalities for people with Learning Disabilities and Autistic people by listening to people and increasing awareness of their needs. Our overall aim is to improve access, improve wellbeing outcomes and reduce premature deaths.

**1. Communicate Compassionately**

“Some reception staff have been rude. It’s very off putting and makes me not want to go back. You feel like you’re wasting people’s time. You can end up feeling pretty worthless”.

**2. Offer Me Reasonable Adjustments**

“The staff at my dentist always have a chat with me. They let me bring in a CD of relaxing music which is what I need”.

**3. Break Down Barriers**

“I went to a breast cancer screening and took my support worker with me. I was nervous. I didn’t know what to expect. In the lead up to the appointment my mind was full of ‘what if’ scenarios. It was scary. It’s the ‘unknown’s’ you worry about”.

**4. Put me at the Centre of my Care and Support**

“Mental and physical health matters to me. If I feel healthy, I feel positive. I feel happy. If I wasn’t healthy, I wouldn’t be able to do what’s important which is to go to my social groups and my employability group. Without these groups I’d feel emotional, bored, and lonely”.

**5. Keep Me Well**

“Due to previous bad experiences of the dentist, I haven’t been since I was fifteen (now early thirties) I would only go to the dentist if it was absolutely necessary, but I’d have to be in pain to actually go”.

# Our Strategy: What We are Going to Do



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**“If I feel healthy, I feel positive, I feel happy”**

Aim: We will work in partnership to reduce inequalities for people with Learning Disabilities and Autistic people by listening to people and increasing awareness of their needs. Our overall aim is to improve access, improve wellbeing outcomes and reduce premature deaths.

## 1. Communicate Compassionately

Planned roll out of the Oliver McGowan Training for all health & care staff  
Deliver Autism awareness training for Primary Care staff, Police & Probation service  
Continue to work with people with a Learning Disability and Autistic people, and their families & carers, to deliver all areas of the strategy

## 2. Offer Me Reasonable Adjustments

Create sensory friendly environments both in the community and inpatient provision  
Co-design accessible educational material for people with Type 2 Diabetes  
Develop an autism pathway across BLMK  
Co-design a series of orientation videos on what to expect when you access your health or care appointment

## 3. Break Down Barriers

Continue to work with people with a Learning Disability and Autistic people, and their families & carers, to broaden our understanding of barriers to accessing services  
Targeted work to increase AHCs for ethnic minority people & those who have not had an AHC in the last 2 years  
Primary Care pilot to identify GP champions for people with a Learning Disability and Autistic people & share learning with practices requiring support

## 4. Put me at the Centre of my Care and Support

Develop a neurodiversity wellbeing model across BLMK, including pre and post diagnostic offer  
Identify an initiative to increase the number of advanced care plans being delivered  
Increase the number of Health Action Plans completed during the Annual Health Check

## 5. Keep Me Well

Develop a pilot project to centralise a BLMK TCP team & ensure compliance with the new guidance  
Commission Autism practitioner roles to support people at risk of admission, project pilot in Bedford & MK  
Develop a weight management initiative focused on prevention  
Review the function & areas of responsibilities of the integrated LD nurses across Beds & LTN  
Review forensic pathways across BLMK

# Step 5 – Develop a Measurement Plan

**How will we measure improvement?**

**What are our outcome, process and balancing measures?**

**What is our data collection plan?**

1. Choose a population segment

2. Identify Assets and Needs

3. Create a Governance Structure

4. Develop a purpose and change theory

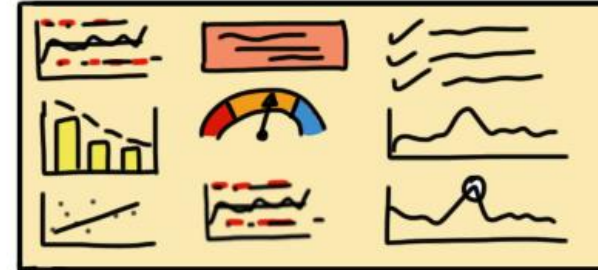
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# Measures in QI

## Outcome Measures

- Tells us whether aim is being achieved.



## Process Measures

- Attached to drivers or change ideas.
- How are the parts or steps in the system that you are trying to influence performing?

## Balancing Measures

- What happened to the system as we improved the outcome?
- Any benefits/untoward consequences?

# Measurement Plan

Measure Type	Measure Name	Operational Definition	Data Collection Plan
Outcome	BLMK LeDeR reviews	100% of all BLMK LeDeR reviews to be completed within 6 months from notification of death	Collected through the BLMK LeDeR programme that is reported into the BLMK TCP Board
Outcome	Premature deaths of people with learning disabilities & autistic people	Retrospective: Adopt the Markov Model to measure progressive diseases, and the cost effectivity of health care provided to a given population.	BLMK LeDeR programme annual report
Process	LD Annual Health Checks (AHC)	Increase the % of people with learning disabilities having received an AHC from 75% to 78% by 2024/25	SystemOne reporting data that is reported into the BLMK LD AHC steering group and TCP board
Process	Emerging themes from the BLMK LeDeR report 2022	Reduce the number of deaths reported in hospital from 78% to 76% by 2024/25	BLMK LeDeR programme annual report
Outcome	Care & Treatment Reviews (CTR)	CTR to be offered to all people with learning disabilities and / or autism within 4 weeks of admission into a mental health inpatient provision where no community CTR took place	Assuring Transformation (AT) database
Outcome	Diabetes	Adults living with Type 2 diabetes who have a learning disability or autism to achieve better long-term health outcomes, in relation to their diabetes	Engagement and co-production through the 'BLMK Equalities Link Worker' pilot project

# Measurement Plan continued ...

Measure Type	Measure Name	Operational Definition	Data Collection Plan
Process	Learning Disability registers	Increase the number of people reported on the learning disability register with known severity of learning disability stratification (mild, moderate, severe, profound)	SystemOne data, reported into the LD AHC steering group and BLMK TCP board
Outcome	Improved communication – Weight Management Services	Supporting patients with a learning disability and family / carers to feel better informed of their journey through Tier 3 and 4 weight management services in BLMK	Ongoing engagement and co-production through the 'BLMK Equalities Link Worker' pilot project 2023/24 - 2024/25
Process	Tier 3 Weight Management Service	Reduce the DNA rate by 5% for people with a learning disability and autistic people living with obesity who are due to attend Tier 3 weight management appointments in BLMK by 2024/25	Tier 3 weight management service. Link in with the lead commissioner to ascertain how this can be captured
Process	Advanced Care Plans – LeDeR	Increase the proportion of people with a learning disability and autistic people who have an advanced care plan in place from 22% to 25% by 2024/25	BLMK LeDeR programme annual report, check with the Bedfordshire and Milton Keynes Hospital Trusts
Balancing	CTR post discharge	CTR to be offered to all people with learning disabilities and autistic people within 6 weeks of discharge from a mental health inpatient provision	Assuring Transformation (AT) database

# Measurement Plan continued ...

Measure Type	Measure Name	Operational Definition	Data Collection Plan
Process	Oliver McGowan training	10% of the health and care workforce across BLMK to have completed the Oliver McGowan training by March 2024	Workforce lead for BLMK
Process	Cancer screening	Increase breast screening for people with learning disabilities of eligible age by 5% in 2024/25	SystemOne data
Balancing	Health Action Plans (HAP)	Increase the total number of people receiving an LDAHC on LD Register aged 14+ that received a HAP between April 2023 - March 2024 from 85% to 87% by 2024/25	SystemOne data reported into the Learning Disabilities Annual Health Check steering group and BLMK TCP board
Process	Learning disability register protected characteristics	Increase the number of people on the learning disability register with known Equality Act 2010 protected characteristics (for example ethnicity, disability, sexual orientation)	SystemOne data reported into the Learning Disabilities Annual Health Check steering group and BLMK TCP board

# Appendix: Language

- Autism can mean many things to many people. There are several terms that different people and groups prefer to use, including; autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference, has autism, is autistic and neurodiversity.
- We have a person centered approach to communicating with individuals and will ask and follow your preferences. Autism Bedfordshire use 'autistic' in their published communications and materials as an umbrella term for all such terms, including Asperger's syndrome. This is in line with the terminology adopted by the National Autistic Society.
- The National Autistic Society: What words do people prefer to use to describe people on the autism spectrum? 'Autistic'?, 'with autism'?, 'has autism'? The language used is important because it embodies and can therefore help change attitudes towards autism.
- A piece of research published in the Autism journal in 2015 looked at the preferences of people on the autism spectrum, their families, friends and professionals around the language used to describe autism. The research was conducted by The National Autistic Society (NAS), the Royal College of GPs and the UCL Institute of Education. The findings confirmed that there is no single term that everyone prefers. However, they suggest a shift towards more positive and assertive language, particularly among autistic communities where autism is seen as integral to the person.
- Survey responses from 3,470 people were analysed, including 502 autistic adults, 2,207 parents of children and adults on the autism spectrum, 1,109 professionals, and 380 extended family members and friends. The research found that all groups like the terms 'on the autism spectrum' and 'Asperger syndrome'. Autistic adults like the identity-first terms 'autistic' and 'Aspie', whereas families didn't like 'Aspie'. Professionals also like the term 'autism spectrum disorder (ASD)'. Some terms were strongly disliked or no longer used, particularly 'low functioning', 'Kanner's autism' and 'classic autism'. The language used is important because it embodies and can therefore help change attitudes towards autism. To reflect the findings of this research, the NAS has begun to gradually increase the use of the term 'autistic' – particularly when talking about and to adults in that group. Another term used 'on the autism spectrum' as the default way of describing people on the autism spectrum.
- The research shows that language preferences are evolving, and research continues to test how different groups prefer to speak about autism. The debate around the way we describe autism in the public domain is different to the terms used to diagnose autism by medical professionals. Find out more about diagnostic terms and criteria.
- For our resources, we have chosen to use identity-first language throughout.