Improving Quality of Life for people with Learning Disabilities in Bedfordshire

Our story… as it happens

Insert image to represent the work, if you'd like to (or just delete if not)

Notes for completion

- This is your document; please do adapt any way you need to. Feel free to change the fonts/colours/borders/headings, to make it personal and fit for your team. The aim is for it to reflect the heart of your work, as you and your population have experienced it.
- Add additional slides if you need more space for any section
- We'd really encourage you to add pictures, feelings, experiences, to bring life to the work. Some suggested ideas for how you could capture the detail are at the end of this document following the pink slide. If you find or come up with any other good methods, please share this with your IA, so we can let other Triple Aim teams know.
- This document should capture all elements and dimensions of the story: including the downs, as well as the ups and the challenges, as well as the wins – please do be honest.
- It might be easiest to complete via a standing item during Project Meetings, perhaps sometimes with people taking away actions to complete different bits
- Also add a longer session periodically (quarterly?) for team to review content together and think about whether anything needs to be added to give an accurate reflection of the real story of the work

Contents

Overall timeline (1)

Month	What happened
???? 2018	Project initiated to reduce antipsychotic prescribing using QI approach
September 2018	Shakeel Islam and Sam Morrison started ILP Wave 8 training
October 2018	Shift achieved, showing reduction in use of antipsychotics across caseload, using QI approach
January 2019	Decision made to shift work to using population health Triple Aim approach. QI Project team put on hold. Core leadership group of Dr Shakeel Islam, Sam Morrison (project leads) and Dr Sanjay Nelson & Ruth Klawza (local sponsors) + Improvement Advisor and Executive Sponsor set up
February 2019	3 part data review undertaken rapidly by service to be ready for Trissa Torres from IHI visit
19 February 2019	Session to share learning from 3 part data review, supported by Trissa Torres
31 May 2019	First go at draft Driver Diagram developed by Dr Shakeel Islam and Jen Taylor-Watt (IA) from 3 part data review feedback
28th June 2019	Engagement Event held with 40+ people from across system to share learning from 3 part data review and develop draft driver diagram
1st November 2019	1st project meeting held
	1st measurement plan at overall measure level developed

Overall timeline (2)

Month	What happened

What is the rationale for the work

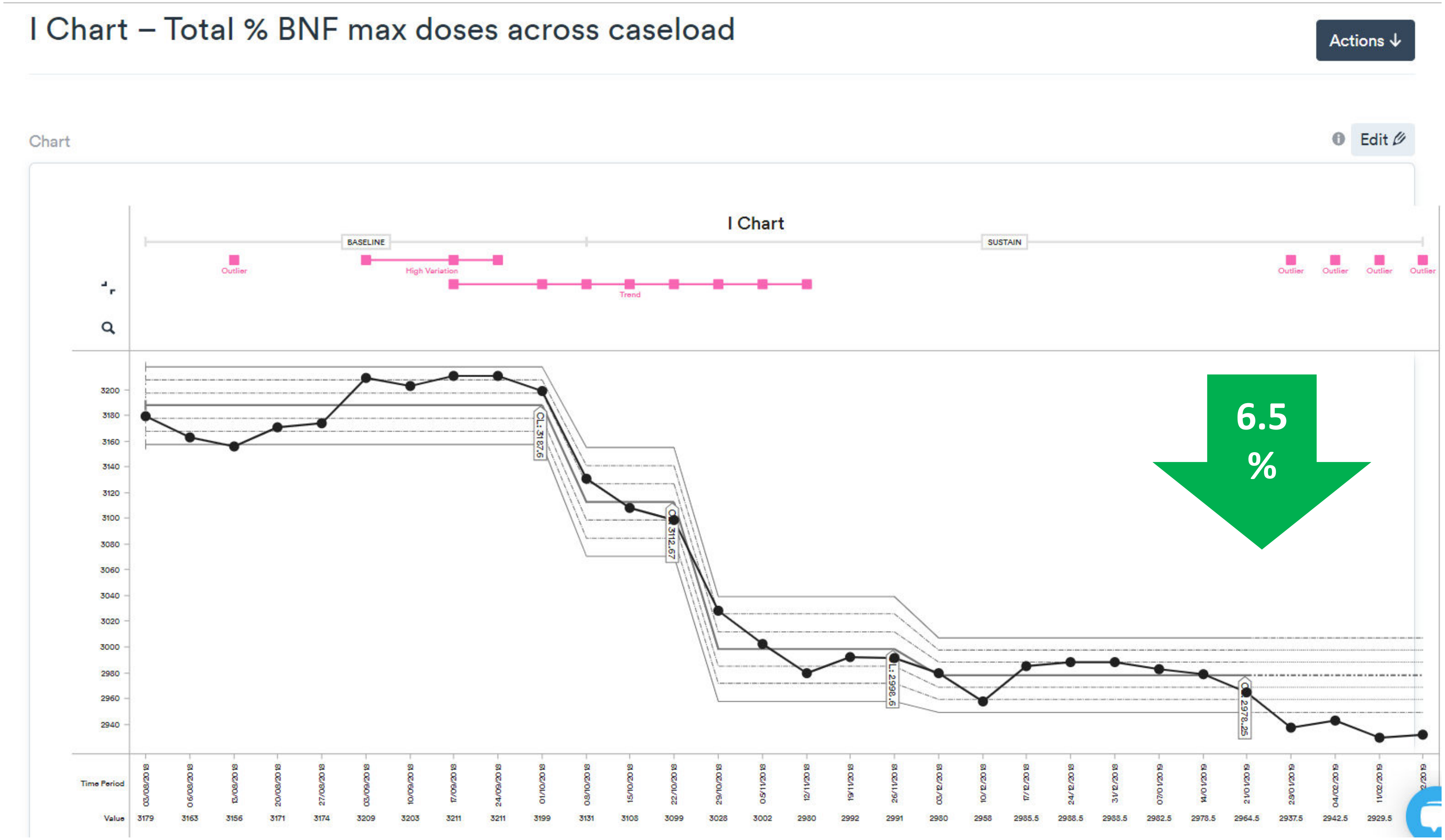
The project started as a QI project to reduce the prescribing of antipsychotics to people with Learning Disabilities, as part of the national STOMP agenda.

STOMP stands for stopping over medication of people with a learning disability, autism or both with psychotropic medicines

Most recent study - Approximately 50% of prescriptions for antipsychotics in primary care to people without intellectual disability are given in the absence of a record of severe mental illness.

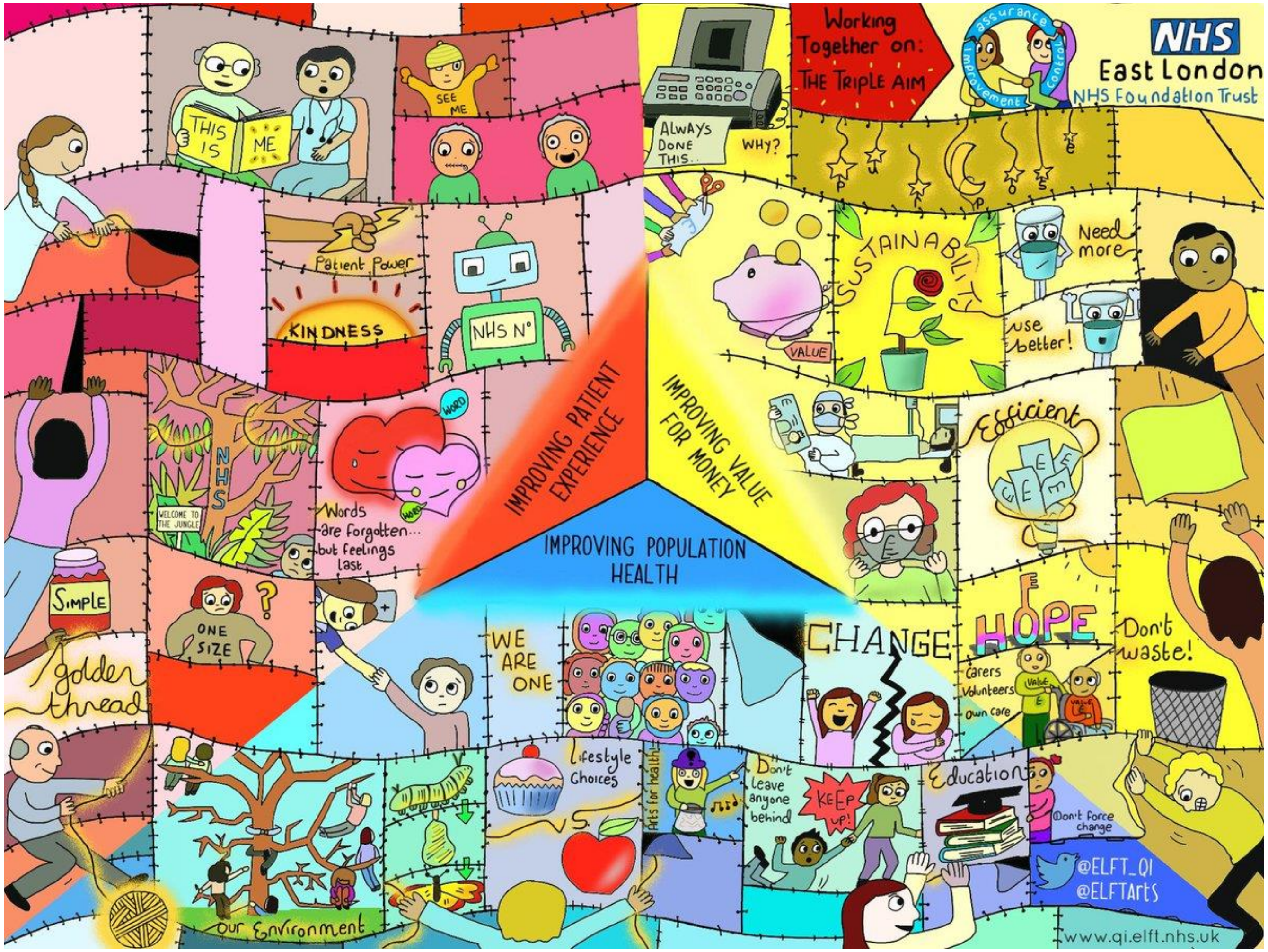
Antipsychotics most commonly cause effects such increased appetite leading to weight gain, increasing the risk of high blood pressure and diabetes…

We achieved a genuine improvement of 6.5% by running our QI project within our team (☺), but we realised that to achieve a bigger change, we'd need to address the deeper reasons underneath why people experience behavioural symptoms – and this would require working beyond our organisation…



I Chart – Total % BNF max doses across caseload

This is why the work is suited to Triple Aim, as it is not just about the prescribing, but instead about acknowledging and supporting the whole person to improve their quality of life, thereby reducing the need for prescribing



Who got the work off the ground? (initial project team)

The original QI project team working on STOMP involved the following people:

- Dr Shakeel Islam, Consultant and Co-project lead
- Sam Morrison, Specialist Health Care Team Manager and Co-project lead
- Sanjay Nelson, Clinical Lead for LD and Sponsor
- Ruth Klawza, Strategic Lead for Learning Disability and Autism, and Interim Associate Clinical Director and Sponsor
- INSERT OTHERS

Who got the work off the ground? (initial project team)

Between February 2019 and August 2019 the set up of the work as a Triple Aim project involved the following people…

Local leadership

- Dr Shakeel Islam, Consultant and Co-project lead
- Sam Morrison, Specialist Health Care Team Manager and Co-project lead
- Sanjay Nelson, Clinical Lead for LD and Local Sponsor
- Ruth Klawza, Strategic Lead for Learning Disability and Autism, and Interim Associate Clinical Director and Sponsor

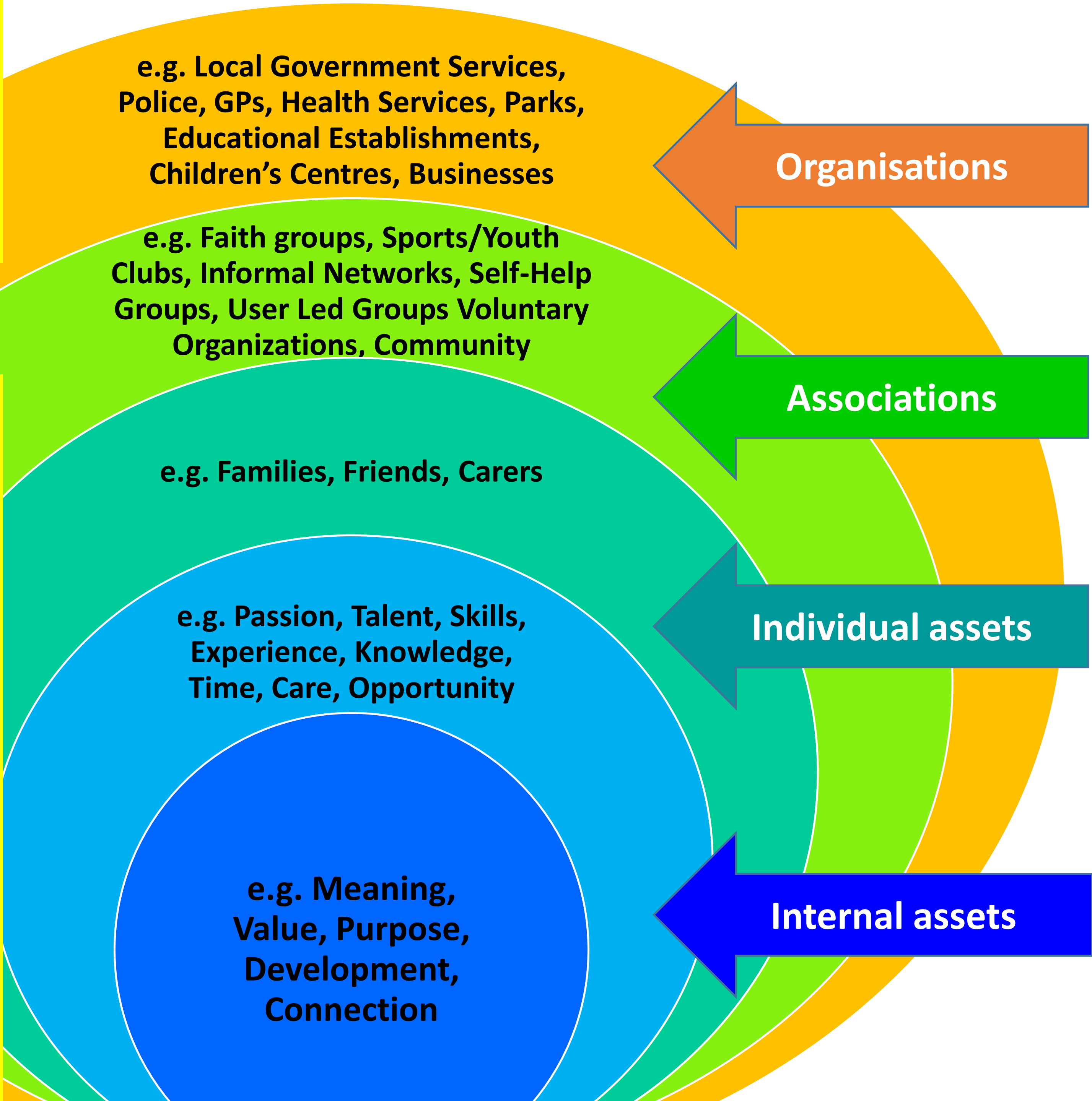
This was supported by Improvement Advisor, Jen Taylor-Watt, Executive Sponsor Paul Gilluley and Silvana Russo from the LD service supported a lot with administrative tasks and event organisation.

How we felt when we started the work as a Triple Aim project…

Meeting with Trissa Torres, 19/02/19

Understanding the population through the three part data review

What have we learnt about the assets of this group of people?



e.g. Local Government Services, Police, GPs, Health Services, Parks, Educational Establishments, Children's Centres, Businesses

Organisations

e.g. Faith groups, Sports/Youth Clubs, Informal Networks, Self-Help Groups, User Led Groups Voluntary Organizations, Community

Associations

e.g. Families, Friends, Carers

e.g. Passion, Talent, Skills, Experience, Knowledge, Time, Care, Opportunity

Individual assets

e.g. Meaning, Value, Purpose, Development, Connection

Internal assets

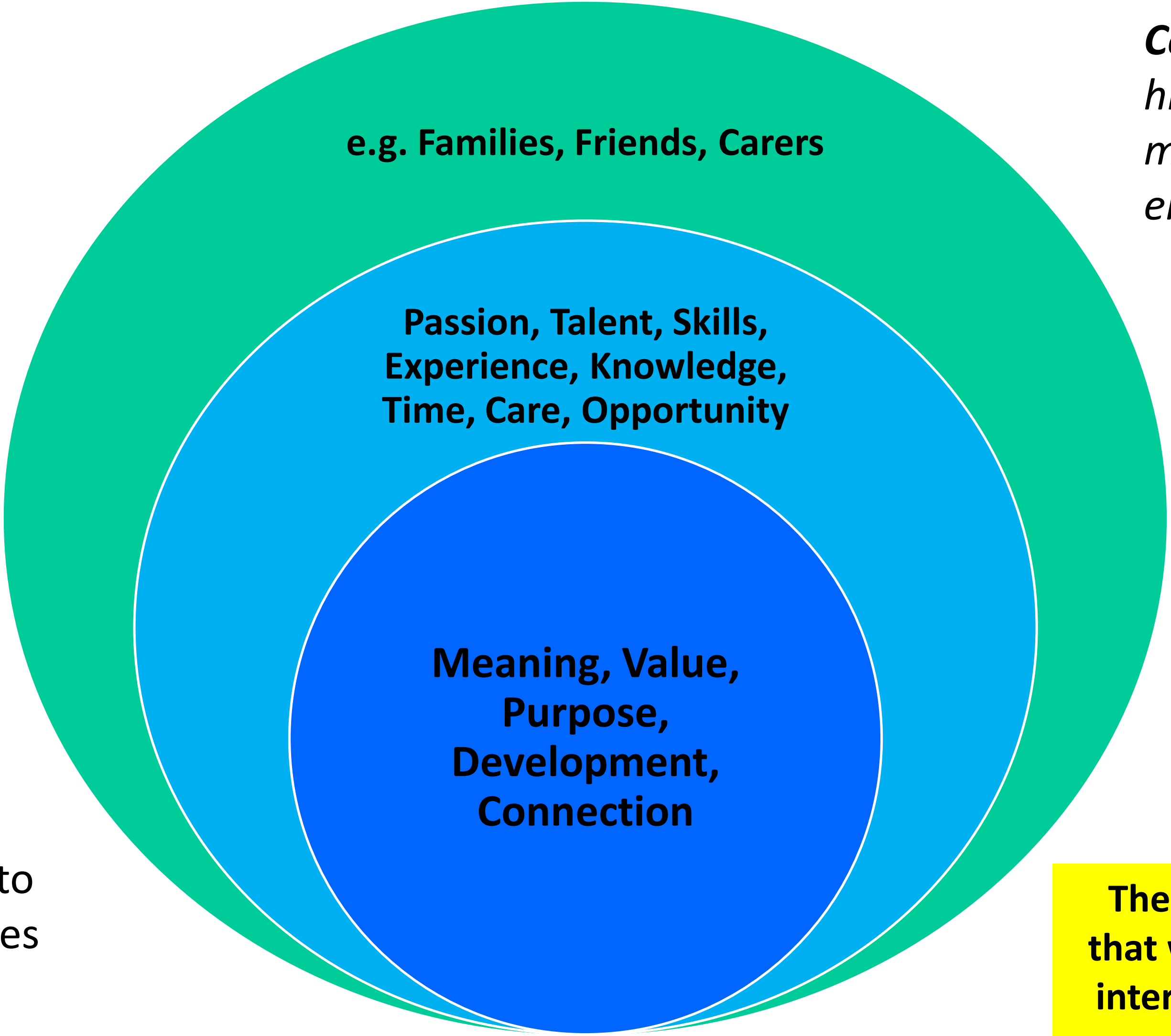
This is a useful model we can use to think about assets of a population, which includes internal assets, individual assets and assets in the broader community.

The model shows the flow from internal to external to the person.

See overleaf for what we found to be important factors for our population: people with LD at risk of antipsychotic prescribing…

Individual and internal assets

Seeing friends & family, being able to attend social activities – ***Day Centres*** *were highlighted by many as key enablers of this*



Having access to meaningful activities

Independence

Being able to make choices

These are the themes that were highlighted in interviews with service users

Community Assets; Organisations and Associations

Day Centres

Shops

Places to go on holiday

Day Centres were the major community asset highlighted by service users and informal carers. They also mentioned the importance of places to shop and to go on holiday.

Stakeholders also identified other potential assets in the community at the engagement event, described below, which are also noted here in non-bold italic. [insert]

Full feedback from the 3 part data review

Interviews with Service Users/ Members of population

Summary

Summary Themes

Strengths and Assets

- Being understood.(Daily routines, consistency, communication strategies, environment)
- Being able to make choices. (Shopping, holidays, daily activities)
- Having access to meaningful activities (Day centres, seeing friends & family, being able to attend social activities)

What is not being met?

- Having my own home
- Not enough meaningful activities away from day centres.

Summary Themes

What did the system not do right?

- Poor care and support arrangements (Life was very limited, more dependant on others, life was less fun)
- Misunderstood (restricted life opportunities, felt scared and angry, didn’t feel valued, risk of harm)
- Communication (limited opportunities to express self and develop interpersonal relationships)

Summary Themes

What are the gaps now?

- Delays in identifying needs (diagnosing mental health condition , carers not understanding what is needed)
- Having to share accommodation / home space. (no choice about who else moves in)
- Not all GPs are interested (only talk to carers, don’t share enough information to hospitals or others)

Interviews with Service Users/ Members of population

Full detail

- 10 completed
- Any challenges? Questions asked may not have been specific enough to get more data about the use of medication

1. What strengths and assets are reflected in the answers

- Like going to the day centre in the week and having the weekends off.
- Seeing friends, watching and playing football, dinner with family on Sundays
- Going on holidays
- Going to day care and having days at home during the week to do own activities is good – helps to have more good days than bad days

- Being able to talk to my friends and family when dad passed away.
- Being able to manage my “head trouble “ much better in the last year because the staff recognise this now and having better medication since January
- Having carers and family to support with bad moods and behaviours

- Going into town one day a week and to my dads in a taxi – by myself (Used to have 3:1 carers support but now independent)
- Support received from social worker / support worker before meetings really helped as meetings make her anxious.
- Being on the right medication has helped.
- Being able to have family, good support workers, an Advocate, good Consultant and CPA meetings has helped me.

1. What strengths and assets are reflected in the answers (cont'd)

- Sticking to my routine each day helps – wake up early, have coffee, the breakfast. Able to stay at home indoors and play with my toys or watch TV. Someday going out for drinks. This has helped me to stay much calmer.
- Having carers who understand this helps, having a familiar, calm environment helps, being supported when I go out helps as I am registered blind.

- Going to day centre three days a week and being at home the other two. Then visiting family every Saturday. Is able to see what carers are working on duty and likes to know this. Is able to go to bowling once a week.
- Communication skills have improved over the years.
- Is supported by people who know him very well and understand him. – Providing a structure to activities has been successful and sharing information in small amounts helps to reduce anxiety

- Being able to chose what I do in the day and being able to go out independently.
- Didn't used to have good support and wasn't able to do things for myself. I still need help each day, especially with managing my money
- I have my family, my carers and the Priminister around me helping things to get better – I am interested in politics

1. What strengths and assets are reflected in the answers (cont'd)

- Having a consistent weekly routine is important – a mix of day care service, no day care service and seeing family at weekends.
- Having had more consistent support since 2011, able to communicate needs better, engaging better with people, enjoying an active life.

- Has own mobility car and consistent carers in the last four years.

- Going to day centre each day and having a consistent routine that carers understand the needs and are able to respond appropriately. Loves being able to socialise and knows lots of people.

- Being engaged in local community and being able to go out – has a very consistent

2. What needs are going unmet

- Wanting to live in own home.
- Wanting to do more activities when not at day centres

3. What did the system do that made it worse?

- When the right care and support was not in place, life was very different/ very limited. Unable to participate independently, wasn’t able to live and enjoy life as much.
- Prior to current care arrangements, wasn’t always understood by carers so was much more unsettled.
- Not having an agreed way of managing the behaviours, limited so many opportunities to engage. When carers didn’t understand how to manage the behaviours.

4. What gaps have been identified?

- Long time getting people to understand the “head trouble” and make sure carers at day centre understood it better.
- Not being able to live in my own home – having to share with others
- GPs aren't always helpful / don’t always seem interested in really helping

5. Any other themes emerging?

- Access to day centres is really important to people
- Having contact with family is really important
- Being able to visit the GP and have the GP talk about tablets and what is good to eat is good.
- Having good carers who know the person well is important to people
- Being able to see the Psychiatrist is good.
- Not having enough activities to explore out side of the day centres.
- Having experienced carers that are able to bring consistency to the care package makes the most impact.
- Better understanding and acknowledgement of peoples needs now compared to years ago.

Interviews with Professionals & Carers

Interviews

- LD Liaison Nurse, Bedford Hospital
- Bedfordshire GP with interest in LD
- Luton Borough CLDT social services
- Bedford Borough ALDT social services
- Manager – Supported Living Scheme, Luton
- Senior Support Worker Supported Living Scheme Luton
- Support workers – Luton x 2, x Macintyre, 1 x Home Farm Trust, 1 x Community Care Solutions
- LD Commissioner – Bedfordshire
- Manager – Care Home Bedford
- Day Care Officers x 2 – Central Beds & Luton Services

1. What is preventing people from this group from living well?

(e.g. being able to go out, for example to visit day centres, to engage with other people, to be able to undertake daily activities and do other things they enjoy doing?)

Difficulty & lack of relationships, interaction and companionship / social isolation (lack of peer networks) - 7 people

Health & Healthcare – 6 people

- Poor physical health / mobility & health needs associated with LD & delays in support x 3
- Inequity in access to primary healthcare

Medication issues – 5 people

- Side effects of medication & over-sedation; including people coming into hospital following falls x 3
- Management of medication changes
- *“Medication continues to be used as a means for controlling people's behaviour, even when alternative evidence-based approaches were available”* – social care is in a unique position to effect change in partnership with others; provide scrutiny & challenge

1. What is preventing people from this group from living well?

(e.g. being able to go out, for example to visit day centres, to engage with other people, to be able to undertake daily activities and do other things they enjoy doing?)

Problems in joint-working – 5 people

- Background information not being shared and support people in the service
- Division/disagreement between health providers around person's support plan; e.g. GPs, hospitals, CMHTs etc not on same page around screening, diagnostics, etc.
- Non-specialist health professionals don't understand LD and how they present; some behaviours/personalities will look like MH, but may be normal for that individual
- Health and social care professionals not listening to provider support staff
- Need to seek information from people who know individual well

Societal attitudes and understanding – 4 people

- Risk aversion in society, including people who care for people with LD x2
- General lack of experience with people with LD and autism

Lack of opportunities employment, education and training – 4 people

1. What is preventing people from this group from living well?

(e.g. being able to go out, for example to visit day centres, to engage with other people, to be able to undertake daily activities and do other things they enjoy doing?)

Vulnerability and exploitation – 2 people

Provider Market – 2 comments, same person

- Provider market at the moment promotes "specialism", but actually heavily relies on interventions from health and social care to meet needs, which theoretically they are supposed to be meeting
- Provider market > not promoting alternative mechanisms to support individuals; e.g. positive behavioural support, intensive interaction

1 person each of below:

- Not having enough staff on duty
- Problems around deterioration of skills
- **Lack of opportunities around activities**, appropriate to individuals needs
- **Ageing parents, no longer able to provide/care for their needs**
- **Access to appropriate housing** is a barrier to social inclusion and citizenship
- **The effects of LD**; difficulties with communication, behaviours and obsessions

2. What is contributing to people deteriorating or getting into crisis?

Physical Health Factors:

- Early indicators of physical health detection is poor
- Detailed patient history not always available
- Over sedation with medication for behaviours x 2
- Co morbidity of people who have been on long term medications.
- Respiratory problems and Dysphagia
- Lack of recognition of early deterioration signs from carers x 2
- Medication changes

Social Factors:

- Poor contact with services / Isolation
- Families not recognising future needs and impact of ageing.

2. What is contributing to people deteriorating or getting into crisis?

Commissioning Awareness / Implications:

- Lack of awareness of therapeutic interventions (PBS) x 2
- Risk averse or poor risk assessment and management
- Lack of quality support within provider organisations x 2
- Lack of resources
- Poor awareness of LD
- MH from GPs x 2
- Services not working together / not sharing information back to carers
- Inappropriate environments, disrupted routines, changes to staff, inexperienced carers

Individual Factors:

- Poor independent living skills and service users vulnerability.

3. What keeps people up at night working with this population? Where do you get stuck?

Local Resources:

- People in hospital ready for discharge but nowhere from them to go
- Not having enough local resources to meet complex needs / Having to place people away from their local area / families X 2
- Too many changes / cost cutting by the council

Service User Experience:

- If the patient journey in hospital has not been good, waiting for test results and not knowing what physical health condition needs to be treated.
- Lack of counselling services in Adult services for those coming from children's services.

3. What keeps people up at night working with this population? Where do you get stuck?

Carer Experience:

- Not always knowing what is the best thing to do or who to go to for support at the time its needed
- Having to keep up with documentation deadlines and support plans, organisational policies
- Long winded guidelines / care plans
- Not having enough information about the person to support them properly
- X 2
- Unpredictable behaviours of service users, Public perception of our service users,

Safeguarding situations !

4. What do you think is missing from the health, care and support system in the way we work with people from this group? Do you feel the system supports people at the right time?/in the right way? If not, what changes should we make?

Commissioning considerations:

- Lack of integration of services to prevent people from falling through the gaps in services
- Lack of commissioned services > supporting the needs of the most vulnerable and complex people > isn't a diversity of support offer, activities, etc. > lack of forensic facilities locally and not being able to support people with these needs in community settlings locally as a result of this. X 3
- Not always the right support available at the time needed – needs to be more joined up
- Lack of local training for carers / families.
- Hospital staff not always understanding the LD needs.
- Not enough emphasis on alternative interventions to medication being prescribed. More awareness raising needed and support for carers to explore and understand the options

4. What do you think is missing from the health, care and support system in the way we work with people from this group? Do you feel the system supports people at the right time?/in the right way? If not, what changes should we make?

Carer Support:

- More health input from Psychology / Behavioural advisors and training for carers / families is needed.
- Too many meetings instead of direct support to people. Long processes, waiting times to be seen, decisions being made by professionals based on history rather than current situations, Incomplete assessments. Lack of confirmed diagnosis being made.
- Better preparation for adulthood and adult services is required

Service User Experience:

- Better patient voice and advocacy within health and social care system is needed. More accessible information needed for service users re MHA
- Need to treat people with LD the same as everyone else. GPs not always interested or sympathetic

- Local health system works well for people with LD – *GP*

5. Are there any interventions you are aware of that help you to support the people you work with? If so, do you feel it helps you to support people with LD?

Processes:

- CTR process works well
- Reasonable adjustments being supported in the hospitals (Hospital Passports, communication passports, staff training)
- good quality care providers being commissioned (RESPOND)
- Actively promoting alternative responses to medication (PBS, Intensive Interaction)
- Involving services users in decision making and their care.
- Keeping people active and busy

Services:

- Local Health Facilitation from SPLD across primary care and acute care settings / Sensory Impairment service supporting sight and hearing services – they know our service users well and provide a good service / Service at Twinwoods is valued x 2
- Sensory Integration assessments within SPLD OT department : should be more of them
- Care teams working and supporting each other.
- De-escalation techniques

5. Are there any interventions you are aware of that help you to support the people you work with?
If so, do you feel it helps you to support people with LD?

Local Knowledge and Expertise:

- Increase the knowledge and understanding of the effects of over medicating people.
- Ensuring proper monitoring and reviewing of prescribed medications.
- Improve quality of training and opportunities for carers within provider organisations.

6. What do you think helps to keep this group of people well? How good do you feel local services are at recognising and responding to your views?

- Professionals, carers and providers needing to really understand the needs of our service users and not be focussed on financial gains X 3
- Having support from people who know them. Local service at Twinwoods is good at this x 2
- More activities to improve physical and mental health X 2 GPs not always aware of where to go to seek this support.
- Good quality , consistent and experienced carers X 5
- Good support to review physical health and support when going into hospital
- Service users having the chance to socialise away from who they live with or go to day care with x 2
- *“Having the LD Liaison nurse was particularly helpful”*

6. What do you think helps to keep this group of people well? How good do you feel local services are at recognising and responding to your views?

- Better training and education for carers / families.
- Information sharing between agencies and professionals.
- CTR
- Person centred practice
- Better commissioning strategies for manging high risk groups and having local resources to do this.
- Better medication management
- Better working with CQC, Local Quality Standards when exploring providers of concern to us.
- Having access to Twinwoods staff to support with Health Action Plans and better access to health services
- Not sure we are listened to, don’t always get feedback

Three part data review; how it felt before and afterwards

Before…

After…

First go at Driver Diagram to bring together our theory of change – Primary Drivers

Population: People with a learning disability, with or without Autism, ADHD and dementia, who are at risk of being prescribed antipsychotic medication, with no confirmed diagnosis of mental illness*

Purpose statement: Improving quality of life for our population.

* e.g. psychosis, severe depression

Working better together for people with LD

Being supported well

Inclusion and experience in society

Recognising and empowering the person

Working together for people with LD

- Providers & carers getting on same page. (information, signposting, timely specialist support for carers, knowing where to go to get support)
- Reducing waste (?too many meetings instead of direct support to people?), long processes, waiting times
- Addressing transition to adult services
- Right care, right place, right time (addressing service gaps; for exforensic support)
- Access to therapeutic interventions

Being supported well

- Stopping over-medication (STOMP), including balancing benefits and risks
- Support with physical health
- Being known and understood by people caring for me
- Routine and consistency in care
- Calm environment
- Decisions based on current situation (not histories)
- Understanding behaviours as unmet needs
- Skills and understanding of LD

Inclusion & Experience in Society

- Addressing vulnerability and exploitation/ safeguarding
- Social life and relationships
- Part of community
- Changing attitudes
- Employment, education and training opportunities

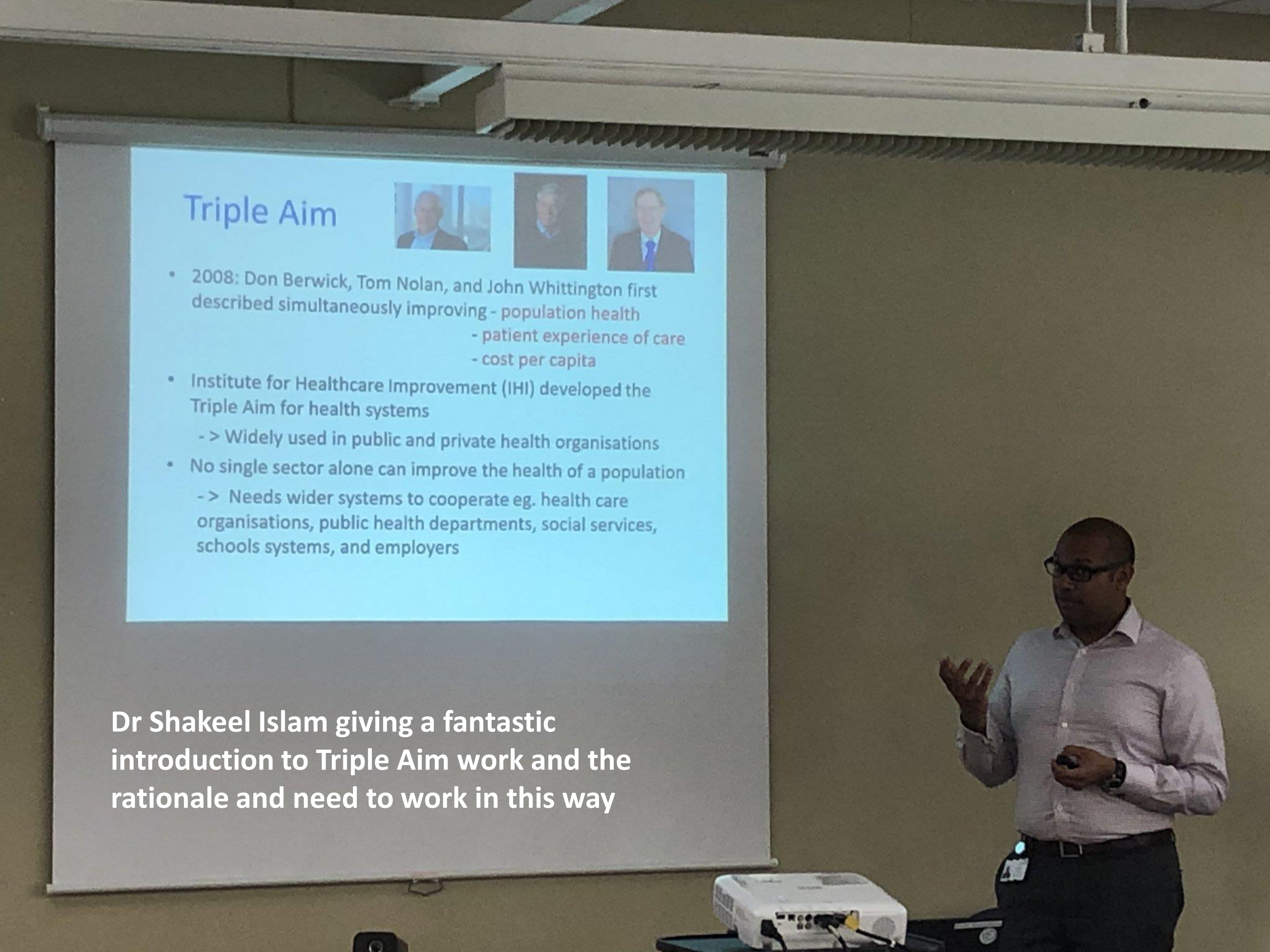
Recognising and empowering the person

- Voice, including advocacy
- Supporting people to take risks
- Strengthening life skills
- Enabling personal interests and activities
- Choice and variety
- Supporting independence, including enabling people to live in own home

1st draft Primary & Secondary Drivers 31/05/2019

Learning Disabilities Partner Engagement Event

28/06/2019



Triple Aim

- 2008: Don Berwick, Tom Nolan, and John Whittington first described simultaneously improving - population health
  - patient experience of care
  - cost per capita
- Institute for Healthcare Improvement (IHI) developed the Triple Aim for health systems
  - -> Widely used in public and private health organisations
- No single sector alone can improve the health of a population
  - -> Needs wider systems to cooperate eg. health care organisations, public health departments, social services, schools systems, and employers

Dr Shakeel Islam giving a fantastic introduction to Triple Aim work and the rationale and need to work in this way

Activity 1: Developing a Theory of Change

In your experience, what are the factors that enable and restrain people with Learning Disabilities living well in our community?

What contributes to people deteriorating or experiencing crisis? What can help prevent this?

[We then got people to circulate to add to Driver Diagram]

Activity 1 – part 2: Additional questions following first look and comment on Driver Diagram

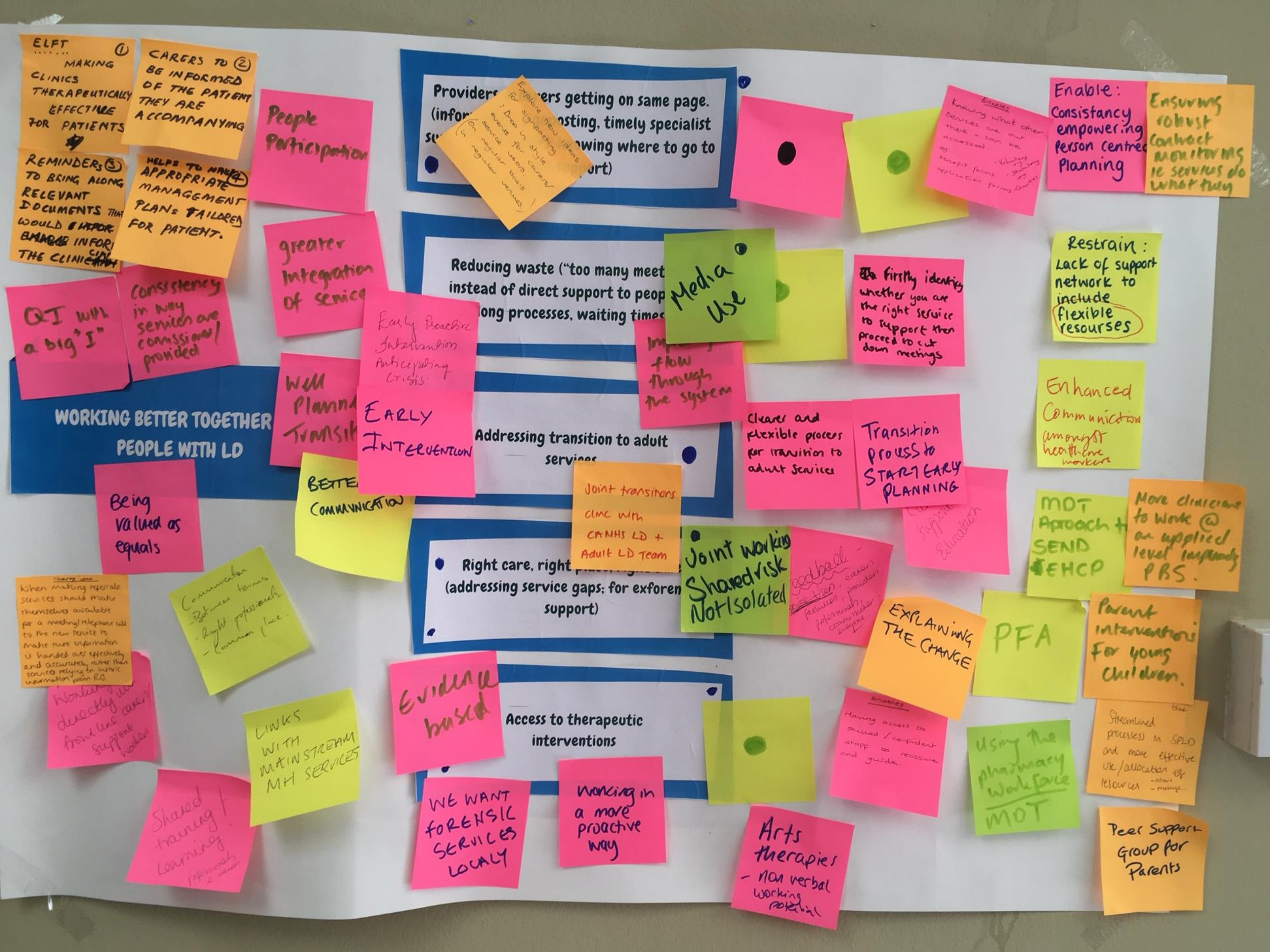
1. *Is anything missing?*

2. *Is there anything your organisation finds particularly difficult in supporting people with LD to live well? What support do you need?*

Activity 3: Change Ideas

After everything you've heard today, what ideas for change do you have?

We used a different colour (orange post-its) and asked people to plot on the driver diagram



WORKING BETTER TOGETHER
PEOPLE WITH LD

Providers ers getting on same page. (infor osting, timely specialist su owing where to go to ort)

Reducing waste ("too many meet instead of direct support to peop ong processes, waiting times

Addressing transition to adult services

Right care, right (addressing service gaps; for exforen support)

Access to therapeutic interventions

ELFT
① MAKING CLINICS THERAPEUTICALLY EFFECTIVE FOR PATIENTS

CARERS TO ② BE INFORMED OF THE PATIENT THEY ARE ACCOMPANYING

REMINDERS ③ TO BRING ALONG RELEVANT DOCUMENTS THAT WOULD INFORM THE CLINICIAN

HELPS TO MAKE ④ APPROPRIATE MANAGEMENT PLANS TAILORED FOR PATIENT.

People Participation

greater Integration of service

QI with a big "I"

consistency in way services are commissioned/ provided

Early Proactive Intervention Anticipating Crisis

Well Planned Transition

EARLY INTERVENTION

Being valued as equals

BETTER COMMUNICATION

Charing ideas
When making referrals services should make themselves available for a meeting/ telephone call to the new service to make sure information is handed over effectively and accurately, rather than services relying on historic information from RiO.

Communication
- Between teams
- Right professionals
- Common place.

Working directly with front line carers/ support workers

LINKS WITH MAINSTREAM MH SERVICES

Shared training + Learning
professionals & carers

Explore new ideas for signposting: Drop in style events for carers/ service users. (On regular basis in regular venues)

Media Use

Improving flow through the system

Joint transitions clinic with CAMHS LD + Adult LD Team

Joint working Shared risk Not Isolated

Feedback - service users, carers, families, providers, informal communication everyone

Evidence based

WE WANT FORENSIC SERVICES LOCALY

working in a more proactive way

Arts therapies - non verbal working potential

Enables
Knowing what other services are out there - can be accessed.
eg. benefit forms, application forms
- Voluntary org - Statutory org - charities

To firstly identify whether you are the right service to support then proceed to cut down meetings

Clearer and flexible process for transition to adult services

Transition process to START EARLY PLANNING

Carer support Education

EXPLAINING THE CHANGE

Enables
Having access to skilled / confident staff to reassure and guide.

Enable: Consistancy empowering Person centred Planning

Ensuring robust contract monitoring ie services do what they

Restrain: Lack of support network to include flexible resourses

Enhanced Communication amongst healthcare workers

MDT Aproach to SEND EHCP

More clinicians to work @ an applied level implementing PBS.

PFA

Parent interventions for young children.

Using the pharmacy workforce
MOT

blue
Streamlined processes in SPLO and more effective use/allocation of resources - admin - meetings

Peer Support Group for Parents

BEING SUPPORTED WELL

- Stopping over-medication (STOMP), including balancing benefits and risks
- Support with physical health
- Being known and understood by people caring for me
- Routine and consistency in care
- Calm Environment
- Decisions based on current situation (Not History)
- Understanding behaviours as unmet needs
- Skills and understanding of LD

OT involvement in stomp QI

IG including Education.

elft ~~[illegible]~~ including PBS in STOMP.

LeDeR Mortality review findings

[SALT] to help with communication.

pharmacist review - involving GP/PCN/care home pharmacist - are they trained?

right meds right time evidenced based

BETTER SCREENING EARLIER

GPs TO LISTEN!

PBS PATHWAY *

Education for providers & carers.

SENSORY ASSESSMENTS

Physical Activity opportunities suitable & accessible

Healthy Living/ Exercise group for SUs

SUPPORTING THEM WITH ASL IN AN INCLUSIVE MANNER

- Patient Choices
- Concordance (stomp)

involvement Primary Care Pharmacist

PBS training including STOMP for Parents/Carers to Start

involvement of OT and capable providers to enable routine & consistency.

technology → medicine review → communication

Communication

kindly. Listen to needs. Take time for them.

SETTING UP Physical activity group - with support of OT

PBS training including STOMP for Staff

* Involvement in PBS training - OT - re: activities routines, structure environment, sensory needs

OT ELFT

well-planned transitions

Consistency of Support to reflect final outcomes of the care plan

DON'T EXCHANGE ONE RESTRAINT FOR ANOTHER E.G MEDICATION FOR 1:2:1 support.

Good Support

* Re-assure Staff Re STOMP

quality

Rolling out PBS training for Student nurses as part of their program

STAMP before STOMP.

FAMILY DISENGAGEMENT

More integrated approach to supporting individuals

Autism friendly

USE PERSON CENTRED CARE PLAN

Sensory needs

... but history is also vital e.g. trauma neglect MH

Based on assessments - ie OT, sensory processing

MORE HOUSING OPTIONS ↗

Formal for planning, reducing and monitoring any medication reduction

LD + MH workshops for carers / services users

* PROMPT GP's Re STOMP

psycho-education those around the SUs

CHALLENGE HEALTH Inequality ?

poor health + mobility

MDT input in Education Health & Social Care Plans

elft. Consideration of Carer involvement at all stages of care

Choice

Transition TO SERVICES

UNDERSTANDING BEHAVIOURS MAY BE UNMET HEALTH NEEDS

specialist inpatient support for people with more LD and complex needs.

Pooled Budgets

Well trained staff

Formulation rather than diagnosis

- / family training
- meaningful activity
- sensory integration

OT ELFT

Home visits for psychiatry

idea of culture community change - scale of Dementia friends. - community is open to everyone.

Education & raising awareness of LD & Autism in the community

Challenge for change

We need to work together with all involved with individual to promote that medication is not the answer!!

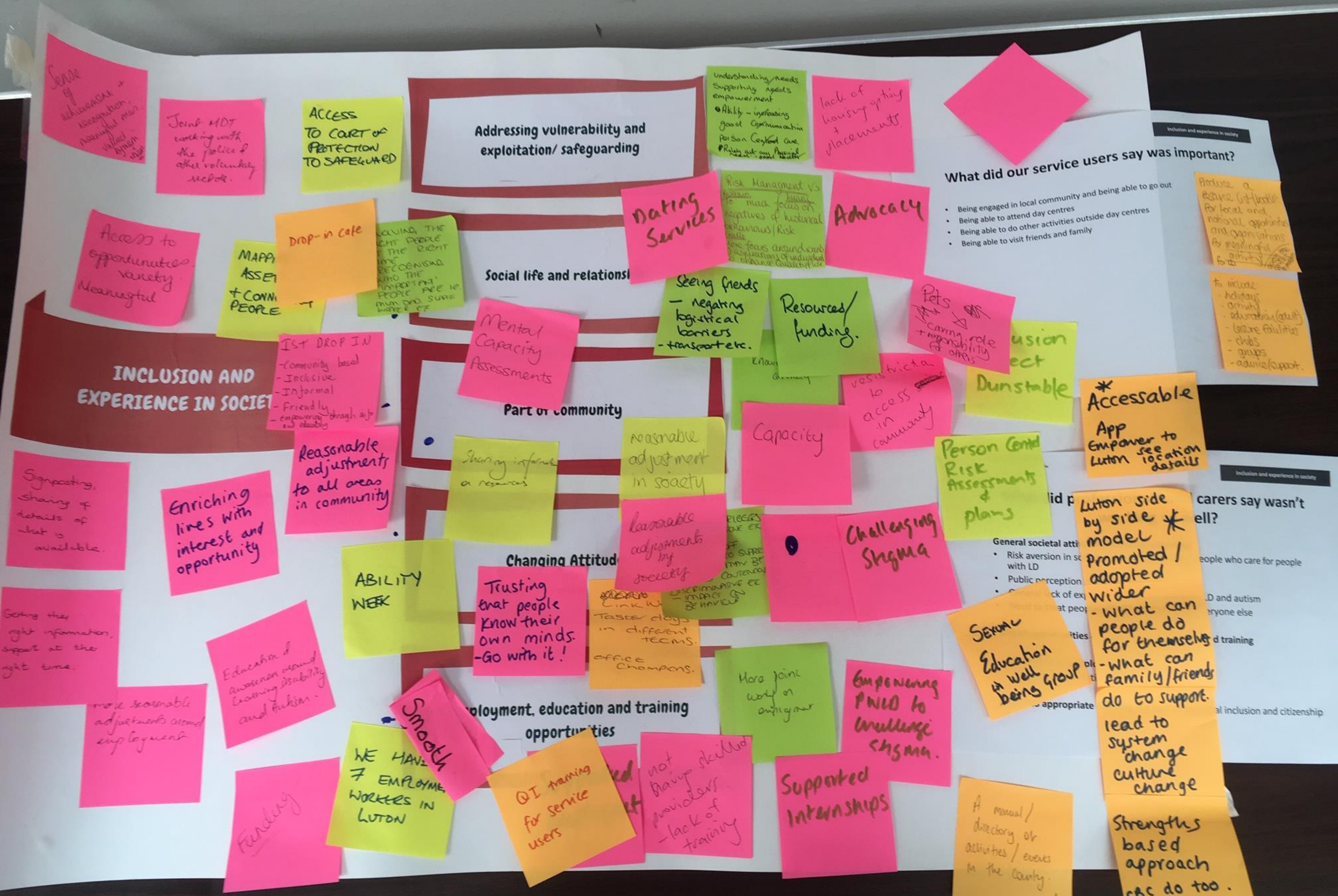
We need to look at strengths and Assets

Train GP's

Staff support + empowerment

Supporting network around person

being valued great understanding patient centred



INCLUSION AND EXPERIENCE IN SOCIET

Addressing vulnerability and exploitation/ safeguarding

Social life and relations

Part o community

Changing Attitud

ployment, education and training opportu ities

Inclusion and experience in society

What did our service users say was important?

- Being engaged in local community and being able to go out
- Being able to attend day centres
- Being able to do other activities outside day centres
- Being able to visit friends and family

Inclusion and experience in society

id p carers say wasn't ell?

General societal atti

- Risk aversion in s eople who care for people with LD
- Public perception
- ck of ex D and autism
- at peo eryone else

ities d training

appropriate l inclusion and citizenship

Sense of achievement + recognition, meaningful roles valued by

Joint MDT working with the police & other voluntary sector.

ACCESS TO CORT OF PROTECTION TO SAFEGUARD

Access to opportunities variety Meaningful

MAPPI ASSET + CONN PEOPLE

Drop-in cafe

VOLVING THE RIGHT PEOPLE AT THE RIGHT TIME RECOGNISING WHO THE 'IMPORTANT' PEOPLE ARE i.e. MUM DAD SUPPORT WORKER ETC

IST DROP IN
- Community based
- Inclusive
- Informal
- Friendly
- empowering through info and educating

Reasonable adjustments to all areas in community

Signposting, sharing of details of what is available.

Enriching lives with interest and opportunity

Getting the right information, support at the right time.

more reasonable adjustments around employment

Education & awareness around Learning Disability and Autism.

Funding

ABILITY WEEK

WE HAV 7 EMPLOYME WORKERS IN LUTON

Smooth

Understanding needs
Supporting needs
empowerment
● Ability – increasing
good Communication
Person Centred Care
● Rule out any Physical health – mental health

lack of housing options + placements

Dating Services

Risk Management vs positive risk taking
Too much focus on negatives of historical behaviours / Risk
More focus around wants & aspirations of individual to enhance Quality of life

Advocacy

Seeing friends – negating logistical barriers – transport etc.

Resources/ funding.

Pets
caring role + responsibility for others

usion ect Dunstable

restriction to access in community

Capacity

Mental Capacity Assessments

Sharing information on resources

reasonable adjustment in society

Reasonable adjustments by society

Challenging Stigma

Person Centred Risk Assessments & plans

Trusting that people know their own minds. – Go with it!

Link W Taster days in different teams. office champions.

More joint work on employment

Empowering PWLD to challenge stigma.

QI training for service users

not having skilled providers – lack of training

Supported Internships

* Accessable App Empower to see Luton location details

Produce a resource list/toolkit for local and national opportunities and organisations for meaningful activity

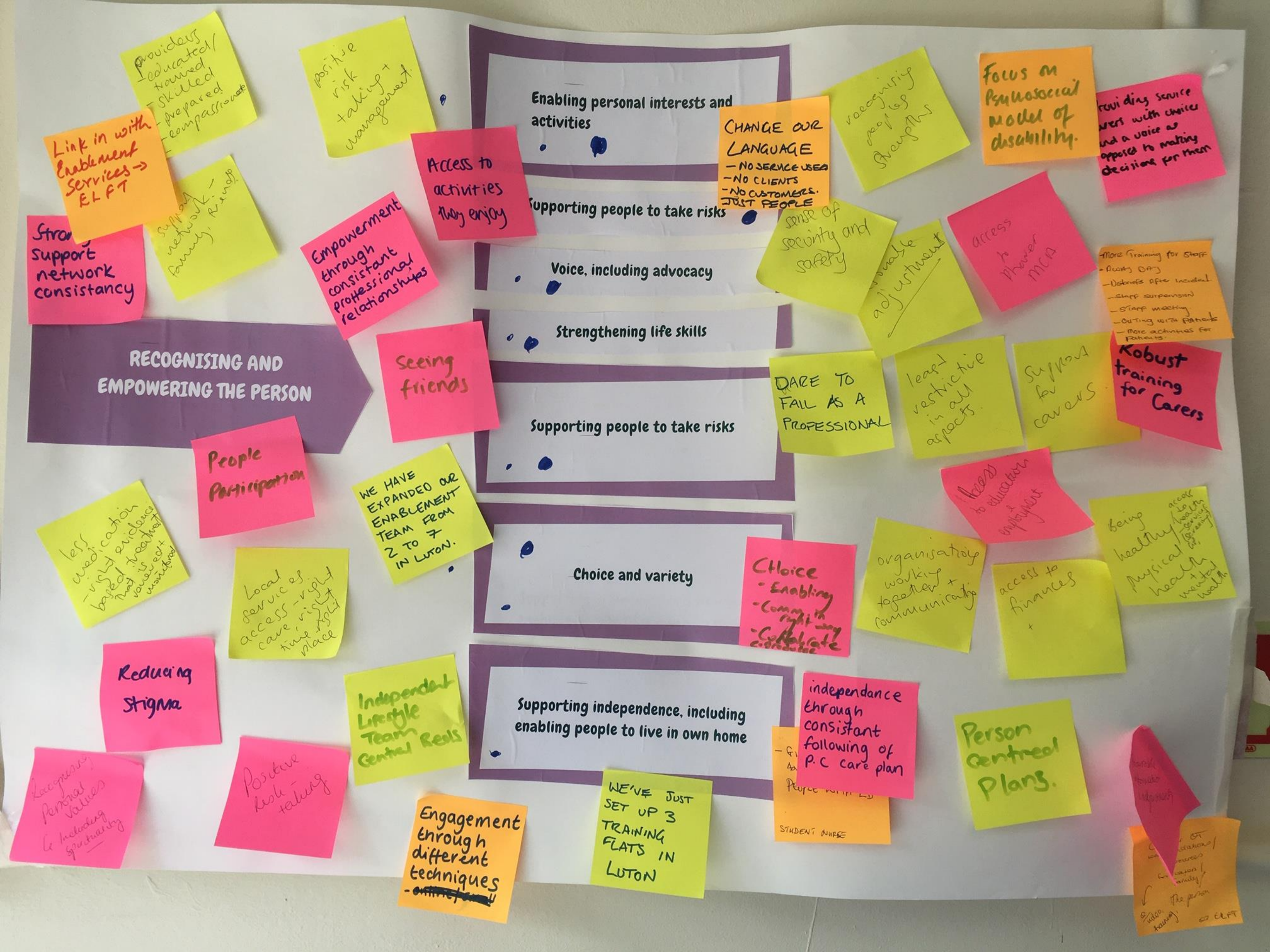
to include
- holidays
- activity
- education (adult)
- leisure facilities
- clubs
- groups
- advice/support.

Sexual Education in well being group

Luton side by side * model promoted / adopted wider
- what can people do for themselves
- what can family/friends do to support.
lead to system change culture change

Strengths based approach CBC do too.

A manual / directory of activities / events in the County.



RECOGNISING AND EMPOWERING THE PERSON

Enabling personal interests and activities

Supporting people to take risks

Voice, including advocacy

Strengthening life skills

Supporting people to take risks

Choice and variety

Supporting independence, including enabling people to live in own home

providers
- educated/trained
- skilled
- prepared
- compassionate

positive risk taking + management.

Link in with Enablement Services → ELFT

support network / family, friends.

Strong support network consistancy

Access to activities they enjoy

Empowerment through consistant proffessional relationships

Seeing friends

People Participation

WE HAVE EXPANDED OUR ENABLEMENT TEAM FROM 2 TO 7 IN LUTON.

less medication - right evidence based treatment that is reviewed + monitored

Local services access - right care, right time, right place

Reducing Stigma

Independent Lifestyle Team Central Beds

Recognising Personal Values i.e. Including Spirituality

Positive Risk-taking

Engagement through different techniques

WE'VE JUST SET UP 3 TRAINING FLATS IN LUTON

CHANGE OUR LANGUAGE
- NO SERVICE USER
- NO CLIENTS
- NO CUSTOMERS.
JUST PEOPLE

recognising peoples strengths

Focus on Psychosocial model of disability.

Providing service users with choices and a voice as opposed to making decisions for them

sense of security and safety

reasonable adjustments

access to power MCA

- More Training for Staff
- Away DAY
- Debriefs After incident
- Staff supervision
- Staff meeting
- Outing with Patients
- more activities for Patients.

DARE TO FAIL AS A PROFESSIONAL

least restrictive in all aspects.

support for carers.

Robust training for Carers

Access to education & employment

Being healthy
access to health services (screening etc)
physical health + mental health

Choice
- Enabling
- Comm in right way
- Collaborate

organisations working together + communicating

access to finances

independance through consistant following of P.C care plan

People with LD

STUDENT NURSE

Person Centred Plans.

ELFT

Activity 2: Sharing our strengths and assets

1. *How do you/ does your organisation contribute to improving quality of life for people with learning disabilities already?*

2. *What could you offer to help this work move forwards working together and supporting each other? What support could you provide others in the system? [asked people to reflect on and connect with what others said they found difficult in activity 1]*

3. *What other assets are you aware of in the community that we could engage further to support this group? Where is there 'untapped potential'*


Contributions
ELFT Service that listens + responds
ELFT Robust Assessment that is MDT focused
Care & Treatment reviews
Commissioner
Quality Assurance
Commissioner
Communication
Commissioner
Support Main Stream Services to Support People
ELFT NHS Decreasing Numbers of deaths
Reducing Pain
CONTRIBUTION
CONNECTING PEOPLE TO MAKE FRIENDS
COMMUNITY MAPPING
SUPPORTING PEOPLE IN TO EMPLOYMENT
3 Training Flats
Transitions
Joint work with housing % of all new builds for people with LD
Home RES
IL
Skills strengths.
Partnership working with CQP/DOLS
Contribute to Transforming Care agenda
Prevent admissions
CONTRIBUTION
- SUPPORTING THEM ACHIEVING THEIR DAILY ACTIVITIES
- FEELING VALUED
- SUPPORT LIVING INDEPENDENT LIFE
- GIVING CHOICES
- BUILDING TRUST
- VALIDATING THEIR CHOICES/DESIRES
Psych ELFT
Psychologist ELFT
OT aims to maximise and encourage meaningful roles for a person to feel valued and of value
OT has an HOLISTIC approach to assessment in mental & physical health
OT aims to improve and maximise the roles and values of an individual for
OT focuses on the barriers and enablers to how a person engages with their environment
OT draws on a persons interests and goals to guide development
Contribution
Working with service users individually to help them voice what helps them to Staff/Parents
Supporting staff to think about PBS
Working with Drs to help for PBS in place before Medication is reduced
Family Support
Staying Healthy Group Hackney
Good relationships with mainstream colleagues
Hackney
Organising Sanjay/Ruth!
Running Training to improve peoples Knowledge on functions of Behaviour
Including service users with LD in Q I projects
Hackney
Chasing SPLD for responses!
Going into generic Services to talk about PBS and how to support people
Supporting mainstreaming
Hackney
Yoga group
Hackney
Sharing info to SPLD/IST.
Transforming care
Hackney
STAMP - reducing antipsychotic prescribing
Hackney
Training Staff teams in PBS
Advocating for PWLD - Human Rights
Reducing Medication
Q-o-L is fundamental to PBS
Hackney
Hackney
Hackney
Hackney
CONTRIBUTION
Transforming care Supporting Discharge from hospital
CTR
LAEP
Engaging with people who use services and their carers
Creating local strategic direction
Provider Market Shaping. Contract and quality assure services. New bussiness
Finding housing solutions
Strategic Planning to return people living out of area
ELFT QI projects
ELFT REDUCING DNA - rate FOR APPOINTMENTS.
ELFT Carers Involvement
ELFT Stopping unnecessary meds
ELFT Involve pts in service development
ELFT MDT
Market Shaping - Quality + effective services CBads
Open to change looking at doing things differently - what works now CB
Engaging with local people + what matters to them CBads
Partnership engagement CB
Housing opportunities Supported living CBads
PFA - CBC Facilitating transition from children services
PFA - CBC Supporting Carers.
PFA - CBC Support Young people to develop independent skills - TILT
PFA CBC Identifying Social Care needs & providing support
PFA - CBC Support customers to find paid/voluntary employment
PFA - CBC Holistic Assessment & Signposting
CBC - PFA Advocating for our customers
CONTRIBUTION
IST
Provide a duty service
IST
IST
Utilise members of MDT to contribute to any assessments/interventions
SHCT/ELFT
SHCT/ELFT
SHCT/ELFT
ELFT/IST
services.
Providing timely support to people in crisis.
IST
Working as a MDT to provide support in all aspects of care
IST

OFFER / SUPPORT

Offer / Support

Knowledge of universal services LBC

SHARING GOOD WORK LBC

FORENSIC OPINION FROM ELFT

Offer / Support.

Managing and sharing information between services better and making yourself available in the event of more input being required IST

OFFER / SUPPORT

Engagement inc LD Partnership board
Autism Partnership board

BLMK Strategic direction. feed ↑ ↓

Joint meetings with all LD Commissioners

Tap in to LD strategy Action Plan

ELFT Consultant in QI

Better internal comms across all ages C Beds

CBC–PFA Shared Team meetings, Roadshows

Engagement events – partnership Boards/ Groups C Beds

Change Management C Beds

Learning from other areas – best practice C Beds

Offer / Support.

Sharing information across Services SPLD

Making time to help others

Come + visit us in Hackney

A cup of coffee + time for a chat

Remember to be kind to each other

Is there anything your organisation / your part of the service finds particularly difficult to support people with LD to live well? *

Please write your organisation / part of the service on your post-it

POOR HEALTH ACCESS TO GPs LUTON

GOOD QUALITY LOCAL PROVISION FOR COMPLEX NEEDS LUTON

CAPACITY – Difficult to respond swiftly or proactively

Integrated Health + Social care TEAMS

LD comm. BHL
Inaccurate referrals / inappropriate referrals taking time/resource to process

We are in the early stages of engaging people with LD in people participation in a meaningful

Hackney LD team

Waiting lists
Hackney LD Team

MEDICAL EMERGENCIES

Lack of specialist services to support complex needs

LD comm. BHL
Long waiting list. Capacity.

LD comm. BHL
No admin for Arts + Psychology meaning resources of time are wasted.

IT problems! eg no access to Rio
Hackney LD Team

Families don't engage with services
IST Townwoods

Limited providers

SPLD
Lack of staff – long waiting lists

SPLD
No Admin for Arts Psychology – waste of clinician resource

SPLD
Difficult to do live care planning No wifi access in some places.

Recruitment into management posts
Hackney LD Team

*(Big pen)

Things you find difficult (cont.)

HFS
Primary Care Restrictions i.e. No of appointments + time Ltd.

HFS
Joint Computer Systems (Speak together)

IST – Strategies not being used – not being shared with teams

LACK OF ACCESS TO PHYSICAL ACTIVITIES OR GROUPS FOR PEOPLE WITH LD – SPLD – ELFT

Central Beds
Inappropriate referrals
LD & MH ??

Working in silo
ELFT

LD + Autism Service user engagement

Central Beds
Identification of mental health needs in children services.

ELFT

Preventing hospital admission at short notice crisis. ∴ Preventative response either needs to be noticed earlier or alternative to hospital found.

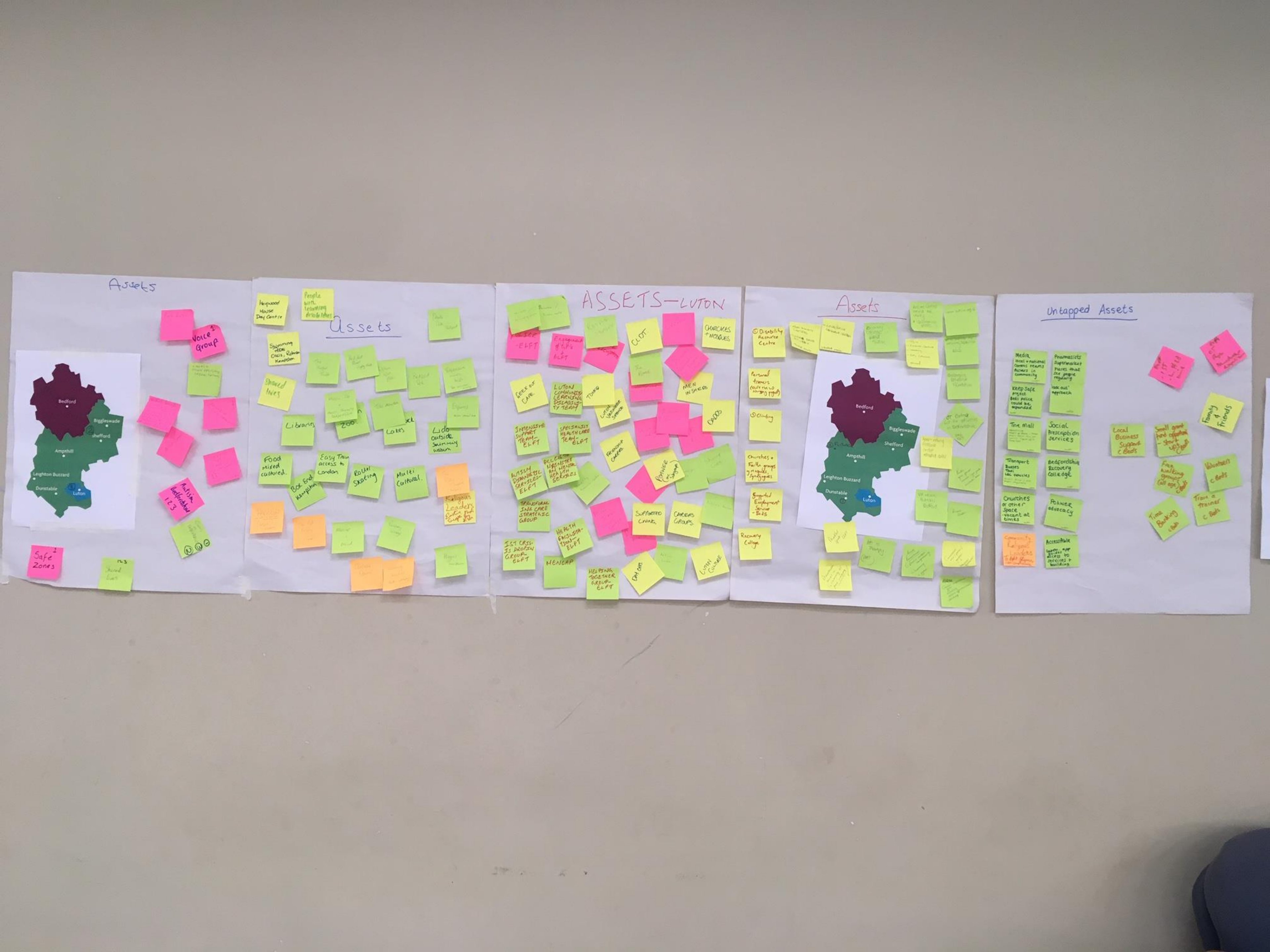
Forensic Services

Having access to info. re: local networks ~~Being~~ able to Support are not the right service (IST / SHCT)

How long it takes to plan a community CTR

Providers for people with Challenging behaviour

Crisis Care response – Short term step up type thing


Assets
Voice Group
Bedford
Biggleswade
Shefford
Ampthill
Leighton Buzzard
Dunstable
Luton
Autism Bedfordshire 1 2 3
Safe Zones
Heywood House Day Centre
People with learning disabilities
Assets
Swimming pools Oasis, Robinson Kempston
Shared lives
Libraries
Zoo
Lakes
Lido outside swimming woburn
Food mixed cultured.
Easy Train access to London
Box End Kempston
Roller Skating
Multi Cultural.
Religious Leaders
ASSETS—LUTON
-ELFT
Engagement of GPs & ELFT
CLDT
CHURCHES + MOSQUES
GEEK OF CARE
LUTON COMMUNITY LEARNING DISABILITY TEAM
TOKKO
LUTON VOLUNTARY SERVICE
MEN IN SHEDS
DADOS
INTENSIVE SUPPORT TEAM-ELFT
SPECIALIST HEALTHCARE TEAM-ELFT
FRIENDSHIP CAREERS
AUTISM DIAGNOSTIC SERVICES-ELFT
ACCESS TO MAINSTREAM MENTAL HEALTH SERVICES
POhWER (ex Sequal)
TRANSFORMING CARE STRATEGIC GROUP
SUPPORTED LIVING
CARERS GROUPS
HEALTH FACILITATION-ELFT
1ST CRISIS DROP IN GROUP-ELFT
MENCAP
HELPING TOGETHER GROUP-ELFT
DAY OPS
LUTON CULTURE
Assets
Disability Resource Centre
Personal trainers
Climbing
Churches + Faith groups mosques, Synagogues
Supported Employment Service - Beds
Recovery College
Untapped Assets
Media local + national Comms teams Partners in community
Pharmacists Supermarket Places that see people regularly
Keep Safe project Beds police could be expanded
'look out' approach
The Mall
Social Prescription services
Transport Buses Taxi
Bedfordshire Recovery College
Churches or other Space -vacant at times
POhWER advocacy
Community Religious Leaders
Accessible
Local Business Support c Beds
Small grant fund opportunities - start ups c Beds
Family & Friends
Free walking groups (all age) c Beds
Volunteers c Beds
Time Banking c Beds
Train a trainer c Beds


Enabling personal interests and activities
Supporting people to take risks
Voice, including advocacy
Strengthening life skills
RECOGNISING AND EMPOWERING THE PERSON
Supporting people to take risks
DARE TO FAIL AS A PROFESSIONAL
Choice and variety
Supporting independence, including enabling people to live in own home

Video of our event

https://www.youtube.com/watch?v=cqn5nf0DnwY

Delegate Feedback

Please tell us your experience of the event today

- *I found it a good opportunity to discuss how we can improve the lives of people with learning disabilities*
- *Great event to collaborate and work together across organisations to implement change, sharing of assets and focusing on the individual holistically*
- *Fantastic to see what some of the stumbling clocks are and how we can overcome these TOGETHER*
- *Good to hear ideas/thoughts from other professionals – from different agencies and hear that these are shared. Good to help engender partnership working between health and social care*
- *I found it very interesting and informative and thorough. I also identified areas in which we can, as services, improve*
- *Very thought provoking*

Delegate Feedback

Please tell us your experience of the event today

- *Very interesting, informative and productive*
- *Very informative*
- *It's been helpful in my wider understanding of people with LD, as a student*
- *Interesting and informative. Lots of ideas to implement and share*
- *Really interesting. Lots of points raised and discussed. Was good to be able to see what others had written and areas they had raised*
- *Great to sit alongside partners across Bedfordshire to discuss how to improve lives. I am eager to be part of the difference this can make*
- *Very positive event. Great to meet a variety of colleagues*
- *Very interesting day to discuss challenges and ways forward. Look forward to making and seeing a difference in LD provision*

Delegate Feedback

Please tell us your experience of the event today

- *Brilliant. Thought-provoking*
- *Good experience. Mixing with another services and getting ideas to move forwards with*
- *Good*
- *Been a great event. Learnt a lot about what other organisations are doing*
- *Informative and thought-provoking. Has given me ideas to take back and test in clinical practice*
- *Very informative. Motivated*
- *Great experience of getting to know other professionals from different departments and areas and sharing information about what is available in the community to support people with LD and what is needed*
- *Great o see everyone working together to really think about improving quality of life for people with LD*

Delegate Feedback

How do you feel about working together to improve quality of life for people with Learning Disabilities?

- *This was the reason I became a social worker*
- *It is so important to work together and be fully committed*
- *I think it is very important for health and social care to work together to improve quality of life*
- *I feel that working together is the way forward, as if we want to effectively improve quality of life, we need to focus on all aspects of care and work together*
- *Feel very strongly that joint/integrated working is a positive way for people who have a learning disability*
- *I feel very positive about working together and breaking professional and organisational boundaries, in order to support people with LD to live well in the community*
- *This has been a great way to discuss and brainstorm ideas and opinions. Good to hear other professions input*

Delegate Feedback

How do you feel about working together to improve quality of life for people with Learning Disabilities?

- *It is really important – working together can lead to better outcomes for the individual –more effective and efficient ways of working*
- *It is essential to work together for this. It is not something that can be achieved in isolation*
- *Made me really think about what we actually do and how small changes can make a huge difference to a person’s quality of life*
- *Optimistic*
- *Great*
- *It is the core of what we do*
- *I think it’s brilliant. The LD community is a wonderful community to be part of*

Delegate Feedback

How do you feel about working together to improve quality of life for people with Learning Disabilities?

- *Collaboration is a big factor, what we learn should be put into practice*
- *I feel enthusiastic to give more of my time and energy to help improve people with Learning Disabilities' quality of life following my graduation as a student*
- *Working together is the only way that this will happen. Sharing knowledge is really important*
- *Passionate*
- *I think it's the way to go and I am happy to be part of that*
- *It should be central to the work we do*
- *Completely <u>for</u> it!*

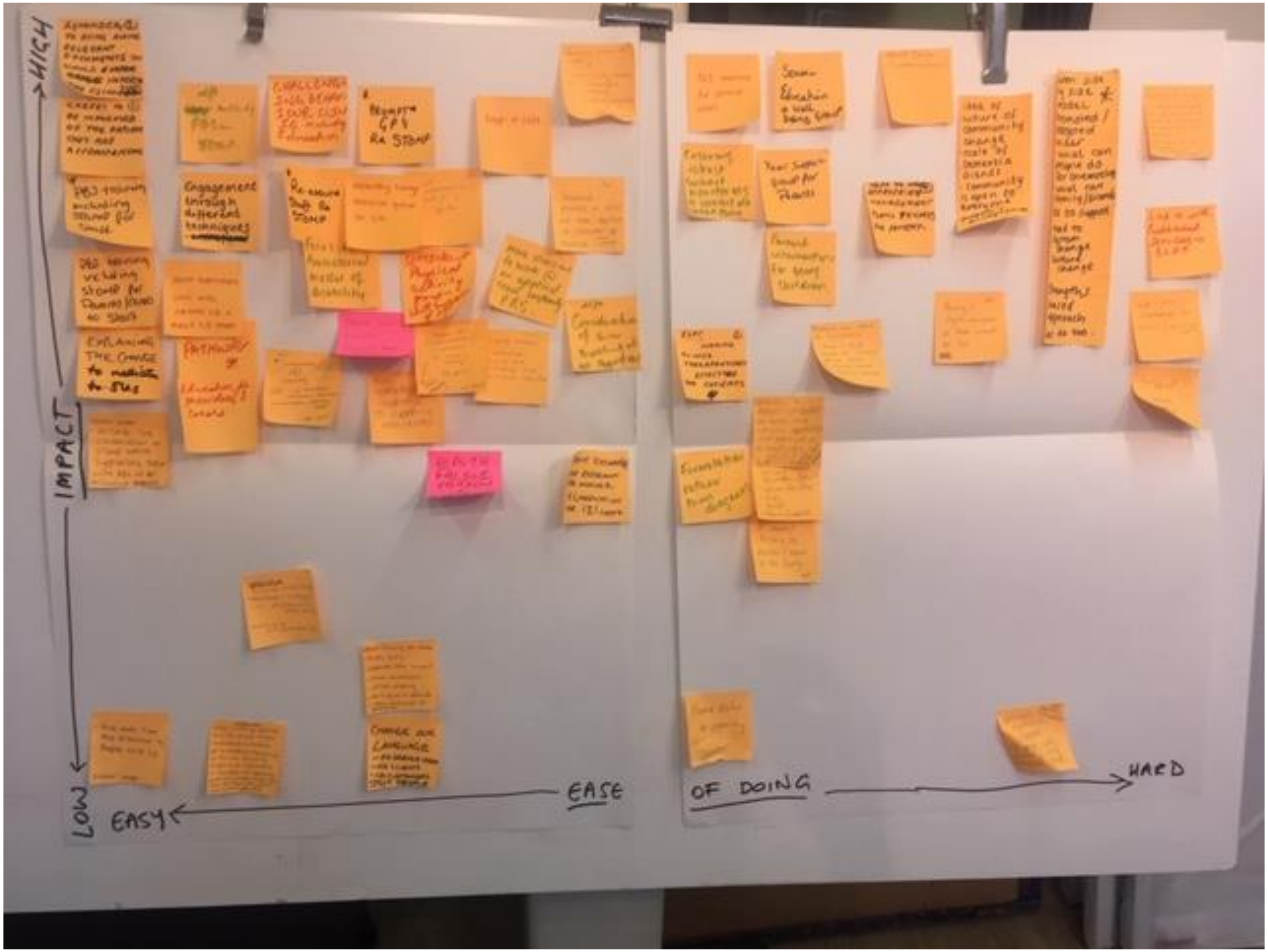
What was our first measurement plan for the work?

In development

Dimension of Triple Aim	Measure	Operational Definition	Data Collection Plan/ Notes
Population health	Total % BNF max doses across caseload	Adds up % BNF max dose for everyone on caseload BNF max dose is …	Local Spreadsheet held by Drs
	Pending: develop tool that explores outcomes identified as important to people	Consider sampling to make manageable	PLACEHOLDER
Experience of Care		Questions TBC	Patient Experience Questionnaire (PEQ)
Value	Cost of antipsychotics (APs) prescribed to population	TBC	Local Spreadsheet held by Drs
	Cost of review appointments for APs prescribed to population	Come up with average estimate model for medical time, other clinical time, admin time. Apply this to number of review appointments conducted per month	Local Spreadsheet held by Drs
	Pending: Number of contacts with Intensive Support Team per month		Link RiO codes for people in population to use of IST

How did we prioritise our drivers/change initiatives?

Step 1: 2x2 grid considering ease and impact following engagement event



How did we prioritise our drivers/change initiatives?

Step 2: 1st Project Team Meeting following engagement event

What drivers/initiatives did we identify as our first priorities?

Initiatives/tests of change; **what did we learn?**

- Insert PDSA details if applicable

Population level measures gathered

- Insert dashboard

How did you manage ensuring you sustained changes (Quality Control)?

The below provides ways to capture key insights through this document whenever you think it’s the right approach

Copy the below slide to keep the template version to use again in future

Challenge, Choice & Outcome (Ganz)

Challenge: Why did you feel it was a challenge? What was so challenging about it? Why was it your challenge?

Choice: Why did you make the choice you did? Where did you get the courage – or not? Where did you get the hope – or not? How did it feel?

Outcome: How did the outcome feel? Why did it feel that way? What did it teach you? What do you want to teach us? How do you want us to feel?

WOW Moment!

[e.g. a big piece of learning, a big opportunity that came up, a moment when something happened that changed how you were thinking / how you understood the issue / how you worked together, etc.]

Please insert the date it happened, add description and insert into the relevant place above to reflect the chronology of the project

WOW (that was a tricky/challenging) Moment!

[flip-side of the above… not everything that happens is positive, but there is still loads of learning in this, so important to capture as well]

Please insert the date it happened, add description and insert into the relevant place above to reflect the chronology of the project