



One world, many voices: co-production
in action

Cristina Serrão

Tanya Lord

Helen Lee

What is meant by the term co-production?

"**Co-production** is a way of working that **involves people** who use health and care services, carers and communities **in equal partnership**; and which engages groups of people at the **earliest stages of service design, development and evaluation**. Co-production acknowledges that **people with 'lived experience'** of a particular condition are **often best placed to advise** on what support and services will make a positive difference to their lives.

Done well, **co-production helps to ground discussions in reality**, and to maintain a person-centred perspective"

[A model for co-production: NHS England and NHS Improvement and Coalition for Personalised Care \(formerly Coalition for Collaborative Care\) \(2020\)](#)

Values and behaviours

For co-production to become part of the way we work, we will create a culture where the following values and behaviours are the norm:



This illustrates the aim of improving experiences of care by co-producing quality improvements together, within a total quality management system



Co-production as one of several ways to work with people and communities

Graphic from: [Working in Partnership with People and Communities. Statutory Guidance for Integrated Care Boards, NHS Trusts, NHS Foundation Trusts and NHS England, July 2022](#)

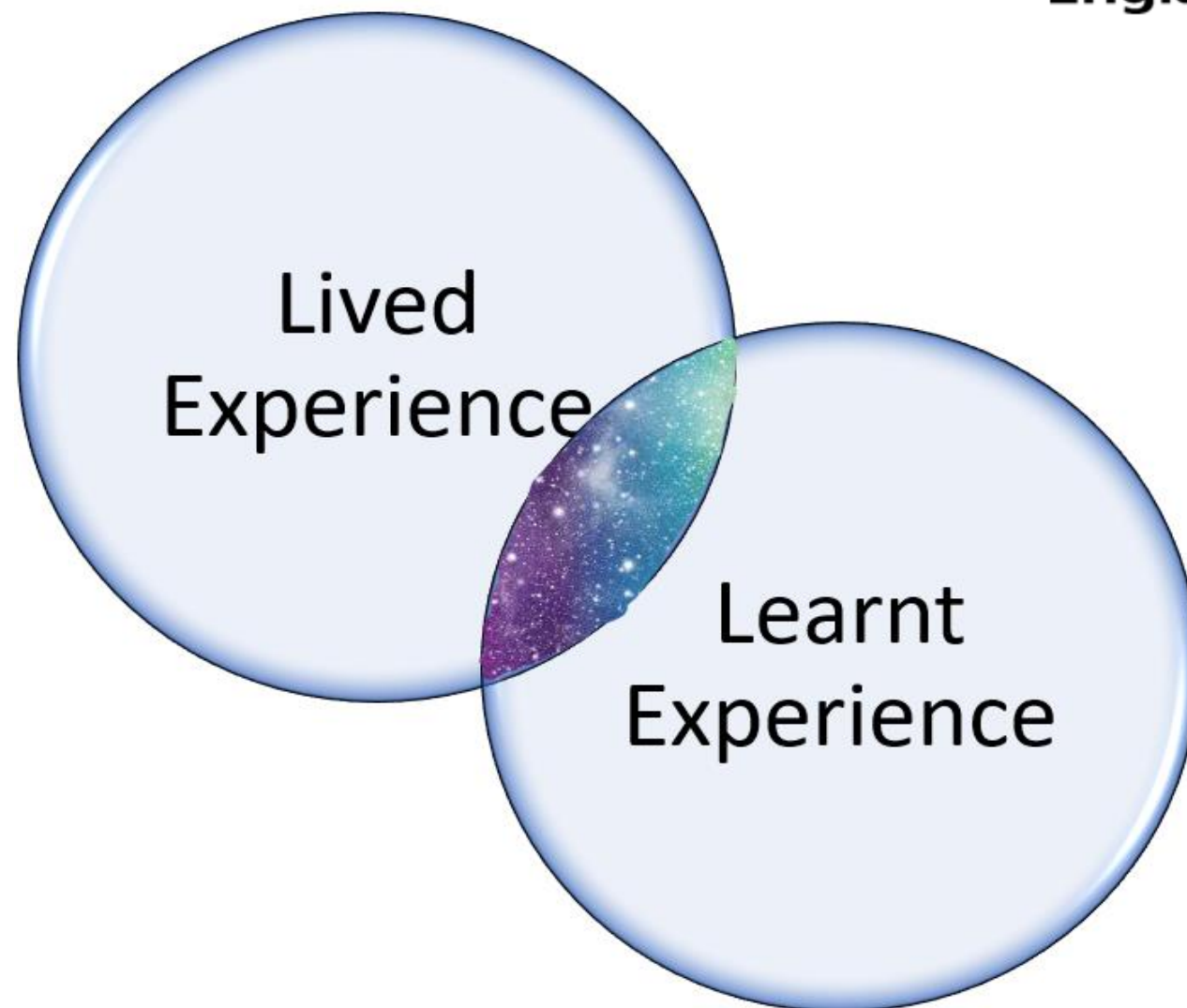


A blended approach to working partnership with people and communities.

Being clear as to the rationale and deciding that with people with lived experience



“But we all
have lived
experience of
healthcare”



Doing things together in a new way



- Change working methods to make **co-production the standard approach**, ensuring people with relevant lived experience are partnered with programmes in your organisation and systems.
- **Sharing power** with people with lived experience to improve care together. Bringing both **'lived and 'learnt'** experience together to work in partnership.
- Understand that we all bring our own experiences and expertise, and **everyone's opinion should be valued and listened to.**
- Putting **'what matters' to people at the heart of every interaction.**

Creating a culture of co-production – top tips



- **Embrace partnership and collaboration** – visibly support co-production at all levels, including senior leadership role modelling and sponsorship.
- **Identify and amplify existing co-production cultures** in the system.
- Support **adoption of co-production approaches** like Always Events®, Experience-Based Co-Design.
- Promote **open and honest conversations** with all involved.
- **Support organisations and systems that amplify the voices** of people and communities.
- **Invest in partners with relevant lived experience and unpaid carers**, to ensure they have the knowledge, skills and confidence for meaningful contributions.

Creating a culture of co-production – top tips



- Consider **employing individuals with lived experience** to role model this way of working, making connections to build sustainability.
- Systematically **build capabilities** for both people with lived experience and staff - **learn together**.
- **Invest in communities to assess needs through networks** of community champions – **grow together**
- **Don't assume** you know what people will say; **listen actively and be open and curious**.
- Embrace uncertainty – be **"comfortable with the uncomfortable."**
- Keep **communicating and moving forward**, despite challenges.
- **Reflect** on challenges **together** so that you improve together.
- **Celebrate successes** and share with others to help them learn too.

Experience Based Co-Design

Tanya Lord PhD, MPH
Chief Innovation Officer
ATW Health Solutions
tanya.lord@atwhealth.com



ATW HEALTH SOLUTIONS
Raising Healthcare's Standard



Experience Based Co-Design

1 Set up and planning

2 Staff and leadership focus group

3 Patient and/or family focus group

4 Co-design meeting

5 Co-design workgroup

6 Celebration Event!



ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

Recruiting Patients

- **Strategy**

- Flier development
- Outreach by email, phone and social media
- Shared with:
 - Governors Task Force
 - Director RCO meetings
 - Administrator at the Bureau of Drugs and Alcohol Se
 - Peer Networks
 - Family Support Networks

We Want to Hear From You!



Help to improve care in rural hospitals for people who have used alcohol

What?

FAIL

Contact: mcadden@healthynh.org for information.

Information will not be shared for any purpose other than for use of this project.



Foundation for
Healthy Communities
Partnering to improve health for all.



ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

Peer Champions



BEST PRACTICE

- Lived Experience
- A trusted:
 - Harm Reduction Worker
 - Peer Supporter
 - Member of other grassroots recovery organizations



ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

MY Own Lived Experience

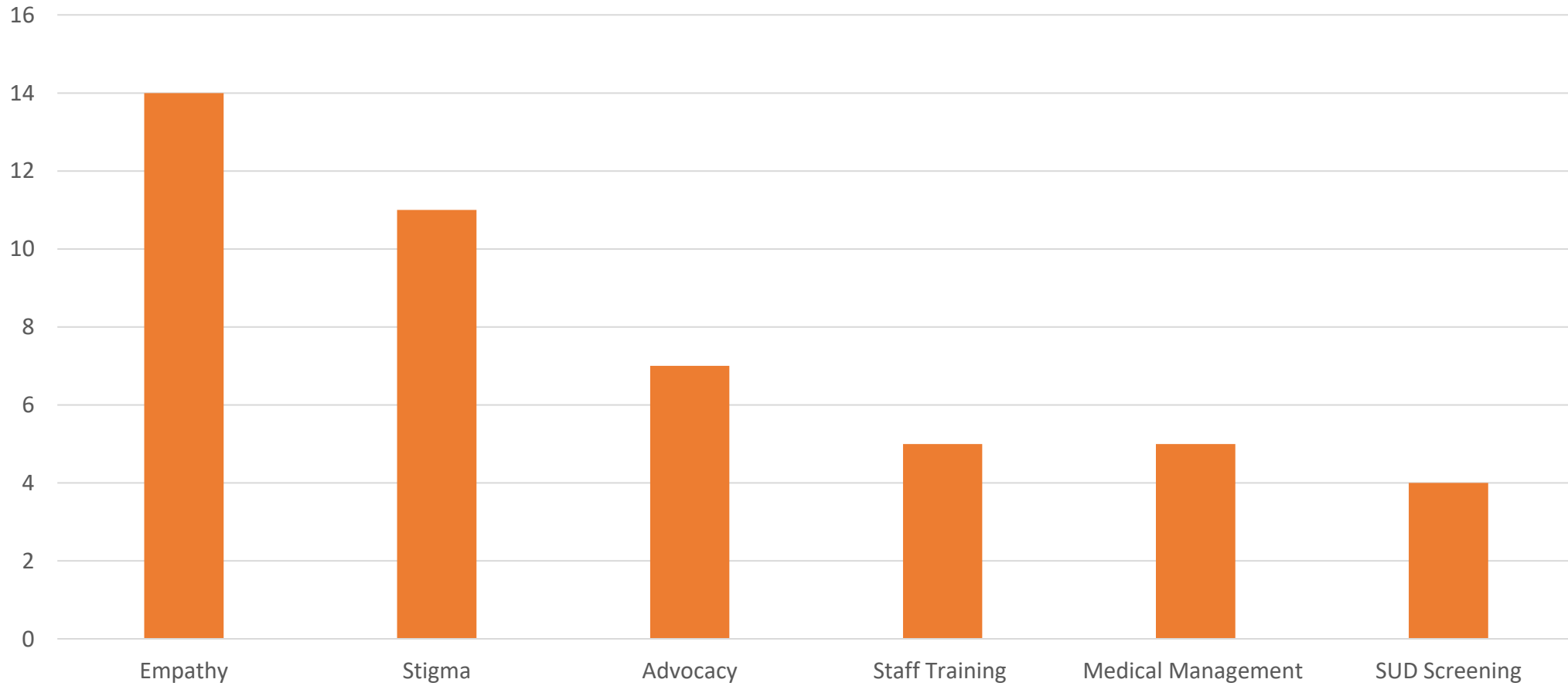




ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

Patient Problem Statement Themes

Patient Themes





ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

Staff and Clinician Problem Statement Themes

Hospital 1	Hospital 2	Hospital 3	Hospital 4
Community Resources	Community Resources	Community Resources	Community Resources
Patient Behaviors	Patient Behaviors	Patient Behaviors	
Medical Management	Medical Management	Medical Management	Medical Management
Empathy			Empathy
Staff Education			Staff Education
Compassion Fatigue			Compassion Fatigue
	Security Issues		
	SUD Screening	SUD Screening	
		Stigma	Stigma
		Insurance Issues	





ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

The Primary Finding: Patients

stigma

/'stigmə/

noun

1. a mark of disgrace associated with a particular circumstance, quality, or person.

"the stigma of mental disorder"

synonyms: **shame, disgrace, dishonour**; [More](#)



ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

Stigma

- **Did not stand out as the top results for all hospitals**
- **However....Survey Results:**
 - “They don’t want to help themselves”
 - “They can’t be trusted to tell us the truth”
 - “They lie 95% of the time and don’t tell the truth the other 5%”
 - “Why are we spending money on people who do not want to be helped”



Stigma = Inequities

- **Stigma:**

- Creates barriers to care
- Creates reluctance to return or do follow up
- Furthers distrust
- Encourages leaving against medical advice
- Endorses poor healthcare quality
- Risks safety
- Lessens the likelihood of seeking SUD treatment

- **Reducing Stigma is a Priority!**





ATW HEALTH SOLUTIONS
Raising Healthcare's Standard

Sample of Solutions Generated

- Provide compensation and time for Anti-Stigma Training
- iPad for patients to fill out SUD screening privately
- When hiring consider diversity: ethnic, racial, personality, tattoos, hairstyles, piercings
- Have Therapy Dogs join for difficult conversations
- Create quiet space for staff to regroup and offer each other support
- Include patients and families in bedside rounding and shift change reports
- Include people with lived SUD experience on PFAC
- Develop a “Buddy Mentor” for Staff
- **Change the measure of success**





ATW HEALTH SOLUTIONS
Raising Healthcare's Standard™

“It is OK to show love to your patients”



@SHSCFT

**Co-production through equal
partnerships:**

**Chairing transformation
programmes together**



Presenters

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Adam Butcher

**Expert by
Experience**

**Chair of multiple
groups**

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Hassan Mahmood

Clinical Director

**Learning Disability
Service**

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Mandy Butcher

**Expert by
Experience/
Volunteer**

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Parya Rostami

**Head of
Improvement**

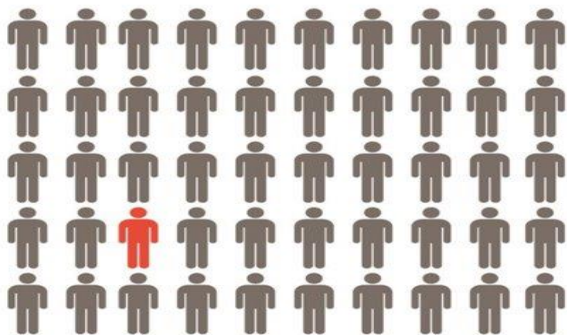
Learning Disability

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.

Learning Disability

There are 1.5 million people with a learning disability in the UK

Approximately 1 in 50 adults in the UK have a learning disability.¹



Stigma and inequality

- People with a learning disability may face **problems getting equal opportunities** for healthcare, education, employment and social pursuits. (Scior & Werner, 2015).
- People with SMI & LD experience a **greater burden of physical health conditions** ¹³
- People with a *learning disability* have **worse physical and mental health** than people without a learning disability (NHS Digital 2017).

² Scior & Werner, 2015, ³Public Health England 2018, ⁴

Stigma and inequality

- On average, the **life expectancy of women** with a learning disability is **18 years shorter** than for women in the general population.
- The **life expectancy of men** with a learning disability is **14 years shorter** than for men in the general population⁴
- Approximately **2/3 deaths** for people with SMI are due to **preventable physical illness** ⁵

Stigma and inequality

Evidence suggest that **mental health problems may be higher** in people with a learning disability than in those without a learning disability.

Some studies suggest the rate of mental health problems in people with a learning disability is **double that of the general population** (NICE, 2016).

Introduction to Sheffield

An aerial photograph of Sheffield, UK, showing a dense urban area with a mix of modern and traditional buildings, interspersed with green spaces and trees. The city is set against a backdrop of rolling hills under a clear sky.

- Greenest city in Europe⁷
- It is 160 miles North of London
- 5th largest city in UK
- Population of 556,500⁸

Inequality in Sheffield

- Sheffield is the 2nd least deprived core city in England
- Yet, 1/4 of Sheffield's areas are in the most deprived 10% nationally
- Five areas are within the 1% most deprived in England⁸
- Around **1 in 4 Sheffield people live in poverty** at any one time.⁹

Sheffield Health & Social Care NHS Foundation Trust

- Provide a range of mental health and learning disability services to the people of Sheffield
- Sheffield Health and Social Care NHS FT (SHSC) employs over 2,500 staff
- We provide services to around 55,000 people a year
- Our vision is to improve the mental, physical and social wellbeing of the people in our communities

SHSC Learning Disability Services

- The care and support of people with Learning Disability has been moving away from institutional services towards personalised, holistic care in community settings.
- To support this Sheffield had a Community Learning Disability Team and a separate small inpatient setting.
- Following a review of the inpatient setting in 2021 by the CQC, the Trust began a full review of Learning Disability Services - But how to do this well?

Our Service User Engagement and Experience strategy

- **Embed** Lived Experience Voices
- Ensuring expert by experience perspectives are **integral at all levels** of SHSC decision making
- Improving the experience of people using our services by **embedding coproduction** throughout SHSC
- Increase **partnership** working

Learning Disability Engagement and co-production



Engagement: You said we will do

Ask Listen Do
Making conversations count
In health, social care and education

NHS
Sheffield Health and Social Care
RHS Foundation Trust

**Sheffield Health & Social Care:
Learning Disabilities Services**

You Said... We will do

The **Community Learning Disability Service** helps people with learning disabilities with their health and well-being

We have been meeting with people with learning disabilities and their **carers**. To hear about what you want from the team.

We want to tell you what we are doing to make the service better

10 Improvements You Would Like

You said there are 10 ways we can make our service better

1
2
3

Better information about our service

A service that is there when you need it

Making coming to visit us more welcoming

4
5
6
7
8

Having named staff who are there to help you access our service

Telling you if we need to send you to a different service.

Helping you understand your medication

Attend community events and talk to you about the service and how it can help

Employ people with learning disabilities as Peer Support Workers

9
10

Offer art and music therapy

Be clear when it's time to and how you can get help in the future. So you don't worry about being discharged

Thank you telling us what you need. It will help us to make services better!

Co-production through equal partnerships:

Chairing Transformation Programmes
Together



Alix Smith



Sarah Ibrahim



Tracy Green



Kai Scott-Bridge



+31



So what have we learnt....

From Adams perspective

What went well?

Bringing real understanding of the service into the room

Having a good relationship with co-chair.

Briefing and debriefing with co-chair was essential.

What could be improved?

Formalise input from more Expert by Experience to check and advise on progress

Pros and Cons to **virtual space** – having to use 2 screens, manage process, timings, questions, chat, engagement etc.
Admin support would have helped.

Need to make meetings SU friendly. **MS Teams can be a barrier** to involvement for some.

Promote **innovation** – such as use of video for reports.

From Hassan's Perspective

Really positive experience – **Adams energy uplifting** and this positively impacted the meetings.

Grounds you as to why this is happening – commissioners and senior leaders are **reminded of patient experience**

Positive impact on tone / environment in **meeting becomes more compassionate**

Equal partnership / Regular meetings to plan helpful

What could be improved?

Some meetings should have been **rescheduled** when Adam wasn't available (on Developing as Leaders course)

Option for **another Expert by Experience co-chair** to cover / support.

Our organisation needs to **develop more relationships** with Experts by Experience – not “over use” know individuals.

Summary

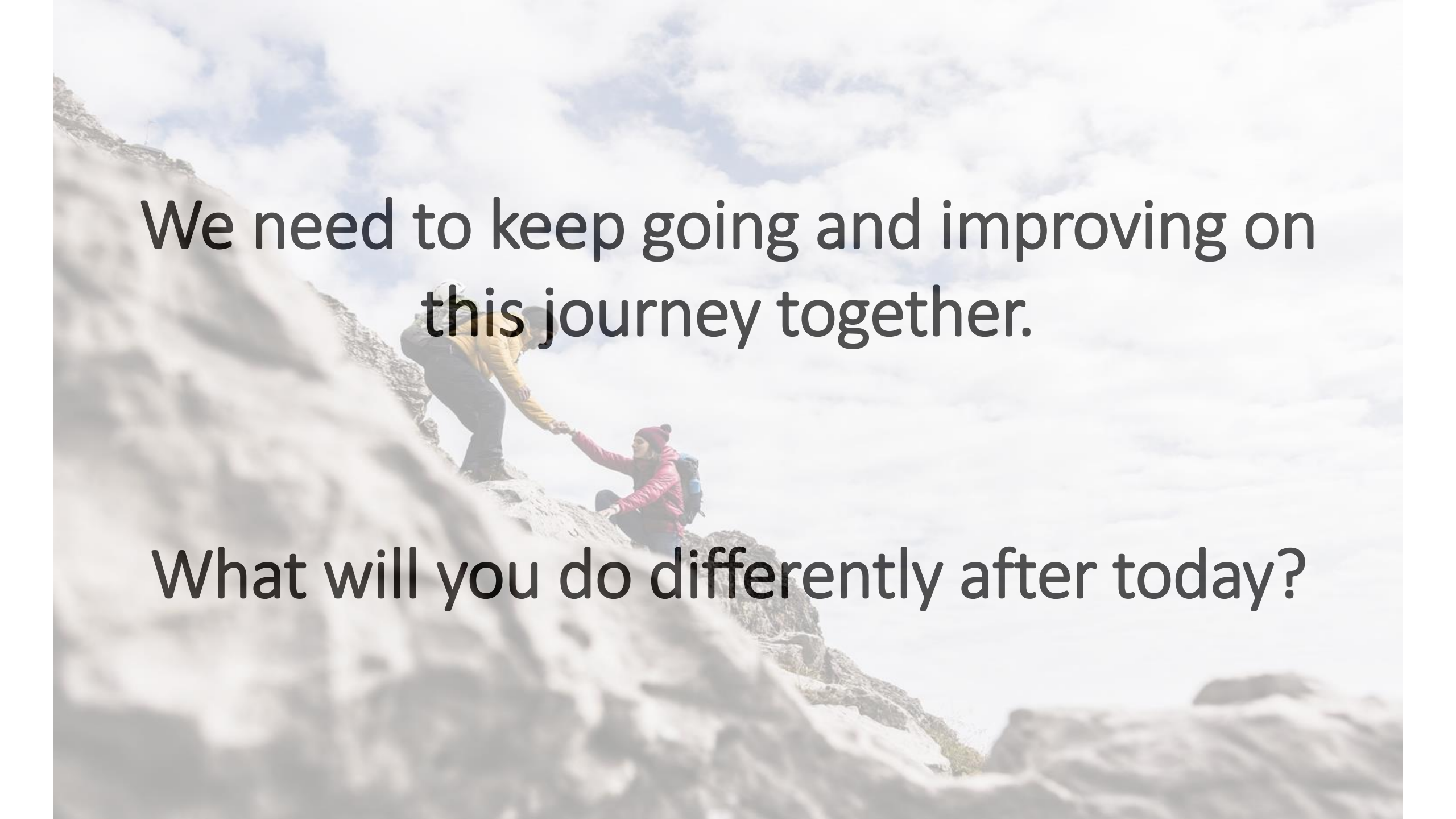
- Be aware and mindful of the health and social impact on marginalised groups.
- Co-production means working in equal partnership – from the beginning. Not consultation at the end.
- Co-production means organisations adapting how they do things.
- There are clear benefits to this approach but there are issues to be mindful of



Questions & Comments Welcome

References

- 1) **Mencap. Learning disability or learning difficulty?** [Learning difficulties | Mencap](#) (accessed 09.04.2024)
- 2) **Scior & Werner (2015)** Scior K, Werner S. Changing attitudes to learning disability. *Posjećeno*. 2015;20(2019):2016-08.
- 3) **Public Health England (2018)** [Severe mental illness \(SMI\) and physical health inequalities: briefing - GOV.UK \(www.gov.uk\)](#) (accessed 11.04.2024)
- 4) **NHS Digital** [Learning Disability Services Statistics - NHS England Digital](#) (accessed 11.04.2024)
- 5) **Office for Health Improvement and disparities (2023)** [Premature mortality in adults with severe mental illness \(SMI\) - GOV.UK \(www.gov.uk\)](#)
- 6) **Cooper et al., (2007)**, The prevalence, incidence, and factors predictive of mental ill-health in adults with profound intellectual disabilities." *Journal of Applied Research in Intellectual Disabilities* 20.6 (2007): 493-501.
- 7) **Eurocities**<https://eurocities.eu/cities/sheffield/#:~:text=And%20with%2061%25%20green%20space,people%20of%20any%20European%20city>. (accessed 08.04.2024)
- 8) **Office for National Statistics**
[google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiF_tOh2bOFAXtV0EAHd8sCWoQFnoECBMQAQ&url=https%3A%2F%2Fwww.ons.gov.uk%2Ffile%3Furi%3D%2Fpeoplepopulationandcommunity%2Fpopulationandmigration%2Finternationalmigration%2Fdatasets%2Fpopulationoftheunitedkingdombycountryofbirthandnationalityunderlyingdatasheets%2Fjuly2020tojune2021%2Funderlyingdatasheetsforpopulationbycountryofbirthandnationalityjul20tojun21.xls&usg=AOvVaw3_yQsxN3jJNPo5GQXpu1yl&opi=89978449](https://www.ons.gov.uk/file%3Furi%3D%2Fpeoplepopulationandcommunity%2Fpopulationandmigration%2Finternationalmigration%2Fdatasets%2Fpopulationoftheunitedkingdombycountryofbirthandnationalityunderlyingdatasheets%2Fjuly2020tojune2021%2Funderlyingdatasheetsforpopulationbycountryofbirthandnationalityjul20tojun21.xls&usg=AOvVaw3_yQsxN3jJNPo5GQXpu1yl&opi=89978449) (accessed 10.04.2024)
- 9) **Sheffield City Council** [Tackling poverty | Sheffield City Council](#) (accessed 11.04.2024)

A photograph of two hikers on a rocky mountain peak. One hiker in a yellow jacket is standing and reaching out to help another hiker in a red jacket who is sitting on the ground. The background shows a cloudy sky and more rocky terrain.

We need to keep going and improving on
this journey together.

What will you do differently after today?



**Co-production through equal
partnerships:
Chairing transformation
programmes together**

Presenters

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Adam Butcher

**Expert by
Experience**

**Chair of multiple
groups**

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Hassan Mahmood

Clinical Director

**Learning Disability
Service**

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Mandy Butcher

**Expert by
Experience/
Volunteer**

NHS
Sheffield Health
and Social Care
NHS Foundation Trust



Parya Rostami

**Head of
Improvement**

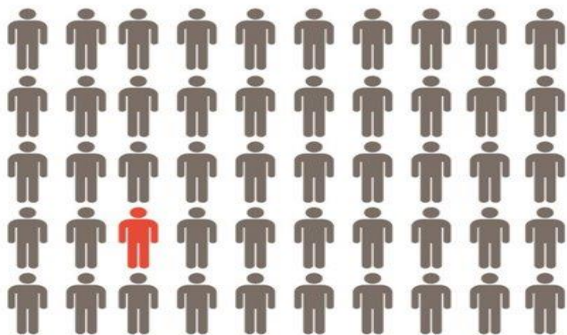
Learning Disability

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.¹

Learning Disability

There are 1.5 million people with a learning disability in the UK

Approximately 1 in 50 adults in the UK have a learning disability. ¹



Stigma and inequality

- People with a learning disability may face **problems getting equal opportunities** for healthcare, education, employment and social pursuits. (Scior & Werner, 2015).
- People with SMI & LD experience a **greater burden of physical health conditions** ¹³
- People with a *learning disability* have **worse physical and mental health** than people without a learning disability (NHS Digital 2017).

² Scior & Werner, 2015, ³Public Health England 2018, ⁴ NHS Digital

Stigma and inequality

- On average, the **life expectancy of women** with a learning disability is **18 years shorter** than for women in the general population.
- The **life expectancy of men** with a learning disability is **14 years shorter** than for men in the general population⁴
- Approximately **2/3 deaths** for people with SMI are due to **preventable physical illness** ⁵

Stigma and inequality

Evidence suggest that **mental health problems may be higher** in people with a learning disability than in those without a learning disability.

Some studies suggest the rate of mental health problems in people with a learning disability is **double that of the general population** (NICE, 2016).

Introduction to Sheffield

An aerial photograph of Sheffield, UK, showing a dense urban area with various buildings, including a prominent tall skyscraper. The city is surrounded by lush green hills and trees, illustrating its reputation as a green city. The image is slightly faded to allow text to be overlaid.

- Greenest city in Europe⁷
- It is 160 miles North of London
- 5th largest city in UK
- Population of 556,500⁸

Inequality in Sheffield

- Sheffield is the 2nd least deprived core city in England
- Yet, 1/4 of Sheffield's areas are in the most deprived 10% nationally
- Five areas are within the 1% most deprived in England ⁸
- Around **1 in 4 Sheffield people live in poverty** at any one time. ⁹

Sheffield Health & Social Care NHS Foundation Trust

- Provide a range of mental health and learning disability services to the people of Sheffield
- Sheffield Health and Social Care NHS FT (SHSC) employs over 2,500 staff
- We provide services to around 55,000 people a year
- Our vision is to improve the mental, physical and social wellbeing of the people in our communities

SHSC Learning Disability Services

- The care and support of people with Learning Disability has been moving away from institutional services towards personalised, holistic care in community settings.
- To support this Sheffield had a Community Learning Disability Team and a separate small inpatient setting.
- Following a review of the inpatient setting in 2021 by the CQC, the Trust began a full review of Learning Disability Services - But how to do this well?

Our Service User Engagement and Experience strategy

- **Embed Lived Experience Voices**
- Ensuring expert by experience perspectives are **integral at all levels** of SHSC decision making
- Improving the experience of people using our services by **embedding coproduction** throughout SHSC
- Increase **partnership** working

Learning Disability Engagement and co-production

Co-production
steering
group

Outreach into
community
centres and
events

Listening to
feedback

Using
feedback to
shape
priorities

Engagement: You said we will do

Ask Listen Do
Making conversations count
In health, social care and education

NHS
Sheffield Health
and Social Care
NHS Foundation Trust

Sheffield Health & Social Care: Learning Disabilities Services

You Said... We will do



The **Community Learning Disability Service** helps people with learning disabilities with their health and well-being



We have been meeting with people with learning disabilities and their **carers**. To hear about what you want from the team.



We want to tell you what we are doing to make the service better

10 Improvements You Would Like



You said there are 10 ways we can make our service better

- 1
- 2
- 3



Better information about our service



A service that is there when you need it



Making coming to visit us more welcoming

- 4
- 5
- 6
- 7
- 8



Having named staff who are there to help you access our service



Telling you if we need to send you to a different service.



Helping you understand your medication



Attend community events and talk to you about the service and how it can help



Employ people with learning disabilities as Peer Support Workers

- 9
- 10



Offer art and music therapy



Be clear when it's time to and how you can get help in the future. So you don't worry about being discharged



Thank you telling us what you need. It will help us to make services better!

Co-production through equal partnerships:



Chairing Transformation Programmes Together





So what have we learnt....

From Adams perspective

What went well?

Bringing **real understanding of the service** into the room

Having a good **relationship with co-chair.**

Briefing and debriefing with co-chair was essential.

What could be improved?

Formalise input from more Expert by Experience to check and advise on progress

Pros and Cons to **virtual space** – having to use 2 screens, manage process, timings, questions, chat, engagement etc. **Admin support** would have helped.

Need to make meetings SU friendly. **MS Teams can be a barrier** to involvement for some.

Promote **innovation** – such as use of video for reports.

From Hassan's Perspective

Really positive experience – **Adams energy uplifting** and this positively impacted the meetings.

Grounds you as to why this is happening – commissioners and senior leaders are **reminded of patient experience**

Positive impact on tone / environment in **meeting becomes more compassionate**

Equal partnership / Regular meetings to plan helpful

What could be improved?

Some meetings should have been **rescheduled** when Adam wasn't available (on Developing as Leaders course)

Option for **another Expert by Experience co-chair** to cover / support.

Our organisation needs to **develop more relationships** with Experts by Experience – not “over use” know individuals.

Summary

- Be aware and mindful of the health and social impact on marginalised groups.
- Co-production means working in equal partnership – from the beginning. Not consultation at the end.
- Co-production means organisations adapting how they do things.
- There are clear benefits to this approach but there are issues to be mindful of



Questions & Comments Welcome

References

- 1) **Mencap. Learning disability or learning difficulty?** [Learning difficulties | Mencap](#) (accessed 09.04.2024)
- 2) **Scior & Werner (2015)** Scior K, Werner S. Changing attitudes to learning disability. *Posjećeno*. 2015;20(2019):2016-08.
- 3) **Public Health England (2018)** [Severe mental illness \(SMI\) and physical health inequalities: briefing - GOV.UK \(www.gov.uk\)](#) (accessed 11.04.2024)
- 4) **NHS Digital** [Learning Disability Services Statistics - NHS England Digital](#) (accessed 11.04.2024)
- 5) **Office for Health Improvement and disparities (2023)** [Premature mortality in adults with severe mental illness \(SMI\) - GOV.UK \(www.gov.uk\)](#)
- 6) **Cooper et al., (2007)**, The prevalence, incidence, and factors predictive of mental ill-health in adults with profound intellectual disabilities." *Journal of Applied Research in Intellectual Disabilities* 20.6 (2007): 493-501.
- 7) **Eurocities**<https://eurocities.eu/cities/sheffield/#:~:text=And%20with%2061%25%20green%20space,people%20of%20any%20European%20city>. (accessed 08.04.2024)
- 8) **Office for National Statistics**
[google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiF_tOh2bOFAxXtV0EAHd8sCWoQFnoECBMQAQ&url=https%3A%2F%2Fwww.ons.gov.uk%2Ffile%3Furi%3D%2Fpeoplepopulationandcommunity%2Fpopulationandmigration%2Finternationalmigration%2Fdatasets%2Fpopulationoftheunitedkingdombycountryofbirthandnationalityunderlyingdatasheets%2Fjuly2020tojune2021%2Funderlyingdatasheetsforpopulationbycountryofbirthandnationalityjul20tojun21.xls&usg=AOvVaw3_yQsxN3jJNPo5GQXpu1yI&opi=89978449](https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/populationandmigration/internationalmigration/datasets/populationoftheunitedkingdombycountryofbirthandnationalityunderlyingdatasheets%2Fjuly2020tojune2021%2Funderlyingdatasheetsforpopulationbycountryofbirthandnationalityjul20tojun21.xls&usg=AOvVaw3_yQsxN3jJNPo5GQXpu1yI&opi=89978449) (accessed 10.04.2024)
- 9) **Sheffield City Council** [Tackling poverty | Sheffield City Council](#) (accessed 11.04.2024)



**We need to keep going and
improving on this journey together.**

**What will you do differently after
today?**