

Nottingham West Primary Care Network

Learning Disability Health & Wellbeing Engagement: 2022/23

The Project

In May 2022, **Nottingham West PCN (NW PCN)** were successful in securing funding from the **East Midlands Academic Health Science Network (EMAHSN)**, aimed at addressing health inequalities and contributing to Core20PLUS5 priorities.

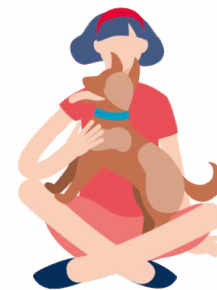
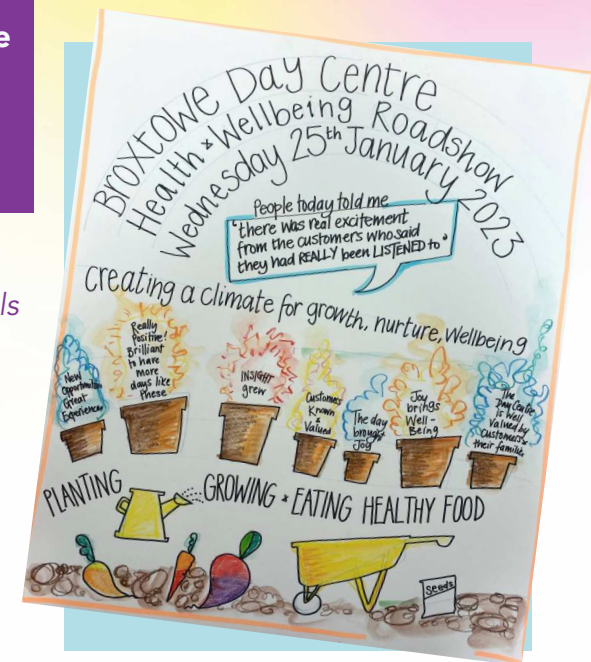
Taking an insight led approach and through collaboration with **Liberty Leisure Ltd (Lleisure)**, **Broxtowe Borough Council**, and **Active Notts** we identified people within our community with a diagnosed learning disability as experiencing significant health inequalities.

We wished to explore the lived experience of this cohort of people relating specifically to their experience of health services and access, as well as the wider determinants of health and wellbeing.

The aim was to improve quality of experience and to support the voice of those involved to be heard more prominently. To be influential in decision making related to elements of care and physical opportunities that directly affect their lives, supporting individuals to lead happy, healthy and fulfilled lives.

Working with local partners across health, social care and the community sectors to coordinate bi-monthly **health and wellbeing roadshows** to *hear the voice of individuals with a learning disability, their parents and carers on what really matters to them.*

To provide an opportunity to showcase all current provision on offer locally for those with a learning disability.



Key Outcomes

6 events in all major towns that make up Broxtowe

35 partner organisations engaged throughout the events

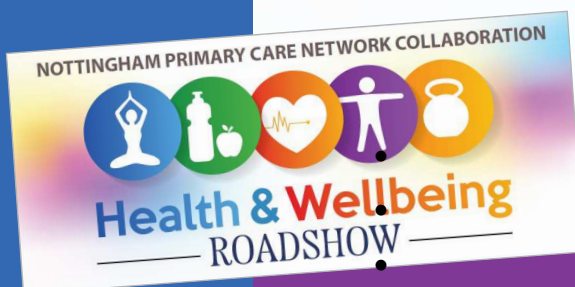
225 people with a learning disability or who care for a person with learning disabilities attended and had their voices heard – An average of **37 attendees** per event

- **A multi-agency partnership pilot** has been implemented with Nottingham West PCN Trainee Nurse Associates (TNA's) to provide robust learning opportunities to see gold-standard communication and engagement with this cohort of people role modelled, building a future workforce with the skills necessary to make this group of patients feel safe and heard.
- The Roadshow has facilitated the set-up of the **first** Nottinghamshire connector for '**Charlottes Tandem**' free loan service – a charity which loans accessible bikes to people with additional needs so they can enjoy the wonders of cycling.
- The roadshow has led to the set up of **two new Boccia clubs** and newly trained leaders within Broxtowe, a totally inclusive sport that can be played by anyone regardless of age, gender, ability or disability.
- Local invites to access the **national screening programme for cytology** (a smear test) have been improved based on direct feedback from people attending the roadshows.
- **Localised training opportunities** across the PCN have been prioritised to ensure that all staff receive the correct level of Oliver McGown training, with LLeisure committing to provide opportunities for all customer facing staff to access this additional learning.
 - Learning disability specific **Nordic walking sessions** will now be supported to run across Broxtowe.
 - The PCN will facilitate the set-up of **sensory flu clinics** for all patients with learning disabilities from September 2024.

Co-hosting an event with a partner based in the community helps gain greater engagement and resident voice.

Working alongside a wider group of partners to coordinate events helps to broaden connections and raise awareness of the events.

Having a local volunteer with learning disabilities on the team facilitates a warm and safe welcome.



Key themes from resident voice

Relationships People want to feel known and know the people who are caring for them.

Good communication Vital to meeting the needs of this group of people, many people with learning disabilities feel they are not spoken to directly.

Gate Keeping Many felt the receptionist role played a vital part in their experience being good or bad

Levels of independence, confidence and social ability of individuals with a learning disability are contributing factors to their experience of healthcare services and leisure facilities. The higher these are, the better the experience.

Personalisation of experience Not always felt by individuals and families when accessing services. Causing frustration and poor experiences.

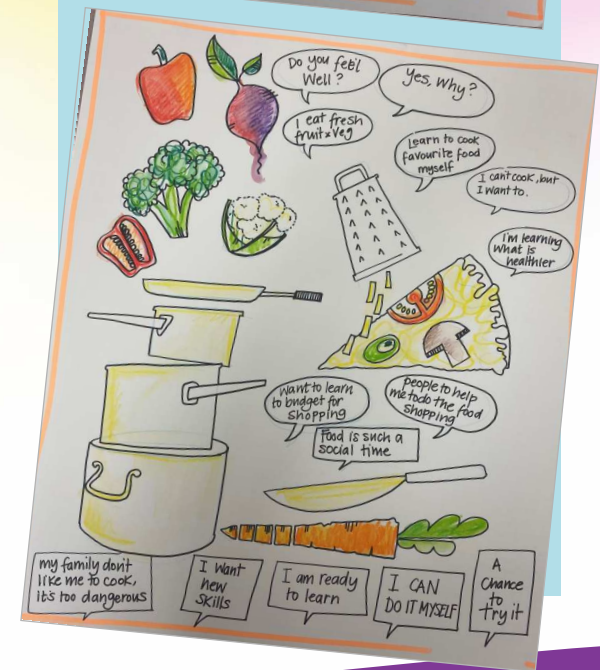
Information about local activities and services to support the wider determinants of health and wellbeing is hard to find.

Fear of professionals and unfamiliar environments can be contributing factors to lack of engagement and negative experience.

Time within appointments helps people feel comfortable and listened to, contributing to positive experiences - appointments need to be longer.

Parents/Carers often feel overwhelmed and unsupported - feelings of guilt are prevalent.

Various community activities Wider provision is necessary within this community, however there is a disparity between individuals who would seek learning disability specific activities and those who's desire is to integrate into mainstream community activities. Both are necessary.



Background to the work

Introduction

We know that the health inequalities faced by people living with a learning disability are stark. People with a learning disability are three times more likely to die from an avoidable medical cause of death than the general population as well as having poorer physical and mental health. To help address this, colleagues from across Nottingham West PCN and LLeisure came together to coordinate a bi-monthly learning disability specific health and wellbeing roadshows to hear about what really matters to residents with the aim of co-producing meaningful system change.

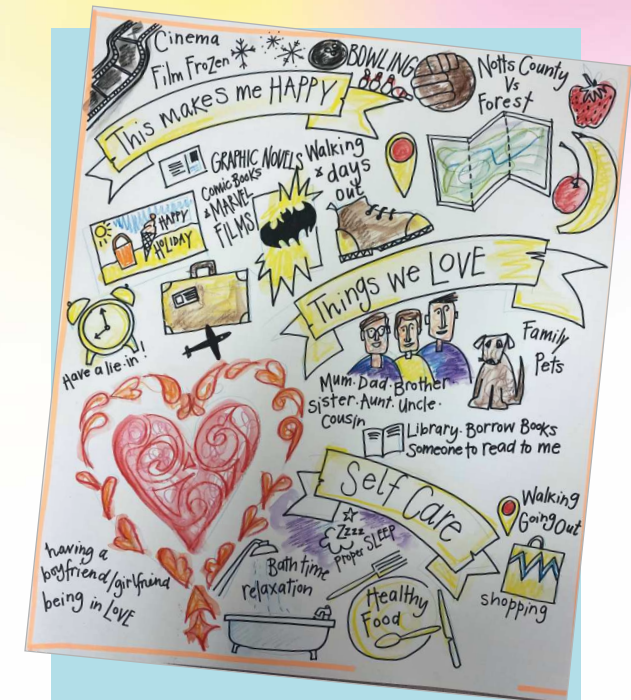
Why the work happened

The purpose of the roadshow was to hear about people's experiences of accessing health services and more broadly physical activity opportunities across Broxtowe, and to include residents in decision making processes linked to meaningful change. We aimed to identify opportunities to make a significant difference to resident's experience of living in Broxtowe borough.

Who made it happen

Nottingham West PCN brought together local partners in September 2022 once funding was secured to help enable the engagement to happen. Events ran from **December 2022** to **November 2023**.

The wider group of partners who were involved included: Broxtowe Day Service, Broxtowe Borough Council, Pulp Friction, Nottinghamshire Healthcare Trust, Transform Training, Rumbletums Café, ABL Health, Inspire Libraries, Social Souls, Charlottes Tandems, and Parish nursing.



What we've heard from citizens



- Confidence in accessing health support: **6.2/10** (average)
- Attendance of health check within the last year (of people who attended the roadshow): **70%**
- How helpful was your health check: **8.7/10** (average)
- Preference of health check in non-clinical setting: **32%**

What would help improve your confidence to access health support?

- Able to attend services with family but to be spoken to directly even with them there
- Not having to repeat myself -being KNOWN
- Being understood, e.g. on the phone
- More regular health checks
- Knowing what to ask
- Options of Male / Female professionals
- Seeing people who 'look like me' when I attend services / groups

What would make health checks more helpful?

- Information about other services and support available
- Having more time to feel comfortable
- Conversations with the individual not just the carer/family member
- Having access to easy read documents and videos before any appointment

What social, leisure and physical activities did people tell us they already do?

(scored highest):

- Walking
- Dance
- Gym
- Group sport activities (disability group)

What social, leisure and physical do people want more of (scored highest):

- Boccia
- Team-sports
- Walking groups (LD specific and non-LD specific)
- Drama
- Singing



NOTTINGHAM PRIMARY CARE NETWORK COLLABORATION



Health & Wellbeing
ROADSHOW

Quotes from individuals, parents and carers and local partners

We have a **designated nurse** who helps us to navigate our appointments, what to say/how to say it which we find really useful and would recommend to anybody. **Parent carer**

It would be amazing if we could access the annual health check at the **day service rather than having to go to the GP**. **Parent carer**

Sometimes I feel that the GPs use this LD check as a **box ticking exercise** and **don't always listen**

We tend to find one service **doesn't know what the other service is doing** e.g. GP, social services, pharmacy. **Parent carer**

It can be **really lonely** being part of this community. I'd love to be **included in more regular activities**, even walks or litter picking

The lady who made me my **special glasses** so that I can carry on doing art **-it makes my heart happy**

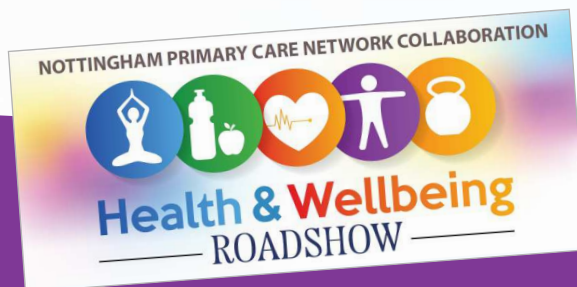
You have **changed someone's life** today
(reflecting on how the event helped an individual with a learning disability connect to an activity they used to do and love).

Tired of explaining my son's condition, complete **lack of understanding** by receptionists

I only leave the house once a month on payday but came today because my GP invited me. I am leaving with leaflets for 5 support groups that I can go to, and I have met the lady prescriber from my surgery **and am seeing her next week**

I love everything about my surgery, I moved there and never looked back. When I ring up for my meds the lady says, 'is that Ken?'

I've **given up** (accessing health services). **Parent**



What did we learn about carrying out the engagement?

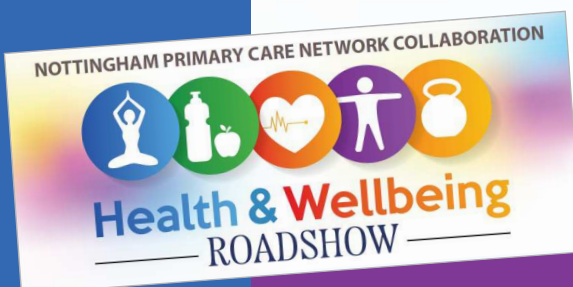
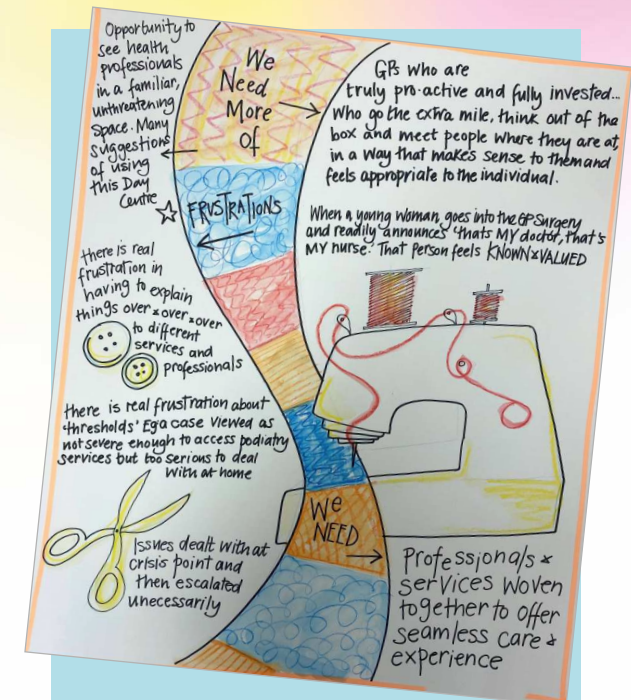
Connecting with trusted local partners

Key to reaching the right audience. For example, working with Broxtowe Day Service enabled us to connect with 40 individuals and their carers/parents. It also helped to develop a relationship with the day service, gain a better understanding of their work and share information between them and other local partners. Working with Rumbletums café was key to the success of the first community-based open event. As a trusted local asset, for many people they were coming to a place they already knew. We also had the opportunity to talk with some of the Rumbletums staff and volunteers who have a learning disability themselves.

Consistent questions Using the same questions with everyone who attended an event helped to hear voices across the same themes and consider any trends. Questions were asked as a survey, completed with an event helper when individuals had been to the marketplace and in return they received a goody bag.

Connecting with groups Organisations who could bring a group of individuals to an event helped make it more accessible to the individual.

Promotion Using a direct text message that targeted patients from GP surgeries with a diagnosed learning disability helped to reach more people; a small group of people attended an event because of this.



Based on what we've heard so far, this framework sets out opportunities for collective action

Areas for action	Including	What change are we trying to create?	What action has already started?
Developing the workforce who support people with a learning disability and their families/carers	Healthcare professionals and wider wellbeing professionals or instructors being exposed to having meaningful conversations with people who have a learning disability.	Healthcare professionals to better understand the needs of people. Healthcare professionals reflect on their approach and make any adaptations. Improve the patient experience.	A multi-agency partnership pilot has been implemented with Nottingham West PCN Trainee Nurse Associates (TNA's) to provide robust learning opportunities to see gold-standard communication and engagement with this cohort of people role modelled, building a future workforce with the skills necessary to make this group of patients feel safe and heard. Pilot launched May 2023, to be fully evaluated by March 2024, with the aim to influence both the regional and the national programme. Nottingham West PCN is working towards all appropriate staff members achieving tier 2 of Oliver McGowan training (Nationally recognised training on Learning Disability and Autism). LLeisure has committed to providing appropriate learning disability training opportunities to all customer facing staff.
Right location, right experience, right offer	Healthcare appointments and services would benefit (for some residents) from being delivered in non-clinical settings that are more welcoming and trusted.	Help create accessible, inclusive and welcoming spaces for people to access health and leisure services. Improve experience. Making it easier for people to access the services that will benefit their health.	Shared findings with Practice Managers and admin staff across all Nottingham West GP surgeries and LLeisure centres. Nottingham West PCN have asked all surgeries to identify a designated lead to support this group of patients. Local invites to access the national screening programme for cytology (a smear test) have been improved based on direct feedback from people attending the roadshows. The PCN will facilitate the set-up of sensory flu clinics for all patients with learning disabilities from September 2024. Explore opportunities to deliver health care and leisure facilities (of all types) within key community settings.



Areas for action	Including	What change are we trying to create?	What action has already started?
Create local inclusive group activities	Physical activity opportunities that are inclusive for people with a learning disability and their parents/carers. Consider what is already happening and available in the local area.	Help build social connections (for both individuals and parents) Promote independence and boost physical and mental health.	The Roadshow has facilitated the set-up of the first Nottinghamshire connector for 'Charlottes Tandem' free loan service – a charity which loans accessible bikes to people with additional needs so they can enjoy the wonders of cycling. The roadshow has led to the set-up of two new Boccia clubs and newly trained leaders within Broxtowe, a totally inclusive sport that can be played by anyone regardless of age, gender, ability or disability. Partnerships have been made across organisations, LLeisure have committed to sourcing funding to support Pulpfriction to establish learning disability specific Nordic walking sessions across the borough. In partnership with British cycling, we have begun work towards the set-up of local cycling clubs to deliver accessible cycling sessions for Broxtowe residents.
Single point of access	Develop one central place that patients and parents / carers can access the information they need to support the health and wellbeing of someone with a learning disability.	Help reduce confusion and make services more accessible by simplifying the process.	Discussions beginning with the Primary Care Network Clinical Directors around how this might be achieved. Considerations of specialist roles or care coordinators to support this work. Learning Disability Specialist Nurse to connect with this discussion. Discussion with Broxtowe Borough Council about the possibility of hosting a learning disabilities directory of services on their website.

Next Steps

NOTTINGHAM PRIMARY CARE NETWORK COLLABORATION



Health & Wellbeing ROADSHOW



FINAL SHOWCASE COLLABORATIVE

Join us to hear the collective voice of people with learning disabilities across Broxtowe. What we heard throughout the 2022/23 roadshows and what, with your help, we hope to do next...

Be a part of shaping the future of LD services



FRIDAY, 16TH
FEB 2024



TROWELL PARISH HALL, STAPLEFORD
ROAD, TROWELL, NOTTINGHAM
NG9 3QA



REGISTRATION FROM
08.45AM
9AM START - 12NOON



HELP US TO MAKE **LASTING** CHANGE
IN BROXTOWE



To book a place at this event please email:

■ clare.watson21@nhs.net ■ chloe.corden@leisure.co.uk

NOTTINGHAM PRIMARY CARE NETWORK COLLABORATION



Acknowledgements

Transform Training
Parish Nurse
Inspire libraries
British Cycling East Midlands
Digital inclusion officers Nottingham West PCN
Social Prescribing Nottingham West PCN
Learning Disability - Primary Care Liaison Nurse
Pulfriction
ABL
Active Notts
Chair based exercise instructor - Lleisure
Charlottes Tandems
Citizens Advice
GP leads
Broxtowe Day service
Broxtowe Borough MP
Rumble Tums Café
Patient volunteers
Broxtowe Borough Council
Tuvida
Boccia England
Broxtowe Borough Council local Councillors
Nottingham Mencap
Diabetes Specialist Nurse
Middle street Resource Centre
Notts healthcare trust podiatry service
St Helens Parish Church
Plumtree Hall
Social Souls
Volunteers with Lived experience of learning disabilities
Arthur Mee College
Care co-ordinators Nottingham West PCN

