

What's important to you?

A report of an event held by Collaborative Newcastle Learning Disability Partnership

31 October 2022 at Newcastle Civic Centre

For easy read report, more information, or to get involved, contact [sam.jangira@skillsforpeople.org.uk](mailto:sam.jangira@skillsforpeople.org.uk)

For future updates <https://skillsforpeople.org.uk/>

## Contents

<b>Summary</b> .....	<b>2</b>
<b>What's important to you? consultation</b> .....	<b>3</b>
<b>The aims of the consultation</b> .....	<b>3</b>
<b>About the consultation</b> .....	<b>3</b>
<b>Thank yous</b> .....	<b>3</b>
<b>Keys to Citizenship</b> .....	<b>4</b>
<b>What's important to us?</b> .....	<b>5</b>
<b>Help</b> .....	<b>5</b>
<b>Love</b> .....	<b>6</b>
<b>Safety</b> .....	<b>7</b>
<b>Purpose</b> .....	<b>7</b>
<b>Freedom</b> .....	<b>8</b>
<b>Money</b> .....	<b>9</b>
<b>Home:</b> .....	<b>9</b>
<b>Health:</b> .....	<b>10</b>
<b>Barriers</b> .....	<b>11</b>
<b>a) Health care</b> .....	<b>11</b>
<b>b) Social care</b> .....	<b>12</b>
<b>c) Organisations (wider than health care and social care)</b> .....	<b>13</b>
<b>d) Travel and Access</b> .....	<b>13</b>
<b>e) Money</b> .....	<b>14</b>
<b>f) Inclusion</b> .....	<b>14</b>
<b>g) Mental Health</b> .....	<b>14</b>
<b>h) Safety</b> .....	<b>15</b>

## Summary

An event 'What's important to you?' was hosted by Collaborative Newcastle Learning Disability Partnership on 31<sup>st</sup> October 2022.

Skills for People <https://skillsforpeople.org.uk/> organised the event.

We set out to hear from local people about what is important to and important for people with a learning disability as well as find out what barriers they face.

The views and ideas shared on the day will form the basis of a plan for the city, to make it the best place to live for people with a learning disability. Local people with personal experience, and those who work in health and care organisations will work together on the priorities identified by local people.

102 people attended the event, a mix of people with a learning disability, their families and supporters, and health and care staff.

We used the Keys to Citizenship as a structure for the day  
<https://citizen-network.org/library/what-are-the-keys-to-citizenship1.html>

Some clear priorities were identified on the day. There are other key areas of concern which are identified in the report.

### 1 Relationships and community

- People want friends and connections: opportunities to spend time with groups of people, to meet friends and maintain friendships.
- Transport – the need for affordable and easy access to reliable public transport was identified.
- We were reminded of the importance of quality time with family, including children

### 2 Jobs

- People want jobs: where they can use their talents, (examples of helping others, training others), improve their self-esteem, and feel valued.
- Earning money would help with the following priority too.

### 3 Money

- The need for help to navigate the benefits system is clear.
- People want their 'own money' (i.e., control over their money); and enough money to be able to spend on what they want (holidays, Primark, 'putting a bet on').
- Some are struggling with very limited income.

### 4 Being safe

- People said they do not feel safe when out and about in their neighbourhoods, or town, but also some feel unsafe at home.
- This may be a mixture of experiencing harassment or hate crime, but also fear.
- Safety online was also identified as a priority.

## What's important to you? consultation

This report includes the findings of a consultation event held by Collaborative Newcastle Learning Disability Partnership to help inform a local plan for people with a learning disability in Newcastle upon Tyne.

## The aims of the consultation

We set out to

- Gather information from people about what is important to and important for people with a learning disability.
- Gather information about the barriers that get in the way of what is important to people.
- Inform a Newcastle Learning Disability Plan.

## About the consultation

We invited people to an event to share their views of what is important to and important for people with a learning disability who live in Newcastle upon Tyne.

The event was held on 31<sup>st</sup> October 2022.

102 people attended. This included:

- adults with a learning disability and autistic people.
- family carers.
- people who are paid to work with people with a learning disability.

There were presentations from

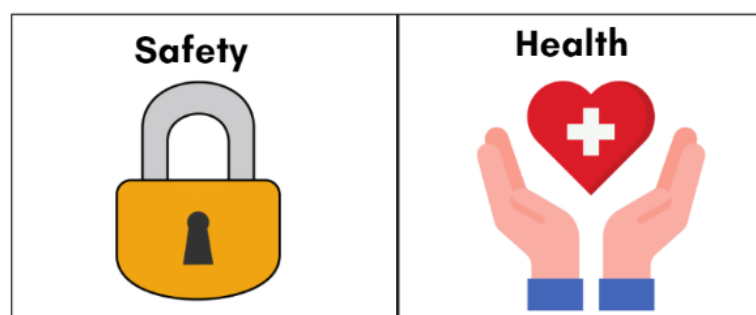
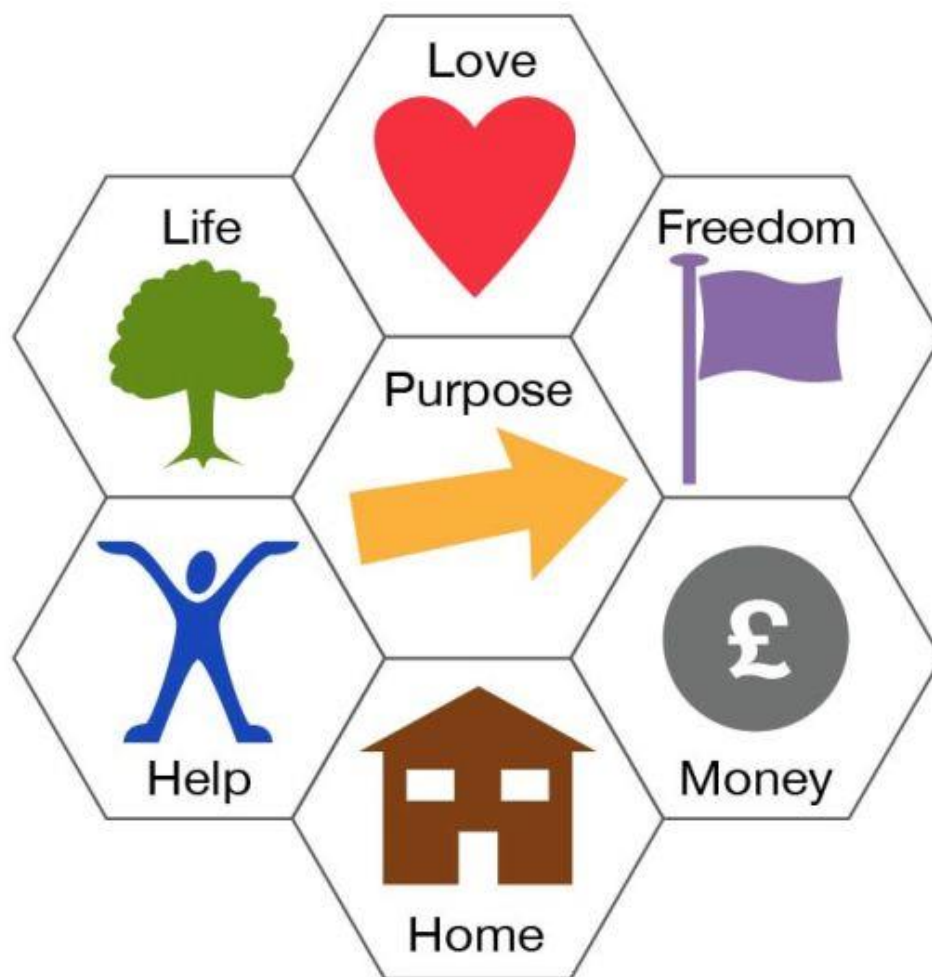
- Jodie Williams, NHS England Learning Disability and Autism Network -about how she has changed her life to the dream life she has now.
- The Twisting Ducks theatre company – about what people had told them when they asked '*What important to you?*'

## Thank yous

A big thank you to everyone who attended the event and shared their stories and experience. And those who helped to make the day a success: Jodie Williams, the Twisting Ducks <https://www.thetwistingducks.co.uk/>.

## Keys to Citizenship

At the event we used the Keys to Citizenship (© Simon Duffy 2010) to help people think about what is important to people with a learning disability.



We also added safety and health as extra topics to help people think about these things which are important **for** people with a learning disability.

## What's important to us?


Views were collated under each of the Keys to Citizenship, (and the extra two topics) through small group discussions, then shared with the wider group, and collected on posters (one poster per Key), using sticky notes. Participants rated/voted for their top priorities among the ideas shared.

The views expressed are listed under each Key, in order of priority, i.e., Number 1 received most 'votes' under each key.

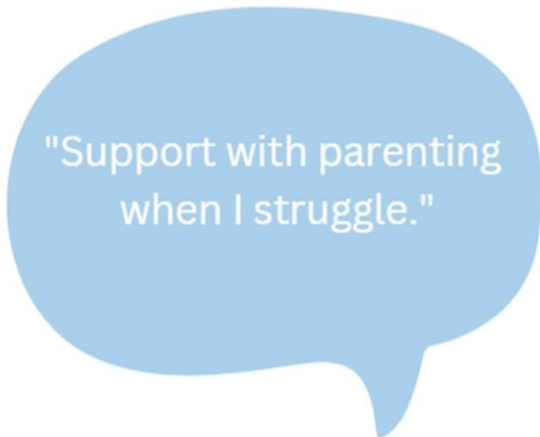
## Help

What does help mean for us?

These themes emerged.



"Making sure I have the right staff looking after me."



"Support with parenting when I struggle."

1. Having the right support at the right time, not dictated by someone else's timetable. Having staff that I have chosen to support me who are also understanding, funny, committed, not on their phones all day or just sitting watching TV with me.
2. Support that is flexible, creative, person centred and not shared.
3. Better pay for support workers and carers to help with staff shortages and high turnovers so there is continuity of care and less reliance on temporary, and often less skilled staff.
4. Floating support, not prescriptive/diagnosis dependant. People looking out for me in the community who I can ask for help when I need it. Confidence to say you are struggling at work or in private life and the help to support you.
5. More practical and emotional support for families to relieve some of the pressure on families and so we do not feel like a burden to family, carers, and society. Furthermore, listening to and respecting the knowledge of carers.
6. More support for young people to help with transition and to have continuity between services. Additionally, more specialist services for under 16-year-olds.
7. Reasonable adjustments so people can access mainstream services.
8. More support for autistic people and more autism friendly spaces.
9. Time to understand things that are important to me and time to do the things I want to do.

## Love

What does love mean to us?

These themes emerged.




1. Inclusive social opportunities and safe spaces that will help us to meet new people and make real friends.
2. Being able to have a partner, get married and have a family of my own and get support to keep my children. Be able to trust professionals to get support when we ask for help not getting punished for it.
3. Choice to live close to family or my support network.
4. Being allowed to be a parent and having time with my kids.
5. To be able to have romantic relationships and have opportunities to learn about trust, safety and boundaries when making friends or getting into romantic relationships.
6. Being able to have time to socialise with other people.




## Safety

What does safety mean to us?

These themes emerged.



"We have learned from those with a learning disability and autism; they don't feel safe, continued to be discriminated against but continue to smile and actively seek change."



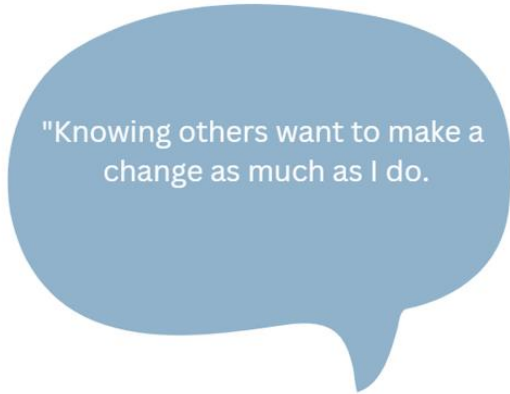
"Feel unsafe going out in the evenings/nights and fear of being attacked."

1. To be able to travel easily and safely, free bus pass that can be used before 9.30am. Travel buddies to help with independent travel and learning travel routes.
2. Social media safety and awareness so we are not targeted and exploited online.
3. Safe and quiet neighbourhoods and streets so we can feel safe.
4. Free from abuse, bullying, financial exploitation, hate and mate crime.
5. More frequent quality checks of services in Newcastle.


## Purpose

What does purpose mean to us?

These themes emerged.



"Knowing others want to make a change as much as I do."



"We still have lots of barriers but there are solutions – and together we can break down these barriers."

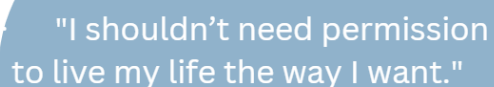
1. The right to have a job and receive good support and training to help maintain a job.
2. Access to education, training, and volunteering opportunities so we can live a purposeful life.
3. To be accepted, feel valued and be part of something. Be able to help and support others and make a difference in my community.
4. Opportunities to train professionals about learning disabilities and helping them understand that we should be valued and respected.



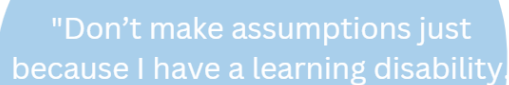
## Freedom

What does freedom mean to us?

These themes emerged.



"I shouldn't need permission to live my life the way I want."



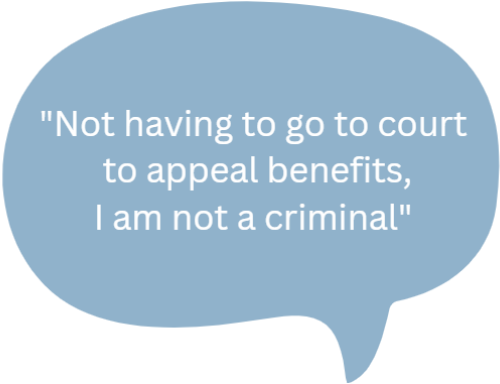
"Don't make assumptions just because I have a learning disability."

1. Walk a mile in my shoes, for professionals. Professionals spending time with us in our communities to find out what barriers we face but also to learn that we have value.
2. Acceptance of my choices. Able to do what I want, not to be dictated to by someone else's timescales or plans.
3. Having opportunities, whether vocational or social that are inclusive and supportive.
4. Being able to take my own risks, make my own mistakes and learn from them.
5. Treated like an adult with the same rights as everyone else and not treated like a child. Respected as an individual, equal to others.
6. Speaking up about important issues, having my opinion and voice heard and valued. Especially by health and social professionals. To be shown that my opinion matters.
7. The right to wear what we want.


## Money

What does money mean to us?

These themes emerged.



"Not having to go to court to appeal benefits, I am not a criminal"




"People with disabilities can have high paying important jobs."


1. Fair, accessible, and easy benefits system or better support to navigate the system.
2. Having enough money to live on and control of how I use it.
3. Cost of living crisis support and support with budgeting.
4. Money for luxuries like holidays, football tickets and buying clothes. Things that help our self-esteem and mental health.

## Home:

What does home mean to us?



"A home that's right for me."



"Being able to keep the family home."


My own home - that's right for me and my needs. A home that I can feel safe in. To be notified about what's happening in my house, such as repairs or who comes into my home. Freedom to do what I want in my home for example invite friends, have pets, and have my own keys.

- Choice in location, who I live with and near my family.
- Support to live independently.
- Safe and nice neighbourhoods.
- Be able to keep the family home or buy a home and easier process to get housing.

## Health:

What does health mean to us?

These themes emerged.



Anxiety and  
depression



"I can't get to see my GP."

1. Easy access to mental health support without long waiting lists or the need to prove diagnosis of a learning disability.
2. More mental health support services for people with a learning disability and autistic people.
3. Better skilled, patient, and supportive health care staff that understand people with a learning disability and talk to me, not my carer.
4. More trauma services and short breaks for crisis situations.
5. More opportunities and support to reduce social isolation and prevent mental health from getting worse.
6. Good quality health care with easy read information and support so that we can understand more about managing our own health, appointments, or medication.
7. Good quality annual health checks, cancer screenings and other necessary health screenings that improve our health prospects, quality of life and life expectancy.
8. More opportunities to improve our wellbeing and prevent serious illnesses.
9. Better collaborative work between health and social care.

## Barriers

We asked people what are the barriers that stop them from having the life that they want.

The barriers listed by participants have been organised under the following headings below (no particular order):

- a) Health care
- b) Social care
- c) Organisations
- d) Travel and access
- e) Money
- f) Inclusion
- g) Mental health
- h) Safety

### a) Health care

- Doctors use too many long words – I try to read letters but cannot – Easy read please I want it simple. GP practice not listening to my communication needs
- Health Support requires diagnosis of learning disability and mental health etc.
- A GP was unaware of referral pathway to Community Learning Disability Team (about diagnosis) ‘we don’t refer adults’ ‘we don’t know how’.
- Cannot get a GP appointment – ringing up at 8.30am just not realistic.
- GP – sometimes bad attitude from reception staff, can be rude.
- Premature death.
- Big waiting lists.
- Communication.
- Covid 19.
- Physical and mental health issues.
- Certain groups are affected more.
- Lack of accountability.
- Investigations/reports and effects following this.
- Misinformation.
- Lack of consideration and lack of flexible appointments – “I shouldn’t have to change my appointments.”
- Funding (lack of).
- Poor listening and lack of good communication.
- Lack of resources for health care staff.

#### b) Social care

- Review of funding every 12 months – people cannot keep improving.
- Person makes progress due to specialist support, which is then withdrawn! So, progress is lost, person is then not sustained.
- Shared support.
- Staff shortages.
- Finding the correct support to be able to go out, the right support as some people have to pay for the support and the right skills to do so.
- Support staff's understanding of what needs you might have.
- Lack of service provision.
- No services for autistic people only.
- Lack of allocated Social Workers.
- Budgets (to be used more creatively).
- Told what I can/can't use benefits for.
- Shared housing (hours impact).
- Wider (person centred plan).
- Personal Assistants.
- Allocated Social Workers.
- Drinking cups of tea – some support staff sometimes don't have time for you which is wrong.
- Appointees not doing their job.
- Turnover of carers.
- No support besides my family so don't do things away from them.
- Support to go with me in the evening and to go on holiday.
- Lack of flexibility, creativity and not dreaming big.
- Shift times.
- Not taking risks/supporting risk.
- Lack of understanding/awareness of needs.
- Communication.
- Outdated models of support e.g., residential.
- Lack of knowledge and experience.
- Consultation events being ignored.
- Quality of care and support.
- Funding (lack of).
- Poor listening and lack of good communication.
- Lack of resources for social care staff.
- Lack of openness or trust.

#### c) Organisations (wider than health care and social care)

- Feeling let down by services e.g., GP, Social workers, the council, care, and support staff.
- It's a fight to get benefits – people get rejected – we have to prove we are 'deserving'. DWP should trust supporters around the person – the process disempowers/disabled people – it's horrendous. It's so negative.
- Generic agencies which support people with benefits **do not** understand about learning disability so they ask the wrong questions and misunderstand the person – a learning disability charity can do this better.
- Not having a diagnosis means I don't get the support I need – Keyring care provider will help and charities.
- People need help with connecting and sign posting – agencies like Skills for People do this but GP's and others often do not know these services exist.
- Bad attitude from call centre staff at Newcastle City Council as well as others.
- Poor housing repairs from Your Homes Newcastle.
- Learning disability is used against me.
- I don't feel I can always trust professionals and people with authority.
- Communication.
- Lack of knowledge and experience.
- Creative partnership – not battles.
- More personal partnerships.
- Lack of future planning.

#### d) Travel and Access

- Unreliable transport.
- Bus Pass – doesn't start till 9.30 and having to prove disability again to renew.
- Limited wheelchair access.
- Lack of staff in public places. i.e., Metro stations.
- People sitting in priority seats who don't have walking aids.
- Even more at night as people don't like travelling at night times.
- City doesn't feel safe at nights.
- Support staff don't or can't drive.
- Support getting to and from activities we love to do.
- Staff shift patterns impacting on what activities people can do.
- Has anyone heard of Stay up Late campaign?
- Poor services – transport late and expensive – impatient wait until I have sat down.
- Taxis very expensive.
- Bus service not fit for purpose.
- Lack of ramps on trains.
- Bus pass can only use at set times.
- Accessibility.
- Technology/ cash less society.
- Independent travel skills.

#### e) Money

- Money – I cannot afford to do anything fun – like trips and holidays.
- Money not having enough – stops me going out – cost of living high.
- Not enough funding for colleges and support.
- Shortage of food.
- I don't have a bank card – I don't feel safe.
- Unfair benefits system.
- I cannot afford to go to more than one place a week.
- Petrol prices.
- Benefit system not clear and not enough money.
- No disability support in banks/services – in cash less society – law is not being followed.
- Cost of living crisis.

#### f) Inclusion

- Discrimination and hate crime still a problem for accessing the community.
- Special School, separate education.
- Societies view of disabled people.
- Being judged.
- Government not taking disability seriously.
- Accessible information not in shops or media.
- lack of involvement/inclusion.
- Lack of provision to meet friends.
- Lack of opportunities.
- Not being listened to.

#### g) Mental Health

- Feeling vulnerable.
- Being scared of meeting new people.
- Low energy and tiredness.
- Being alone – not having friends.
- Low confidence.
- Panic attacks.
- Poor health.
- Depression.
- Anxiety, social anxiety, claustrophobic.
- Mental health.
- How you are treated.
- Fear.
- Past experiences.
- Phobia.
- Lack of choice, freedom, or support.
- Lack of instruction and encouragement.



#### h) Safety

- Streets are too dark – I do not feel safe.
- Worried about being attacked or mugged.
- Bad streetlights.
- Dark nights make me feel unsafe.
- Anti-social behaviour.
- Lack of housing and safe housing.
- Roads are not safe to cross – cars driving fast.
- Abuse from neighbours.
- Flats are noisy and unsafe to live in.
- Feel unsafe going out evenings/nights fear of being attacked.
- Noise where I live – I want to move house – I am not a priority 'Band D'.
- Unsuitable online sites (online safety).
- Lack of community resources.
- Not making reasonable adjustments.
- My mam does not like me out in the dark.
- Family worry about my safety and stops me doing things I would like to do.
- Your Homes Newcastle not responding to complaints we have neighbour issues.
- Drugs – behaviour from others.
- Accessibility.
- Hate, mate crime.
- Other people who do not understand learning disability.